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**UNIVERSITY OF SOUTHAMPTON**

**THE EMOTIONAL REACTIONS OF PARENTALLY AIDS-BEREAVED YOUNG PEOPLE: A QUALITATIVE STUDY OF BEREAVED YOUNG PEOPLE, CARERS AND PROFESSIONALS IN THE GAMBIA**

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## **ABSTRACT**

AIDS is a major cause of death in sub-Saharan Africa and for many social reasons coming to terms with AIDS-related loss is complicated and difficult for bereaved young people. Yet, understanding of African AIDS-bereaved young people's perspectives about their grief and perceptions of adults (health professionals and carers) about the young people's reactions to loss is under-developed. This qualitative study therefore explores the emotional reactions of AIDS-bereaved young people and social factors that help or hinder their ability to cope with loss by comparing the similarities and differences between the perceptions of bereaved young people, their carers and professionals working with them.

Individual open-ended interviews were carried out with ten carers of the young people and six professionals. Twelve individual open-ended interviews and a single focus group discussion were conducted with AIDS-bereaved young people aged between 15 and 18 years whose parent died of AIDS three to five years before this research. These were tape recorded and transcribed in full and the subsequent data analysed using constant comparative method. Key findings are that bereaved young people react to their loss with a range of emotions and that adults and young people differ regarding their perception of the intensity of their reactions.

Many examples of differences in perception were identified, including young people's view that they were overwhelmed by their loss while the adults, on the other hand, believed that they were coping with their loss. Young people wished to be told about their loss and to discuss it; however, neither the professionals nor carers were involved in such discussion with the young people. Secrecy, stigma, isolation and discrimination experienced by the young people were perceived as unhelpful to their coping; whilst being allowed to talk about loss, the feeling of being listened to, interacting with peers and the addressing of immediate basic concerns were perceived as helpful.

Understanding differences in perceptions between AIDS-bereaved young people and the adults around them appears to be the first stage in developing strategies to create an enabling environment for the young people. In addition, building the capacity of carers and professionals working with the young people to acknowledge their loss, understand their reactions and establish effective communication with them is an essential aspect of helping them to cope with their loss.

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# INTRODUCTION

## **Personal motivation**

Everything looked so black...I wanted to be like everyone else. I wanted to forget about death, grief and pain, but it seemed impossible.

(Abrams, 1999, p.76)

The responses of Rebecca Abrams (a Western bereavement scholar) to her father's death when she was just 18 years old suggest that life may be extremely challenging for many bereaved young people and they may require adults' greater understanding and support (Abrams, 1999). As a public health promotion officer in the Gambia, I have always had the desire to help enable young people to take control of and improve their lives. Through following this desire and as a Gambian, I started working with young people in implementing HIV/AIDS and other health-related programs. I have also wished to understand the experiences of young people like Abrams.

My years of experience in this area (young people and AIDS) motivated me to undertake a postgraduate program on health promotion in Ireland. As part of the program, I gave talks on HIV/AIDS transmission and prevention to secondary school children in the city of Galway. In 2000, I undertook my first real study in 'Assessing Secondary School Children's Knowledge, Attitude and Behaviour on HIV/AIDS in Galway City' (Unpublished). The project was supported by the research unit of the Public Health Department Western Health Board and AIDS Help West, an organisation that supports People Living with AIDS (PLWA). I am also co-author of a paper published by Health Promotion International in 2005 entitled 'Rural Women's Knowledge of AIDS in the Higher Prevalence State of India: Reproductive Health and Socio-cultural Correlates' (Pallikadavath et al, 2005). In this paper my role was to incorporate aspects of health promotion in the overall write-up of the research report. From these studies I have learnt a great deal about how young people and women struggle with issues of AIDS and how devastating AIDS-related death may be to some families.

The above research and practical work with young people stimulated my interest in the National AIDS Control Program (NACP), where I worked as part of a team implementing all AIDS-related programs in the Gambia, in partnership with other organisations, departments and communities. Here, I was involved in a series of training workshops with adults and young people living with AIDS. I also met and supported, emotionally and materially, people living with AIDS.

Although my professional involvement with young people in general and young people from AIDS-affected families has played a great part in shaping my desire to conduct this research, I feel that a further strong motivation has been my personal experience of losing several people close to me, including grandparents, brothers, sisters and friends. However, the overriding impetus arose from my witnessing what I believe was the painful experience of the AIDS-bereaved children of a close friend in the Gambia.

This friend died of AIDS four years ago and I was unhappy with the way I felt his children were treated. Even though the older child was aged ten, he and his brother were not even informed that their father had died. On the day of the funeral, both children were isolated in a corner of the lounge. In spite of there being over a hundred people in and around their home that day, no one was seen interacting with them. The children constantly sought to make eye contact with the people milling around, while none of them seemed to be crying. The children, who were very close to their father, observing their non-engaging body language at such an emotionally charged moment, disturbed me greatly and it started me wondering about their subjective state of mind.

The experience of powerlessness manifested itself to me in questions like: How do they feel? What could have been done differently to help? How can I help to bring comfort? What literature is available in the Gambian context? What does the literature say about this? My wondering set me on a quest to understand what the children were going through and what could have been helpful to them; and it has culminated in this research investigating the emotional reactions of young people whose parents have died of AIDS and the social factors that have been helpful or unhelpful in coping with their loss.

### **Timely nature of this study**

There are several reasons for the study relating to young people's emotional reactions to the AIDS-related death of a parent being both timely and important in Africa and, in particular, the Gambia. First, AIDS has become the major cause of both morbidity and mortality globally, but more specifically in sub-Saharan Africa (UNAIDS, 2006) (countries of the African continent that are not considered part of North Africa, including nations in Central Africa, East Africa, Southern Africa, West Africa and African island nations), which constitutes 63% (24.6 million HIV-infected people for 2006, an increase of 1.1 million in two years) of the overall HIV infection globally. The highest mortality due to AIDS is registered by sub-Saharan Africa: 2.1 million deaths from a global total of 3.8 million deaths (an increase of 0.2 million in the space of two years) (UNAIDS, 2006).

HIV/AIDS is a pandemic threatening lives all over the globe. The increasing rate of parental mortality due to AIDS has led to an increased number of bereaved young people (UNAIDS, 2001). UNAIDS (2001) reported that, in the 19 years between 1981 and 2000, 13.2 million young people were bereaved. In one year alone (2000), an astonishing 2.3 million young people (under 18 years) were bereaved - one young person every 14 seconds. The report indicated that, by 2001 in sub-Saharan Africa, 10% of all young people were bereaved by AIDS.

Epidemiological evidence (UNAIDS, 2006) indicates that prevalence of HIV/AIDS in the Gambia is around 2.4% and the number of deaths from the beginning of the epidemic (1981) to 2005 was 1,300. About 1% (n=4,100) of young people under 18 years of age have lost one or both parents to AIDS. Although this figure is relatively small when compared with parentally AIDS-bereaved young people in many African countries, there is no room for complacency. Since many Gambians are living with HIV/AIDS and many are becoming infected, parents will continue to die. Many young people will therefore reach puberty without their biological parents.

Study of emotional reactions to loss is a new area in the African context. In the last eight years the number of scientific studies conducted in this area has increased but there is still paucity of evidence in this field. A majority of the studies have been conducted in the

southern part of Africa, and many have not taken on board the complexity of bereaved young people's emotional reactions to their loss, understanding of which may be useful in helping them cope.

In addition, although the joint UN, UNICEF, USAIDS (2004) document *Children on the Brink* stresses that the psychological needs of children made vulnerable by AIDS must be met, and suggests that children should be helped in their homes, there is little research as to how such psychological support can be achieved in Africa in the face of stigma and discrimination. Research shows there is lack of understanding among adults about the emotional experiences of African AIDS-bereaved young people (Wood et al, 2006). More research is required to understand their reactions and find ways of helping them to cope with their loss. In consequence, this thesis has focused upon exploring and obtaining, within the Gambian context, greater understanding of the phenomenon of emotional reaction to AIDS-related death of a parent, from the perspectives of AIDS-bereaved young people and adults supporting them.

Arising from these issues, the research has had three main aims.

Aim 1: To explore young people's emotional reactions to the loss of a parent from HIV/AIDS and to compare that with the perceptions of carers and professionals.

Aim 2: To explore young people's experiences regarding the impact of social factors, including stigma and discrimination, on their reactions and ability to cope with losing a parent from HIV/AIDS and to compare that with the perceptions of carers and professionals.

Aim 3: To explore how support from families, peers and agencies, particularly the Orphans and Vulnerable Children's (OVC) project, affect the young people's ability to cope with loss and to compare that with the perceptions of carers and professionals

## **Structure of the thesis**

Chapter 1 presents the literature on emotional reactions to loss, divided into two sections, commencing with a rundown of grief theories and models relevant to this study. Since there are no psychological models on grief relating to the African context, the Dual Process Model (DPM) has been used as a guide and this has been justified using African literature. The review is extended in the second part to include aspects of emotional reactions. It begins with an analytical review of all the studies used in this thesis before presenting their findings. Subsequent sections include examination of emotional reactions and their intensity, emotional expressions, basic emotional reactions, continuous emotional bonds and defensive mechanisms, all of which may influence how young people respond to loss. The third aspect of this chapter examines stigma and discrimination, which may have a negative effect on bereaved young people's ability to cope. The review finishes with an examination of the role of family, peer and OVC support, all of which may have a positive or negative influence on their coping.

Chapter 2 describes methods of data collection and analysis in this study. The chapter begins with descriptions of ontological and epistemological perspectives, before going on to justify use of the qualitative approach and grounded theory method of analysis in this thesis. The data was collected from 17 young people between 15 and 18 years of age with a parent who had died from AIDS, ten carers and six professionals in Brikama town in the Gambia, using one focus group interview and 28 open-ended individual interviews.

Chapter 3 presents findings from interviews and the focus group discussion conducted with AIDS-bereaved young people.

Chapter 4 outlines the findings from individual open-ended interviews with carers and professionals working with the young people. It includes sections on emotional reactions, emotional intensity and expression, immediate and long-term reactions (sadness, anger, fear and anxiety, emotional loneliness and continuous emotional bond). Next, data on restoration-oriented coping is presented, including discrimination and isolation, stigma and secrecy, social support from the family, carers and the Orphan and Vulnerable Children's (OVC) project.

Chapter 5 discusses the main findings, using triangulation of data from the carers, professionals and young people; and explores the differences in perception between young people and the adults regarding the young people's reactions to their parent's death. The contribution of this thesis to the existing knowledge is considered, followed by a brief discussion on the DPM model. Chapter 5 ends with a conclusion and recommendations.

# CHAPTER 1: LITERATURE REVIEW

## 1.1 Introduction to the chapter

This literature review aims to review relevant literature on: the prevalence of parental HIV infection and mortality due to AIDS, the Dual Process Model (DPM) of grief to guide this thesis, a wide range of perspectives in literature to inform the research aims of this thesis; and finally important issues to be explored with participating groups (young people and adults surrounding them).

One key purpose of this review is to synthesise literature that is relevant to the emotional reactions and basic responses (e.g. sadness, anger, fear/anxiety and emotional loneliness) of AIDS-bereaved young people in Africa; and to show whether and to what extent they have reacted to their loss. It is hoped that exploration of emotional reaction will inform discussion on the intensity of feelings and expressiveness of bereaved young people; and also create avenues to examine how young people manage in an African context to live without their parents. The second key purpose is to explore the social factors which may give an insight into how family care, support from peers and OVC (the only project that supports bereaved young people), as well as stigma and discrimination, have influenced young people's ability to cope with loss, as suggested by one African study (Cluver and Gardner, 2007).

The first part of this chapter provides the background for this thesis. It includes a brief discussion on HIV infection and mortality; the advancement of knowledge on grief, and justification for the use of DPM to guide this thesis in the African cultural context

The second part focuses on AIDS-bereaved young people's internalising and externalising experiences as a result of loss. It considers intensity of reactions and whether young people have freely expressed these emotions without restrictions. It also includes a detailed discussion on sadness, anger, anxiety, fear and emotional loneliness, including psychological denial and avoidance response.

The third part focuses on the impact of several social factors upon young people's coping, such as care and support from families, peers and the OVC project; as well as stigma and discrimination. Recommendations for possible cultural interventions are also included.

## **1.2 HIV/AIDS prevalence and young people**

The HIV and AIDS epidemic is one of the greatest tragedies of our generation and it has become the major cause of both morbidity and mortality globally (WHO and UNICEF, 2007). The magnitude of the crisis is almost unthinkable (Ansah-Koi, 2006). More than 15 million people have already died, the majority of them in their reproductive age (UNAIDS 2006). In the space of 19 years (between 1981 and 2000), 13.2 million young people were bereaved (UNAIDS, 2001). In 2000 alone, an astonishing 2.3 million young people (under 18 years) were bereaved - one young person every 14 seconds.

In sub-Saharan Africa the scale of the epidemic exposes young people to all sorts of hardship and insecurity about the future (UNAIDS 2006). Sub-Saharan Africa is home to just 10% of the world's population, but constitutes over 80% of all HIV and AIDS death and over a third of all new HIV infections globally (UNICEF, 2007). By 2001 in sub-Saharan Africa, 10% of all young people were bereaved by AIDS (UNAIDS, 2001). However, the recent Millennium Development Goal progress report by UNAIDS (2010) showed that new HIV infections, child and maternal mortality have declined. There is a cause to be optimistic about the future. Access to anti retroviral drugs in African countries has increased in the recent years, but less than 50% of 8.8 million people who were in need of life-sustaining HIV treatment were receiving it (UNAIDS, 2010). Stigma, discrimination and poverty all contribute to families' inability to access health services (Foster, 2005). Since HIV/AIDS in Africa is predominantly a heterosexual disease affecting couples and the communities, young people become one of the most affected and exposed population groups (UNICEF, 2004). Characteristics normally related with young people are fast becoming unattainable dreams in the face of loss, grief, stigma and poverty (Wild, 2001, Foster et al, 2004).

The Gambia, already one of the poorest countries in Africa, is also a country where young people, their families and communities are increasingly affected by AIDS. Epidemiological evidence (UNAIDS, 2010) indicates 4150 new cases of HIV in 2009 representing 0.3% of the

Gambian population. However, there is a decline in the HIV prevalence rate from 2.4% in 2006 (UNAIDS, 2006) to 1.2% in 2009 (UNAIDS, 2010). The Gambia is also among a few African countries with the lowest (<1000) number of deaths due to AIDS and lowest percentage (about 1%) of young people under 18 years of age who have lost one or both parents to AIDS (UNAIDS, 2010).

Although this figure is relatively small when compared with parentally AIDS-bereaved young people in many African countries, there is no room for complacency; especially since the Western division (Western Local Authority Area), where this present research was conducted, has the highest rate of HIV prevalence which is coupled with higher levels of poverty than many other Divisions (Local Authority Areas) in the country (Dept. of Health, 2004). Since many Gambians are living with HIV/AIDS and many are becoming infected, parents will continue to die. Many young people will therefore reach adulthood without their biological parents.

Whilst prevalence of parental AIDS bereavement in the Gambia (1%) is relatively small when compared with most African countries (see UNAIDS, 2010), the growing number of AIDS bereavements in Africa is astonishing. In 2003, AIDS killed one or both parents of an estimated 12 million children in sub-Saharan Africa (UNAIDS, 2004). By the end of 2005, almost (90%) all the 15 million children who had lost one or both parents to AIDS lived in sub-Saharan Africa (UNICEF, 2006). Among 12 African countries with over 75% of their orphans due to AIDS, orphans will soon account for 15-25% of all children in these countries (UNICEF, 2005).

Often forgotten are the disease's devastating effects on children left behind (Naicker and Tshenase, 2004). AIDS orphans encounter challenges specific to their own situations (Atwine et al, 2005). Going through the psychological impact of the loss of a loved-one can be devastating and traumatic for some children (Hunter, 2001). When a parent dies, apart from the loss itself, young people react to events unfolding daily in the family environment including several changes occurring (Nymbedha et al, 2003). The potential to lose the surviving parent or a sibling to AIDS is real and may further impact on young people's coping (Nyamukapa, et al, 2006).

Whilst some young people may adjust themselves, many - especially with the negativity associated with AIDS - may struggle to cope with their loss (Richter et al, 2004). AIDS-related death being the most stigmatised event, far too many of these orphans are not properly cared for (UNAIDS, 2004). The negative impact of stigma, discrimination and poverty associated with AIDS makes coping more difficult for them (Deacon and Harrett, 2007).

For many Africans illness and death are parts of the fabric of life crises, which are dealt with by the existing social coping mechanisms (Ankrah, 1993). Traditionally, extended families served as the safety net for all types of crises including caring for bereaved young people (Ankrah, 1993). In some countries multiple deaths, labour loss and migration due to the impact of HIV/AIDS have stretched this net to breaking point (Foster et al, 1996). There are more orphan and widow households than ever before and more elderly people taking care of orphans than ever before (Foster, 2005), yet such an impact is not obvious in some African countries (UNICEF, 2004), suggesting the contextual nature of AIDS' impact on young people. Greater understanding of the nature of young people's bereavement is required especially in situations where the social aspects of their lives are likely to impact on their coping. The following section will help to locate these experiences of the young people in the existing theoretical models.

### **1.3 Theoretical perspective of grief and bereavement**

#### **1.3.1 Grief as a natural experience**

The term 'bereavement' has been defined as the objective situation of having lost someone significant (Stroebe et al, 2003); 'grief' is described as the cognitive, emotional and behavioural response to one's loss (Payne et al, 1999). It is the emotional aspect that is the focus of this thesis. Writings about grief as a natural response to loss have a long history: the first publication was in 1761 by Robert Burton (Archer, 1999), followed by several writers, including Charles Darwin (1872) whose theory of evolution paved the way for advancement in the biological aspect of grief. Darwin's theory was influenced by his deep attachment relationships with his daughters and his efforts to understand suffering and death (Keynes, 2001). The anguish over the death of his ten-year-old daughter 'Annie' reinforced his opinion on the biological nature of grief. His conclusion that grief was a

natural response to loss still holds its position in modern day bereavement literature, as shown in the work of Bowlby (1980).

It was not until the 1960s that scientific writings and research on grief started to have an impact on people's understanding of grief and responses to loss. Bowlby (1961), focusing on the biological origin of grief, was among the first British psychologists to support Darwin's claim that grief was a natural response to loss. According to Stroebe (1992), Bowlby's attachment theory made the greatest impact and it still serves as the cornerstone in understanding the impact of separation on partners. It provides a biological explanation of how emotional ties are developed and the consequences of breaking those ties through separation or death

According to Bowlby, an attachment relationship is based on three things: proximity and constant interaction; reciprocity of response to social signal (based on innate rather than induced responses); and quality of interaction. For example, the constant, reciprocal, innate responses (responses not induced by rewards) to social signals by a mother and her child lead to an attachment relationship, the quality of which depends on the quality of interaction (Bowlby, 1980). Consequently, a person naturally responds to anything disrupting this relationship (e.g. death or separation) and basic, natural responses include sadness, anxiety, fear, emotional loneliness and anger (Bowlby, 1998).

The models outlined below explore the concept of grief and how it impacts upon coping with loss.

### **1.3.2 Stage and Task of Grief models**

After he developed the attachment theory explaining the intensity and importance of emotional relationship between an attachment figure (especially the mother) and the child, Bowlby (2005) explored how the temporary absence of an attachment figure would affect the child. Bowlby (1980) conducted a series of brief observational studies with children in the UK, to understand their reactions to separation from their primary attachment figure (mother). When children were briefly separated from their mothers in hospital settings, Bowlby observed them experiencing 'separation anxiety', initially

categorised into: protest, despair and detachment. Inspired by Parkes' (1975) study with bereaved adults, Bowlby added another stage - 'an initial one of numbness and disbelief'. The final 'phase model' proposed that the bereaved must go through four stages of grief work (numbness/disbelief, yearning and searching accompanied by anxiety and periods of anger, despair, and recovery) to fully recover from loss and function normally.

Considering the amount of scholarly and non-scholarly literature available on the Stage theory, it is clear that it took the West by storm, capturing the imaginations of laypeople, scholars and professionals alike (Bowlby, 2005). In addition to Bowlby's (1980) contribution, the work of Kübler-Ross (1973) brought mainstream awareness to the sensitivity required for better treatment of individuals who were dying and their bereaved families. Kübler-Ross's (1969) five stage model (denial, anger, bargain, depression and acceptance), originally developed to understand the terminally ill, was later applied to death and events such as divorce, drug addiction and infertility (Kübler-Ross, 1973).

Although it would now appear that the stages are not linear, they do cover many of the sometimes unexpected responses to loss and grief, such as denial and anger. However, the main problem with the Stage model is that it does not recognise individual differences in loss and claims that failure to complete the stages in a particular order may lead to psychological suffering and possible pathology. Its interpretation also seems to neglect the bereaved person's situation such as relationships with others and how they could affect the cycle (Stroebe and Schut, 1999).

Bereavement writers have now tended to move away from seeing grief as a matter of moving through stages to viewing it as a process, generally perceived as several intermingling reactions, changing over time and not as a smooth progression (Stroebe and Schut, 1999). The Task of Grief model, developed by Silverman and Worden in 1992 among American bereaved adults, saw grief as a process (Worden, 1996). Although both Stage and the Task of Grief models agreed that the bereaved must 'work through' grief, the latter proposed that bereaved people must: 1. accept the reality of the loss; 2. work through emotional pain; 3. adjust to the environment without the deceased; and 4. move ahead; but not necessarily in this order.

The Task of Grief and Stage models emphasised an intrapersonal journey in bereavement, because coping could not be achieved without gradually working through the stages or processes described above. The link between the intrapersonal (private experience) and the interpersonal (public involvement) aspects of grief was unclear in the models. Moreover, the models proposed that, for a full recovery and to avoid any pathology, it was necessary to complete the stages (Bowlby, 1980), or tasks and processes (Worden, 1996). Yet, according to Stroebe (1998), some may not necessarily complete these processes. According to Rosenblatt (1983) the bereaved required an informal support system from families and friends in processing their grief.

Recent models have addressed some of the above concerns, such as the link between interpersonal and intrapersonal relationships in grieving. Walter's (1996) 'New Model of Grief' emphasised the interpersonal relationship between the bereaved and people around them. This model proposed that the bereaved benefitted from speaking to people who knew the deceased but seemed to discount the importance of others who knew little or nothing about the deceased. The model may not therefore be helpful in circumstances where those who knew the deceased have died or when communication is hindered by stigma.

### **1.3.3 The Dual Process Model (DPM): origin and description**

Considering the several limitations of the models outlined above, the DPM has built on rather than replaced the Stage and Task of Grief models.

#### **1.3.3.1 Origin of the DPM**

The DPM was developed in the Netherlands by Stroebe (1998), when she reviewed empirical evidence concerning gender differences in coping with loss of a partner. She found gender difference in coping styles, with widowers focusing more on their problems and practical things such as financial commitment than on the loss itself, whereas many widows were found focusing more on their loss than on problems. Furthermore, Stroebe (1998) argued that bereaved partners should understand each other's coping style; otherwise they may accuse one another of not grieving or grieving too much, which may disrupt supportive communication and complicate their grieving process.

She also showed that, instead of categorising someone's grief as pathological or non-pathological because the person was or was not fully committed to grief work theory, one should acknowledge individual differences in the way people confront loss.

Stroebe (1998) drew on the findings of an intervention research conducted by her colleague, Schut (1998), in the Netherlands. In this, widowers who avoided loss by focusing mainly on their problems were taught how to focus more on loss; and widows more on their problems. The intervention was found to reduce distress in both genders. On this basis, Stroebe (1998) proposed the need for a model capturing the two processes in an individual bereavement experience, individual differences in coping style and the relationship between the bereaved (intrapersonal) and their external world (interpersonal). Neither the Task of Grief nor the Stage model captured all these complexities; the DPM was developed to understand them.

#### 1.3.3.2 Description of the DPM

The DPM describes two processes (Stroebe and Schut, 1999) relating to grief. One is loss-orientation, involving the emotional aspects of loss and reminiscence discussed earlier (see Stage and Task of Grief models – section 1.2.2 above). The other process is restoration-orientation, which includes both secondary consequences of loss (multiple stressors) and coping with the new situation independently or with support from others. Stroebe and Schut (1999) stressed the importance of both orientations. The central tenet of this model is alternation (oscillation) between loss- and restoration-orientations throughout the bereavement period (Stroebe and Schut, 1999). Therefore, this model does not discard Bowlby or Silverman and Worden's ideas of grief work; rather, it has added another component not covered by these models: restoration-orientation.

The first dimension, loss-orientation, 'refers to the concentration on, and dealing with, processing of some aspect of the loss experience itself, most particularly with respect to the deceased person', (Stroebe and Schut, 1999; p.212). Stroebe and Schut (1999) explained that grief work, the primary concept of Bowlby's (1980) and Silverman and Worden's (1992) models, falls within this loss-orientation dimension of the DPM.

In both models and in this dimension, the bereaved mainly attend to the relationship with the deceased, reflecting upon the person and circumstances of death. This dimension, which includes yearning for and ruminating about the deceased, includes a range of emotional reactions (in the form of a process), often totally unpredictable and unexpected.

Stroebe and Schut (1999) stated that loss-orientation is likely to be the more dominant dimension early in bereavement; but several substantial sources of stress (e.g. stigma and discrimination) and secondary consequences (e.g. communication problems) must also be confronted. The bereaved must find ways of addressing these problems, either directly or in cooperation with others. Attending to these multiple stressors means temporarily shifting attention away from the loss itself. In summary, shifting of attention away from the loss (or from loss-orientation) is referred to as 'restoration-orientation'.

Oscillation is a dynamic process perceived as fundamental to successful coping. It is described as the alternation between loss- and restoration-orientation coping and a juxtaposition of confrontation and avoidance of different stressors associated with bereavement (Stroebe and Schut, 1999). At times the bereaved confront their loss, at other times they avoid memories, are distracted or seek relief by concentration on other things (e.g. managing household chores) or engaging with other people. Several alternations may take place in a day, months or years: for example, a child who wakes up feeling sad (loss-orientation) becomes lively again and able to focus on her homework (restoration-orientation), then sinks back to loss (loss-orientation) when she watches a particular film which brings on a wave of emotion.

It should be noted that this model has been developed in the West where basic human needs (e.g. food, water, peace, health) are met and where attachment relationships are not as widespread as in Africa. These factors, including beliefs about life and death, may influence how loss is perceived and how reactions are culturally sanctioned. Since the DPM has not been tested (Payne et al, 1999) on young people or in Africa, as far as I am aware, the following section justifies its suitability in African bereavement studies.

### **1.3.4 The DPM - application in the African context**

Whilst this section discusses the suitability of the DPM in Africa, care must be taken not to adopt an overly homogeneous view of different African contexts. Beliefs and practices differ not only from one African country to another but also between cultural/ethnic groups within the same country. Socio-economic and political variation may have an impact on how loss is perceived and how mourning practices are conducted. The following sections give detailed accounts of such practices.

#### 1.3.4.1 The DPM and African mourning practice

Kilonzo and Hogan's (1999) extensive review of mourning practices from over 120 ethnic groups in Kenya appears to be in line with the claims made by the DPM. Many of the bereaved had their own mourning rituals, but in general adults tended to confront their loss by actively engaging in wailing, verbalisation of emotions and participating in several rituals. Although this suggests that in general bereaved adults in Kenya were involved in loss-oriented coping, responses in communities where the impact of HIV/AIDS was high was different from those where it was low. Where it was low, it was not uncommon for the bereaved to demonstrate openly the intensity of their sorrow and remorse, which forced them to accept and face the reality of death (Kilonzo and Hogan, 1999). Where the impact of HIV/AIDS was high, emotion appeared to be contained or distracted by funeral arrangements, dealing with finances, stigma, discrimination, and communication problems, suggesting that this group was more restoration-oriented. What this review seems to suggest is that loss- or restoration-oriented coping may have been dependent on the context within which the loss occurred, rather than the culture from which the bereaved came, for example, whether they were Western or African.

At both individual and cultural levels, expectations of how one should react to loss can be different. For example, there is a contrasting cultural expectation between the two Muslim communities of Bali (in Indonesia) and Egypt (in Africa) (Wikan, 1988). Among Egyptians, expression of emotions is encouraged and openly shared. In contrast, although crying is viewed in Bali as a natural response, people work hard to replace it with cheerfulness and laughter, intending to induce inner happiness to replace sadness, sorrow

being perceived as detrimental to health and happiness. In Kagwahiv Indian culture of the Brazilian Amazon, 'despite their headhunting heritage, there is strong disapproval of the expression of anger (or even aggressive self-assertion) in a face to face relationship' (Kracke, 1988, p.211) and, open expression of grief is discouraged even in people's immediate response to loss (except for women). Underlying all these patterns are cultural belief systems dictating the way grief is manifested and whether the bereaved are more loss- or restoration-oriented.

Normality and the duration of grief are also culturally sanctioned. McGoldrick et al (cited in Webb, 1993) emphasised the need to be cautious about the 'definition of "normality" because the manner and the length of time assumed normal for mourning differs greatly from culture to culture' (p.14). For example, mutilation of the body and tearing of the hair amongst aboriginal peoples (see Stroebe and Stroebe, 1987) would be considered abnormal in the Gambia. For bereaved people among the Navajo in North American, the accepted mourning period is limited to four days; only during this time is emotional expression and discussion of the deceased condoned (Miller and Schoenfeld, 1973). After this, no grief may be shown; there may be no talk about loss: the bereaved are expected to return to everyday life. From personal experience in the Gambia, the formal mourning period is seven days for adults, 40 days for widows and nothing for young people. During this period men tend to show less emotion and to be involved in fewer rituals than women. As well as participating in a wide range of rituals (e.g. wearing special black clothing) in which men are not involved, women also seem to receive more support and encouragement (in terms of communal wailing, epic chanting and condolences) from other women to engage with their loss. Therefore, in my view, it is not surprising that Gambian women appear more loss-oriented than men.

In general, it is traditional for African bereaved families to receive support from extended family members. Ankrah (1993) suggests that Africans deal with crises using local resources: for example, psychological problems with diviners/marabouts, medical with traditional healers, and social problems with traditional leaders within their social network. These resources may be depleted by the impact of AIDS. Multiple losses and stigma attached to AIDS may reduce availability of the traditional support. Whilst families appear to be the main providers of support (UNICEF, 2004), the impact of multiple death on families may

already be evident; in some African countries family members may be struggling to support each other; in others grandparents, who may be physically weak, appear to be the largest group providing support (Chatterji et al, 2005). This is in line with Foster's (2002) prediction that, with new cases of AIDS and increased numbers of bereaved young people, the impact of loss on families would be compounded. The several stressors that accompany multiple deaths may require significantly more time and energy from the bereaved than is perceived culturally as normal, thus obstructing oscillation from occurring. The model suggests that this situation detracts from the ability of the bereaved to cope and may lead to emotional problems.

#### 1.3.4.2 The DPM - African young people as forgotten mourners

The DPM is a Western model developed for helping in partner bereavement but it has also been perceived as helpful to all bereaved people (Stroebe and Schut, 1999). Yet, Western developmental psychologists have maintained that young people's understanding of death differs from that of adults. Evidence has suggested that children as young as five in the West understood death, grief and loss, but age and developmental stages remained relevant to how individual children responded to their loss (Bowlby, 1980). This implies that unlike adults, bereaved children were only able to actively engage with their loss in smaller doses (Chris, 2000), showing that by adult standards they spent much of their time in shifting their attention away from loss or focusing on other things and avoiding engagement (restoration-orientation).

Western literature suggests that difficulty in dealing with loss is even more profound among teenagers. For them, death is untimely and unexpected; as Abrams (1992, XVI) put it: 'There is simply not enough time, energy or emotional strength to cope with everything'. This difficulty is associated with the complex developmental tasks they have to accomplish (Balk, 1996); death therefore multiplies their tasks but it does not necessarily mean that they are always vulnerable to psychological problems (Chris, 2000). Optimal coping may have taken place when young people were able to alternate their focus between developmental tasks (restoration-orientation) and death (loss-orientation), as suggested by the DPM.

In Africa, young people may be exposed to more problems than their peers in Europe and America owing to poverty and multiple deaths through AIDS (UNAIDS, 2002). However, despite the large number of bereaved young people in sub-Saharan Africa, there is no information on how AIDS-bereaved young people in the Gambia and elsewhere in Africa participate in the cultural mourning practice. This is a surprise, considering the extensive mourning practice of African adults and the fact that young people live in the midst of adults who are permitted by culture to openly express their emotion in an appropriate manner (Kilonzo and Hogan, 1999). It seems likely that many African bereaved young people's loss has not been recognised and emotional support may be lacking. For such young people, confronting loss may be too overwhelming and they may spend more time on restoration than required.

Despite decades of the impact of AIDS on them, it was not until recently (2002) that the UN started considering the psychological needs of young people made vulnerable by AIDS in Africa. The joint UN, UNICEF, USAIDS (2002) publication 'Children on the Brink' was the first of its kind. Although stressing that the psychological needs of young people made vulnerable by AIDS must be met, emphasis was placed mainly on HIV-positive young people. There was little attention to the psychological aspects of AIDS-bereaved young people's experience. Emphasis was placed on addressing their economic needs at the expense of their emotional needs. In summary, little attention has been paid to the psychological needs of African young people; yet, some may have been emotionally troubled by their loss. It is therefore necessary to review existing knowledge about African AIDS-bereaved young people's reactions to loss and the social factors that may have an influence on their coping with their loss. The following section considers sources of evidence, mainly in the African context.

## **1.4 Overview of studies on African bereaved young people**

### **1.4.1 Literature search strategy**

The literature reviewed in this study draws upon studies conducted mainly in sub-Saharan Africa, including both quantitative and qualitative studies on AIDS orphans. In addition to personal communications with researchers in South Africa (e.g. Cluver), a search on Assia, Psychinfo, Pubmed, Medline, Embase, Vulnerable Children, Science direct, AIDS Care and

Google SCHOLAR using ‘HIV + Orphans + Africa’ generated 2800 citations containing one, two or all of the following: ‘HIV, Orphan and Africa’. The researcher went through the citations to identify the ones that seemed to focus either in part or full on African bereaved young people’s bereavement experiences. 180 references were identified and abstracts of these articles were read. Several of these articles were published in other journals too. In situations like this, the researcher selected only one of the sources. The criterion for the full review of an article was: the study fully or partly focused on African young people’s parental bereavement experiences with special attention paid to their emotional reactions to loss, experience of stigma and discrimination, and access to social support. Studies that focused exclusively on a sibling, close relative, grandparent, or neighbour’s death were excluded.

Studies that focused exclusively on age ten and below and over 18s were all excluded. Studies that focused on Afro-Americans or African-American children were also excluded. Using this criterion, the researcher identified 61 studies that attempted to explain parental bereavement experiences in Africa.

Apart from two longitudinal studies conducted in the USA (Silverman and Worden, 1992; Worden, 1996) and France (Van Eerdewegh et al, 1982), all the evidence was gathered from studies conducted in 17 African countries. The two non-African studies were selected to give an international dimension to this thesis. As they were longitudinal studies they effectively measured young people’s emotional reactions over time (Archer, 1999). Some other Western literature was accessed as part of the background reading; this included grief models and literature on emotional expressions.

#### **1.4.2 Sources and limitations of the evidence**

As shown above, the African-based evidence in this review was drawn from 17 different countries across sub-Saharan Africa with the majority from Southern African countries. South Africa alone accounts for 18 studies followed by Zimbabwe (14). Only a few studies were conducted in the Western part of Africa, with Guinea Bissau accounting for two followed by Nigeria, Ghana and Gambia. The single study, ‘Situational Analysis of Orphans and Vulnerable Children in the Gambia’, is the only Gambian research reviewed here (UNICEF, 2004).

Country	Focus of the study		
	Controlled psychological studies (excluding psychosocial studies)		
South Africa	Cluver et al (2007)	Wild et al (2006)	
Zimbabwe	Nyamukapa et al (2008)	Nyamukapa et al (2006)	Poulter (1996)
Uganda	Atwine et al (2005)	Sengendo and Nambi (1997)	<b>Kumakech et al (2009)</b>
	<b>Musis et al (2007)</b>		
Tanzania	Makame et al (2002)		
USA	Silverman and Worden (1992), Worden (1996)		
France	Van Eerdewegh et al (1982)		
<b>Non-controlled psychological studies</b>			
Rwanda	Brown et al (2005)		
Ethopia	<b>Bhargava (2005)</b>		
Mozambique	<b>Manuel et al (2002)</b>		
Zimbabwe	<b>USAID/Zambia SCOPE et al (2002)</b>		
South Africa	<b>Mbizana (2007)</b>	<b>Cluver and Orkin (2009)</b>	<b>Cluver et al (2009)</b>
Kenya	<b>Zidron (2008)</b>		
<b>Controlled psychosocial and sociological studies</b>			
South Africa	Cluver et al (2007) (effects of stigma)	Clacherty (2001)	Strode and Barrett-Grant (2001)
	<b>Palin and Armistead (2007)</b>		
Rwanda and Zambia	Chatterji et al (2005)		
Uganda	<b>Gilborn et al (2001)</b>		
Guinea Bissau	<b>Aaby et al (2004)</b>	<b>Masmas et al (2004)</b>	
Nigeria	<b>Hilhorst et al (2006)</b>		
<b>Non-controlled psychosocial and sociological studies</b>			
Zimbabwe	Wood et al (2006)	Nampaya-Serpell (1998)	<b>Volle et al (2002)</b>
	<b>Chase et al (2006)</b>	<b>Foster (2005)</b>	
	<b>Rusakaniko et al (2006)</b>		
South Africa	Cluver and Gardner (2007) – risk and protective factors	<b>Nkomo (2006)</b>	
Malawi	<b>Kidman and Heymann (2009)</b>		
Uganda	Ntozi and Mukiza-Gapere (1995)	<b>Kamali et al (1996)</b>	
Botswana	<b>Tsheko et al (2007)</b>		
Rwanda	<b>Thurman et al (2006)</b>		

Non-controlled sociological studies			
South Africa	Masondo (2006)	Hirasawa (2007)	Giese et al, (2003)
	Van Den Berg, (2006)	Henderson	
	Heymann et al (2007)		
??	Nyambedha et al (2001)		
Zimbabwe	Mahati et al. (2006)	Foster et al (1997)	Foster et al (1996)
Uganda	Ntozi (1997)	Oleke et al (2005) (when the obvious brother is not there)	Ntozi et al (1999)
	Ntozi and Mukiza-Gapere (1995)		
Lesotho	Robson et al (2006)		
Ghana, Burkina Faso And Uganda	Stephenson (2009)		
Gambia	UNICEF(2004)		
Controlled sociological studies			
South Africa	Hosegood and Ford (2003)		

**Figure 1.1 Controlled and non-controlled studies**

Although this study, the first of its kind in the Gambia, provides useful information about social aspects of vulnerable young people (see Figure 1.1), it neither focused on AIDS-bereaved young people nor discussed psychological aspects of their loss. Bereaved young people from other parts of Africa served as an important comparison group for those in the Gambia; diversity of beliefs and practices surrounding death and mourning in different cultures in the same country and moreover across Africa (Kilonzo and Hogan, 1999) inevitably make comparison difficult. Stein (2003) warned researchers of the danger of assuming that study evidence from one African setting is relevant in all African contexts. African children grow up in diverse socio-cultural, economic, and political contexts with large variations between countries and in urban and rural areas within countries (Snider and Dawes, 2006). Such variations suggest paying attention to the contextual nature of research.

#### **1.4.3 Focus and characteristics of the studies**

Since the aim of this study has been to examine young people's emotional reactions and the social factors that influenced their coping, it was important to review literature incorporating both psychological and social aspects of young peoples' experience. The studies reviewed generally fell into two categories: (a) those focusing mainly on psychological reactions of bereaved young people; and (b) those discussing psychosocial or social aspects of bereaved

Countries	Authors	Sample characteristics	Control groups	Participants	Instruments
<b>African studies</b>					
<b>Gambia</b>	<b>UNICEF(2004)</b>	Nationwide survey 14523 adults, 14523 total young people, (1322 bereaved, 13201 non-bereaved young people) (under 12 years, 12-17 years old)	Street children, children of parent with chronic illness	All household members of selected young people included, all carers of under-12s and young people under 18 years	Non-standardised - structured questionnaire, interviews and focus group interviews
<b>South Africa</b>	<b>Clacherty (2001)</b>	20 HIV-positive young people living with positive carer, 39 young people from community, 29 HIV-positive adults, 26 adults from the community (under 18 years)	Non-HIV-positive children from community	HIV-positive young people living with positive carer, young people from community, HIV-positive adults, adults from the community	Non-standardised - participatory activities, Silhouetten figures (pictorial presentations of a family dynamic)
	<b>Cluver et al (2008) (effects of stigma)</b>	1025 participants 425 AIDS-bereaved 241 non-AIDS-bereaved 278 non-bereaved (10-19 years old)	Non-AIDS-bereaved young people, non-bereaved young people	Non-AIDS-bereaved young people, non-bereaved young people	Standardised - CDI, RCMAS, PTSD, peer problem, delinquency, conduct problem
	<b>Cluver et al (2007) (focused on psychological distress)</b>	425 AIDS-bereaved 241 non-AIDS-bereaved, 278 non-bereaved young people (10-19 years old)	Non-bereaved and non-AIDS-bereaved young people	Young people	Standardised - Child Depression Inventory (CDI), Revised Children's Manifest Anxiety Scale (RCMAS), Children's Behavioural Checklist (CBCL), Children's Post Traumatic Stress Disorder (PTSD) check list
	<b>Cluver and Gardner (2007) (risk and protective factors)</b>	60 bereaved young people 42 carers 20 professionals (10-19 years old)	No controls	Young people carers professionals	Non-standardised - worksheet based, semi-structured interview, focus group discussions
	<b>Cluver and Gardner (2006)</b>	30 AIDS-bereaved young people, 30 non-AIDS-bereaved young people, and non-bereaved (10-19 years old)	Bereaved young people and non-bereaved	Young people	Standardised - Strength and difficulties questionnaire (SDQ), Impact of Event Scale (IES), PTSD

<b>South Africa</b>	<b>Cluver, Gardner and Operario (2009)</b>	1025 adolescents	No controls	Adolescents	Standardised - Depression, anxiety, and SPSD
	<b>Cluver and Orkin (2009)</b>	1025 adolescents Cross-sectional survey	No control	Adolescents	Standardised - Depression, anxiety, and SPSD
	<b>Giese et al, (2003)</b>	21 participants 4 carers 5 orphans 12 key informants	No controls	Participants carers orphans teachers key informants	Non-standardised - instruments
	<b>Henderson, (2002)</b>	31 rural children and youth Aged 14-22	No control	Rural children and youth	Non-standardised - Ethnographic interviews
	<b>Hirasawa (2007)</b>	7 (13-24years old) from 6 Child-headed households	No control	Child-headed household heads	Non-standardised - Interview and observation
	<b>Hosegood and Ford (2003)</b>	10490 Household Orphan + household Non-orphans were interviewed	Non-orphaned household	Orphan, non-orphaned, adults from household with orphan and non-orphans	Non-standardised - interview
	<b>Masondo (2006)</b>	Ethnographic study of 8 orphans aged 13 to 19	No control	Orphans	Non-standardised - interview and observations
	<b>Mbizana (2007)</b>	30 bereaved zulu families	No control	Children and adults in the family	Standardised - questionnaire
	<b>Nkomo (2006)</b>	14 household heads (15-20)	No controls	Household heads	Non-standardised – interviews

<b>South Africa</b>	<b>Palin and Armistead (2007)</b>	225 Non-infected children (11-16 years) whose mothers were infected  225 infected mothers (24-53 years old)	Children whose parents were not infected.  Uninfected parents	Children whose parents were infected; children whose parents were not infected; infected parents; non-infected children	Standardised scales - Household Economic Social Status Index (HESSI), Child behavior checklist (CBCL), The Centre for Epidemiological Studies Depression Scale (CES-D), Social Resource, Social Support Questionnaire (SRSQ)
	<b>Strode and Barrett-Grant (2001)</b>	Replica study of Clacherty with additional informants - key role players (number not mentioned)	Non-HIV-positive children from community	In addition to the above - key role players working with children, HIV/AIDS and human rights	In addition to the above - interview with key role players
	<b>Van Den Berg, (2006)</b>	5 orphans, 4 carers, 12 key informants	No control	Carers, orphans and key informants	Non-standardised - interviews, observation
	<b>Wild et al (2006)</b>	81 AIDS orphans 78 'other causes' orphans 43 non-orphans	Other orphans and non-orphans	AIDS orphans, non-AIDS orphans, non-orphans	Standardised - Children's Manifest Anxiety Scale-Revised (R-CMAS), CDI, CBCL-YSR and the SEQ
<b>Ethiopia</b>	<b>Bhargava, A. (2005)</b>	1000 maternally orphaned children by AIDS or other cause	No controls	Maternally orphaned children	60 of 657 items from MMPI
<b>Mozambique</b>	<b>Manuel et al (2002)</b>	76 orphans 74 non-orphans carers	Non-orphans	Orphans and non-orphans Carers	Non-standardised - questionnaire

<b>Congo</b>	<b>Makaya et al</b>	354 orphans.	No control	Orphans	Non-standardised - Examination and interviews by clinical Psychologists
<b>Zimbabwe</b>	<b>Chase, E., Wood, K., and Aggleton, P. (2006) – see next page for continuation</b>	<b>Ethnography study</b> Household case study – 6 sites, each with 3 case studies, in a household with the head chronically ill, with a youth as the head, where a young person had been fostered	No controls	Household members	Non-standardised - Observations, in-depth interviews and drawing pictures
	<b>Foster et al (1997)</b>	570 households (Sample: 60 clusters of 10 households randomly selected)  12 key informants	No controls	Community members, carers, teachers	Non-standardised - Orphan Enumeration survey Interview, Focus group
	<b>Foster et al (1996)</b>	25 volunteers, 300 orphan households; 292 orphans and 17 non-orphans (majority are under 10 years) from 702 households	Non-control	Orphans, non-orphans, adults	Non-standardised - instrument - interviews
	<b>Foster et al (2005)</b>	Orphans (n=292), volunteers (n=25) and non-orphans (n=19)	Non-orphans	Orphans, non-orphans	Non-standardised - interviews
	<b>Mahati et al (2006)</b>	27 carers, 33 OVC (6-24 years), 23 members of the community	No control	carers, orphans, vulnerable children, community members	Non-standardised measures - interviews
	<b>Nampaya-Serpell (1998)</b>	Carers: 645 urban and 291 rural orphans (0-15 years old)	No control	Carers	Non-standardised - interviews
	<b>Nyambedha et al (2001) Longitudinal study</b>	100 orphans caretakers 24 key informants, 14 women in 40s, 14 men in 50s, 5 orphans aged 10-14.	No controls	Orphans, caretakers, key informants	Non-standardised - in-depth interviews focus groups narratives and household monitoring

<b>Uganda</b>	<b>Atwine et al (2005)</b>	123 AIDS-bereaved 110 non-bereaved (11-15 years old)	Non-bereaved	Young people	Standardised - Beck Youth Inventory (BYI)
	<b>Gilborn et al (2001)</b>	On-going study 1407 study participants: 728 children, 353 parents, and 326 standby or current guardians from PLHA (n=353) households and orphan households (n=227)	Ongoing quasi-experimental study with 2 study sites. One control arm and 2 experimental arms	Study participants consist of parents who are living with HIV/AIDS, current and standby guardians, children of PLHA, and orphans	Non-standardised - interviews
	<b>Kamali et al (1996)</b>	10000 participants; 518 (under 15) orphans	No control	Young people, carers	Non-standardised - interviews
	<b>Kumakech et al, (2009)</b>	326 AIDS-orphans (10-15) 159 orphans 167 non-orphans	Randomised controlled	AIDS orphans, orphans and non-orphans	Standardised - BYI
	<b>Musis et al (2007)</b>	Unmatched cross-sectional case control of randomly selected orphans (210) and non-orphans (210)	Non-orphans	Primary school orphans, non-orphans; teachers	Standardised - Rutter scales, psychometric assessment, Cooper's self report measures, FGD
	<b>Ntozi et al (1999)</b>	1206 household members	No control	Household members	Non-standardised - interviews
	<b>Ntozi (1997)</b>	1797 households affected by death - under 18 years (n=4502); 18 years old (n=744) and above 18 years old (n=605 )	No controls	Under 18 years old	Non-standardised - interview
	<b>Ntozi and Mukiza-Gapere (1995)</b>	232 adults (35-92) - 24 focus groups; 557 young people and adults (aged 14-34) - 22 focus groups	Non-controlled study	Young people and adults	Non-standardised - Focus group discussion

<b>Uganda</b>	<b>Oleke et al (2005) (when the obvious brother is not there)</b>	Community leaders (21), household heads (45) and orphans (35) from 402 households	No controls	Carers, orphans community leaders	Non-standardised - FGD
	<b>Sengendo and Nambi (1997)</b>	169 AIDS-bereaved 24 non-bereaved (6-20 years old)	Non-bereaved	Young people, teachers, carers	Non-standardised - interviews and depression scale
<b>Ghana, Burkina Faso, Uganda</b>	<b>Stephenson (2009)</b>	Aged Male (15-45) Female (15-59): Burkina Faso M = 1158, F = 3620; Ghana M = 1478, F = 1628; Zambia M = 728, F = 2805	No control	Nationally representative sample - all eligible people in the sample households	Non-standardised - interviews
<b>Malawi</b>	<b>Kidman, and Heymann (2009)</b>	Integrated household survey: 27975 children from 9331 households. Study children under 18	No control	Young people under 18	Non-standardised - interviews
<b>Botswana</b>	<b>Heymann et al (2007)</b>	Family Health Needs Survey, 1033 adults	No controls	HIV-positive adult carers from general out-patient, maternal and child health, and paediatrics clinics from 3 hospitals	Non-standardised - interviews
	<b>Tsheko et al (2007)</b>	Survey Palapye village - 139 (15-18years) orphans	No controls	Orphans, vulnerable children	Non-standardised-interviews
<b>Nigeria</b>	<b>Hilhorst et al (2006)</b>	Household survey (508); 179 participants (15-49) from households with chronic illness and recent death	No control	Adolescents, adults, and community leaders	Non-standardised - FGD and interviews
<b>Lesotho Tanzania Zimbabwe</b>	<b>Robson et al (2006)</b>	Tanzania 781 children, Lesotho 100 (10-17years) children, Zambia 9 children household heads	Cross-cultural study	Orphans and non-orphans 10-17 years	Non-standardised - interviews

<b>Guinea Bissau</b>	<b>Aaby et al (2004)</b>	Relatives of a cohort of rural (128) and urban (192) children were interviewed with a control of 808 individuals	Group of adults	Relatives of the samples, non-relatives of the sample	Non-standardised - interviews
	<b>Masmas et al (2004)</b>	128 rural and 192 urban cohort of children had been followed by surveillance since 1990. Relatives of these children interviewed and non-relatives (808)	Cohort of non-relatives of orphans	Close relatives, other adults	Non-standardised - interview
<b>Kenya</b>	<b>Zidron (2008)</b>	411 (9-11) children	No control	Children	Standardised - BDI-Y, self report questionnaire
<b>Tanzania</b>	<b>Makame et al (2002)</b>	41 bereaved, 41 non-bereaved young people (10-14 years old)	Non-bereaved	Young people	Standardised - Randal Mental Health Inventory (RMHI) and Beck Depression Index (BDI)

**Figure 1.2: Summary of the studies reviewed**

young people's experience (see Figure 1.1). The majority (40) of the studies fell into the second category (b), with the remainder (21) being psychological studies.

The majority (39) of the studies reviewed were qualitative in nature and without controls, which increased their potential to be biased. Yet, these studies provided a wealth of information which could not be found in the quantitative studies. A good number (22) of studies were controlled, but there was no consistency in the way samples were matched with their controls (see Figure 1.2). In many studies reviewed here (e.g. Cluver et al, 2007; Nyamukapa, 2006; Atwine et al, 2005; Poulter, 1996; Cluver et al, 2007; Clacherty, 2001; Strode and Barrett-Grant, 2001; Chatterji et al, 2005; UNICEF, 2004; Sengendo and Nambi, 1997; and Van Eederwegh et al, 1982), age, gender or number of participants in the sample did not match those of their controls (see Figure 1.2).

Complexity of comparing these studies was compounded by the variation in the nature of controls used. Families (Poulter, 1996) households and communities (Robson et al, 2006; Aaby et al), non-relatives (Masmus et al, 2004), non-bereaved parents (Worden, 1996), non-AIDS-bereaved and non-bereaved were all used as controls (see Figure 1.2), with researchers using one (e.g. Clacherty, 2001; Strode and Barrett-Grant, 2001; Atwine et al, 2005; Sengendo and Nambi, 1997; Nyamukapa, 1996), two (e.g. UNICEF, 2004; Cluver et al, 2007; and Chatterjee et al, 2005) or no controls at all (e.g. Cluver and Gardner, 2007; Ntozi and Mukiza-Gapere, 1995; Brown et al, 2005; Wood et al, 2006; Nampaya-Serpell, 1998; Makame et al, 2002) (1.2).

Studies reviewed varied greatly in terms of size, the nature and age of participants. The majority of the evidence was gathered from studies (44) with sample sizes ranging from 123 (Atwine et al, 2005) to 1,322 (UNICEF, 2004); some was also gathered from studies (nine) with sample sizes ranging from 20 (Clacherty, 2001) to 105 (Van Eerdewegh et al, 1982), with the remainder gathered from studies with sample sizes smaller than 20. In addition to this variation, studies themselves varied regarding the participants, with some gathering evidence from young people, professionals and their attachment figures (see Figure 1.2), some only from young people (Atwine et al, 2005; Nyamukapa, 2006; Chatterjee et al, 2005; Makame et al, 2002; Brown et al, 2005; and Cluver et al, 2007), and others from only family members (Poulter, 1996 and Nampaya-Serpell, 1998). Using several groups of participants may have produced a better picture of the true experiences of bereaved young people, whilst evidence from only one source may have been more limited.

We know from developmental psychology that different age groups of bereaved young people may have a different level of understanding about death; and the nature of their reactions may be dependent on that understanding (Chris, 2000). Consequently, studies that used similar age groups should be compared to eliminate age-related bias. However, in this review, different researchers tended to use different terminologies (e.g. children, young people, adolescents, orphans). In this thesis, the term 'young people' (or 'bereaved young people') will be used but the differing nature of the age groups of those participating in these studies remains (see Figure 1.2). Apart from a few studies (Cluver and Gardner, 2007; Cluver et al, 2008; and Cluver et al, 2007), where the age group is ten to 19, every study has its own separate age group or range of age groups. With none of the existing studies dedicated

specifically to AIDS-bereaved young people between 15 and 18 (the target group for this thesis), comparison will be difficult.

In existing studies, several research methods were used to gather data, including standardised measures or scales developed in the West and on Western people (e.g. Cluver et al, 2007; Atwine et al, 2005; Poulter, 1996; Brown et al, 2005; Makame et al, 2002; Silverman and Worden, 1992; Van Eerdewegh et al, 1982). The scales used in these studies (see Figure 1.2) were as diverse as the studies themselves. One possible reason for this was the difficulty in capturing the diverse experiences of young people, and therefore the need to combine several scales to do that job; however, the diversity has made it difficult to compare studies.

Whilst this thesis intends to explore basic emotions, these scales generally focused on examining young people's vulnerability by measuring the intensity of their emotional reactions to loss. Categorising bereaved young people's experiences into internalising (e.g. depression) and externalising (e.g. antisocial) behaviours was not helpful in understanding their basic emotions in detail, or the complexity of their reactions to loss, and so quantitative work of this kind is not the focus of this thesis.

#### **1.4.4 The limitations of the existing literature**

Even though the literature is growing, it remains difficult to draw definitive conclusions because the reported studies, almost all conducted in countries other than the Gambia, used diverse methodological approaches and different sample sizes. None has focused on the specific age group to be studied in this research. Furthermore, only a few studies considered the influence of social factors on bereaved young people's ability to cope with loss. Consequently, there is inadequate research evidence accounting for the experiences of AIDS-bereaved young people (15-18 years) from the Gambia within this broader context. Since knowledge on the subject is incomplete, this thesis aims to help bridge the gap.

With all these challenges, the last eight years (see Figure 1.1) have brought more attention to the emotional impact on AIDS-bereaved young people; furthermore, there has been progress in research and consistent evidence suggesting not only that young people might experience

emotional reactions but that these reactions might also be intense. The following sections discuss findings from these studies.

## **1.5 Psychological impact of AIDS-related death of a parent**

### **1.5.1 Internalising and externalising behaviours**

#### **1.5.1.1 Internalising problems (emotional response)**

A review of the relevant literature suggests that a substantial amount of research pays attention to the socio-economic effects of HIV/AIDS on children and there is a tendency to avoid the ‘hidden wounds’ or emotional suffering of AIDS-bereaved young people who are trying to cope with their loss (Stein, 2003). The socio-economic aspects of AIDS-related loss and the stigma and discrimination attached to it suggest that bereaved young people might be experiencing multiple impacts (Cluver et al, 2009). Whilst these factors may remain crucial regarding how young people cope with their loss (Cluver et al, 2009), this section focuses more on the psychological impact of loss itself (bereavement). As we have seen, Cluver and Gardner (2008) defined reactions to loss into two broad areas: internalising and externalising problems. Internalising refers to internal manifestations of psychological distress (e.g. depression, anxiety, sadness, worries, loneliness and anger) in contrast to externalising through acting out behaviours (e.g. behavioural problems and conduct problems).

Although there is still a paucity of research evidence in this field, there is encouraging evidence that some progress has been made in Africa (Cluver and Gardner, 2007). The various studies have shown remarkable agreement regarding the association between death and young people’s emotional reactions to loss (Nyamukapa et al, 2006; Makame et al, 2005; Manuel, 2002; Sengendo and Nambi, 1997). There is strong evidence that the common basic emotional reactions included sadness, anger, anxiety, emotional loneliness, fear and denial (Poulter, 1996; Nyamukapa et al 2006; Silverman and Worden, 1992 Worden, 1996; Van Eerdewegh et al, 1982), which will be explored in a separate section later in this chapter.

Studies in Zimbabwe (Nyamukapa et al, 2006), Tanzania (Makame et al, 2005), Mozambique (Manuel, 2002) and Uganda (Sengendo and Nambi, 1997) reported statistically significant

findings for increased internalising problems (depression, anxiety, worry/stress) when bereaved young people were compared with non-bereaved, or children living with HIV-positive parents or sick adults. For example, in a large study in Zimbabwe, the bereaved status of the young people in Nyamukapa et al's (2006) study remained associated with internalising problems after controlling for differences in poverty, sex and age of the head of household, school enrolment and support from the closest adult and external sources. However, young people whose parents had died within the last year showed signs of more severe psychological distress than those whose parents had died further into the past but these differences were not significant. The researchers did not show the date, so it is not clear what 'further into the past' stood for in their research.

In a study in Tanzania using non standardised internalising problem scale, Makame et al (2005) interviewed bereaved young people and their controls (non-orphans). They found that bereaved young people had increased internalising problems ( $p < .0001$ ) such as depression compared with non-bereaved young people. Manuel (2002) used an internalising scale adapted from the above study and found bereaved young people experiencing more internalising problems than non-orphans. The bereaved young people were more likely to be depressed and bullied ( $< .001$ ) than non-bereaved. In Uganda, bereaved young people were found to be significantly more depressed ( $< .05$ ) and more worried about the future than non-bereaved young people ( $< 0.05$ ).

Whilst this finding suggested that bereaved young people experienced internalising problems such as depression, worries, sadness and anger primarily as a result of the loss of a loved-one, the effects of stigma and discrimination might have compounded this finding. In their study, Makame et al (2005) also reported 'going to bed hungry', 'being a female child', and 'not being in school' influenced the bereaved young people's internalising problems but it is not clear to what degree this had influenced bereaved young people's experiences. In Nyamukapa et al's (2006) study, despite the overall significant difference between the bereaved and the non-bereaved young people in internalising behaviours, there were a few significant differences in anxiety or self-esteem between bereaved and non-bereaved young people. Cluver and Gardner (2006) noted that both orphans and non-orphans scored highly for psychosocial distress and there were no statistically significant differences on total scale

scores. The small sample size might not have been enough to detect any significant differences in the total score.

However, other studies found little or no difference between bereaved and non-bereaved young people's internalising problems. For example in Uganda, Musis et al (2007) conducted a cross sectional case controlled study and found significant levels of emotional and behavioural problems, but overall there was no significant difference between the bereaved and non-bereaved young people. In contrast to the scales used on the bereaved young people, the focus group discussions with the teachers and guardians described bereaved young people as poor, clinging and difficult to please.

In South Africa, Wild et al (2006) also found non-AIDS-bereaved young people (whose parents died due to other causes) reported more anxiety and depression than non-bereaved young people and lower self-esteem than non-bereaved and AIDS-bereaved young people. However, the AIDS-bereaved young people's reported internalising behaviour was not significantly different from either samples. The researchers speculated that, as the sample was recruited through a sponsored (NGO) organisation, they were likely to receive support that had a protective effect on psychological outcomes.

Whilst the analysis of this literature seemed to suggest that AIDS-bereaved young people reacted to the loss of a parent, it is not clear the degree of influence other factors such as stigma, discrimination and poverty had on their responses. Therefore this study will investigate the psychological impact of loss on bereaved young people focusing on internalising behaviours.

#### 1.5.1.2 Parental death and externalising behaviour

Wild's (2001) review of studies conducted worldwide reported a high rate of externalising behaviours among American samples. However, until now very little evidence has existed in Africa to suggest that AIDS-bereaved young people experience acting out behaviours as a result of the loss of a loved-one (Cluver and Gardner, 2007); this supports Bray's (2003) view that predictions of a large number of antisocial agents and criminals emerging in Africa as a result of parental death are without evidence.

However, there is a little evidence to suggest that bereaved young people are involved in acting out behaviours.

Studies in child-headed households in South Africa (Nkomo, 2006; Masondo, 2006; Nelson Mandela Children's Fund, 2004) and Zimbabwe (USAIDS/Zambia/SCOPE, 2002) pointed to the difficulties experienced with controlling and managing siblings as well as lack of respect among siblings. Often heads of household felt frustrated and helpless because they had lost control of their siblings. They were found to be frequently involved in wrongdoings such as gambling and stealing (Masondo, 2006) and some were involved in conflicts with other young people (USAIDS/Zambia/SCOPE, 2002).

However, none of these researchers claimed that the behaviour of the bereaved young people was a reaction to their loss. For example, Nelson Mandela Children's Fund (2004) on the subject of young people in child-headed households claimed that 'the children lack guidance, they have no one to give a sense of direction, and they don't have a role model in the home so they adopt a less desirable value' (p.22). In contrast, Bray (2003) noted that young people lacking adult guidance were not prone to externalising behaviour, unless they lived in communities where people stigmatised and discriminated against them.

There is mixed evidence amongst controlled studies. In South Africa, Cluver et al (2007) investigated internalising and externalising behaviour of bereaved young people and their controls. They found AIDS-bereaved young people reporting higher levels of peer problems, conduct problems and delinquency ( $p < .001$ ) than non-bereaved and other bereaved young people. Makame et al (2002) reported a high level of hyperactivity and antisocial behaviour, such as fighting with peers. They also suggested that bereaved young people may not have had the opportunity to mourn loss properly as the social environment discouraged such behaviour. This may support the view expressed by Bray (2003) that bereaved young people are only likely to act out if they are discriminated against or stigmatised.

In terms of risk behaviours, one study examined the relationship between the onset of sexual activity and psychosocial well-being in OVC. Nyamukapa et al (2006) found that maternal and paternal orphans (although not double orphans) aged 12-17 were more likely to have had sex than non-orphans, and early onset of sexual activity was associated with two factors:

being out of school, and increased psychosocial disorder. Other controlled studies found no group difference between the bereaved and non-bereaved regarding externalising behaviour (Wild et al, 2006; Poulter, 1997; and Cluver and Gardner, 2006).

Cluver and Gardner (2006) used a Stress and Difficulty Questionnaire, in which both groups were found to score highly for peer problems and emotional problems, suggesting that the environment was violent and stressful. Although orphans were more likely than their peers to view themselves as having no good friend ( $p=0.01$ ), there was no evidence of acting out behaviour. Since there is no clear evidence as to whether or not bereaved young people are involved in acting out behaviour purely in response to their loss, this thesis will further investigate the phenomenon.

### **1.5.2 The extent of emotional reactions to the loss of a parent**

Current research in Africa seems to suggest that becoming an orphan has a negative impact on a child's mental health (Cluver et al, 2007). This section reviews literature on the severity of the psychological impact of death on the bereaved young people. Although evidence is inconsistent, several studies investigating emotional problems in AIDS-bereaved young people have reported that bereaved young people are more likely to suffer from poor mental health than non-bereaved young people (Brown et al, 2005; Makame et al, 2002; Chatterji et al, 2005; Atwine et al, 2005; Nyambedha et al, 2001; and Sengendo and Nambi, 1997). Such reactions from an African perspective include: suicidal ideation, depression, persistent crying, running away, and withdrawal. In their recent Rwandan study on the psychological problems of AIDS-bereaved youth household heads aged 12 to 14 years, Brown et al (2005) found them experiencing emotional reactions beyond what may have been perceived as 'normal' in the African context. This was manifested by suicidal ideation, suggesting that young people experienced intense emotional reactions.

Consistent with Brown et al (2005), Makame et al (2002) provided evidence from a Tanzanian study of 10- to 14-year-old AIDS-bereaved young people that showed elevated levels of depression, irritability, hyperactivity, hopelessness and suicidal ideation. The researchers reached a general conclusion that the long-term mental health of bereaved young people was in jeopardy in the absence of mitigating interventions. Whilst they found more

bereaved young people (34%) than non-bereaved (12%) wishing themselves dead, there was no concrete evidence to suggest that the high rate (34%) of suicidal ideation was directly related to their loss itself. It might be that environmental factors influenced the high percentage of suicidal ideation in bereaved young people. Similar study in a different environment may lead to different outcomes.

In their Zimbabwean study, after controlling several factors, Nyambedha et al (2001) and Atwine et al (2005) found that 'being bereaved' was the only independent predictor of depression among the young people. Atwine et al (2005) used regression analysis to reach this conclusion. Consistent with the above two studies, there is evidence from Zimbabwe that the death of a parent ('being bereaved') remained closely connected with young people's intense emotional reactions (Nyamukapa et al, 2006). This conclusion was reached after controlling several factors (e.g. age of the household head, sex, poverty, school enrolment, support from friends and adults).

In Kenya, Zidron (2008) examined the association between young people's bereavement and depression using Chi-square analysis. The researcher found bereaved young people had significantly higher scores than non-orphans. There was a higher tendency towards depressive feelings. Bereaved young people were significantly ( $p=0.001$ ) more depressed than non-bereaved young people in general. Yet, in terms of gender, there was no difference between male-bereaved and non-male-bereaved young people. However, the researchers reported trouble in translating several items in the Beck's Depression Index they used. They also questioned the cultural validity of the instrument in Kenya.

Cluver and Gardner (2006) measured post traumatic disorder using the Impact of Events Scale (IES) on only the bereaved young people and found 73% of the participants experiencing post-traumatic stress disorder (PTSD). Since this study did not control the traumatic effects of stigma and discrimination, it is difficult to know whether the experiences of the bereaved young people were mainly as a result of the bereavement alone or the associated experience of abuse, stigma, exploitation and high levels of daily stress.

Whilst the above studies seem to agree that AIDS-bereaved young people experienced intense emotional reactions, there are national and international reports suggesting that not all

bereaved young people have experienced the same degree of emotional reaction to their loss. Consistent with Makame et al (2002), Worden (1996) found that only a minority in the USA had some form of emotional difficulty. Similar evidence has also been found in African studies. Poulter (1996) found in Zambia that, although bereaved young people scored more highly in emotional reactions than non-bereaved, their reaction was at the normal level.

In Gilborn et al's (2001) Uganda study, all the young people reported high levels of exposure to traumatic events and daily life stresses, with girls more likely to experience psychosocial distress and trauma than the rest. There was no difference between bereaved and non-bereaved young people, suggesting that multiple factors may be responsible for this distress and trauma.

Other studies have not reported any differences between bereaved and non-bereaved young people's experiences (Tsheko et al, 2007 and Palin and Armstead, 2007). Palin and Armstead's (2007) study reported that parental HIV infection did not serve as a unique stressor. Muis et al (2007) also found HIV stigma and discrimination influencing intense emotional reactions amongst bereaved young people, suggesting that bereavement alone might not lead to the intense emotional reactions experienced by bereaved young people. Therefore this study will investigate the extent to which bereaved young people react to their loss.

### **1.5.3 Emotional expression and its importance to bereaved young people**

The study of emotional expression dates back to Charles Darwin's scientific investigations (in 1870) that contributed to the development of an evolutionary-expressive approach to emotions (Darwin, 1965). Darwin's basic message was that emotional expression is evolved and (at least at some point in the past) 'adaptive' (Hess and Pascal, 2009, p.120) and it is viewed as expression of an underlying emotional state. Fridlund (1994) considered Darwin's definition as a misnomer and argued that facial expression for example is a communicative signal only and may not be related to an underlying emotional state; yet after an extensive review of literature, Parkinson (2005) concluded that facial expression may serve as both communicative signal and symptom of underlying state. Drawing from this literature one may define emotional expression in this thesis as an observable behaviour that communicates

and/or symbolises a strong feeling with/without the awareness of the person experiencing it. To some extent an individual may control such expression or may have deliberate intent in displaying it (Kennedy-Moore and Watson, 1999).

Emotional expression is the heart and soul of Western talking therapy. There is a widely held belief among laypeople and professionals in the Western culture that expression of feelings is healing and bottling them up is a danger to health (Bowlby, 1980). The idea of bottling up (also referred to as the hydraulic model of emotions), which has been rejected by some Western scholars (Kennedy-Moore and Watson, 1999), suggests that emotions build up inside us like steam in an engine. This hydraulic metaphor suggests that unpleasant experiences bottled up create discomfort and may be dangerous (Kennedy-Moore and Watson, 1999).

In the West, it is not uncommon to hear the expressions 'letting off steam', 'releasing emotion', 'let it all out' and 'release pent up emotions'. All these show how culturally ingrained hydraulic philosophy is. Kennedy-Moore and Watson (1999) proposed a venting hypothesis that attempted to capture the essence of the 'hydraulic model of emotion', which referred to the idea that the more one expresses emotions, the greater the relief and the immediate beneficial effects of such an expression.

Bereavement literature has consistently suggested that choosing not to express in the early aftermath of a loss is actively harmful if not pathological (Middleton, Moylan, Raphael, Burnett, and Martinek, 1993). Some have suggested that it leads to: distance in relationships as it impairs communication and intimacy (Gross, 1989); development of chronic stress, and stress exhaustion (related to a number of physical problems) (Jewett, 1994; Watson and Pennebaker, 1989); and unhealthy coping such as substance misuse (Jewett, 1994).

Despite the strong belief that emotional expression is helpful in coping with traumatic events including loss of a parent, research has not always supported these assumptions. Wortman and Silver (2001) argued that such an assumption was a myth and Zech and Rime (2005) showed that emotional expression did not produce recovery. From the findings of their September 11 study, Seery et al (2008) suggested that bottling up of emotions was even more helpful than emotional expression. This suggests that it might be helpful to review the bottling up theory (Zech and Rime, 2005 and Seery et al, 2008).

Whilst these studies suggested the need for more research in emotional expression and inhibition, there is growing evidence in the West supporting the assertion that emotional expression can play an important role in individual adjustment, social interaction and therapeutic success. There is evidence that, when people express their thoughts and feelings after a traumatic event like death, they report fewer illnesses (Pennebaker 1988), decreased painfulness of thoughts surrounding traumatic experiences, reduction of distress and depression, improved physical and mental health (Pennebaker, 1997; Greenberg and Stone, 1992; Greenberg et al, 1996) and immune functioning (Pennebaker, 1988). Emotional suppression reduces rapport and positive relationship as well as producing a physiologically stressful encounter for the individual engaged in conversation with the suppressor (Butler et al, 2003).

Although there is little research evidence to suggest that Africans or Gambians in particular, share the same assumption with the West regarding emotional expression, African rituals and mourning practices are indications of the significance Africans attach to emotional expression after loss. Kilonzo and Hogan's (1999) extensive review of mourning practices from over 120 ethnic groups in Kenya generated a theory that seemed to support the Western assumption of emotional expression. The authors reported that African mourning practice is characterised with extensive emotional expression mostly in the form of rituals. Apart from wailing and chanting which is often attributed to women after the loss, several other rituals are observed that demonstrate openly the intensity of their sorrow and remorse, and facilitate acceptance of their loss (Kilonzo and Hogan, 1999). Kilonzo and Hogan (1999) reported that the following are common: wailing on arrival at the funeral home; narrative from the widow/widower about how it (death) all happened; sobbing by the widow/widower; special black cloth for the widow; restriction of movement away from funeral home for the widow; seven and 40 days' ritual which allow them to reflect on the event. All these rituals show the extent to which Kenyan people have expressed their emotions. Similarly, emotional expression through crying and rituals in Egypt (in Africa) (Wikan, 1988) are culturally sanctioned, encouraged and openly shared. Yet in Kenya, where the impact of HIV/AIDS is high, emotion appears to be contained or distracted by funeral arrangements, dealing with finances, stigma, discrimination, and communication problems, suggesting that the contextual nature of loss determines the extent to which one may express emotions.

Although the contributions of Kilonzo and Hogan (1999) and Wikan (1988) suggested that African and Western culture shared the same view regarding emotional expression, there has been a proliferation of literature from the West suggesting young people expressed their emotions in the same way as adults (e.g. Abrams, 1999, and Jewett, 1994). Yet neither African literature nor cultural practice seemed to hold the same position. Both the Kenyan and the Egyptian models of emotional expression through mourning rituals are based on bereaved adults and do not include bereaved young people. So we know very little about how the latter express their emotions and whether they do so in the same way as adults in Africa. Little is known as to whether they are forced to bottle up their feelings or they do so voluntarily, not wanting to express them.

Whilst several kinds of emotional expression have been identified by literature, which includes writing (Pennebaker, 1997), the review in this section focuses on two forms of emotional behaviour that may be indicative of young people's emotional expression.

The first is crying behaviour (Silverman and Worden, 1992) and the second emotional verbalisation (see the following section).

#### 1.5.3.1 Crying as a behavioural reaction to parental loss – was it sanctioned?

The evidence from both the Western (and Worden, 1992; Worden, 1996 and Van Eederwegh, 1982) and African studies (Brown et al, 2005; Poulter, 1996; Segendo and Nambi, 1997) that focused on the psychological impact of loss, suggested that one of the most common forms of behavioural manifestation of emotional expression among bereaved young people was crying.

In the Harvard Bereavement Study of American young people (Worden, 1996), emotional expression through crying occurred in 91% of the sample immediately (within the day) news was heard. Although there was no significant difference between boys and girls, more immediate crying was reported when death was sudden rather than expected; and younger children were likely to cry more than older ones. In France, Van Eerdewegh (1982) observed crying behaviour within the first 13 months after the death, suggesting that emotional expression through crying occurred at the aftermath of loss.

Turning to African studies, research by Brown et al (2005) in the poorest regions of Rwanda produced results consistent with the Western studies regarding emotional expression through crying behaviour. The main purposes of the study were: to gather local vocabulary on psychosocial distress for use in developing a survey instrument; and to enhance understanding of emotional experiences and factors influencing them. In this study, especially at the beginning of their interviews, the young people contained their emotions. But as time went by (during one interview) they expressed intense emotions through crying. There is reason to believe that the initial containment of emotions during the interviews was an indication that young people had bottled up their emotions and the interview provided them the opportunity to unravel the burden. Whilst HIV/AIDS is associated with stigma and discrimination (Foster et al, 2004) the bottling up of emotions by young people may be due to the fear of negative attitudes of people towards them.

Other African psychological studies included crying as one of their measures. For example, both in Zimbabwe (Poulter, 1996) and Uganda (Segendo and Nambi, 1997; Musis et al, 2007) studies found crying after the loss of a parent to be a common emotional reaction among bereaved young people. These studies were interested only in identifying the presence or absence of crying behaviour among bereaved young people. Whilst crying seemed to be interpreted as a sign of sadness, neither of the studies showed when exactly crying occurred, or whether adults allowed bereaved young people to cry. Although expression of emotions was perceived to be helpful in coping by Western researchers (see section 1.4.2 above), this information might have been more useful if the attitude of adults towards bereaved young people's crying behaviour was known. It will also be important to know whether or not a young person cries frequently months and years after the loss, because that will give us a clue as to whether young people are coping with their loss. This study will investigate whether bereaved young people cried after their loss and, if they did, how such a reaction was perceived by adults.

### 1.5.3.2. Emotional verbalisation – the importance of allowing bereaved young people to talk

Talking about emotions or talking therapy is the main thrust in bereavement interventions or counselling in the West (Jewett, 1994). It is underpinned by the assumption that for the bereaved to cope with the loss, they have to talk about their feelings. It is therefore not a surprise that there is a proliferation of scholarly and non-scholarly literature on the need for the bereaved to talk about their loss so that they will release tension – this being required for adequate coping to occur. Bowlby (2005) went to the extent of seeing active engagement with loss often through talking as the only means of attaining adequate coping. Whilst this assumption is refuted by some other scholars (see DPM), talking about feelings remains an important aspect of bereavement literature.

Researchers have investigated the reasons people discuss negative experiences. These include the natural urge to express emotions (Rime et al, 1998), minimise anxiety (Festinger, 1954), and look out for support (Davison, Pennebaker, and Dickerson, 2000). Talking about negative experiences such as loss may go on for years, but most social expression of emotions occurs in the aftermath of the event (Rime et al, 1998). Two unpublished studies in the Netherlands (cited in Rime et al, 1998) that examined whether young people (aged eight to 17 years) spoke to others about their feelings after an emotional event experienced in the past reported talking about feelings in more than 90.4% of the cases.

Whilst 90.4% may suggest prevalence of talking after a traumatic incident, fewer people may be engaged in talking as time passes by. Pennebaker and Harber (1993) showed how sufferers from Loma Prieta earthquake initially engaged in very high levels of talking in the immediate aftermath of the event. After six weeks the sufferers encouraged others not to talk about their experiences and they started bottling up their thoughts and feelings but they reported the desire to discuss their own experiences. Pennebaker and Harber (1993) also developed a social stage model reflecting the experiences of Persian Gulf War sufferers. According to the author, in the immediate aftermath of the event there was prevalence of thinking and talking about the event; thinking continued but talking stopped in the first two weeks after the loss. Then individuals experienced physical and social problems, and by six to twelve weeks after the event individuals adjusted to the situation and then adapted.

Other studies reported the health benefits of talking about loss. Two randomised controlled studies in the Netherlands that were conducted by Zech and Rime (2005) among psychology students reported that talking about an emotional event was associated with more emotional relief and better understanding of their experiences than their controls. It also made them feel understood and more comforted by those who listened to them. However, Lepore et al's (2004) study in the USA and Spain on college students reported that talking alone was not very helpful to female college students. When they compared several groups of participants, Lepore et al (2004) found that students whose reactions to an emotional event were challenged by their confederates reported significantly lower distress when they were exposed to the same emotional event two days later than students who did not talk and students who talked but did not receive any feedback from their confederates. They were also found to gain new perspectives on their stressful situations that may have helped to reduce some of the negative psychological distress associated with the event.

Despite what appears to be an important role of 'talking cure/therapy', many scholars have warned against reliance on this theory. Kennedy-Moore and Watson (1999) warned that individual differences may count when it comes to expression or non-expression of emotions. Seery et al (2008) argued that, 'if people who are more distressed are more likely to express (e.g., see Pennebaker, Zech, and Rime, 2001), choosing not to express in the wake of a trauma may reflect resilience rather than vulnerability' (p.658). Consistent with this view, Seery et al (2008) suggested that we should not always tell people that they should express their thoughts and feelings, but should also tell them that it's okay not to express them if one is not yet ready. This view was consistent with Stroebe and Schut's (1999) DPM model which suggested that expression (loss-orientation) should oscillate with non-expression (restoration-orientation) of grief. Whilst these scholars recognised the importance of verbalisation of emotions, they seemed to suggest flexibility and choice regarding participation in talking therapy.

### 1.5.3.3 Are bereaved young people permitted to verbalise their emotions?

The UN Convention on the Rights of the Child emphasised the child's right to freedom of expression and opportunity to be heard. This included the right to share their worries and concerns with others. Although this convention was adopted by many states including the

Gambia (UNICEF, 2004), many young people across the world still seemed to be deprived of the opportunity to be heard (Casas et al, 2006).

Whilst there is no evidence that young people in the Gambia are sanctioned by the culture to verbalise their thoughts and feelings at the aftermath of loss, there is evidence that young people have the desire to be involved in family decision making. A household survey of adults (14,523), orphans and vulnerable children (under 12 and 12-17 year-olds) (14,523) conducted by UNICEF (2004), reported that young people identified freedom to express their views and their involvement in decisions affecting them as part of their rights (UNICEF, 2004). Whilst adults interviewed in this study generally agreed with these views, those from one ethnic group (Jola) said that they expected that all decisions would be made on behalf of young people by adults.

In addition, there seemed to be evidence from the other ethnic groups that when there was disagreement, adults' decisions stood, suggesting that young people were likely to be passive participants in matters affecting them. This implies that young people may have been restricted by their culture in expressing negative thoughts and feelings at the aftermath of death. Such a restricted model of emotional expression for bereaved young people has been supported by studies conducted in other parts of Africa (Nampanya-Serpell, 1998; Wood et al, 2006).

Whilst adults might be comfortable discussing death with their fellow adults (Kilonzo and Harrett, 1999), there is evidence that they may have difficulty in communicating and helping young people to talk openly about their concerns, especially those related to loss (Wild, 2001). A study in Lusaka (Nampanya-Serpell 1998) collected data about the psychological well-being of Orphans and Vulnerable Children (OVC – 'orphan' refers to a child under 18 years of age whose parent has died of AIDS; 'vulnerable' refers to a child under 18 whose parent has HIV). The research reported that less than one-third of the carers were involved in discussions relating to loss, suggesting that the majority of the bereaved young people were unheard.

Consistent with this finding, a Zimbabwean (Wood et al, 2006) anthropological case study with bereaved families and families with a terminally ill parent, found that many bereaved

young people were not told that their parent had died, let alone been given the opportunity to discuss their loss-related feelings. Although many of the bereaved young people said they wished to be told, most adults did not entertain any kind of discussion about death. This anthropological study suggested this was to protect young people from distress. Consistent with this Zimbabwean study (Wood et al, 2006), another study from Uganda (Sengendo and Nambi, 1997) found adults misinterpreting signs of emotional reactions as unacceptably bad behaviour. In these studies coping well seemed to be strongly associated with avoiding any sort of expression of emotions, and constitutes as being 'strong'. The researchers in these studies concluded that adults were not well enough equipped to identify and help young people to manage or positively cope in their loss.

Whilst the need for adults to help young people verbalise emotions at the aftermath of death has been advocated by many scholars (Wood et al, 2006), listening to the problems of others can be distressing (Pennebaker, 2004). Adults who are themselves trying to cope with the loss, and possibly their own HIV-positive status and impending death, may wish to avoid any reminders. Such a burden may force some people to request one to stop talking about the painful event, change the topic or give an ineffective answer (Pennebaker et al, 1997), disregard the question or evade the speaker (Lepore and Greenberg, 2002). However, not all studies seemed to support the evidence that adults have difficulty sharing negative thoughts and feelings with young people. In Botswana, Tsheko et al (2007) found open communication between bereaved young people, carers, other adults and friends. In this study almost all (70) the young people were encouraged by their carers to talk when they were down, most (62) felt they had been listened to and many were spoken with kindness. However, as the instrument used in the study was administered among the under 15s, the findings may not be totally applicable to the study participants (15 to 18 years) in this thesis.

Whilst some evidence has suggested that young people's lack of verbalisation is the result of cultural norms (UNICEF, 2004), it is suggested elsewhere that carers lack adequate skills to encourage verbalisation (Wood et al, 2006; Sengendo and Nambi, 1997); however, Tshek et al (2007) found no problem in communication and stated that young people felt supported in verbalising their emotions. This inconsistency suggests the need for further research into the phenomenon, which this thesis aims to achieve.

## **1.5.4 Short and long-term reactions to the loss of a parent**

### 1.5.4.1 Do bereaved young people accept or deny the reality of their loss?

The term denial has a long history in the West (i.e. Europe and the USA) and it was first used in psychoanalytical theory by Freud (1961) who described it in the context of children and psychosis. From that perspective denial was seen as pathological (Freud, 1961). Researchers have now moved away from that pathological model to a more positive model. Dorpat (1983) described it as a defence mechanism that allowed us to escape either consciously or unconsciously from painful feelings or events. According to Horowitz (1983), denial is a normal phenomenon and it is often a temporary response to overwhelmingly stressful and disruptive situations. Clearly 'denial' is one's 'natural defence mechanism [that] may allow us to shutdown our emotional awareness and screen out potentially overwhelming or devastating information' (Jewett, 1994; p.66). It functions as a buffer after unexpected shocking news of death is received (Kubler-Ross, 1969). This implies that denial can be experienced as numbness, because it is a mechanism that does not permit us to feel and/or believe that loss has really happened. From a layman's perspective it can be seen as a black out, at least temporarily, before one becomes fully aware and feels about what is going on.

There is a common belief among laypeople, mental health scholars, and professionals that the very first reaction to loss is denial. The DPM also recognised that denial is an integral part of the process of mourning and is required when loss becomes too overwhelming (Stroebe and Schut, 1999). As there is inadequate literature on denial responses in the African context, much of this section will rely on Western literature.

This definition clearly suggested that the purpose of denial is to alter our perception about the reality of loss and make it appear unreal so as to create some form of comfort. This could be especially useful for bereaved young people who may face the mammoth challenge of engaging with both their developmental tasks and their loss (Balk, 1996). Archer (2001) suggested that having a break from intense emotions helped us to regain our strength to deal with our loss. According to Western literature, young people may be particularly prone to denial, in that they do not have the same capacity as adults (Shamoo and Patros, 1997) to process and actively engage with intense emotions for long (Chris, 2000). They process these

intense emotions in what Archer (1999, p.69) called 'smaller manageable doses' (p.69), allowing them to avoid being too overwhelmed by their loss (Kastenbaum, 2000).

Kastenbaum (2000) commented that denial becomes helpful when it 'allows people to selectively deny parts of the loss whilst linking and responding to what has taken place' (p.23). However, in situations when young people are too frightened to confront their emotions, they may get stuck in their denial responses, leading to depression or anger (Gebella et al, 1995). This may be even more prominent among AIDS-affected young people confronted with the social consequences of their parent's AIDS-related death.

Denial response amongst young people may begin when death is imminent, especially from chronic illness where there is a periodic 'remission and improvement' (Jewett, 1994, p.32), as in the case of AIDS. Drawing on Western academic literature, Jewett (1994) suggested that children and young people's 'wish that things could be different tends to override their ability to recognise the seriousness of the circumstances' (p.39) when their parents are extremely ill. The death of a parent may even intensify this experience. Dwelling on her Western experience of working with bereaved children, Dyregrov (1996) observed them responding to their loss with denial, with phrases such as 'it can't be true, you are wrong I don't believe you' (Dyregrov, 1996, p.13).

In a Western context there is evidence of denial response among young people in the USA (Worden, 1996). Worden, (1996) presented evidence that the bereaved young people were unable to discuss their loss with their peers and family members. This silence was found to be more common among young people showing aggressive behaviour, suggesting a prolonged denial response.

The evidence for denial response in Africa in general is scanty. Three studies have been reviewed of which only two have constructs directly related to denial response. One is a longitudinal study from the West (Worden, 1996) and the remaining two are African studies (Wood et al, 2006; and Sengendo and Nambi, 1997).

Wood et al's (2006) study in Zimbabwe found bereaved people expressing difficulty in accepting the death of their parents, responses which those around them saw as normal. The

researchers suggested that this response was related to the lack of communication within the family about the loss and its causes. In Sengendo and Nambi's (1997) study, although a majority of the young people responded to their questions, 4% of the participants gave no response. According to the researchers, their failure to answer questions could be interpreted as a denial response. The fact that they did not want to discuss their parents' death prompted the researchers to conclude that the young people were experiencing a chronic denial response, one similar to a primitive response. The researchers based their justification on Freud's psychoanalytical theory which suggested that the young people had bottled up their emotions and continued to find it painful to talk about them. They suggested that, unless they were helped to accept and discuss their loss with ease, they would not overcome their painful experiences. However the use of a Western standardised depression scale in this case may have been inappropriate and it may have been more appropriate to use methods with which Africans were familiar. In addition, the fact that this was a case study suggests that it might not have been applied to the larger population, especially to young people from the Gambia.

It is evident that there is a paucity of evidence from Africa regarding denial response to loss, yet there is evidence that young people may experience an intense emotional response (Atwine et al, 2005). Naturally one might think that bereaved young people would require a break from these intense emotions; however, the beliefs held in the society may not sanction this. From personal experience in the Gambia, both the religious and cultural (Mandinka) beliefs disapprove of disbelief expressed regarding death. As discussed later (see Anger, 1.4.3.4), there is a culturally induced perception that death is beyond our control and determined by God's absolute power. In view of this belief, it makes no sense to disbelieve, especially when it is seen as doubting the powers of God - in itself seen as a major sin. People are urged by religion to have faith and accept death as a predetermined event. It may be that this belief has been internalised by both African researchers and young people so that no one would like to be associated with it. However, if denial as suggested by psychologists is an unconscious reaction, young people's cultural belief may do little to deter it. This therefore begs the question whether Gambian young people, who are often religious, experience denial and, if they do, whether they communicate it to others. This thesis will examine denial from this perspective.

#### 1.5.4.2 Avoiding loss-related situations

Avoidance is a particular form of denial, described as a defence mechanism consisting of a refusal to deal with situations, objects and activities as a means of either complying with social expectations or preventing further painful emotional experiences (Jewett, 1994). The concept of 'avoidance' differs from psychological denial in that it is often based on a conscious decision to act. This implies that the bereaved consciously make decisions regarding their choice of response to loss. With avoidance, they embark on strategies to distance themselves from emotionally charged situations (Worden, 2006).

Preoccupation with caring responsibilities can be a way of avoiding thinking about the lost one. Many studies have found bereaved young people taking adult responsibilities. Such responsibilities are often seen as a burden, yet it is possible that they may derive emotional support from it. Robson et al (2006) found the caring roles of children to have both positive and negative consequences for young people, with some reporting that it gave them a feeling of warmth in caring for a loved-one. For young people the caring experience may be part of their strategy for basic psychological survival.

Payne et al (1999) claimed that it was not unusual for people to fall into the trap of fulfilling social expectations by acting in a certain way when they experienced loss. Facing stressful situations was always difficult, especially for young people dealing with the loss of their parents (Balk, 1996). One response of young people to loss was to temporarily distance themselves from all reminders that were likely to trigger or intensify their emotions. Jewett (1994) suggested that allowing such a person to have her own space would give her the chance to experience her emotions in a way suitable for her, but warned also that too much social withdrawal might affect relationships with others.

The only study that discussed the concept of avoidance within the African context was that of Wood et al (2006) who found a prevalence of avoidance in Zimbabwean society: both avoidance by adults of informing young people that a parent had died; and avoidance by both young people and adults of talking about death. The researchers reported that the bereaved young people had withdrawn and were not talking about their loss. Whilst their silence may have been related to fear of stigma and discrimination, Wood et al (2006) found the feeling

that it was a sign of strength, meaning that young people were coping with their loss, when the opposite might have been the truth.

The emergence of child-headed households in Africa may suggest that many bereaved young people will be involved in the avoidance approach to their loss through engagement in several activities that were previously accomplished by the deceased or ill parent. Evidence from research on child-headed households in Africa has shown the magnitude of responsibilities the so-called child-headed households held (Masondo, 2006). These young people often assumed the responsibilities of the deceased parent which included day-to-day running of the family (Urassa et al, 1997), provision of daily bread (meal), engagement in domestic chores (cooking, cleaning and washing) clothing and shelter (Naicker and Tshenase, 2004, USAID/Zimbabwe/ SCOPE, 2002), ensuring that their siblings go to school, they themselves go to school (Nkomo, 2006), ensuring siblings respect the house rules, family property is protected (Masondo, 2006; Nelson Mandela Children's Fund 2001) and siblings are protected from sexual exploitation (Nelson Mandela Children's Fund 2001; Nkomo, 2006). Whilst none of these studies linked the position of bereaved young people with the concept of avoidance, young people's engagement with all these activities simply meant that they would have little time to engage with the loss itself.

Young people's engagement and handling of these issues is referred to as restoration-oriented coping. Consistent with this view, Worden (1996) reported that in the Harvard Bereavement Study in the USA the bereaved young people were found to be acting as grown-ups and tried to be good to their surviving parents (trying to take care of them) in order to please them. They protected their surviving parent by behaving differently so that their emotional response and behaviour would not be considered a burden.

However, the evidence regarding African AIDS-bereaved young people is limited and consequently little is available with which to compare the findings in this thesis. Furthermore, none of the studies in this review defined 'avoidance'. Since their meaning may be different from the definition in this thesis, it would be unrealistic to rely too much on the findings of these studies (Wood et al, 2006; and Worden, 1996) for the purpose of comparison. It also seems that Wood et al's (2006) findings may not be appropriately generalised in the Gambian

context owing to the study's small size and research strategy (case study). This thesis will attempt to bring some light to this area.

Although the DPM suggested that a certain degree of avoidance either of the main stressor (e.g. loss) or minor stressors (secondary losses – e.g. financial) may be helpful in the short-term as a way of coping, it viewed permanent avoidance as unhelpful for the bereaved.

#### 1.5.4.3 Sadness

Sadness, a natural human experience, is expected to be felt by anyone who experiences loss (Jewett, 1994) and even possibly some animals (Bowlby, 1980). Bowlby (2005) commented that sorrow is a reaction to the loss of an attachment figure. The desire for the return of the lost one (e.g. yearning, pining, searching, withdrawing and weeping/crying) could be seen as behavioural manifestations of sadness (Archer, 1999); it is often verbally expressed as unhappiness, melancholy, feeling low, or temporary mood change (Payne et al, 1999).

The Harvard Bereavement Study in the USA found that the majority of bereaved young people (91%) expressed their feeling of sadness upon hearing the news on the very day their parent died; but it fluctuated over time (sometimes there were signs of sadness; and at other times there was none) (Worden, 1996). This fluctuating nature of sadness responses was also reported by Van Eerdewegh et al (1982) in France but only one to 13 months after the loss.

Only a few African studies reviewed in this thesis discuss young people's sad responses to loss (Sengendo and Nambi, 1997; Wood et al, 2000; Atwine et al, 2005; Worden, 1996; Van Eerdewegh et al, 1982; Poulter, 1996). Some African studies show that sadness is a basic response to the loss of a parent (Sengendo and Nambi, 1997; Wood et al, 2000; Atwine et al, 2005; Worden, 1996; Van Eerdewegh et al, 1982); however the evidence is weak in terms of detail.

The few available African studies on this topic have demonstrated agreement in terms of the prevalence of sadness among bereaved young people; however, they differed as to the degree of sadness experienced. Sengendo and Nambi (1997) provided evidence from Uganda that young people's sadness began during their parent's illness but the degree of their sadness worsened during their bereavement. After the loss, only 2% said they were sad but determined to face the future. Extreme forms of sadness (sad and hopeless, sad and scared)

were common (63%). Overall more bereaved (77%) than non-bereaved (24%) young people reported feeling 'sad all the time', suggesting the influence of a high degree of environmental stressors on bereaved young people's sad response.

Consistent with Sengendo and Nambi (1997) regarding intense sadness among bereaved young people, a Ugandan study by Atwine et al (2005) found young people were overwhelmed by sadness and had not recovered from it. This differs from an earlier study conducted in Zambia by Poulter (1996). Although the latter reported sadness among young people whose parents were ill, the researcher failed to report any experiences of sadness after the death (Poulter, 1996). It may be there were no changes in the level of sadness after the loss.

In Uganda Musis et al (2007) found sadness to be associated with both loss and other stressors. In their study, when the participants were asked their saddest moments they identified a parent's death, being excluded from the family and being considered an outsider. Whilst this indicated the association between young people's feelings of sadness and the loss of a parent, it was clear that stigma and discrimination associated with their loss had also triggered their feelings of sadness. This may have been true especially since many of them said they did not want to be called 'orphaned' as it showed that they were different from others.

Similarly, Tshenko et al (2007) reported that a majority (63%) of the bereaved young people in their study reported they had been unhappy at different times since their loss with some (5.1%) indicating that maltreatment of a parent (4.5%) made them unhappy.

Others found sad responses associated with missed opportunities (Sengendo and Nambi, 1997) and roles as caretakers (Masondo, 2006) rather than loss itself. In South Africa an ethnographic study of child-headed households found feelings of sadness associated with the roles of caretakers and providers of material support to their siblings (Masondo, 2006). They felt sad because the younger children looked up to them to do things for them and they were not always able to meet their needs. Whilst the researchers claimed to use the grounded theory approach, the sample might have been too small to reach the point of saturation and as a result valuable information might have been left out.

In Zimbabwe, Wood et al (2000) found that young people experienced recurrent episodes of sadness triggered by lack of day-to-day things that they desired, such as material support and attachment relationship with the deceased. Seeing other people with their attachment figures was found to trigger episodes of sadness. Since Gambians live in an extended family set-up (UNICEF, 2004), it would be hard to avoid seeing other young people with their parents, and so the above findings suggest that bereaved young people in similar African countries will continue to live with feelings of sadness.

Clearly the small amount of literature available on sad responses to loss suggests paucity of research in this area. Even the limited amount available is inconsistent, with some reporting a very mild form of sadness (Poulter, 1996), some severe (Sengendo and Nambi, 1997; Atwine et al, 2005; Van Eerdewegh et al, 1982), and one reporting chronic sadness (Sengendo and Nambi, 1997). These inconsistencies may be partly related to the lack of an operational definition of sadness in these studies. Therefore it is not always clear whether the studies are referring to depression or sadness, making it hard to compare the existing evidence.

This thesis intends to increase our understanding of the extent of young people's sad responses to their loss in the African context.

#### 1.5.4.4 Anger

The word 'anger' may be commonly used, but it is hard to define and even harder to find a single definition. Schieman (2000, p 2586) defined it as an inner experience: 'uncomfortable feelings and thoughts and ... expressed in the form of resentment, irritation, annoyance, rage, exasperation, disgust, envy, torment'. Behavioural perspectives of anger focus on the outward signs of anger such as yelling, sarcasm, glaring, hitting and cutting; according to Thomas et al, (1970) it can also be experienced 'inwardly' or in the form of 'escape behaviours' such as rationalisation, denial and use of defensive methods. Crying may therefore be a behavioural sign of both sadness and sometimes of anger (Jewett, 1994) whether or not it accompanies aggression.

What seems clear is that anger is an intense emotional reaction associated with a fight against what is perceived to be undesirable. Bowlby (1998) suggested that anger is an intense

reaction to disruption of attachment relationships. It may be directed at someone perceived as responsible for the loss or those reminders and people who bring home the reality of loss (Parkes, 1970). However, it is not uncommon for even very young children (at least in the West) to redirect or displace anger towards other targets such as peers, which may lead to distorted communication and difficulty in coming to terms with their loss (Jewett, 1994).

The evidence in the West for anger as a response to bereavement is mixed. In France anger was experienced both as an immediate response to loss and during the aftermath of loss. For example, Van Eerdewegh (1982) observed young people's anger response immediately after the loss but there was also an increase in fighting behaviour among siblings at 13 months, suggesting an increasing presence of anger among young people. However, in the US, Silverman and Worden (1992) found that in the Harvard Bereavement Study anger as an immediate response to loss was found in only a few (7%) bereaved young people.

Consistent with Cluver and Gardner's (2007) extensive review of literature, there would appear to be only five African studies (Sengendo and Nambi, 1997; Atwine et al, 2005; and Cluver and Gardner, 2006, Makame et al, 2002; Nkomo, 2006) that discussed anger during young people's bereavement.

In their investigation of bereaved young people's internalising and externalising behaviour, Makame et al (2002) found Tanzanian bereaved young people experiencing a high level of internalising behaviour which included anger and resentment. However, as the study employed qualitative techniques there was no further information available on these reactions. In Uganda, Atwine et al (2005) controlled several factors (e.g. health problems, other relatives having died of AIDS, household size, and socio-economic group). Although the researchers reported that loss of a parent was significantly associated with angry response, they also found higher scores of anger in those performing 'chores sometimes or always' than among those who seldom or never performed them, suggesting that anger was also related to factors other than loss itself. In another Ugandan study Sengendo and Nambi (1997) found that living arrangements influenced young people's anger. Young people living with their fathers (43%) or alone (47%) were less likely than those living with relatives (65%), grandparents (57%), and mothers (48%) to report anger. The higher prevalence of anger among young people living with relatives other than parents might have been because they

had lost the emotional support of both parents, as opposed to a lack of material support suggested by Sengendo and Nambi (1997). The focus group discussions with the bereaved young people from child-headed households supported this view. The young people reported that they felt angry for periods ranging from one to three months when a parent died. The presence of relatives during a funeral appeared to improve matters, although these feelings and behavioural patterns returned once relatives left after the funeral.

In South Africa, anger was found to be associated with the consequences of loss as opposed to loss itself (Nkomo, 2006). The research found that in child-headed households the members had a sense of abandonment by their relatives, and viewed their past experiences of taking care of a dying parent and their present experience of taking care of their siblings with some anger. They were disappointed and angry that their relatives did not play a significant role in their care in the event of parent's death. Making sense of the parents' absence in view of all these challenges made them feel angry.

The evidence that African young people, whose parents were HIV-positive or had died of AIDS, have been stigmatised and discriminated against (Clacherty, 2001) may be a clear indication that they have experienced anger. Yet, apart from Atwine et al's (2005) study that suggested a relationship between anger and discrimination (see section 1.5.1 below: Stigma and Discrimination) there is no evidence from the African context that links angry responses with unfair treatment. Lack of evidence may not be indicative of an absence of angry response to unfair treatment. It may just be that it is not culturally sanctioned to show anger in such a situation or that researchers have failed to focus on such topics.

In South Africa, Cluver and Gardner (2006) found that bereaved young people were more likely than non-bereaved to show symptoms of anxiety, and display anger through loss of temper. Tsheko et al (2007) indicated that several factors led bereaved young people (52%) in their study to get angry and the least among them was their loss. These factors included scary dreams (14.8%), sickness (13%), lack of material possession (10.4%) and thinking about the late parent (11.1%).

It is not completely clear whether the anger reported in some studies was as a result of the death or experiences after the death (Sengendo and Nambi, 1997; Atwine et al, 2005). Lack

of a definition of anger by these researchers (Sengendo and Nambi, 1997; Atwine et al, 2005; Silverman and Worden, 1992) also blurred their findings. Whilst anger sometimes resulted from unfair treatment (Archer 1999), from personal experience the Gambians are forbidden to challenge the will of God, who is believed to be responsible for life and death. The Gambians believe that life and death are predetermined by God. A protest against death may therefore be perceived as one being disobedient towards God. These beliefs may have a direct influence on how young people express their angry responses to their loss.

However, clinical experience in the West shows that angry feelings towards the deceased are some of the most difficult to deal with in mourning (Bowlby, 1980). It therefore appears that religious or cultural disapproval of the anger response when present may force a young person to further avoid it and make coping difficult for him/her.

One goal of this thesis is to investigate the extent to which bereaved young people experience angry responses to loss.

#### 1.5.4.5 Anxiety and fear

Fear has been described as a powerful biological experience of an unpleasant risk or danger, either real or imagined (Payne, 1999), while anxiety has been described as fear of uncertainty or a state of being troubled in the mind about an uncertain event (Dunant, 1996). Anxiety is manifested by difficulty concentrating, restlessness and sleeplessness. People who experience anxiety often use adjectives such as concerned, worrying, uneasy, and nervous (Payne, 1999). Fear may be 'evident when an individual poses a threat to attachment figure's availability' (Kobak in Cassidy and Shaver, 1999, p.38). Bowlby (2005) commented that any behaviour that functions as a protection (escape behaviour) against perceived or actual danger is known as fearful response. These behaviours may include running away from danger, withdrawal from people and environments perceived to be dangerous, and clinging to the attachment figure for safety.

Often fear and anxiety are viewed as unpleasant and unwanted reactions but Western bereavement literature suggests that they can be useful. According to Cassidy and Shaver (1999), when availability of an attachment figure is endangered fear overcomes other

activities, leading to attachment behaviours (e.g. searching, longing or even crying), which serve both as communicative signals alerting the attachment figure about the child's distress, and as a motivation eliciting a comforting response. However, when these signals are ignored or misread by adults, they may no longer fulfil their purpose and attachment related fears may lead to chronic anxiety (see Bowlby, 1973).

There is evidence from African studies (Atwine et al, 2005; Poulter, 1996; Sengendo and Nambi, 2005; Cluver and Gardner, 2007; UNICEF, 2004; Clacherty, 2001; Strode and Barrett-Grant, 2001; Makaya et al, 2002) that bereaved young people experience fear and anxiety. After eliminating several variables (current health problems, death of other relatives from AIDS, household size, socio-economic group) that may cause anxiety, Atwine et al (2005) found the bereaved were significantly more likely than their controls to experience anxiety, suggesting death as the primary cause of anxiety. In South Africa, Clacherty (2001) found young people's sense of security being threatened by their parents' AIDS-related illness and death, and their own HIV-positive status.

Consistent with Atwine et al (2005) and Clacherty (2001), in Uganda death of a parent was found to be associated with worries (Sengendo and Nambi, 2005). The bereaved young people in Sengendo and Nambi's (2005) research had trouble sleeping (71%) at night and expressed their worries from the time their parents were ill till the aftermath of the death. In Congo Makaya et al, (2002) found them experiencing concentration difficulties. Poulter (1996) found bereaved young people more likely than their controls to have fears and worries about new situations, although on the whole these fears were not reported as intense.

Several studies (Atwine et al, 2005; Nkomo, 2006; Cluver and Gardner, 2007; Sengendo and Nambi, 1997; and Chatterji et al, 2005) have shown that young people experience intense fear and anxiety. A high level of fear and anxiety is related to being the head of a child-headed household, having a poor sense of security (Nkomo, 2006), poverty (Chatterji et al, 2005), AIDS-related illness (Clacherty, 2001), secrecy surrounding a parent's illness, stigma and discrimination (Malinga, 2002).

For many heads of child-headed households their worries were not limited to the death of their parent but also included other concerns. In a South African study, Nkomo (2006) found

young people's uncertainty about what the future held for them. They were found to be preoccupied with personal safety and the safety of family members. The young people were also concerned over several things including survival, fear of failure in their roles at home and as students. Musis et al (2007) also reported that bereaved young people's worries and anxieties were associated with poor academic performance. Despite the bereavement status of the young people, the researchers found significant associations ( $p=0.00$ ) between worries, fears and anxiety and poor academic performance.

While evidence suggests that young people were willing to share their troubles with others, fear that they would be stigmatised could deter them. Consistent with this South African study, Ugandan children were first subjected to the fear and anxiety of witnessing a parent suffer from debilitating and fatal illness (Malinga, 2002). Their anxiety was compounded by secrecy surrounding the HIV status of the parent and potential dissolution of the family and separation of siblings. The researcher found that lack of openness deprived the young people of the opportunity to share and voice their fears and concerns. Whilst this study focused on parental illness, it gave valuable information on young people's emotional state before death and served as a pointer to what would happen when death occurred.

In their survey, Chatterji et al (2005) also found that measures of worry, sense of overburden and poor locus of control in children and adolescents were often correlated with household socio-economic status and/or material possessions. Higher socio-economic status and/or material possessions, as well as an increased sense of community support, were protective against a sense of overburden and responsibility for children and adolescents, worry and stress in children. Gilborn et al (2001) found almost all (91.5%) HIV-positive parents expressing worries about their children's future. A majority (56%) showed greatest concern about their children's basic necessities for survival (i.e. education, food, and clothes); many (29.5%) showed concern that their children would be exploited, and some (23.5%) feared they would become victims of property grabbing and lack an appropriate carer. However, the least they were concerned about was the bereavement experience of their children.

From the Gambia, among 29,046 young people and adults, UNICEF (2004) reported that although many young people were optimistic about the future, some reported worries about getting jobs, taking care of themselves and their surviving parents. Whilst young people in this Gambian study were diverse, no specific analysis was made of the experiences of AIDS-

bereaved young people; as a result, it is hard to distinguish the experiences of the latter from others in this group, making the findings difficult to compare with the rest of the literature in this thesis.

Other studies further suggested that young people's anxiety was heightened by other factors. Cluver and Gardner (2007) found 10% of AIDS-bereaved young people and 8% of other bereaved and non-bereaved experiencing a significantly high level of anxiety. However, the researchers found no association between the bereaved status and anxiety when variables (for example age, gender - especially female - and types of dwelling) were controlled, suggesting that anxiety was not directly associated with death but with the material consequences. In their South African study, Cluver et al (2007) reported a mild form of anxiety with no difference between bereaved and non-bereaved young people.

Fear of stigma and isolation was also found to intensify secrecy surrounding a parent's cause of death and worries about the future. Sengendo and Nambi (1997) found that, when the young people's parents were seriously sick, the young people responded with fear of the impending death. In their research those who expressed their thoughts reported their parents' looming death was frightening. Although the presence of their grandparents was comforting, their departure was characterised by fear. This shows that although young people's fear and anxiety may have been related to the illness and the impending death of their parent, separation from their significant others such as grandparents at this time when they were likely to be needed provoked more fear and anxiety for young people.

Although the limited evidence suggested that AIDS-bereaved young people experienced both fear and anxiety, there was disagreement regarding the intensity and the nature of their experiences. One of the studies suggested that young people experienced intense fear and anxiety because of the loss (Atwine et al, 2005); others supported the view that they experienced fear and anxiety but that the experience was within a milder range (Cluver and Gardner, 2006; Cluver et al, 2007; Poulter, 1996). In contrast, other studies suggested that other factors heightened young people's fear and anxiety (Cluver and Gardner, 2007; Clacherty, 2001; Strode and Barrett-Grant, 2001 and UNICEF, 2004). It is not clear whether the inconsistency can be attributed to lack of standard definitions or the differing sociological

contexts within which these studies were conducted. These limitations suggest the need for further research, to which this thesis will try to contribute.

#### 1.5.4.6 Emotional loneliness

Whilst ‘fear’ and ‘anxiety’ are often concerned with the future, emotional loneliness is concerned with the missing relationship. In an attachment relationship there is a strong bond between individuals so that, when a person close to us no longer lives with us, we tend to experience a void (Bowlby, 1998). Following on from this concept of attachment relationship, emotional loneliness ‘reflects an interpersonal deficit that exists as a result of...less satisfying relationships than a person desires’ (Ponzetti, 1990, p.336). In the context of loss, it remains even when the bereaved appears to be surrounded by others (Payne, 1999).

A few African studies (Sengendo and Nambi, 1998; Wood et al, 2006; and Poulter 1996) examined young people’s emotional loneliness. Although, these studies agreed on the presence of emotional loneliness, they differed as to its severity and prevalence among the bereaved young people. In the Ugandan study, Sengendo and Nambi (1998) assessed young people for the psychological impact of their loss. They found that the majority of AIDS-bereaved young people (67%), despite living in a collective society, were more likely to have experienced a profound sense of emotional loneliness (feeling lonely all the time) than non-bereaved young people. Consistent with this, Brown et al (2005) and Wood et al (2006) found that in Zimbabwe AIDS-bereaved young people were experiencing overwhelming emotional loneliness. Despite an extensive family network, bereaved young people felt lonely. Lack of recognition of the members of the family network seemed to suggest the bereaved young people were preoccupied with their missing relationship, which in itself signalled a profound sense of emotional loneliness.

In contrast to the above two studies, a Rwandan study by Brown et al (2005) reported both a profound sense of emotional loneliness in a young age group, and a milder emotional loneliness among the older age group of the AIDS-bereaved young people. Consistent with the attachment theory by Bowlby (1998), where the attachment relationship with the mother was stronger among younger children than older ones, Brown et al (2005) reported that the younger the bereaved young people the more likely they were to miss their parent and to say

they experienced a deeper sense of loss. However, it is important to note that in some circumstances and in some cultures (e.g. the Ashanti community), attachment relationships for older siblings may be stronger; in consequence, older siblings may experience more profound emotional loneliness than younger ones (see section 1.4.1 above: The extent of emotional reactions to the loss of a parent).

Emotional loneliness may not be exclusively related to the loss of the loved-one. Other factors may influence this experience. Tsheko et al's (2007) Botswana study on bereaved young people was interested to find out what young people missed about their deceased parents. They compared two different age groups: 12-14 years old and 14-18 years old. Both groups were likely to miss the financial support of their late father. However, almost half of those aged 12 to 14 missed the love of the mother but those aged 15 to 18 years did not miss their mother at all, suggesting that the older children were more interested in basic survival needs.

The biggest cause of loneliness would appear to have been either distancing oneself (withdrawal) or being excluded by society. There is evidence of bereaved young people finding it hard to get along with others in their families (Muis et al, 2007), which could have been associated with the fear of stigma and discrimination. There is evidence that people suffering from self-stigma (see stigma) tend to distance themselves from others because of the feeling of inferiority or fear of other people knowing their discrediting attributes (see discrimination). Studies in South Africa have reported that because of fear of stigma and discrimination, AIDS-affected young people and their carers either distanced themselves from other members of the community or were marginalised by members of the community (Strode, 2001; Clacherty, 2001).

There is evidence that emotional loneliness may even be experienced before death, especially among HIV-affected families (Poulter, 1996). As part of the assessment of the impact on young people of AIDS-related illness and death of an HIV-positive parent, Poulter (1996) found an association between HIV-related illness of a parent and a mild form of emotional loneliness among young people. It is important to note that the young people involved had their ill parents available to them. The researchers' failure to report emotional loneliness after death deprived us of the opportunity to understand the relationship between emotional loneliness prior to and post death and how they impacted each other.

From the few African studies reviewed, there seems to be some degree of agreement that young people's emotional loneliness may have been associated with the loss of a parent (Sengendo and Nambi, 1998; Brown et al, 2005; Wood et al, 2006). However, Poulter's (1996) findings suggested that emotional loneliness may not be restricted to the loss of a parent from death; even illness of a significant attachment figure provoked such emotions. Since young people's experiences of emotional loneliness before death were not reported by these studies (Sengendo and Nambi, 1998; Brown et al, 2005; Wood et al, 2006) and the emotional relationship between the ill parent and the young person is unknown, it would be hard to claim that loss alone was the predictor of young people's emotional loneliness. This may be the reason why a differing degree of emotional loneliness was reported by the studies. Therefore, this thesis intends to bridge this gap by examining the emotional reactions of bereaved young people who are traditionally close to their parents.

Whilst emotional loneliness seems to show that bereaved young people perceived that their deceased parent left a vacuum in their heart, the following section suggests that despite the feeling of loneliness the deceased remained part of their lives.

#### 1.5.4.7 Continuous bond

Like emotional loneliness, continuous bond is a long-term reaction, one indicative of loss-oriented coping. There is a growing literature in the West which suggests that death does not necessarily end the relationship between the bereaved and the deceased (BecVar, 2003; Abrams, 1999; Stroebe, 1987; Klass et al, 1996). There is a belief that, 'death ends a life but does not end a relationship' (cited in McGoldrick, 1991, p.50). There is sometimes a continuous, internal, emotional connection between the bereaved and the deceased person despite the physical absence of the loved-one (Walter, 1996).

Traditionally, bereavement literature has laid emphasis on the psychological importance of letting go of the deceased and forming new relationships as a healthy way of mourning (BecVar, 2003). In contrast, the DPM proposed that optimal coping depended on successful oscillation between loss- and restoration-orientations. Therefore it is not a surprise that several writers have suggested that letting go of the deceased may not always be inevitable,

desirable or necessary (Abrams, 1999; Stroebe, 1987; Klass et al, 1996) and that there was an interesting oscillation between the two processes

Stroebe (1987) suggested that whilst the concept of letting go may be predominant in the West, it may be that some cultures are not keen to let go totally of their deceased ones, and indeed that this may have benefits. According to BecVar (2003), in some contexts it may be unacceptable to let go of one's loved-one and this may incapacitate some people. Abrams (1999) suggested that 'getting on with your life does not mean you must forget all about the past, but rather you must discover a place for the past in the future' (p. 174). This suggested the need for maintaining a right balance between continuous emotional relationship and a moving on process, which may paradoxically prevent some people getting stuck in their grief. There is evidence for continuous bond in the West. The recent Harvard longitudinal Bereavement Study in the USA (Worden, 1996) has given us an extended knowledge about how young people maintained connection with their deceased parent. Despite its high attrition rate, most bereaved young people in this study maintained relationships with their deceased parent through their inner representations of the deceased. Apart from reflecting on the deceased and reminiscence about the activities they enjoyed with them, many bereaved young people (77%) kept an item belonging to the deceased parent including music tapes, league pin, shirt, and a rabbit. Each of the items carried a special meaning for the young people and was either given to them by a deceased parent, surviving parent or collected by themselves. Retaining connection with the deceased can help a bereaved person to accept the permanence of loss and it is also comforting, but it neither precludes the experience of pain nor does it mitigate emotional problems (Worden, 1996).

There is some evidence for continuous bond in the African context. Wood et al (2006) have found, despite all the intense emotions experienced by AIDS-bereaved young people in Zimbabwe, some of them sought refuge in churches and found comfort through their prayers. Although it is unclear whether or not the prayers were in pursuit of maintaining connection with the deceased, or just to mitigate the pain they were encountering, Worden (1996) maintained that bereaved young people who were likely to retain connection with their deceased parents were those who come from families with a lower level of stress, and who laid emphasis on religious and spiritual support. On this basis, one may suggest that the

young people in Wood et al's (2006) study were maintaining connection with their deceased parents.

Retention of special items of the deceased parent is reported in Africa. In Botswana (Tsheko et al, 2007) and Zimbabwe (Rusakaniko et al, 2006), researchers reported that a significant proportion (40.5%; 35%) of bereaved young people received special items from their deceased parent, such as photographs of their parents (35.7%; 30%) and clothes (21.4%, 67%) . Many bereaved young people (51%, 48%) from Botswana and Zimbabwe looked at some of these items whenever they felt sad or lonely and some (70%; 23%) looked at them when they wanted to be closer. However, in Zimbabwe more than half (58%) did not wish to have any of the items that had belonged to their parent. Whilst in both studies some young people showed the importance of retaining connections with the deceased parent, it was only the Ugandan bereaved young people who really valued their connectedness with their deceased parent. It is not clear whether the difference was the result of cultural differences. HIV prevalence in this study area is the highest (43%) in Africa, which may suggest high prevalence of multiple deaths depriving young people of love and affection and making them particularly keen to maintain a link with the deceased, so these special items might have been used as an alternative strategy to retain connection with the loved-one. There is evidence from South Africa that child-headed household members in this context have a particularly strong belief in their ancestors' protection, love and guidance; their ancestors continued to live within their communities in the form of spirit (Masondo, 2006).

However, this bond may be very important in the first place and then fade over time, being balanced out by a greater degree of 'letting go'. Worden's (1996) Harvard Bereavement Study in the USA found the material objects left by a parent were closely used at the first anniversary but rarely used after that and became less important to the bereaved over time. The reasons behind the change of usage were not made explicit. One possible explanation was that the need for the sense of a continuous relationship with the deceased faded over time, which may have led to the bereaved person eventually being able to 'let go'.

Generalising on the strength and duration of bereaved young people's continuous emotional bond with the deceased through their closeness to the objects left behind may be difficult. The value of such objects in different cultures may differ. In some cultures emphasis may be

placed on prayers rather than objects, and the bereaved may switch attention from prayers to objects (and *vice versa*) depending on which one works out for him/her. From personal experience, in the Gambia emphasis is placed on the material benefit of objects left behind by parents; but whether such objects have emotional value for the young people is yet to be investigated. Since no firm conclusion could be reached as to how long bereaved young people retain emotional connection with their deceased parent, and with no evidence in the African context regarding young people's continuous bond with the deceased, this thesis intends to bridge the gap by exploring this topic with Gambian young people.

## **1.6 Social factors influencing young people's coping with their loss**

The previous sections focused on emotional reactions to loss, including a discussion on the intensity of these reactions. This section will focus on the impact that social relationships can have on bereaved young people's ability to cope with their loss. Consistent with the DPM that proposed the importance of interpersonal aspects of bereavement research (Stroebe and Schut, 1999), the following subsections will discuss the nature and impact of stigma, discrimination, isolation, secrecy, family support, peer and agency support for AIDS-bereaved young people.

### **1.6.1 Stigma, discrimination and poverty**

#### **1.6.1.1 Nature of stigma and discrimination**

The DPM identified two types of stressors: loss of a loved-one is referred to as the major stressor and secondary consequences of loss are referred to as minor stressors. Owing to the emotional impact stigma has on stigmatised people, stigma may be considered a secondary stressor, especially for young people (Garmezy, 1983). Before going into describing young people's experience of stigma, this section and the one that follows will describe in general the nature of stigma and how people are coping.

Since the first case of AIDS was discovered, social responses of fear, denial, stigma and discrimination have accompanied the epidemic (Mlobeli, 2007). Although, the concept of stigma is not new, 'more recent discussions of stigma, particularly in relation to HIV and

AIDS, have their point of departure in the now classic work of Goffman' (Aggleton et al, 2003, p.3). Goffman (1963) defined stigma as a significantly discrediting attribute that in the eyes of the people reduces the person possessing it, who can therefore be denigrated. 'More recent analyses have concentrated on patterns of dominance and oppression, viewed as expressions of a struggle for power and privilege' (Marshall, 1998, cited in Aggleton et al, 2003, p.5).

Since the publication of Goffman's (1963) work, the stigma concept has been associated with the following characteristics: labelling differences, attaching human differences with negative characteristics, separating 'us' as normal from 'them' as abnormal, and loss of social status (Ogden and Nyblade, 2005). Stigma is now seen as felt or enacted stigma (Nziyane, 2005). Felt stigma is when an individual is targeted by a stigmatised condition, perceives it and then internalises it (Rankin et al, 2005) and actions taken against the stigmatised person concerned are referred to as enacted stigma/discrimination. Some may prefer to use verbal stigma, self-stigma and discrimination (Ogden and Nyblade, 2005). (This will be discussed later.)

Recent understanding of HIV-related stigma is that it is linked with a complex social process and builds upon and reinforces pre-existing stigma (Aggleton and Parker, 2002). These include prejudice associated with sexuality (e.g. promiscuity) and gender (Ablon, 2002). Stigma and discrimination associated with women reinforces pre-existing economic, educational, cultural, and social disadvantages and unequal access to services (Aggleton and Warwick, 1999). HIV/AIDS-related stigma and discrimination interact with pre-existing stigma and discrimination associated with economic marginalisation (Park and Aggleton, 2002). Stigma and discrimination also build on pre-existing fears associated with HIV infection and illness and the earlier metaphors such as seeing AIDS as: horror, guilt, shame, and otherness which in turn reinforce existing fears. These conditions are created by people and, therefore, stigmatisation describes a systematic process of devaluation based on power and domination (Aggleton et al, 2003).

### 1.6.1.2 How do individuals and societies cope with stigma and discrimination?

Whilst knowledge about how young people cope with loss and at the same time cope with layers of stigma and discrimination might be limited, knowledge about how people cope with stigma in general is well advanced. Several frameworks and models to conceptualise stigma and discrimination have been developed (Ogden and Nyblade, 2005; Parker and Aggleton, 2003; Deacon et al, 2005; Banteyerga et al, 2004; Hong et al, 2004; Nyblade et al, 2003; USAID, POLICY Project, 2003; National Institute of Public Health of Mexico, 2004; Brown et al, 2005; Phelan et al, 2008; Kalichman, et al. 2005), and several practical tools designed to reduce stigma and discrimination (Kidd et al, 2007) have also been successfully implemented with a range of target groups (Horizons, 2005; ICRW, 2006; ISDS, 2006; Hong et al, 2006).

There appear to be two general principles of reducing stigma and discrimination. The first is to address the course of stigma by increasing people's awareness and knowledge about their own attitude and behaviour and its impact on the affected people, addressing misconceptions around HIV transmission and challenging social beliefs and values that leads to stigma (DFID, 2007). The second is to break the cycle of stigma and discrimination which involves greater confidentiality or secrecy which may reduce exposure to potential perpetrators or may slow down susceptibility/vulnerability to stigma (Morrison and Negroni, 2006). However, this may not address internal stigma.

There are several community interventions (as we shall see at the end of this chapter) supporting bereaved young people (Schenk, 2009) with some trying to strengthen the psychological well-being of child headed households (Horizons, 2005); but the most successful programmes have used a combination of methods including participatory and empowerment approaches (Stephens, 2004) and approaches to provide an enabling environment. For example, a successful stigma reducing program in Vietnam created an enabling environment by working with policy makers and also using participatory methods with large audiences including media practitioners (Hong et al, 2004). A politically motivated stigma reduction program in the Caribbean region, through champions for change, has used multiple strategies such as mobilisation of opinion leaders, media practitioners and champion for change participatory conferences (PANCAP Coordinating Unit, CARICOM Secretariat, 2007). In Zambia, a combination of both empowerment and participatory approaches has

been used. For example, young people were trained to provide support to HIV-affected families, by visiting houses and supporting the sick and the elderly. The program was found to reduce social isolation and stigmatisation, but more involvement of community leaders was crucial for their future interventions (Esu-Williams et al, 2004). The treatment action campaign for change in South Africa was a successful initiative that empowered people living with HIV/AIDS to force Government to make drugs available to them, and also created awareness among the public about HIV/AIDS, stigma and discrimination. These interventions suggest that practitioners are making efforts to address the very core of our beliefs upon which HIV/stigma is built and by which it is reinforced.

Despite these efforts young people might be suffering from stigma in silence. The following sections review the stigma experienced by bereaved young people.

#### 1.6.1.3 Bereaved young people - HIV/AIDS, bereavement and secrecy

Stigma is another factor which influences whether, and how, children are told about a parent's death due to HIV/AIDS, as well as carers' disclosure of their HIV status to children (Nzivane, 2005). Evidence from Uganda (Gilborn et al, 2005), Botswana (Tsheko et al, 2007) and Zimbabwe (Rusakaniko, 2006; Wood et al, 2006) suggested that many people are in favour of the disclosure of HIV-positive status. For example, 68% of guardians in Uganda, 93% and 82% of bereaved young people in Botswana and Zimbabwe respectively called for more HIV-positive disclosure. Many young people in South Africa wished they had the opportunity to be told about the cause of their parent's illness (Giese et al, 2003). Zimbabwean young people felt disclosure would help them to know the nature of their parent's illness (53%) and that would prepare them emotionally (Rusakaniko, 2006). However, despite these professed opinions, secrets remain a problem in sub-Saharan Africa.

A key piece of participatory research in South Africa by Clacherty (2001) and a replica study by Strode and Barrett-Grant (2001) reported the role of stigma and discrimination and associated secrecy in increasing the vulnerability of HIV-positive young people. This research suggested a relationship between perceived (imagined) or actual stigma and high prevalence of secrecy surrounding HIV-positive status and AIDS-related death of a family member (Strode and Barrett-Grant, 2001; and Clacherty, 2001). Strode and Barrett-Grant

(2001) found widespread secrecy surrounding sharing of information on both young people's HIV-positive status and the status of their family members. The stigma experienced by young people, and the fear of further experience of stigma prevented young people from sharing HIV-positive information within and outside the extended families and also limited their access to the support they required from the community and service providers (health service and social welfare). Since the literature on emotional support suggests that coping requires support from those around them, it is clear that stigma is preventing the very relationships young people need to cope with their loss (Clacherty, 2001).

Clacherty (2001) supported the above finding and in addition reported that the silence of HIV-positive young people surrounding treatment by their families supported the view that they might have been stigmatised - a topic that might have been too painful for them to discuss.

In a cross-cultural study Stephenson (2009) found wide spread stigma and discrimination among bereaved young people in Zambia and Burkina Faso. Despite the widespread stigma and secrecy surrounding AIDS, the participants in South African studies (Strode and Barrett-Grant, 2001 and Clacherty, 2001) reported that there seemed to be increasing openness about HIV-status and declining AIDS-related stigma in the community. The researchers reported a growing shift from AIDS-related stigma to poverty-related stigma (see Material discrimination). A recent baseline study on psychological support for AIDS-bereaved young people in Botswana found mixed evidence regarding disclosure (Tsheko et al, 2007). In one of the research sites, a majority (23 of the 41) of bereaved young people said their parents had discussed their health status with them. However, in another site, despite accepting that HIV was a problem, only 30.2% of guardians reported that they had told their children their parents' cause of death.

Owing to their HIV-positive status, the young people in Strode and Barrett-Grant's (2001) and Clacherty's (2001) studies may have experienced a higher level of stigma than young people who were not HIV-positive. In addition, the evidence about young people's experiences of stigma in these studies has been derived largely from the views of adults, and we do not therefore know directly what young people might have actually experienced. Since young people are stigmatised by adults, it is likely that the same adults will under-report

young people's actual experiences of stigma. In view of this and several other limitations in this section, this thesis examines the nature of stigma and secrecy from the perspective of both AIDS-bereaved young people (the key participants) and the adults surrounding them.

#### 1.6.1.4 Verbal stigma

Stigma has been viewed as a social process that produces and reproduces relations of power and control (Parker and Aggleton, 2003). From this point of view, stigma and discrimination are used by dominant groups to propagate social inequalities and exert social control through the marginalisation of stigmatised groups (Ogden and Nyblade, 2005). Bray (2003) observed that the media as an institution tends to victimise bereaved young people, labelling them as criminals and antisocial agents, although there is no evidence that bereavement leads to externalising behaviours. Such messages of the media continue to marginalise the group of already needy young people, re-affirming the assumption that the media reinforces the previously defined boundaries between 'us' as normal and 'them' as deviant people (Yang et al, 2005). For example, the media uses powerful metaphors like 'risky', 'promiscuous', 'AIDS carriers' 'AIDS sufferers' and lately 'AIDS orphans' to create images of powerlessness and helplessness causing irrational fears and prejudice among people (Ogden and Nyblade, 2005).

Verbal stigma can take different forms and be exhibited to different degrees (e.g. pointing fingers, insulting, blaming, gossip and rumours) (Ogden and Nyblade, 2005). Stigmatising and derogatory comments or fear of them can be experienced at individual and at community level. For an example, a study in Nigeria uncovered worries and despair among community leaders regarding the HIV/AIDS status of their villages (Hilhost et al, 2006). According to the researchers, due to the fear of being labelled as an AIDS community, half of the community leaders in their research denied that people living with HIV/AIDS were present in their villages. Whilst the focus group discussions showed association between multiple sexual partners, AIDS and social rejection in these communities, it is not clear whether the community leaders involved were really aware of the prevalence of HIV/AIDS in their community.

A South African study reported discrimination and stigmatisation in schools. Giesse et al (2003) found teachers viewing AIDS-bereaved young people as dangerous and infectious, and said that they were worried about them in school. Teachers were also found to be calling them skinny children and pointing fingers at them to other children. They tended to be teased more often by other students from intact families. In a recent study by Cluver and Gardner (2007) in South Africa, none of the bereaved young people mentioned AIDS or HIV during their interviews. The researchers concluded that the gossiping and shouting which young people suffered from may have been a manifestation of AIDS-related stigma. Gossiping and teasing were also reported by studies on child-headed households (Nkomo, 2006)

At community level, HIV-positive young people have been laughed at, and gossiped about in churches and at school, because of their own HIV/AIDS status and that of their parents (Clacherty, 2001). In Strode and Barrett-Grant's (2001) study, many parents wished their children to attend different schools from HIV-infected people. In both Strode and Barrett-Grant (2001) and Clacherty's (2001) studies, there was blame and unwillingness to take in HIV-positive young people for fear of infection. Many of the bereaved young people in Giesse et al's (2003) South African study expressed their unhappiness due to stigma and discrimination they encountered in their new household; many also expressed that they were safely and happily living with carers other than their biological parents. Rusakaniko et al (2006) also found that nearly three-quarters of bereaved young people in their study felt happy about living in their current household and that nothing much had changed in their lives since moving there. The inconsistency of these findings suggests the need for further research, which this thesis aims to do.

#### 1.6.1.5 Self-stigma/shame

Goffman (1963) conceived stigma as an attribute that is deeply discrediting and that reduces an individual in our minds from a whole and usual person to a tainted, discounted one. Stigma of self arises from the same discrediting attribute. Poku et al, (2005) suggested that stigma of self arises out of symbolic expressions and symbols that aid in the derivation of meanings that one attaches to ideals of self and others (Poku et al, 2005; p.347) and, according to Mead (cited in Poku et al, 2005) are a product of social interaction. For example, since all HIV-positive individuals necessarily share the same social values and act according

to their social norms, when they confirm their own HIV-positive status they develop towards themselves the same rejection, denial, disregarding and underrating as non-HIV-positive individuals. Fife and Wright's modelling theory (cited in Poku et al, 2005) suggested that, once negative beliefs become internalised, stigma can lead to negative self-conceptions (e.g. relating to dignity, inferiority and social standing) and overwhelming feelings of shame.

According to Ogden and Nyblade (2005), there is an association between self-stigma, secrecy and self-distancing. People suffering from self-stigma are more likely to keep the discrediting attribute (e.g. the HIV status of their parent) secret and are more likely to distance themselves from potential discriminators in their societies (Poku et al, 2005). Evidence from South Africa seems to suggest a relationship between perceived/actual stigma and a high prevalence of secrecy surrounding HIV-positive status and AIDS-related death of a family member (Strode and Barrett-Grant, 2001; and Clacherty, 2001) and self-stigma.

Strode and Barrett-Grant (2001) found widespread secrecy surrounding sharing of information on both young people's HIV-positive status and the status of their family members. The stigma experienced by young people, and the fear of further experience of stigma, prevented them from sharing HIV-positive information within and outside the extended families. Clacherty (2001) supported this finding and in addition reported that silence surrounding how HIV-positive young people were treated by family members suggested that they might have been stigmatised.

Derogatory comments and related feelings of humiliation were perceived to be the major consequence of parental death by Strode and Barrett-Grant (2001). The researchers reported a relationship between degradation of one's dignity/self-worth and exacerbation of emotional reactions among HIV-positive young people. The participants, who consisted of young people and adults supporting them, considered that their dignity was compromised and felt humiliated by derogatory comments they received about their HIV-status and the social circumstances (e.g. poverty) in which they lived. This humiliation prevented them from sharing their concerns with others, and in some circumstances they internalised the comments and perceived themselves to be bad and not worthy of living.

In South Africa self-stigmatisation was also found to be associated with material poverty, lack of support and poor school attendance. In Giesse et al's (2003) study, many teachers perceived that their students from HIV/AIDS-affected families were reluctant to speak about their home circumstances and 'to be seen as needy' and that this prevented them from accessing support at school. Bereaved young people noted their embarrassment at lacking a uniform or having no alternative but to wear uniform that was too small and worn out. Some did not go to school because of the embarrassment of not having what their peers had. This finding is corroborated by a Ugandan study (Foster et al, 1997) which observed absenteeism from school because of hunger and embarrassment at having tattered clothes. According to Poku et al (2005), the effects of stigma are similar across cultural variations but to understand the extent to which stigma affects individuals, one must delve into the social system from a cultural perspective (p. 346).

This study will therefore investigate the nature and the extent of shame and self-stigma among young people.

#### 1.6.1.6 Social exclusion or enacted stigma

In African literature, where discrimination is the focus it is often closely linked with social isolation, and indeed sometimes the two terms are used synonymously (see Clacherty, 2001). Social isolation can be viewed as a low level of contact with people from one's social network of support (e.g. families, friends, neighbours, community) (Strode and Barrett-Grant, 2001). The term 'social isolation' therefore means rarely coming into bodily contact with, rarely communicating (verbally or non-verbally) with or rarely seeing people from one's community. However, the number of people, the nature of the people (e.g. uncle, aunts), the number/frequency of contacts (e.g. monthly) and the nature of contact (e.g. visiting, sharing food) perceived to be desirable may differ between individuals. For example, in traditional Gambian culture members of different households in the same family share food and eat from the same basin on a daily basis (UNICEF, 2004). Exclusion of one household member from this very intimate eating process may be therefore be seen as isolation

Since the beginning of the epidemic, discrimination and resultant isolation of families affected by AIDS has been considered a characteristic of the AIDS epidemic (Clacherty,

2001). The Panos Institute of London calls discrimination the ‘third epidemic’ (p.1) but at the moment very little is known about the exact nature and the extent of discrimination and isolation of young people in Africa (Strode and Barrett-Grant, 2001). Whilst literature on AIDS orphans and discrimination is growing, only a few studies have been completely dedicated to the study of discrimination and isolation of AIDS-affected young people in the African context (Deacon and Harrett, 2007).

In a study of youth-headed households in Rwanda (Thurman et al, 2006), half reported feeling that no one cared for them and that they were isolated from the community. 57% reported the community would rather hurt them than help them, over half reported people behaving towards them in stigmatising ways, and 86% felt rejected by their community. It may be that the impact of Rwandan genocide had a major influence on the experiences of bereaved young people. Recent studies have shown stigma and discrimination among child household heads (Nelson Mandela Children Fund Programme, 2001; USAID/Zimbabwe/ SCOPE, 2002; Hirasawa, 2007 and Nkomo, 2006).

Whilst the child heads needed the adults to help them give guidance and assurance to their younger siblings, they were often left isolated and exploited by the extended family members (Masondo, 2006). A study, which aimed to obtain information to support the Nelson Mandela Children Fund Programme (2001) targeting households headed by children, found that in addition to lack of support, stigma and rejection, there was fear of sexual and physical abuse. Other studies found child heads’ concerns over their own safety (Hirasawa, 2007) and safety of their siblings (Masondo, 2006).

In South Africa, there is evidence of avoidance of sharing, touching, sitting with, talking to AIDS-affected young people (Clacherty, 2001); being chased away, denied visiting and playing, removed from the funeral home, parental care and support (Strode and Barrett-Grant, 2001). However the proportion of young people experiencing stigma and discrimination is not known, so a definitive conclusion regarding the prevalence of the problem cannot be drawn. In another South African study, Cluver and Gardner (2007) interviewed young people, professionals and carers. The researchers found that, although the young people they studied had been taken in by their extended families, materially they were not treated equally

with the foster parents' biological children. The latter were more likely to be bought clothes and given school lunches than the fostered bereaved young people.

There is evidence that refusal to have physical or emotional contact with HIV-positive young people has increased young people's level of distress and made them more anxious towards members of their supportive network (Cluver et al, 2008). In addition, isolation from social, material and emotional support has increased young people's risk to emotional problems (Clacherty, 2001, Cluver et al, 2008).

Another South African study (Cluver and Gardner, 2007) seemed to suggest that young people subjected to stigma and discrimination in general struggled to cope with their loss. The participants in Cluver and Gardner's (2007) study perceived that lack of contact with family members made life hard for young people and they even viewed it as a risk factor that increased mental health problems. Despite this perception, it was surprising to note that only the street children in this research reported anger over another's family visit. Bereaved young people's silence about such anger may have been a result of AIDS-related secrecy rather than a lack of anger itself.

In contrast to the view that bereaved young people were discriminated against in their extended families, Foster et al (1997) found that many bereaved young people were satisfactorily looked after, and there was a strong will to look after these young people. The extended families in Malawi have also shown similar conviction. 75% of the bereaved young people lived in the households that had received food, cash or in kind gifts in the past year (Kidman and Heyman, 2009). In addition, although Cluver and Gardner (2007) suggested bereaved young people may have experienced discrimination, their study was conducted in South Africa, which has a higher percentage of AIDS-bereaved young people and a higher prevalence of HIV/AIDS than the Gambia (see UNAIDS, 2006). It may be that this variation influences the nature and the extent of discrimination young people experience.

This thesis therefore aims to investigate the nature and extent to which social exclusion and enacted stigma is experienced by AIDS-bereaved young people in the Gambian context.

#### 1.6.1.7 Loss of access to resources and care

'It goes without saying that the vast majority of children affected by HIV/AIDS in sub-Saharan Africa are no strangers to the ravages of trans-generational, long term poverty' (Snider and Dawes, 2006, p.20). It is commonly accepted that HIV/AIDS disproportionately impacts upon poor communities (Gebella and Gruendel, 1998), and it further weakens already poor families and their ability to provide a safety net for bereaved young people (Foster and Williams, 2000 and Rochat, 2007).

The increasing number of child-headed households, widow and elderly household heads was an indication that HIV/AIDS weakens the wealth of families and the communities they live in by killing the most productive members of the population (Foster et al, 1996). Some were now living with carers who were rejected (Van Den Berg, 2006), too old (Musis et al, 2007), too young (Nkomo, 2006) too ill (Palin, 2006) or too weak (Oleke et al, 2005) to provide adequate support.

Bray (2003) suggested that poverty was the main medium through which AIDS further disadvantaged bereaved young people. Hunter (2001) argued that bereaved young people lacked the necessary affection, protection and understanding. Chase et al (2006) reported that bereaved young people in Zimbabwe experienced considerable hardship. Evidence from Nigeria (Hillhorst, 2006), Botswana (Heymann et al, 2007; Tsheko et al, 2007), Zimbabwe (UNAID/Zimbabwe/SCOPE, 2002; Chase et al, 2006 and Mahati, 2006), Ethiopia (Bhargava, 2005) and South Africa (Malinga, 2002; Nelson Mandela Children's Fund, 2001 and Masondo, 2006) supported this view. For example Tsheko et al (2007) and Gilborn et al (2001) found the carers complaining about the shortage of food and financial support. There is evidence of young people going to bed hungrier than their peers (Zidron, 2008), going to school with torn clothes (Clacherty, 2001), suffering from property grabbing (Musis et al, 2007) and having a heavier workload than normal (Mahati et al, 2006).

Stein (2003) stated that it was necessary to accept that, in Africa, poverty was one of the major psychological stressors for AIDS-bereaved young people, yet poverty and material discrimination were found to be interrelated (Cluver et al, 2009). Evidence from South Africa (Giese et al, 2003; Clacherty, 2001; Strode and Barrett-Grant, 2001), Uganda (Ntozi, 1997;

Gilborn, 2001), Tanzania, Lesotho and Zimbabwe (Robson, et al 2006), and Namibia (Van den Berg, 2006) indicated that bereaved young people were materially discriminated against and often lived in poverty. Young people who were materially discriminated against were more likely to be poorer than their peers (Nelson Mandela Children's Fund, 2001). In their South African study, Cluver et al (2009) found significant associations between poverty, stigma, discrimination and poor mental health. Van den Berg (2006) argued that, in Namibia, most carers wanted to do as much for bereaved young people as for their own biological children, but because of financial constraints they had to make difficult choices regarding who to pay for. The researcher commented that cases of discrimination and stigmatisation needed to be interpreted in the light of the economic deprivation of a large number of families caring for orphans.

According to Foster et al (1997), in Ugandan households where bereaved young people were required to work, 23 out of 28 participants felt that significant differences existed between their own lifestyle compared to that of the non-bereaved young people in these households. Whilst their workload of domestic chores was excessive compared to their peers', they were not allowed to complain of unfair treatment. In South Africa, there were several instances of children not going to school because they were required to complete domestic chores, look after young siblings and sick adults or to beg in support of themselves. Some said that they were punished by their carers if they went to school and left their chores unfinished (Giese et al, 2003).

Bereaved young people did not always have the opportunity to access education in the same way as their peers (Giese et al, 2003; Foster et al, 1997; Ntozi et al, 1999 and Ntozi, 1997); yet in Lesotho and Tanzania (Robson et al, 2006) they were stigmatised and discriminated against for either being absent from school or for not paying school fees in time. There is also evidence of discrimination at home in Ntozi et al's (1999) study, which reported that young people's lack of money and mistreatment by aunts and surviving parents was seen as distressing.

Economic problems were a significant cause of mental distress (Ntozi, 1997). In South Africa, all three groups of participants (Young people, n=53; carers, n=12; and professionals, n=10) in Cluver and Gardner's (2007) study identified food and starvation as a risk factor for

emotional problems. Participants believed that when young people lacked food or were starved, it made them emotionally disturbed, although they did not specify the nature or degree of emotional disturbance. A similar study found young people going to school in torn uniforms, no shoes, with no school fees and no book, distressed by the attitude of their peers and teachers towards them (Strode and Barrett-Grant, 2001).

Two recent studies in South Africa have shown significant association between the poverty and psychological stress of AIDS-bereaved young people. The first of the two (Cluver et al, 2009) measured the association between poverty and the mental health of AIDS-bereaved young people. The researchers found significant association between poverty and depression, suggesting that poverty increased AIDS-bereaved young people's vulnerability to mental health problems. The second study (Cluver and Orkin, 2009) assessed the cumulative risk effects of stigma, bullying and poverty on child mental health; poverty and stigma were found to interact strongly and, with both present, the likelihood of disorder rose from 19% to 83%. However, Poulter et al (1997) found no clear link between psychological disturbance and economic stress in her study, interviewing carers from 22 households with orphans, 66 households with HIV-positive parents and 75 control families.

Whilst there is strong evidence that African bereaved young people are both poor and materially discriminated against (Snider and Dawes, 2003, Nziyane, 2005), many other studies found no significant differences between bereaved and non-bereaved young people (Hosegood and Ford, 2003; Masmus et al, 2004; UNICEF, 2004).

There was no difference in terms of household wealth (Chatterji et al, 2005), nutritional status, use of health care services, quality of housing and clothing (Aaby et al, 2004 and Henderson, 2006), household chores, ownership of clothing (Masmus, 2004) and school attendance (Kamali et al, 1996). However, some of these studies focused only on maternally bereaved young people (Aaby et al, 2004 and Masmus, 2004), others either lack controls (Kamali et al, 1996) or had a small sample size (Henderson, 2006). It appears that there is no forgoing the conclusion that households with bereaved young people are more vulnerable to poverty and material discrimination than other households. Moreover, the stigmatisation of bereaved young people in households, families and communities is likely to make them more

vulnerable to poverty and material discrimination than other children. This study will examine material discrimination amongst bereaved young people in the Gambian context.

Support is clearly needed to help bereaved young people who are trying to cope with the wide range of issues that result from their loss. Traditionally in Africa, families are the main source of support but of late questions have been raised as to whether families are able to cope with the increasing number of losses in their families (Foster and William, 2000). The following section will discuss the support from families, peers and agencies working with bereaved young people

## **1.6.2 Social support**

### 1.6.2.1 Sources of support

The DPM proposed that bereaved people may require interpersonal relationships to deal with their grief; otherwise they may need the love and support of other people to adequately deal with their loss (Stroebe and Schut, 1999). This is consistent with the recent call by the UN (2002) for all Governments, Non-Governmental Organisations, community groups and families to support bereaved and disadvantaged young people and their families in dealing with their problems. Interestingly, in Rusakaniko et al's (2006) Zimbabwean study only a minority of participants (17%) perceived socio-emotional support was needed by bereaved young people.

Although the previous sections show that bereaved young people have been stigmatised, abused and discriminated against, it is also the case that many African bereaved young people receive support from their primary carers, extended family members and other organisations in the community (Foster, 2005). The aim of the following sections is to examine these actual and potential sources of support in greater detail.

### 1.6.2.2 The impact of social support

Families remain the main sources of support for bereaved young especially immediately after their loss (Madhavan, 2004). The term ‘social support’ means the physical and emotional assistance given to one by a family and others. It shows that one is part of a community of people who love and care for one in times of need. This includes providing instrumental (e.g. assistance with a problem), tangible (e.g. material aid), informational (e.g. advice) and emotional (e.g. assurance) support (House et al, 1988).

Social support may help bereaved young people to cope with their loss. It is well established that increased social support predicts lower levels of depression (Shertkat and Reed, 1992); suicidal ideation (Stroebe et al, 2005); mortality (Murata et al, 2005); illness (Davidson et al 2002; House et al, 1988); and bereavement (Krause, 1986; Stroebe et al, 2005). Studies have indicated that higher levels of social support in relation to HIV-infection are associated with increased positive states of mind (positive mood, focused attention, productivity, responsible caretaking, and sharing) (Gonzalez et al., 2004), adherence to anti-retroviral treatment and improved immune status functioning (Hays et al, 1992). Others have reported that satisfaction with emotional, informational and practical social support is associated with positive adjustment (Turner-Cobb et al, 2004). The perceived inadequacy of support is strongly related to HIV disease progressions, poverty, low level of HIV-positive disclosure (Kalichman et al, 2005) and more intense symptoms of grief (Lennon et al, 1990). A recent study by Cluver and Orkin (2009) in South Africa found an association between stressors (poverty, stigma and discrimination) and elevated level of grief. Social support that addresses these factors may help in primary carers’ psychological functioning and their ability to provide adequate support for young people.

### 1.6.2.3 Religious perspective on social support and its impact

The concept of religion refers to linking ‘humans together beyond the purely physical domain to supernatural realm’ (Ladd and McIntosh, 2008, p.23). Clearly this definition views religious groups as a potential network of support. Ankrah (1993) identified the importance of social support in general and the role of spiritual leaders in particular. He suggested that while African society in general provided a supportive network in times of crisis, it was the

spiritual leaders who served as traditional counsellors and provided the necessary psychological support for victims of crises. Ladd and McIntosh (2008) proposed that social support underpinned by religious belief differed from other support in three spheres: provision of meaning; perceived presence of deity; and practice of prayer. The following sections explore these three areas.

#### 1.6.2.3.1 Provision of meaning

The first aspect of religious social support is within the framework of meaning making. Every religious group has an explicit and implicit framework of belief system that makes sense to its members and one that they may use as a benchmark in their day-to-day living (Spiro, 1987). This system creates a religious social network as a readymade resource to be tapped when needed. Its primary role in providing support appears to be twofold (Ladd and McIntosh, 2008). First, since this group is likely to be highly prepared and motivated compared to ordinary networks (McIntosh, 2003 and McIntosh (1995); Ladd and McIntosh, (2008) suggested it ‘may facilitate integration of stressful or traumatic events into one’s beliefs about the world and oneself that leads to more positive post crises outcome’ (p.28). Secondly, the sharing of an explicit worldview with others in the society may enhance interpersonal support (Hackney and Sanders, 2003), as people living in a society that supports their faith are likely to get most benefit from their religion (Pargament, 2002).

#### 1.6.2.3.2 Impact of divine support

The second aspect of religious support is the perceived supernatural support which serves as an exceptionally powerful source of support for individuals with faith. Divine support can be in two forms: either a loving God is perceived to be acting on behalf of an individual; or social support from a religious community is perceived as a direct/indirect support of a deity (Krause et al, 1998). In either case, the belief and the influence of such a belief about the supernatural power of the deity may be crucial as to how one approaches a difficult situation like death or coping with it. According to Pargament (2002), where individuals’ attempts to change their own situation hang on a thread, they can sustain the belief that all will not be lost since God remains firmly in control and explicitly supporting the supplicant. Some have even suggested that divine support may have health benefits. Perceived closeness with a loving

God may provide emotional support (Kirkpatrick, 2005) and better physical health (McIntosh and Spilka, 1990).

#### 1.6.2.3.3 Impact of prayer

The third aspect of religious support is prayer. Prayer is defined as ‘the typically intentional expression of one’s self in an attempt to establish or enhance connectivity with the Divine, with others in a religious or spiritual framework, and with the self’ (McIntosh and Ladd, 2008; p.29). This definition suggests the intrapersonal (self) and interpersonal (others) context of prayer. The characteristics of prayer itself, such as reciting text, perceived closeness with the deity during the prayer and attending congregational prayers, all show the important relationship between religion and social support. McIntosh and Ladd (2008) suggested that prayer by its nature facilitates engagement in care taking behaviours (e.g. intercessory prayer) and as such it ‘has the ability to meet humans’ built in needs to provide and receive care taking’ (p. 34), and it may help to ‘keeps a person’s perceptions of internal or external stress well under control’ (p.34).

Since religion by its definition means supportive network and the characteristics ingrained within it (such as a common worldview, availability of supernatural support and provision of interpersonal relationships) may serve as protective factors, the role of religious leaders is crucial in helping young people to cope with their loss.

#### 1.6.2.4 Family and its importance

‘Man is by nature committed to social existence and is therefore inevitably involved in the dilemma between serving his own interest and recognising those of the group’ (Yalom, 1995, p.18). It was therefore not a surprise when Foster (2002) described Africa as a collective society characterised by its numerous kinship and community networks. Ankrah (1993) maintained that in Africa ‘belonging to family is propagated through numerous bonds’ (Ankrah, 1993, p.6), suggesting that family in the African context is normally very broad, often including young people and their biological parents, members of their lineage (e.g. uncles, aunts and grandparents), as is the case in this thesis.

A family is considered as fundamentally the most useful unit that provides young people with security, sense of belonging and identity (Mallmann 2001). 'It is the first environment in which a child experiences love, affection and makes discoveries' (Mallmann, 2001, p.6). Walsh (1996) proposed that coping occurs in a relational context and as such a family may function as a protective factor in the time of crisis. Yet, various scholars have differing ideas as to what constitutes the familial protective factor. McCabbin and McCabbin (1998) identified family characteristics, size, and possessions as helpful; in contrast love, appreciation, communication, spending good times together, sense of spiritual wellbeing, ability to deal with stress have been identified by Stinnett and DeFrain (1985) as qualities helpful in an adverse social conditions. Garmezy (1984) emphasised the need for a committed carer and a strong social network. Several researchers suggested that family characteristic (Mbizana, 2007; Foster and Jiwli, 2001 and Foster 2005) such as positive relationships with primary carers, stable family environment, consistent family discipline patterns, and family variables served as protective factors. Clearly all this highlights the social fabric of human existence as young people are more likely to depend on the several characteristics of their extended family to cope with their loss.

#### 1.6.2.5 Family support and care for bereaved young people

Whilst there were many bereaved young people who were stigmatised and discriminated against (see Stigma and Discrimination), some young people have received care and support from their surviving parents, uncles, aunts, grandparents and siblings (Harber, 2001). The extensive network of potential sources of familial support for young people is evident in the literature. The surviving parents, uncles and aunts are still the main sources of support for many bereaved young people in Africa (Foster and William, 2000), but several studies in Africa have shown increased sibling support in the hard hit areas. For example, studies in South Africa (Nelson Mandela Children's Fund, 2001; Naicker and Tshenase, 2002; Masondo, 2006; Malinga, 2002; Sengendo and Nambi, 1997) and Zimbabwe (USAID/Zimbabwe/SCOPE, 2004) reported siblings as the main breadwinners in child-headed households. Whilst the presence of a child-headed household is often associated with failure of an extended family (Foster, 2002), Mallmann (2001) commented that 'teenagers have for many years looked after households in rural areas whilst mothers migrate on weekly basis... to work as domestic workers in nearby cities' (p.18).

In support of the important roles played by siblings, a study in South Africa by Hirasawa (2007) found that despite economic hardship the love, affection and appreciation between the siblings was obvious in child-headed households.

Although, in African tradition, neither women nor elderly people are expected to occupy the position of a household head (Oleke et al, 2005), the emergence of AIDS has forced the extended families to adapt to the challenges HIV/AIDS have brought along (Ankrah, 1993). The emergence of child-headed households, widow-headed households and elderly-headed households is far from addressing the impact of AIDS, but seems to show African culture to some extent as being adaptable to adverse social condition, as predicted by Ankrah (1993). The presence of widow household heads in Botswana (Heymann et al, 2007), elderly female heads in Nigeria (Hillhorst, 2006) and Botswana (Tsheko et al, 2007) were indications that young people may differ in their carers and in the nature and the quality of support they receive.

Evidence from African studies have suggested that the majority of support young people receive is material in nature. In Gambia, UNICEF (2004) reported families as the main providers of food, shelter and clothing for bereaved and vulnerable (those whose parents were ill) young people. In addition to the above, Chatterji et al (2005) and Nampanya-Serpell (2001) reported families' contributions towards payment of school fees and other school expenses. Whilst material support is important, other studies have emphasised the need for young people to be provided with emotional support.

In South Africa, Cluver and Gardner (2007) reported that care and love have been perceived as protective factors by their research participants. This finding has been corroborated by a study conducted in Zimbabwe. Nyamukapa (2006) reported that bereaved young people living in female headed households ( $p < 0.02$ ) and those receiving psychosocial support from the closest carer ( $p < 0.01$ ) were significantly less likely to develop emotional problems. The researchers speculated that it may have been that females were more caring than men towards the bereaved young people. Although no such gender differences were reported by Cluver and Gardner (2007) in their South African study, the researchers found their participants perceiving the function of primary carers as a factor protecting young people from emotional

disturbance. Overwhelmingly the young people in this study perceived that the feeling of being loved, cared for and respected enhanced their ability to cope with loss, suggesting that young people will cope better when these factors are considered.

The young people in the same study also perceived regular contact with significant people, including being accompanied to attend hospital appointments after their loss, as a sign of caring and a protective factor. More than a quarter (n=19) of them perceived contact with the extended family as helpful, with some seeing aunts as a particular source of consolation. In line with the perception of the young people, both the carers and professionals perceived that maintaining closeness was useful for bereaved young people, with the carers perceiving that engaging and participating in school meetings on behalf of bereaved young people was a sign of caring and loving.

Problem solving through engagement and information sharing between the young people and carers may be considered as a sign of caring for bereaved young people (Jewett, 1994). In Cluver and Gardner's (2007) study the young people perceived that being informed about what was wrong and what to do was helpful. Engaging with bereaved young people and helping them with their homework and reading was perceived by the carers as helpful. However, it was not made clear to what extent these factors influenced young people's ability to cope with their loss.

Whilst these studies have shown that, despite poverty, stigma and discrimination, some young people will access support from their household heads, yet, what constituted household heads in these studies (whether the household was headed by a woman or a child), is far from clear. It is not clear whether the decision to call one a head of a household is based on moral authority, social status, material gain, and decision making power, or being the oldest in the family (Mallmann, 2001). The responsibilities of the carer will determine to a great extent the nature and quality of support young people will receive. This thesis will examine the nature of familial support and its impact on young people's coping.

The following section reviews relationships that exist between bereaved young people and their carers.

#### 1.6.2.6 Carer / bereaved young person's relationship

The significance of families and positive developmental history of young people in influencing their psychological state when confronted with stressful life events was captured in Bowlby's (1980) attachment theory. This posited that young people who have secured an attachment relationship with their parents are better equipped with psychological resources to deal with stressful life events than those without such an attachment. Although it is hard to justify to what extent these young people would be considered secure or insecure and the extent to which this would impact on their psychological functioning, other theories seemed to support Bowlby's theories. Mallmann, (2002) suggested that positive parenting provides children with resourcefulness and resilience to cope with parental bereavement; and that it can be a predictor of bereaved children's ability to cope with mental health problems. These theories suggested the importance of family in mitigating the psychological impact of loss on bereaved young people.

In the context of this thesis, Bowlby's (1980) attachment theory suggested the need for good positive interpersonal relationships between bereaved young people and their carers. However, only a few African bereavement studies seemed to look into the relationship between the primary carers and the bereaved young people. Studies suggested that bereaved young people were likely to be cared for by their close relatives (Hillhorst, 2006). A large proportion (80.8%) of bereaved young people in Botswana (Tsheko et al, 2007) and the majority of the bereaved young people in Zimbabwe (Rusakaniko et al, 2006) knew their guardians well before they moved into their houses. A majority (55.4%) of the bereaved young people in Botswana got along and spent more time with their carers (Tsheko et al, 2007).

Bereaved young people's positive relationships with their carers were manifested by their feelings of happiness living in their new households. Rusakaniko et al (2006) found close to half (40%) of the Orphans and Vulnerable Children (OVC) reported that their guardians treated them with care and more than half reported that they were treated the same as biological children, while the majority did not want their guardians to change anything.

Although Giese et al (2003) reported some positive relationships between bereaved young people and their carers, they and Ntozi et al (1999) also found several instances where the relationship between the bereaved and the carer was not so cordial.

According to Mallman (2002), to encourage normal responses in bereaved young people, primary carers needed to recognise their creativity, initiative and coping capacity and should always listen to them. A piece of research in Ethiopia found the attitude of guardians of young people whose mothers had died as a significant predictor of emotional and psychological adjustment for the bereaved young people, indicating that primary carers with positive and sympathetic attitudes may help the young people to cope more effectively (Bhargava, 2005).

Cordial relationships between the bereaved and their guardians may lead to openness and sharing of concerns. Studies have shown that positive relations leads to more emotional support from the primary carers in terms of giving assurance, advice and caring for the bereaved young people (Tsheko et al, 2007) and more openness (69%) between the bereaved and their primary carers (Rusakaniko et al, 2006). In Uganda, a majority (79.2%) of the bereaved young people were found to be happy, comforted and relieved at living with a primary carer they were familiar with (Gilborn et al, 2001). Bereaved young people's familiarity with a guardian they are living with is associated with their greater emotional well-being (Nampanya-Serpell, 1998).

In Zimbabwe, Nyamukapa (2006) reported that bereaved young people living in female headed households ( $p < 0.02$ ) and those receiving psychosocial support from the closest carer ( $p < 0.01$ ) were significantly less likely to develop emotional problems. The researchers speculated that it may have been that females were more caring than men towards the bereaved young people. Although no such gender differences were reported by Cluver and Gardner (2007) in their South African study, the researchers found their participants perceiving the function of primary carers as a factor protecting young people from emotional disturbance. Overwhelmingly the young people in this study perceived that the feeling of being loved, cared for and respected enhanced their ability to cope with loss.

Other studies have also documented the importance of social connection in a variety of spheres in relation to psychosocial outcomes. In their analysis of moderating factors, Wild et al (2006) found that perceptions of connection, regulation and autonomy in the bereaved young people's relationship with their carers was associated with better adjustment in orphans. Makame et al (2002) found that not having a reward for good behaviour (as a carer may provide) was an independent predictor of internalising problems among bereaved young people in Tanzania. The findings of these studies should be treated with caution, especially since HIV-positive carers and carers of bereaved young people in general (Manuel et, 2002 and Nampaya-Serpell, 1998) were found to suffer from poor psychological health themselves; and such a depression may interfere with supportive interactions with the bereaved young people they are supporting (Stein 2003). For example, McCarty and McMahan (2003) found that less maternal social support leads to maternal depression and internalising disorders among young people. Several reports have also suggested that young people have experienced stigma and discrimination (Van den Berg, 2006; Clacherty, 2001; Strode and Barrett-Grant, 2001 and Cluver et al, 2009). However, it appeared that bereaved young people in positive relationships with their carers coped better than their peers without such a relationship.

Therefore this study will investigate young people's relationships with their guardians and the impact of that relationship on their coping.

#### 1.6.2.7 Bereaved young people's living arrangements and their impact

Before the advent of HIV/AIDS, the sense of duty and responsibility of extended families towards other members was almost without limits (Foster and William, 2000). Even though a family did not have sufficient resources to care for existing members, orphans were taken in (Van Den Berg, 2006). This was the basis of the assertion that, traditionally, 'there is no such thing as an orphan in Africa' (Van Den Berg, 2006; p.44). Today, whilst this claim may be seen as a myth in some societies, evidence suggests that young people are still taken in by their extended families.

Studies have shown movement of children between households as one of the coping strategies families have used to mitigate the impact of the death of an adult household head

(Hosegood and Ford, 2003 and Rusakaniko et al, 2006), with a majority of the young people taken in by a close relative (Hillhorst, 2006). In most cases guardians are well known to the bereaved (Tsheko et al, 2007).

Whilst relocation of the bereaved young people after the loss was very uncommon in the Gambia (UNICEF, 2004), multiple migrations were reported in Nigeria (Hillhorst, 2006) and Malawi (Ansell and Young, 2004) and the reasons for these migrations were due to change of circumstances such as death of a guardians, stigma and discrimination (Ansell and Young, 2004). Separation of siblings was also reported. In Zimbabwe a large proportion (38%) of bereaved young people reported that they had been separated from their siblings, 64% were moved into other households, 32% lived in one other household and 20% lived in two other households (Rusakaniko et al, 2006). In another Zimbabwean study, in half of the participating households, siblings were not living together and more than a quarter never had the chance to see their siblings again (USAID/Zimbabwe/SCOPE, 2002). Although this finding is consistent with a recent Zimbabwean study conducted by Nyamukapa et al (2008), Poulter (1997) early on found no clear evidence of sibling dispersion as a consequence of adult mortality in Zimbabwe.

According to Volle et al (2002) in Zambia young people's emotional disturbance was related to separation from siblings. However, there is increasing evidence that separation does not always lead to emotional disturbance. A study conducted in Botswana (Tsheko et al, 2007) and Zimbabwe (Nyamupaka et al, 2008) reported no negative effect of separation on siblings. In fact relocation from parental to their carer's household engendered family warmth. 50% of the siblings who had been separated visited each other on a regular basis to maintain the family warmth. Though a large majority felt worried about being separated from their siblings, they reported no changes in their relationships with their siblings. Forehand et al (1999), suggest that a single relocation and stability of the family environment was helpful to bereaved young people.

However, this evidence should be treated with caution as sibling dispersion also exposes young people to stigma and discrimination (Ansell and Young, 2004) and increased emotional distress (Nampanya-Serpell, 2001). Clearly there is conflicting evidence in these

studies requiring further investigation into the phenomenon. Therefore this thesis aims to investigate the living arrangements of bereaved young people.

#### 1.6.2.8 Peer support and its influence on ability to cope with loss

The term 'peer' represents people belonging to an age group (usually less than two years) within which there is a degree of what Miller (1960) called 'mutual awareness and continuity' (p.320). Based on this definition, peer support may be manifested by belonging to a group of young people such as a girls' club, boys' club, young farmers' club, drama clubs, village youth groups, a football team, young Muslims' and Christian associations. Members of these groups not only share the same age, culture or religion but they may also share some common concerns as young people at a particular age and stage of development,

A Harvard Bereavement study (Worden, 1996) reported that peer support for bereaved young people created a conducive environment within which discussion about death and sharing of emotion was facilitated. According to this study, when death occurred, one-fifth of the bereaved young people spent more time with friends than before the death, and in the early months after death, half of the bereaved young people engaged in talking with peers about their loss. This demonstrated that, in the West, young people trust each other and confide in each other when the need arises. This trusting relationship helps them to share with their peers their most difficult experiences such as death. (The benefit of talking and sharing emotion has already been discussed in section 1.4.2.3).

The influence of peer relationship on the lives of young people within the African context was acknowledged by Leis (1960). According to Leis (1960), in the early part of young people's development, their primary motivation is to please their parents; but as they grow they confide in their peers and rely on each other for mutual benefit and protection from danger. They celebrate their important occasions with them and turn to them when in need. Yet the role of peers in helping bereaved young people's adaptation to their loss seems to have been overshadowed by the function of the traditional extended family and decision-making process of adults (UNICEF, 2004).

Peer support for bereaved young people seems to be a new area in African research. However a few references to it were found in studies reviewed here that were dedicated to psychosocial adjustment to loss (Cluver and Gardner, 2007; Wood et al, 2006 and Atwine et al, 1997). Although the focus in this section is on the beneficial effects of peer support, it is important to note that peer relations are not always supportive. In South Africa peer problems, stigma and discrimination have commonly been reported among AIDS-bereaved young people (Cluver and Gardner, 2007) and HIV-positive young people (Clacherty, 2001) (section 1.5.1: Stigma and discrimination). They were also less likely than other young people to have a friend (Cluver and Gardner, 2007).

However, there is evidence that peer support is generally helpful. In their Zambian study Atwine et al (2005) found peer support to be particularly useful for young people who had been stigmatised: interaction with their peers diminished their feelings of stigma and shame. This research shows that peer support enhanced bereaved young people's ability to cope because it minimised what was considered the main hindrance to successful coping (see section 1.5.1: Stigma and discrimination). Unfortunately not all bereaved young people have the confidence to access peer support (Atwine et al, 2005) and as a result they may continue to suffer from the impact of stigma and discrimination.

In contrast, Wood et al's (2006) Zimbabwean study on young people whose parents were ill or had died of AIDS found them using their peers as respite when confronted with intense episodes of emotion. Interaction with peers who had similar experience gave them the belief that they were not alone in their bereavement and as a result they were comforted and better able to address their loneliness. However, in contrast to the accounts of the bereaved young people, the adult participants reported that, by having beneficial emotional relationships with non-bereaved peers, young people were prevented from focusing on their loss.

However, Cluver and Gardner (2007) found peer support addressing neither stigma nor loneliness. Although, in this South African study, the researchers found that the young people perceived socialisation with peers as a beneficial factor, its specific role in helping them to cope with their loss was not highlighted. However, many bereaved young people in this study perceived that peer support protected them from psychological problems and enhanced their coping. Consistent with this finding, a cluster randomised controlled study of AIDS-bereaved

young people (n=159) and their controls (n=169) was conducted in Uganda (Kumackech et al, 2009). The intervention group experienced a school based peer support group while the controls were not assigned to any support group. After adjusting for baseline scores, follow-up scores for the peer support group in comparison with controls showed significant improvement in depression, anger, and anxiety, although not in self concept. This implied that bereaved young people who received support from their peers in times of distress were significantly more able to reduce symptoms of depression anxiety and anger.

Whilst there is general agreement that peer support is beneficial, there seems to be a difference between the researchers on what exactly peer support does for bereaved young people. Some studies suggested that peer support prevented psychological problems and facilitated coping (Cluver and Gardner, 2007), decreased levels of depression, anger and anxiety (Kumackech et al, 2009); another study suggested it created comfort and prevented isolation (Wood et al, 2006); and Atwine et al (2005) suggested that it reduced anxiety and depression. Whilst no clear conclusion can be drawn from these studies, this thesis will investigate what exactly peer support provides for Gambian AIDS-bereaved young people who are trying to cope with their loss.

#### 1.6.2.9 Contribution of agencies supporting AIDS-affected young people

As this review has shown, many studies have suggested that bereaved young people were prone to emotional disturbances (Makeme et al, 2002), but many do not seem to be receiving the necessary support from their families to help them cope with their loss (see section 1.5.2.1: The extended family). Further help would appear to be needed. The UNAIDS and USA (2002) joint report 'Children on the Brink' proposed agencies to work with Governments, families and communities to address the economic, social and psychological needs of bereaved and vulnerable young people.

The strategies identified for addressing these needs included strengthening the capacities of families, creating supportive environments, providing support to community-based interventions, ensuring access to services and ensuring that Government policies protected vulnerable young people (UNAIDS, 2002).

UNAIDS and UNICEF have recognised the potential of the HUMULIZA and Masiye projects to provide practical psychosocial support for young people affected by AIDS on a large scale. Both projects have featured in UNAIDS' (2001) Best Practice publication on psychosocial support for young people affected by AIDS. Foster and Jiwli (2001) described Masiye Camp as a Zimbabwean project initiated by the Salvation Army (a Christian organisation). The first camp took place in 1998 in the Bulawayo area and comprised 45 young people (six to 20 years). A year later ten camps of 45 young people each took place in Zimbabwe. The goals of Masiye camp are provision of life skills to address the psychological needs of young people; a specialised training in teenage parenting; and training by targeting teachers, carers and social workers on how to create an enabling environment at household and community level.

In their efforts to evaluate the ten day Masiye Camp project for young people, Foster and Jiwli (2001) described life skill training exercises, such as learning trust and team building through exciting activities. The activities included swimming and canoeing which were designed to boost young people's confidence and mental strength, and aerobics and running for the improvement of fitness and discipline. Role plays, participating in traditional dance, drawing pictures and using puppets to share their own stories in a safe environment were designed to help them learn coping strategies and self-confidence. The authors acknowledged that this method of training through bush camps was an old African tradition revived to address the psychological needs of bereaved young people and has often been led by Masiye trained voluntary counsellors (aged over 20 years) who may have lost a parent.

Foster and Jiwli (2001) reported that their interview and focus group discussions with 46 youths and children (ex-camp participants and Kids Club Supervisors) and 50 adults (staff, government, NGO, community based organisations and community partners, puppetry group members, carers/parents and church leaders) suggested the aims of the project were achieved. The participants said they particularly appreciated the love and care that they received from staff and volunteers. Almost half (four) of the ex-camp participants interviewed indicated that their attitudes or behaviour after the training had changed. The changes included greater ability to cope with feelings, to handle difficulties and show more acceptable behaviour. The lectures on faith led to more spiritual inclination, with belief in God providing a defence mechanism against loneliness during tough times. Seventeen who attended the parenting

course found the informal sharing of problems and experiences with volunteer counsellors and their peers who were in a similar situation addressed their earlier concerns that they were alone in their pain and gave them comfort and strength. Their confidence was boosted by the realisation that some of their non-bereaved peers were in worse situations than their own. It must be noted that only a few out of more than a thousand people who were trained by Masiye Camp since the inception of the project participated in this study and as a result there may be valuable information about the impact of training that has been missed out.

Other agencies or projects have tried to create an environment that enable bereaved young people to effectively engage with their loss and address stressors that might be related to it. HUMULIZA is a small rural pilot project based in Muleba district in Tanzania, and functions under the Western Victoria Development Health Association (UNAIDS, 2001). This project with four permanent members of staff was launched in 1997 with the aim of enabling young people to develop their coping capacities and influence their own situations through creation of a conducive environment. Practical instruments, such as training manuals, were developed that would enable teachers and carers to understand and provide psychological support to young people. An example of one intervention creating a supportive environment took place at Ganyamukanda Primary School in Tanzania, with a teacher population of 16, 685 students and 291 bereaved young people. Although the UNAIDS (2001) did not give details of the evaluation process, it reported that, during post training (e.g. post-test) evaluation and follow-up of teachers, their attitude and commitment towards bereaved young people had changed. There was a better understanding about young people's problems, and follow-up visits with teachers and carers were conducted to address some issues of discrimination such as property grabbing and inheritance.

In the same report, the teachers described better communication, and so it is to be hoped that the bereaved young people were made to feel that they had been listened to. One of the problems identified by the teachers was isolation in class. This was tackled by the teachers after the training, attempting to make clear to the bereaved young people that they had the same rights to education as their non-bereaved peers. This report did not indicate young people's perceptions on the impact of the intervention on their coping, and there is a danger in over-relying on the account of the teachers, who may have exaggerated their achievements.

The report indicated that high priority was given in HUMULIZA's programs to involve youths in effecting changes to their situation through a project created by youths themselves, the Vijana Simama Imara (VSI) Organisation project (UNAIDS, 2001). Although VSI receives financial support from HUMULIZA, it is entirely youth-run. The members have created their own membership rules (e.g. they must be aged 13 to 20; self-motivated; trustworthy and unmarried) and goals, including: supporting each other during difficult times, planning and promoting income generating projects, unity and mutual cooperation, and helping the elderly). In line with these goals, young children may participate in project planning, but it is the young graduates (over 20 years of age) who serve as resources and role models for new members. UNAIDS (2001) reported that the young people involved in the project assisted the elderly in their community and did things like preparing funeral meals for their peers' parents, and there was even an incident of a house being built for a young person who had been chased out by a sibling. Whilst the young people might have been given the power to effect change to their own situations, this report did not indicate how this power helped them to cope with their loss. In addition UNAIDS' (2001) report suggested that the provision of school fees and financial support to Vijana Simama Imara (VSI) youth-run organisation was not sustainable and was creating dependency, suggesting the need for that aspect of the project to be reviewed.

Sustainable youth programs include the Farm Orphan Support Trust (FOST), reported in the UNAIDS (2001) publication as among the projects considered to demonstrate best practice. In this report FOST was described as a national community school based programme in Zimbabwe. This is a rural project where the families of farm workers reside on the land and their children attend school on the farm or nearby.

FOST has established community project clubs at a number of farm schools around Harare that aim to equip bereaved young people with life skills and vocational training, with the overall goal being to increase the capability of farming communities in responding to the orphan crisis, and to ensure that a mechanism is in place to care for the most vulnerable. Community-wide peer awareness education programs have been held on the needs of vulnerable young people. Farm lands have been used by the community to grow crops in order to combat economic hardship. The report (UNAIDS, 2001) suggested that working on the farm had two important functions. First, it reduced economic crises and sibling dispersion

through relocations. Secondly, it created an environment where young people from AIDS-affected families could interact with their peers with similar experiences and those not affected by AIDS. In addition to providing equal access to services, this report suggested that there was a reduction of isolation and discrimination experienced by AIDS-bereaved young people. However, there was no commentary about how this project was evaluated, which would have been useful.

The UNAIDS (2001) report identified the ‘memory book’ initiative in Zimbabwe as having potential to ‘help children to understand the past and move on to a more secure future’ (p.51). The memory book contains journal entries, a photograph, family trees and histories and other artefacts that remind the young person of their relationship with their parents prior to death. In some instances the book contains stories about a parent’s cause of death, a parent’s legacy, a special note from parents, favourite memories, family traditions, or special events that were celebrated together (Pillay, 2005). Whilst discussions about death had been viewed as difficult for families, UNAIDS (2001) reported that items of memory book had been used in Zimbabwe both to trigger emotions and initiate discussions about loss. It had further provided young people with the opportunity to clear their doubts by asking questions related to their parent's death. Although clarification of doubts may have reduced bereaved young people’s anxiety, this report has not shown how it arrived at that conclusion. In addition, using the memory book in communicating AIDS-related death may also have unintended consequences such as the surviving parent being blamed for the transmission of HIV and the death of the deceased.

The diversity of evidence in this section suggests that no single agency is able to provide all the needs of the bereaved young people; however, Masiye Camp’s method of training through bush camps was an old African tradition which allows young people to interact informally while learning through African drama, singing and dancing. This contextualised traditional approach made psychological intervention for young people more culturally sensitive. It is revived to address the psychological needs of bereaved young people and it is more likely to be successful (Foster and Jiwli, 2001). The following section discusses the project the Researcher is using for the research based in the Gambia.

#### 1.6.2.10 The OVC support project

This thesis has used the OVC support project as the basis for this research. The staff of the project acted as the primary gatekeepers to access bereaved young people, their families and the staff they were working with. Apart from being a gatekeeper they also provided for me a space and access to a computer and database that contained the list of HIV-affected and non-affected young people they were supporting. Whilst the space was only used once for the focus group discussion held with bereaved young people, the project was frequently visited to acquaint myself with the staff who worked with the young people. All the interviews except those with the professionals were conducted away from the project.

The OVC (Orphans and Vulnerable Children) project is the first of its kind in the Gambia that intends to support children and young people (five to 18 years) whose parents have died of AIDS, died of other types of chronic illness or have chronic illness. The goal of the project is to give economic, social and psychological support to them. It covers only Brikama town and its surrounding villages, which constitute less than 1% of the population. The project provides school fees, skills' development (such as learning tie and dying) and brings young people together at quarterly meetings. The purpose of these meetings is to provide them with the opportunity to share their experiences with others who are in similar situations. However, there is neither a publication nor an evaluation report on this project, making it hard to judge its potential to provide practical psychological support to young people.

Laying more emphasis on socio-cultural structures and approaches may provide better help for bereaved young people and their families to cope with loss (UNAIDS, 2001). It may also be helpful to increase the involvement of diviners, who occupy important roles in giving advice on support for bereavement in the African context (Ankrah, 1993). However, it would be unwise to assume that they have adequate knowledge about the impact of AIDS-related bereavement on young people's ability to cope with their loss.

Like the OVC project in the Gambia, the VSI project lays emphasis on involving youths in the activities of the organisation so that they can effect changes in their own situations (UNAIDS, 2001), but little is known about the exact impact VSI intervention made on young people's ability to cope with their loss. Since the OVC project in the Gambia has not been

evaluated, it is not clear whether young people will find the project helpful in addressing their psychological needs. This study will therefore investigate the views of bereaved young people and the adults surrounding them regarding the nature and the beneficial effect of the OVC project upon AIDS-bereaved young people's coping.

### **1.7 Research aims and objectives**

Arising from these issues, the research has had three main aims.

Aim 1: To explore young people's emotional reactions to the loss of a parent from HIV/AIDS and to compare that with the perceptions of carers and professionals. Objectives include identification of whether, and to what extent AIDS-bereaved young people:

- react to their loss emotionally
- are permitted emotional expression through crying and talking about their feelings
- react with sadness, anger, anxiety/fear, emotional loneliness
- remain emotionally connected to deceased parents
- employ denial and avoidance approaches

Aim 2: To explore young people's experiences regarding the impact of social factors, including stigma and discrimination, on their reactions and ability to cope with losing a parent from HIV/AIDS and to compare that with the perceptions of carers and professionals.

Objectives include:

- whether, and to what extent, AIDS-bereaved young people experience stigma, discrimination and poverty
- to what extent stigma, discrimination and poverty influence their coping

Aim 3: To explore how support from families, peers and agencies, particularly the Orphans and Vulnerable Children's (OVC) project, affect the young people's ability to cope with loss and to compare that with the perceptions of carers and professionals. Objectives include identifying the extent to which their ability to cope with loss is affected by:

- family care and support
- religious support
- peer support and OVC support

## CHAPTER 2: METHODS

### **2.1 Ontological and epistemological assumptions of this thesis**

Anderson et al (2003) suggested that when the reason for social science is to comprehend the ‘reality as different people see it and to show how their views shape the action which they take within that reality’ (p.153), then stating ontological assumptions and epistemological perspectives becomes an important part of the research process. Ontology is concerned with questions of whether there is a ‘real’ world ‘out there’ that is independent of our knowledge of it and epistemology is concerned with what we can know about the world and how we can know it (Lincoln and Guba, 2000).

Bitter-Davis and Parker (1997) differentiated two main ontological perspectives: fundamentalist and non-fundamentalist world views. Gallagher (2008) further differentiated them into objectivism and constructivism. The former (fundamentalism/objectivism) assumes that knowledge as absolute, an external entity separated from the knower and responsive to specific scientific method of analysis, and was traditionally informed by the domain of the physical sciences such as physics and mathematics (Gallagher, 2008). In contrast, the latter (non-fundamentalist or constructivist) assumes that there is no real social world out there to be discovered which exists independently of the meaning actors attach to their actions (Lincoln and Guba, 2000); knowledge is part of the knower and is relative to the knower’s experiences within his/her environment (Gergen, 1985). From the constructivists’ point of view, Lincoln and Guba (2000) suggested that knowledge is gained through social construction and shared meanings and as such no researcher can be completely objective because they live in the social world and are affected by the social construction of reality. Since the aim of this thesis is to understand young people’s reactions to their loss from their own perspective, constructivism and its epistemological assumptions underpin this thesis.

In the context of this research, it has been assumed that the young people, carers and professionals who are the participants in this study lived as active agents in their societies. They not only responded to AIDS-related deaths but they actively participated in the construction of the meaning of their loss.

These meanings were constructed through their daily active engagement in conversations and actions; and through their interpretations of their own actions and the actions of others (Lincoln et al, 2000). According to Rowlands (2005), by adopting the constructivist method the researcher is assuming that the social 'world and reality are interpreted by the people in the context of history and social practice' (p.83), suggesting that participants' reality itself is subjective and may be 'too complex to define and measure with standard instruments' (p.83). Investigating subjective experiences of the young people requires professionals and carers and the use of appropriate research approaches.

## **2.2 Rationale for the selection of the qualitative research method**

The choice of an appropriate approach is shaped by the ontological assumptions and epistemological perspective of the research (Lincoln and Guba, 1994). The worldview of the researcher is that of social constructivist; and as such accessing such knowledge therefore required understanding and interpretation of the meanings bereaved young people, their carers and professionals attached to their experiences. Meaning making is a central tenet in qualitative research; it is therefore a qualitative rather than quantitative approach that can uncover these experiences (Punch, 1994).

Although qualitative methods have been criticised for their inability to establish the prevalence of human behaviour, they are suitable when it comes to understanding people's theories of their behaviour (Powell and Single, 1996), as is the case in this thesis. According to Chenail (2000), if the researcher's aim is to know the formerly unknown or uncover more about an area where little is known, then the most appropriate approach is a qualitative one. Powell and Single (1996) suggest it is only a qualitative method that is capable of identifying and understanding new or complex social issues. Since this research is the first of its kind to explore the issues around bereavement in this particular society and deals with a complex human response (reactions to AIDS-related death), it was felt that a qualitative approach was the most suitable to generate relevant data.

According to Myers (2000), the aim of qualitative research is to understand participants' experience from their own perspective 'through detailed descriptions of their cognitive and symbolic actions and through the richness of meanings' (p.1).

It is from this context that Stanfield (1994) suggested that such an approach makes it possible for the researcher to develop an understanding about socially situated experiences by engaging with the people who have first-hand experiences of the phenomenon. It was felt that this approach would enable the researcher to investigate and understand bereaved young people's emotional response to their loss from their own perspective and from the perspective of their carers and the professionals supporting them.

Although studies have continued to criticise the qualitative approach's lack of objectivity and generalisability (Myers, 2000), Myers (2000) warned qualitative researchers to focus on the goals of the study because issues of generalisability and sample size 'may have little relevance to the goals of the study and reality of the situation' (p.2). She argued that, owing to the qualitative approach's in-depth inscriptions of a phenomenon, a small sample size examining a phenomenon from various perspectives may be more useful than a large sample that may be 'inconsequential' (p.2). Since the aim of this thesis is to explore the emotional reactions of AIDS-bereaved young people from multiple perspectives using a small sample size, it was felt fitting to apply a qualitative approach. Among the several qualitative research methods available, the researcher chose the one most likely to help develop an African model of bereavement.

### **2.3 Grounded theory**

Grounded theory is a qualitative approach attributed to Glaser and Strauss (1967), initially described by them as an approach to the development of inductive theory. The authors suggested that if one conceptualises from the data and if the data are accurately recorded, then the construct and the categories arise fitting the data and can be said to be subsequently 'grounded' in the data.

The role of the researcher in the constant comparative method of analysis is to explain a phenomenon from within the social situation itself and to identify the process operating therein (Barker et al, 1999). This approach was appealing since it was the aim of the study to gain an in-depth understanding of young people's experiences of their reactions to their loss. However, its emphasis on the generation of a conceptual framework based on data rather than previous studies represented a dilemma, since the literature review commenced several years

before the method of data analysis had been decided. In consequence, it was decided to borrow aspects of the grounded theory method that were most likely to add structure and therefore rigour to the research.

Strauss and Corbin (1990) described three approaches to the analysis of qualitative data. The first is one in which the data is presented without analysis. In the second approach, researchers describe as accurately as possible what they have understood. This requires interpretations of data, weaving descriptions, speakers' words and their own interpretations into a rich, believable descriptive narrative. The third approach to data analysis requires interpretation in order to develop theory from the data. The approach taken in this thesis is similar to the third approach described by Strauss and Corbin (1990).

The analytical approach used in this thesis is the constant comparative method, described as a 'systematic asking of generative and concept relating questions, theoretical sampling and systematic coding procedures (Strauss and Corbin, 1994, pp.59-60). The model's strength lies in its systematic nature. Such an approach was considered highly desirable, since it offered the opportunity to demonstrate a clear research trail that might otherwise be difficult to illustrate.

## **2.4 The participants and recruitment process**

### **2.4.1 The research participants**

Interpretive researchers perceive that the most important knowledge is gained from the people who have experienced the phenomenon (Rowlands, 2005). This thesis has included 15- to 18-year-old AIDS-bereaved young people, their carers and the professionals who were working with them. All the participants were Muslims and black Africans except one professional counsellor who was a black Caribbean. The participants (black Africans) belonged to the four major ethnic groups (Mandinka, Fula, Wolof and Jolla) in Gambia. Except for a few professionals, all the participants were living within the same locality (Brikama town).

The majority of the participants in this study were young people all of whom were selected from the OVC project (see Table 2.1). The majority had lost a father and some had lost a mother and others had lost both parents to AIDS. In addition, some surviving parents and carers were seriously ill at the time of data collection. A few bereaved young people had also lost a brother or a step-mother.

**Table 2.1: Basic demographic information of the participants**

	Young people	Carers	Professionals
Recruited through OVC/Hands on care	17	10	3
Recruited through Santayalla	0	0	3
Total	17	10	6
Lost father	9	0	0
Lost mother	4	0	0
Lost both	4	0	0
Lost brother	3	0	0
Lost step-mother	2	0	0

All the young people were going to school. Their school fees and lunches were paid for by the Catholic Children’s Fund (CCF) through the OVC project. Their families also received benefits such as nutritional supplements for children under five. None of the young people were diagnosed with HIV, and none had shown any signs or symptoms that might suggest that they were HIV-positive. It was felt that using known HIV-positive young people would have compounded the findings and might upset them more since the young people’s concern would be influenced by their HIV status (Hundis, 1995). As a result of this, the research includes only parentally AIDS-bereaved young people whom appeared to be HIV free (see Gatekeepers – for details on recruitment).

The carers involved were the adults young people lived with and upon whom they depended for their day to day needs. None of the carers in this research had attended schooling and therefore none of them was in formal employment. The majority were in petty trading or farming, or they were unemployed and dependent on other people. The HIV status of the

carers was not disclosed to the researcher but almost all of them seemed to be attending HIV clinics, suggesting that they might be HIV-positive.

The smallest sample of participants in this research consists of professionals (see Table 2.1). The term 'professional' refers to adult health professionals working for an AIDS agency specialising in supporting AIDS-affected families, especially bereaved young people. The professionals included male and female participants, recruited from both Hands on Care (see section on Hands on Care) and a sister project 'Santayalla' Support Society. Santayalla is a Support Society for People Living With HIV/AIDS (PLWA) and the professionals included in the research give counselling, care and support to PLWA and their families. All the professionals from this project and those from Hands on Care who consented to participate in this research worked closely with both the carers and the young people they cared for.

#### **2.4.2 The Hands on Care/OVC project**

As all the bereaved young people and half of the professionals were recruited from OVC, the daughter project of the Hands on Care program, and cares from Hands on Care these organisations are of great importance in this thesis. Hands on Care is a World Evangelical Church (WEC) program designed to provide home-based care for chronically ill people, the majority of whom are infected by AIDS. The project intends to provide material and psychosocial support to the ill and families affected by their illness. It aims to reduce admissions to hospitals by providing free medication and the necessary support, with volunteers comforting the dying and helping them with domestic chores. It offers younger children practical help such as giving them a shower and combing their hair.

There has been concern around the world over the plight of children as it has become clear that the existing services were not addressing their needs (UNAIDS, 2002). This remains a concern. The UN has urged governments and faith organisations to react to this growing concern and implement services that reflect the needs of young people. OVC was set up in 2000 under the auspices of the Hands on Care project to address the material and psychological needs of bereaved and vulnerable children of parents with chronic illness. This service, supported by the WEC mission, Medical Research Council, National AIDS Control

Program and CCF, has focused only on families that have already registered with Hands on Care, leaving out a majority of the young people who may need a similar opportunity.

Although one goal of the OVC project is to bring children and young people in similar circumstances together, its coverage is extremely small as it focuses only on Brikama Town and its surrounding villages. At the time of data collection, only 300 children and young people aged 5 to 21 were registered. A majority (80) of the young people were vulnerable, having a parent who was chronically ill with HIV/other conditions, and facing the loss of one or both parents in the near future. However, this thesis is particularly interested in the remaining 20% of the young people who had already lost one or both their parents to AIDS. It focuses specifically on 15- to 18-year-old AIDS-bereaved young people and their carers. Considering the fact that, in the Gambia, between 2,200 and 6,000 of the population of half a million young people were estimated to have been bereaved by AIDS (UNAIDS, 2006), this project covers only a very small proportion of young people in need. The majority of AIDS-bereaved young people lives elsewhere.

Although the main aim of this project is to provide emotional and material support for bereaved young people, the focus so far has been centred on provision of school fees, uniform, school lunches, and bicycles for young people and nutritional supplements for babies. Whilst this support may be helpful, projects that provide financial support of this nature are not always sustainable and may cause dependency (UNAIDS 2001). By implementing skills development and income generating activities (e.g. tie and dying, Batik, soap making and petty business), the OVC project has given its members the potential to provide the sustenance required and also improved the living conditions of bereaved young people. Even though all the bereaved young people were receiving funding for their education at the time of data collection, none of the young people participating in this study was yet trained. Some of these young people may have had special concerns in dealing with their loss and its consequences. However, during the early part of the recruitment process the professionals working with them confessed that, until that time, they had been unable to initiate discussion about loss.

There is evidence that projects empowering bereaved young people have the potential to make a difference in their lives (UNAIDS, 2006). One of the aims of OVC is to enable young

people to run the project by themselves. At present, the general members meet quarterly and the executive members (12 young people) meet twice more to develop agendas for the general membership meetings.

Although none of the participants in this thesis were executive members, it was planned that in the future each member of the executive committee would be assigned ten younger people to visit in their homes. The purpose was to consolidate relationships and to build trust. Whilst this aspect of the project was at the planning stage, quarterly meetings created an avenue for young people to socialise with their peers, which may have helped them to cope.

### **2.4.3 Rationale for the selection of the participants**

The decision to select AIDS-bereaved young people, their carers and professionals for this research was based not only on accessibility and interest in the research but also on the belief that they would bring something special to the research that would facilitate understanding of the emotional experiences of AIDS-bereaved young people within the Gambian context.

It is evident that although many young people have been bereaved by AIDS in Gambia, many others will reach puberty without their biological parents (UNDP, 2006). Consequently, they will lose the people who matter most to their emotional and social growth. 15- to 18-year-olds especially are likely to receive less care than their younger siblings; this will expose them to difficulty in coping with their experiences. In addition, since the young people in this research have shown no signs or symptoms of HIV infection, they are less likely to attract attention and support than their peers with HIV (Hudis, 1995). The young people might be experiencing hidden emotions and stigma that has not been recognised by the public but which needs to be shared with interested people.

The carers were the adults the young people lived with and upon whom they depended for their day to day living. Since the carers were mostly surviving parents who might also have reacted to the loss of the significant relationship, it was felt that they would empathise with the young people. This was especially so because they were mostly living with the young people and they may consciously or unconsciously have learned about their emotions and behaviour before and after losing a parent. In addition, young people may have confided their trust in them and shared their experiences with them, making them good candidates for this

research. Although several studies have used adult carers to elicit information on bereaved young people's experiences (see the previous chapter), it is not always possible for adults to understand young people's experiences. There is evidence that carers lack knowledge and understanding of bereaved young people's reactions (Wood et al, 2006).

The professionals were the actual people working closely with the carers and the young people they were supporting. Since health workers have professional working relationships with bereaved young people, their years of interactions with them as individuals and as part of a family expose them to learning about young people's responses to loss. Apart from the HIV sero-positive tests to confirm the diagnosis of the deceased parent, professionals are involved throughout. So, naturally, professionals are dealing with both the infected parents and the affected young people before and after the death of their parent. The length of HIV illness suggests that the longer association may help professionals to learn about emotions and possibly detect any changes that may occur after the death of their parents. The belief that professionals are important informants is shown by the use of professionals in several studies reviewed in the previous chapter. Some may be suspicious of the information from professionals, especially since there is a belief that some teachers struggle to understand bereaved young people's reactions in classrooms (UNAIDS, 2001). In any case, it appears that apart from the carers, professionals are the closest to bereaved young people.

#### **2.4.4 Gatekeepers and the recruitment process**

Accessing potential informants such as AIDS-bereaved young people, carers and professionals required a series of consultations. In the Gambia, any form of research relating to AIDS is authorised by the National AIDS Secretariat (NAS). This responsibility includes researching AIDS-bereaved young people, their carers and professionals. It was therefore fitting to consider the NAS as the key gatekeeper for this research. Although NAS does not deal directly with individual participants, the institutions that do are directly answerable to NAS and likely to act upon the requests of the NAS. As Hammersley and Atkinson (1995) suggested, knowing your key gatekeepers will help ease access to the participants with whom you are concerned. Although the director of NAS was the former boss of the researcher, it was clear that, the researcher knew he would, rightly, not compromise his position if he viewed the research as unethical.

Permission was granted after a series of email and telephone consultations with the director of NAS, who later requested the research proposal and also asked questions on ethical issues regarding the research. The key issue the gatekeeper wanted to clarify was whether or not children would be asked questions on AIDS, a concern that was also raised by other gatekeepers. It was made clear to them that, unless children raised the point, they would not be asked. A similar approach had been used by other researchers in this field (Makame et al, 2002). After this clarification, the researcher was granted permission to access the coordinator of Hands on Care and the Santayalla Support Society. NAS also made consultations to the heads of relevant institutions and forwarded the proposal to them.

Follow-up consultations through email and telephone calls were initiated. Having the initial permission did not guarantee access to research participants, because gatekeepers might have had a completely different perception of the research. Walsh (2005) commented that concerns of gatekeepers about parents' perceptions regarding their children's participation, gatekeepers' own perceptions of the damage the research could cause, and fear that the research would reveal their own dubious practices all contribute to their decisions. However, the researcher clarified the doubts the gatekeepers voiced through continuous consultations. After months of consultations, the researcher then personally managed to meet up with the head of Hands on Care and the staff working with the bereaved young people. A similar meeting was held with the staff of Santayalla Support Society. The reason for the meetings was to explain the purpose of the study, the target group needed and the procedures that would be used to access the participants. For the Santayalla Support Society, the researcher was interested in the professionals who always or sometimes worked with AIDS-bereaved young people. It was felt that, although the program focused on HIV-positive adults, some professionals might have first-hand experience of AIDS-bereaved young people's reaction to their parents' deaths. At the end of the meeting three professionals volunteered to participate in the research. These professionals were working closely with their colleagues from the OVC project and they both worked closely with the carers and the young people in this thesis.

In the case of the Hands on Care/OVC project, the gatekeepers were told that the researcher was interested in young people whose parents had died of AIDS, their carers and the professionals looking after them (see section on Participants). Although permission was

granted and three members of staff were willing to participate, the parents of the young people and the young people themselves needed to be identified and approached. The eligible participants were identified and selected from the OVC register kept in the office. Although the initial intention was to select all 25 of the eligible participants, because of a problem of access 17 eligible young people living in Brikama were studied.

An initial meeting was organised by Hands on Care. Young people and their carers were invited, informed about the research project, and asked for their willingness to participate. Only five families attended the meeting. Although the researcher was told that all the eligible participants had been informed, it later became clear that this was not the case. The researcher avoided discussing with the project worker anything to do with the absentees to prevent dispute. Although the researcher did not know the motive behind the project worker's behaviour, he became more cautious of the power this member of staff might have possessed. Hammersley and Atkinson (1995) suggested that, despite the good intentions of a researcher, gatekeepers may perceive or in reality may believe that undesirable public attention would be generated by the research. This possible fear and vulnerability of gatekeepers might have implications for the development of openness and trust and could impede the research process (Hammersley and Atkinson, 1995). Despite gatekeepers being reassured that there was no intention to implicate or harm any member of staff or participant, access remained problematic and the researcher had to use the families that participated in the initial meeting to locate other eligible families.

All the families were visited at least twice before any data was collected from them. The initial visit was mainly to introduce the research to them, including the ethical issues; to explain procedures and ask whether they would like to take part (see Section 2.10: Ethical issues). It was also meant to initiate age specific rapport with them. Since the research aimed to seek information from both the carers and the young people, the researcher always ensured that, when he visited homes, he spoke to them together as a family (except during interviews). Such an approach made it possible for both participants to receive the same type of information.

## **2.5 Data collection and the participants**

### **2.5.1 Selection of data collection method with the participants**

Various methods of data collection were considered for use with the bereaved young people, their carers and professionals but open-ended interviews (see Section 2.6.2) and focus group discussions (FGD) (see Section 2.6.3) emerged as the methods of choice in this research. Whilst a one-to-one interview has been described as a two person conversation initiated by the interviewer for the specific purpose of retaining research-relevant information (Cannell and Kahn, 1968), the FGD may be described as a form of group discussion involving people with knowledge and interest on a particular topic and with a facilitator guiding the discussion (Morgan, 1996).

One reason for using these methods was that it was considered the young people would prefer to have both individual interviews and FGDs; and secondly these two methods are suitable for an interpretive research approach because they place emphasis on giving the participants greater control over the topic under discussion (Parker 1984; MacNaughton and Smith, 2005). This was perceived to be particularly important for AIDS-bereaved young people who might have been stigmatised, discriminated against, isolated in their societies, or whose voices might not have been heard (Wood et al, 2006). Cuskelly (2005, p.114) suggested:

Research methods should empower those who take part by enabling them to represent their own situations, to reflect on their own experiences and to influence change. These tools appear to have particular relevance when seeking to reveal the multiple perspectives of young people.

Accordingly, it was felt that, if AIDS-bereaved young people felt empowered, rather than incompetent and vulnerable, they were more likely to share their experiences with others. Open-ended interviews and FGDs reduced intimidation and created for participants the opportunity to share issues that concerned them (David et al, 2005). Such an experience in Pakistan was articulated in David et al's (2005) study in which young people were asked their views about the research process. They were found to be comfortable with the open-ended method of individual and FGD which gave them time and space to discuss issues pertaining to their families. They spoke about preferring spoken to written answers, because they felt it

was easier to talk than to write. In line with this, David et al (2005) claimed that open-ended and FGDs were less invasive and less intimidating to young people than other structured methods. Even so, it may have been that, due to fear of stigma and discrimination, some AIDS-bereaved young people and their carers would find it hard to discuss their loss with others, even if open-ended and FGDs were used. In such situations, direct, structured questioning might be required.

Morgan (1996) suggested that starting a qualitative study with an FGD and following it up with open-ended interviews enhances rich, quality data. Although such an approach was used among the bereaved young people, it was not always practicable among carers and professionals owing to their busy schedules. The carers had different schedules owing to their busy farming period and this would have made it very difficult, had they been asked to converge at one place for FGD. Efforts were made to bring all the professionals together for FGD but failed. The reasons were that the professionals did not come to work at the same time; they could not use their break for interviews and not all of them could stop work to attend interviews. The researcher resorted to using only the open-ended interview method.

### **2.5.2 Rationale for selecting open-ended interview method**

Denzin and Lincoln (1994) viewed interviews as ‘a conversation; the art of asking questions and listening’ (Denzin and Lincoln, 1994, p.353). Although there are several types, Couchman (1990) perceived that interviews follow a continuum from extremely formal (i.e. structured interviews) to extremely informal (i.e. non-directional interviews). The technique that was used in this research to elicit information on bereaved young people’s reactions to their loss was primarily an open-ended format of questioning located at the informal end of the continuum. It involved approaching the bereaved young people, carers and professionals with an open agenda and aimed to enable them to talk about AIDS-bereaved young people’s reactions to the loss of their parent.

Since one of the goals of this thesis is to describe the experiences of AIDS-bereaved young people as they are lived, a data collection method was required that allowed a greater freedom for them to narrate their stories in ways convenient to them. An open-ended interview was found to fulfil this criterion, the strength of which was its flexibility.

Mack et al (2005) commented that an open-ended interview ‘unveils individual perspectives because it facilitates talk about their personal feelings, opinions and experiences’ (p.30), which seems to reflect the central themes of this thesis.

Parker (1984) specifically described the significant roles played by an open-ended interview in understanding issues affecting young people. They are not only capable of revealing young people’s perceptions, memories, attitudes and beliefs but also create an opportunity for their emotions to be uncovered making them accessible to the researchers (Parker et al, 1984). Although it may not be possible through observation to uncover some of this data, other quantitative methods such as questionnaires and attitude scales might do so. These, however, require literacy, which would be inappropriate for young people whose formal education level was very low as it could lead to their embarrassment (Parker, 1984); furthermore, such a method may not be feasible for use with carers with literacy problems or not much formal education.

The open-ended interview method has greater capacity to facilitate talk on personal issues (Miles and Huberman, 1994) such as loss, loss-related stressors, and the feelings of AIDS-bereaved young people. According to Parker (1984), a social phenomenon is understood better by keenly listening to people ‘...narrating their stories on what they have experienced and believed and by actively connecting their beliefs, events and activity’ (p.30). This thesis emphasises the need for AIDS-bereaved young people to be listened to and heard, and it was felt that this method would make that possible.

However, the open-ended interviews method is not without its drawbacks. The bereaved who are very distressed may be reluctant to talk about their loss in depth. In such situations, the direct question and answer format of interviewing may be more useful than open-ended interviews. It is also apparent that an open-ended interview method is only applicable to young people who are capable of speaking, understanding language and willing to give their account (Parker, 1984). However, during the initial rapport with the participants, the candidates appeared willing to talk about their experiences.

### **2.5.3 Rationale for selecting focus group discussions**

As indicated earlier, FGDs were conducted only with AIDS-bereaved young people. This is a single research technique that is characterised by both observational and individual interview methods (Madriz, 2000), suggesting that researchers can both observe and interview at the same time and within the same setting. With these characteristics, the technique is exploratory in nature as it gives the researcher the opportunity to learn a great deal from the participants (Schearer, 1981). However, the focus of this thesis is on the interview aspects of the FGD method.

FGD allows participants to interact and share their thoughts and feeling with others (Schwandt, 2000), as discussed earlier. It was believed that such an approach would be appealing to AIDS-bereaved young people who may be reluctant to participate in individual interviews through fear of being singled out in the community, especially in a society where stigmatisation may be prevalent. As Morgan (1996) noted, FGD is not only capable of giving participants the role of experts but also makes it possible for the concerns of the marginalised and vulnerable, such as AIDS-bereaved young people, to be heard.

According to Bryman (2004), the interaction that occurs in a group interview is an important aspect in investigating complex human behaviour and motivation. It is common knowledge that such interaction, agreeing and disagreeing, is a characteristic of peer relationships (Smith, 1998). However, Krueger et al (2000) warned that sharing the same sex, age, gender and ethnic background, often described as the characteristics of a homogeneous group, does not necessarily result in young people having similar levels of openness when it comes to sharing information. They maintained that people are naturally different.

Rabiee (2004) suggested that many researchers think FGD participants should not know each other because, when they are not acquainted, they are more likely to be honest and hold views that are divergent from one another, thus making data rich. However, Kitzinger (1994) held a different view and advocated the use of pre-existing groups (as in the case of this research) because they are able to relate to each others' comments and challenge each other better if there is a degree of acquaintance.

Consistent with the latter, it was thought to be a good idea to hold FGDs with AIDS-bereaved young people who were all recruited from the same project because they were peers who seemed to know each other; they were, therefore, expected to participate effectively in discussions during FGD.

FGD has its limitations. The interaction that is considered as the strength of FGD may also serve as the source of its weakness because the participants do not always engage fully in discussions (Rabiee, 2004). Whilst Rabiee (2004) commented that all participants need to be comfortable, Krueger and Casey (2000) recognised that trust is needed for the participants to narrate their stories. The process of building trust among the participants themselves can be long and painful. However, it was felt that the young people in this research were a homogeneous group and might have confided in each other (see section on OVC).

## **2.6 The process of data collection with the participants**

### **2.6.1 The interview and focus group guides with the participants**

Several aims and objectives, arrived at through the literature review, suggested that the phenomena being explored were complex and required a data gathering method that would enable the participants (carers, professionals and bereaved young people) to give information relevant to the research question. Two of the most common methods that help people to gather data from such a complex social situation are an open-ended individual interview and FGD methods of interview (Mack et al, 2005). Despite the rejection by interpretive research of a researcher's preconceived view about a topic, it was still possible for the researcher to generate broad questions from the literature reviewed that would facilitate discovery of new theories (Patton, 1990). Patton (1990) said it would be difficult to ask any question without having some theoretical knowledge about the phenomenon but warns that researchers should not be too occupied with theoretical knowledge at the expense of discovery. Complete interview and FGD guides are shown in Appendices 1 and 2 respectively.

The guides, which consisted of key themes generated from the literature and were underpinned by the Dual Process Model (DPM), were selected in order to explore a broad range of young people's emotional reactions and factors that influenced their coping with their loss. This model suggested that for bereaved people to cope with their loss, they should

experience loss-oriented coping and restoration-oriented coping (Stroebe and Schut, 1999). The alternation between these two coping processes is referred to as oscillation. With oscillation, the bereaved at times actively engage with their loss (loss-oriented coping) and at times they disengage with their loss (avoidance), either voluntarily or involuntarily, by focusing on other stressors (restoration-oriented coping). Restoration-oriented coping includes dealing with stressors like discrimination, isolation and stigma; and engaging with support from families, peers and organisations working with AIDS-bereaved young people. Loss-oriented coping includes engaging with thoughts about the deceased person and emotional reactions surrounding this thought. According to Stroebe and Schut (1999), whether the bereaved seek support or not, engaging with both loss and these minor stressors is required for optimum coping to occur. However, knowing that this model has been developed in the West and has not yet been tested (Payne et al, 1999), especially with young people in Africa or elsewhere, it was something of a risk using it to guide this research. However, Stroebe and Schut (1999) suggested that the model could be used in many different cultures, contexts and on different age groups.

## **2.6.2 The interview process for all the participants**

Whilst the interview guides on bereaved young people's experience may help to generate good qualitative data, the physical setting of an interview can also have a significant influence on the content and the quality of data (Hammersley, 1983). David et al (2005, p.131) suggested that:

It is crucial to consider context when conducting interviews with children and young people. Getting a simple logistic wrong such as venue, timing and group dynamic can ruin an otherwise a carefully planned research.

The quality of data gathered from research subjects in a particular setting depends largely on how comfortable the research subjects feel. Morgan (1996) commented that it is vital the research subjects are comfortable with their surroundings, as this helps a discussion to take place.

Similarly, David et al (2005) advised that research with children must be conducted in a safe environment and researchers working with young people to ensure adults are present when

conducting interviews with children and young people. This is not always practicable as the presence of adults may in fact compromise the safety advocated by David et al (2005).

However, David et al (2005) have identified 'home' as a natural habitat that permits sharing of honest views about individuals' experiences of phenomena. They suggested that interviewing at home aids young people to feel comfortable. The bereaved young people's decision regarding their preferred site for interviews in this study made the researcher doubtful about David et al's (2005) theory that suggests home is the best place for interviews. The young people selected neither their homes nor the OVC centre for their individual interviews. They selected an alternative location and this led to the renting of a private room for the interviews. The reason for their choice was that they felt their homes could be too noisy and lacking in privacy. The fact that young people were allowed to make such important choices demonstrates the respect the researcher attempted to show them.

The timing of the interview is crucial and must be considered when dealing with young people. Their choice regarding timing concurred with David et al's (2005) suggestion that research conducted at weekends and during holidays is likely to be preferable and more useful when there is a need to discuss issues at length. In this research, young people preferred to be interviewed during the weekend when they would not be attending classes and there would be someone at home to take care of the domestic chores. The selection of young people was based on convenience of access, but despite the prior exclusion of eight families on these grounds, accessibility for data collection remained problematic and time-consuming. Many a time appointments were made with bereaved young people, but they failed to turn up for the interviews. The reasons varied from not having time, being busy with domestic chores, forgetting about it, or rain. In each case, the researcher had to make several follow-ups to ensure that the interview was held as agreed with the young people.

Unlike the young people, carers preferred to be interviewed at home and at night or in the late evening rather than in the morning or afternoon. The reason was that carers' participation during the day would mean that they had to forgo some of their daily routine activities to attend the research.

Although none of the carers was interviewed at night, they preferred to be interviewed when they had already eaten and were relaxing at the end of the day. As one carer said, if she felt sad before eating, she would not then be able to eat; so it would be better to eat before discussing death. In addition two interviews with carers were postponed several times before finally being held. Each time the researcher visited their houses, they were either out or complained of tiredness because of a long day's work.

Coming from this culture, the researcher had a detailed understanding of what preparations are necessary to acquire an adequate response from the participants. As Burgess (1984) suggested, adequate knowledge of the culture in which participants live helps a researcher to appreciate the participant's lived experiences. It also helps the researcher to choose appropriate dressing for the interviews. Unlike Measor (1985), who suggested the need to dress formally especially when interviewing, it felt appropriate for the researcher to dress casually in a gown that is traditionally accepted in both formal and informal gatherings. Both during the recruitment and data collection, the researcher dressed in simple and inexpensive clothing to give the impression that he was not different from the participants. Cornwell (1984) suggested that where the research participant views the researcher as similar and equal to her, she may be more likely to discuss her personal experiences. (Issues of power imbalance are discussed later).

In terms of the actual interviews, the professionals differed from the young people and carers in that their interviews were conducted in an unnatural home environment. The professionals' interviews were conducted in their offices. This was based on their request to be interviewed there. Except in a few circumstances when a professional was too busy with a patient to attend to the researcher, access for interviews was straightforward.

In terms of the actual interviews, the professionals differed from the young people and carers in that their interviews were conducted in their offices. The interviews with young people were conducted in a conducive, natural home environment where little disruption was encountered. Although the interviews with carers were also conducted in a natural home setting, the environment was not equally conducive. For example, some of the rooms where interviews were conducted were small.

Interviews with carers in an extended family set-up were frequently disrupted due to the movement of people in and out of the room and noise made by children in the house. Interviews with professionals were conducted in an office environment. In these, there were differences of size and other arrangements. However, all offices had telephones that interrupted the interview process at frequent intervals. In addition, movement of people in and out of offices was disruptive, breaking the flow of discussions.

Although much of what we transcribe from interviews is words spoken to us (see Transcription), human communication is not only verbal; it can also be non-verbal. Sensitivity to non-verbal cues is required if the researchers are to capture and analyse some important data (Rose, 1994). It is understood that in practical terms it is extremely difficult, especially for a novice, single researcher like myself, to gather data from non-verbal cues. However, was aware that all the bereaved young people cried during the interviews. It is obvious that a large part of the non-verbal data might have been left out.

Each open-ended interview was preceded by social introductions as discussed in the section on Ethics. At the beginning of each interview, the researcher made explicit the purpose of the study before reminding the participants about the confidentiality issues. This open-ended format for gathering data on this topic was found to be sensitive because it allowed the participants the freedom to gain a degree of control over the research process. One of the reasons for doing this was to avoid being viewed as a judgmental, opinionated sort of person who was only interested in gathering information, which may be the case when a more direct approach is used (Finch, 1984).

Once the interview commenced, themes were explored with the participants with general descriptive questions (Patton, 1990). For example, in the case of young people the researcher asked: 'When your father/mother died how different did you feel?' (e.g. sadness, anger, loneliness, continuous bond). The other group of participants were asked similar questions. This was followed by a series of probes as directed by the discussion, with the hope that the young people would identify certain emotions and dwell further on them. This first question was in line with loss-orientated adaptation, being focused on emotions and memories of the deceased, as suggested by Stroebe and Schut's (1999) DPM. For the remaining questions, see Appendix 1.

The individual open-ended interviews were tape-recorded with the permission of the participants. The average time for adults' interviews was 30 minutes. However, interviews with the bereaved young people were longer. Whenever young people cried during an interview, the researcher stopped the tape recorder allowing the young people to express their emotions in their own ways. As a result of this, the time spent on each interview grew longer. The average time for an interview with the young people was one hour. As commonly happens in the Gambia, there was no refusal and all interviews were tape-recorded.

### **2.6.3 Focus group interview process with young people**

A FGD held with AIDS-bereaved young people was initially considered as a pilot study, but the significance of the findings and the limited number of eligible participants forced the researcher to integrate the result into the main findings. In this FGD only five young people (four girls and one boy) between the ages of 15 and 18 participated. Since the quality of discussion is better in places where people are comfortable (Morgan, 1996), it was felt that the research participants would be more comfortable meeting at their usual meeting centre, which may increase the quality of the data. On behalf of the participants, the gatekeepers suggested that the researcher might use the centre used for meetings with the young people. Following consultation with participants, the centre at Hands on Care was used. The young people were happy to meet there for the purpose of the FGD.

The room used for the FGD was quiet, spacious, and conducive for group discussions and interviews. The FGD was conducted at a time when none of the workers were around. To make the place conducive for the discussion, telephones were removed from their hooks and the tables were cleared of anything that might distract the attention. Soft drinks and a light snack were prepared for interviewees to enjoy, while informal conversation about anything including football was held. The reason for such discussion was to facilitate interaction and to let young people start talking even before the actual interview began. It was felt that this approach would make the bereaved young people more comfortable. All the arrangements for the interviews, including discussion on confidentiality (see below and Section 2.10.1: Consent) went as planned.

Prior to the interviews, the researcher discussed the issue of confidentiality with the participants. Although they were assured them of confidentiality and non-sharing of

information without their consent in an FGD it was not possible to guarantee confidentiality. However an agreement was therefore reached that all information except the tape and the transcript remained in the room where it was shared and, to the knowledge of the researcher, the agreement was observed.

The recruitment of research participants and the conduct of the FGDs were preceded by a review of literature. Despite this review, the researcher was open to new ideas and views and allowed the research participants time and space to talk about their experiences as discussed earlier. For example, during the introductions, participants described themselves as members of the Orphans and Vulnerable Children (OVC) support group. This initial introduction provided a platform for discussion on the particular topic of the death of a parent (see Interview guide in Appendix 2).

The young people's introduction of themselves as members of the OVC suggested that they had already identified themselves as a homogeneous group, not only based on demographic factors but also their bereaved status. They seemed to realise that they were not alone in their experiences right from the start of the interviews (Rabiee, 2004), as discussed above. It was anticipated that homogeneity of the participants would facilitate open and frank discussion on sensitive topics like this because the participants had shared interests and circumstances, and were acquainted (Kitzinger (1994). Although all the participants showed an interest in sharing their experiences by volunteering to talk when asked a question, it was hard for them to discuss their experience in depth and interaction, as suggested by Morgan (1996), was virtually non-existent. Although the main questions were easily answered, some probes were either given short answers (like a question and answer session) or the initial answers were repeated by the participants. There were also instances when the participants did not respond to probing questions: in such situations, it was assumed that the young person was preoccupied either with thoughts or distress. In such cases, another question was asked or the question was skipped to another participant, especially since the researcher had told them they had the right not to answer any question with which they were uncomfortable. Secondly, there was an ethical duty to protect the young person especially when they were distressed. (See Section 2.10: Ethical issues.)

The young people already found the topic hard to discuss; and there might have been a level of discomfort discussing such personal issues with peers who knew very little if anything about their circumstances. Rabiee (2004) suggested that discomfort with a peer inhibits open discussions. Well before the research, was informed that, although the young people had been participating in group meetings regularly, their discussions did not focus on their parents' illness, death and their responses to death. In contrast to the view that FGD reduces intimidation, this research suggests that the young people might have felt uncomfortable sharing in-depth personal information that was bothering them, despite being acquainted. It may also suggest that disclosing such personal information for the first time, especially to people who had no idea about their circumstances, was threatening. The young people would have been more comfortable talking about their experiences if they had been discussing their loss in their regular group meetings. Although the participants were not asked whether they felt intimidated, many of them admitted they had been distressed, but also felt they had learnt a lot and that they could now discuss their loss with others.

Despite the limitations of the method, the findings were similar (but in less depth) to the information gathered in individual interviews, as suggested by Morgan (1996).

#### **2.6.4 The use of probes in the interviews and focus group discussions**

Probing, which is a further exploration of questions on inquiry, is a technique that has been highly recognised as an effective way of gathering information from people who are in difficult situations (Jewett, 1994). In the case of research, Patton (1990) acknowledged the importance of using probing in interviews. He said its purposes are many but in interviews it is used for clarifying issues, obtaining a better understanding of the phenomena under study and generating more in-depth data. Probing was used throughout the interviews to clarify and generate more data for analysis. For example, when the young people were asked: '*How different did you feel when you lost your father?*', emotional reactions were described such as '*I felt it was painful*'; this was followed with a probe such as '*Can you elaborate more on that, please?*', '*Do you experience any other form of emotion?*', '*How about anger?*', '*How about denial?*' '*How does it feel to experience this emotion?*', '*It appears that your emotional experience is intense; what do you think?*', '*What then happened?*', '*How difficult was that?*', '*Very interesting.*', '*You said ...; did that affect you in any way?*' These probing questions were not general: rather, they were triggered by the initial response of the participants.

## **2.7. Data analysis**

### **2.7.1 Data analysis through constant comparison method**

The constant comparative method was described by Strauss and Corbin (1994) as a 'systematic asking of generative and concept relating questions, theoretical sampling and systematic coding procedures', (p.59-60). However, theoretical sampling has not been applied as the samples for this research were identified before the research was conducted. In addition, although constant comparison uses a data collection method that evolves with analysis throughout the research process until saturation is reached (Glaser, 1967), such a method has not been applied in this research. Analysis of the data was conducted after the completion of the data collection process.

Glaser and Strauss (1967) viewed constant comparison as an analytical process that maintains a close relationship between data and its corresponding concepts and categories throughout the process of data analysis. The most important role of this method is that it helps researchers constantly to compare phenomena (e.g. concepts) that have been coded under a certain category so that a theoretical explanation grounded in the accounts of the participants emerges (see section on Category – 2.8.2). Olson (2004) said the relevance of constant comparison is that it discovers what exactly the research participants are saying (emergence) without the researcher interpreting its meaning differently. This was supported by Glaser (1998). Since the interpretive approach used in this thesis is flexible and has allowed bereaved young people to narrate their stories openly, it was felt that the constant comparative method of analysis would make it possible for the genuine concerns of the participants to emerge from the data.

After the completion of transcriptions of data in this thesis, each transcript was read several times to capture an overview of the main storyline of the participants. According to Glaser (1978), the use of an overview analysis alone is not sufficient in detail to ensure rigour, but it is useful in developing what is termed theoretical sensitivity – that is, a researcher's consciousness of possible concepts and categories in the data. Whilst repeatedly listening to the tapes during transcriptions, ideas regarding the possible codes started to come to mind, confirming or rejecting initial thoughts. The findings presented in this thesis are the result of an in-depth comparative analysis of data as shown in the following sections.

### **2.7.2 Transcriptions and coding**

The transcription of portions of the data would have been helpful, but the researcher conducted verbatim transcription of the two interviews and the focus group discussion (FGD) in their entirety because he felt that it would give more detail about the experiences of the bereaved young people. The need for such a detailed transcription can be captured in Denzin's (1994) account. Whilst discussing the art and politics of interpretation, Denzin (1994) said 'the task is to produce richly detailed inscriptions and accounts of such experience' (p.510).

Consistent with the constant comparative method, it was essential that the transcriptions should reflect the actual accounts of the participants and that the theory generated to explain bereaved young people's emotional reactions to loss should 'emerge' from the data (Glaser and Strauss 1967). It has been argued that, despite the importance of scientific integrity, both transcription and theory emerge from the researchers themselves (Daly, 1997). This is based on the assumption that researchers interpret the interpretations of the participants. Daly (1997) referred to this as second-order stories. It suggests that in this research, at least at a fundamental level, the transcripts and theory have emerged from interpretations and meaning making of the data by the researcher himself. While the researcher was aware that his professional and personal background and his familiarity with the literature are bound to have influenced interpretations, he has not lost sight of the challenge to preserve the participants' meanings. Strauss and Corbin (1990) suggested that theoretical sensitivity is important for having insight into the 'subtleties of meaning of data' and is essential for the development of a theory that is 'grounded, conceptually dense and well integrated' (pp.41-42). However, it is also argued that preconceived ideas can prevent researchers from thinking imaginatively about the interpretive theories that lie beneath the situations studied (Denzin, 1994). The researcher's prior experience, discussed above, has not only given him a familiarity with relevant issues but also enhanced his ability to make sense of the data.

In the process of transcription and making sense of the data in this thesis, each transcription was initially read several times in order to get the feeling of the main storyline (Olson, 2004). The comparative method of in-depth data analysis was adopted. This approach involved a line-by-line analysis of transcripts. The relevant sentences and phrases were highlighted and

codes were developed and assigned to these properties accordingly (Stern, 1980). Dick (2002) has claimed to use Glaser's grounded theory approach and suggests ways in which researchers can understand the author's storyline to ensure adequate coding. These techniques consist of asking a series of questions of the data in a systematic manner. The types of question that he found helpful were: What is going on here? What is the situation? How is the person managing the situation? What categories were suggested by that sentence? (Dick, 2002, p.6.) A similar method has been adopted in this thesis, with the transcripts being read to identify the storyline (e.g. whether the story focuses on loss or restoration-orientation), and then the contextual nature of the story (e.g. feelings of sadness because of seeing other young people with their parents), which included how they managed the situation (e.g. by crying or avoiding people and places) (see Table 2.3).

Each sentence and phrase identified through this process was assigned a code (for example, 'sadness' and 'fear') written on the right-hand side of the transcript. Each code represented a portion of the participant's story. On completion of the first transcript, the researcher went through it again to compare similar codes and contrast them with other codes in the transcript. This process allowed him to drop some codes and replace them with new codes. For example, 'relationship with the deceased' was dropped in favour of 'continuous bond', as the latter is sensitive to the duration of the relationship. This process continued until all the transcripts were coded. On completion of the transcripts, codes from one transcript were then compared with similar codes across all other interview transcripts (Dick, 2000).

These codes were later transferred and clustered together as concepts or categories, depending on their definitive power (Olson, 2004). For example, Emotional reaction, which has the highest definitive power, was labelled as core category **1**. For the purpose of clustering, the categories (second highest definitive power) of core category ('emotional intensity', 'emotional expression', 'short and long-term reactions') were labelled **A**, **B**, and **C** respectively, as seen in Table 2.2.

**Table 2.2: Examples of core categories and their sub-category relationships**

<b>Core category</b>	<b>Category</b>	<b>Sub-category</b>
<b>1. Emotional reactions</b>	<b>A Emotional intensity</b>	
	<b>B Emotional expression</b>	Emotional verbalisation
		Crying
	<b>C Short and long-term reactions</b>	Denial
		Sadness
		Anger
		Fear and Anxiety
		Emotional loneliness
		Avoidance
		Continuous emotional bond
<b>2. Social factors influencing coping</b>	<b>A Stigma and Discrimination</b>	Discrimination and isolation
		Stigma and Secrecy
	<b>B Social support</b>	Extended family
		Peers
		OVC

### 2.7.3 Category formation

Categories are high level concepts. According to Corbin and Strauss (1990, p.7), ‘concepts are the basic units of analysis since it is from conceptualization of data not the actual data per se, that theory is developed’. Since sentences/phrases (concepts) were insufficient in the constant comparative method, it made sense for them to be clustered together and presented in the form of categories. In this study, categorisation began with identifying the concepts and putting similar concepts together to form a category. For example, one of the orphans said ‘*I was very sad*’; another orphan said ‘*I cried because I felt sad*’. Being similar incidents, these were grouped and labelled as ‘Sadness’ (see Table 2.3).

As the analysis progressed, categories developed from one transcript were refined by categories emerging from subsequent transcripts. The categories were either collapsed or expanded by adding or removing some properties. For example, in Table 2.3, one of the participants said ‘*I cried because I felt sad*’. Because this broadened the category of ‘sadness’ to include ‘expression of sadness’ or ‘emotional expression’, the category was later broken down into ‘sadness’ and ‘crying’. Crying later became a sub-category of emotional expression.

Some categories were overloaded with information; where the need arose, such categories were collapsed. Either sub-categories were formed, or the category was reformulated altogether. For example, since the category ‘initial emotional reactions’ was overloaded, it was broken down into ‘anger’, ‘sadness’, ‘fear’, ‘anxiety’, ‘emotional loneliness’ and ‘denial’. The emerging patterns, collapsing and reformulation of categories sometimes required revisiting category and sub-category names. The category ‘immediate reactions’ was changed to ‘short and long-term reactions’ because some of the immediate responses (e.g. sadness, loneliness and fear) were also experienced years after the loss. Names were tightened regarding the information contained so that the heading precisely depicted the content or the properties/segments (Dick, 2002).

**Table 2.3: Examples of categories and properties**

Category	Definition/properties
Sadness	<p>I was very sad.</p> <p>I cried because I felt sad.</p> <p>When he died I felt very sad... and I went and sat on my own privately and cried ... Many people cried too because it was a sad day ... the only family member I did not see crying was my dad [brother of biological father] but he appeared sad. He was very quiet that day, he must have been very sad.</p>
Worry/anxiety	<p>It was scary to learn that my father had died. You know at my age you expect to enjoy [being] with your parents, live with them and do all that children do with their parents. But when he died I thought about so many things and became worried about all these things.</p>
Continuous bond	<p>I have got my mother's pictures and some of her audio cassettes. Where she is smiling I will say she is happy here.</p> <p>Like if we are telling stories I will say this one was from my mum.</p> <p>I can still remember what she was saying when she was going to buy that dress.</p>

**2.8 Reliability and validity**

Hammersley (1987) states that in qualitative research participants account is considered valid 'if it represents accurately those features of the phenomena that it is intended to describe, explain or theorise' (p. 69) and Whitemore et al (2001) argued that definition of validity as a state of being sound is viewed as a reasonable component of all investigations. On the other hand according to Pyett (2003, p.1170) with reliability in qualitative research 'we seek not to measure but rather to understand, represent, explain something, usually some fairly complex social phenomenon' (p.1170).

However, the concepts of validity and reliability in qualitative research have undergone numerous transformations since the 1980s, which strengthen the unique contributions this scientific tradition offers to the growth of knowledge. Initial conceptualisation of validity and

reliability was directly applied from quantitative and experimental research perspective (LeCompte and Goetz, 1982), and they were felt to be applicable and credible benchmark by which the quality of all research could be judged (Pope et al, 1998). Traditionally, reliability referred to the stability of findings and validity represented the extent to which these findings accurately describe the reality (Altheides and Johnson 1994). Lincoln and Guba (1985) state that ‘the determination of such isomorphism is in principle impossible’ (p. 294), because one would have to know the ‘precise nature of that reality’ and, if one knew this already, there would be no need to test it (p. 295). On the other hand qualitative researchers assume the presence of multiple realities and attempts to represent them adequately.

The incompatibility of these terms with the underlying assumptions and tenets of qualitative research resulted in several attempts to translate the terms to be more aligned with ontological and epistemological assumptions of qualitative research. Lincoln and Guba (1985) translated internal validity to credibility, external validity to transferability, reliability to dependability and objectivity to confirmability as suitable criteria to judge the qualitative research, yet, Khan (1993) emphasised that use of terminology should not obscure understanding.

### **2.8.1 Internal validity/ credibility/ trustworthiness**

Whilst in conventional research, internal validity refers to the degree to which the findings correctly demonstrate universal truth; creditability/trustworthiness refers to how well the findings are a true reflection of the participant’s account (Denzin, 2003). The credibility criteria involve establishing that the results of qualitative research are credible or believable from the perspective of the participant in the research. According to Janesick (2000) qualitative researchers must understand that the cornerstone of qualitative research is description and explanation of a person, place and event because ‘this is the qualitative researchers’ reasons of being’ (p 393). The question that is feasible in qualitative research is therefore: ‘Is the explanation credible?’ (p.393). Several strategies were employed to ensure credibility in this thesis. More recently, carers’ data has been presented to a Gambian woman (researcher’s guest) who was once a carer of a bereaved girl.

From a carer’s perspective, she recognised and accepted the findings as a true reflection of carers’ perceptions of bereaved young people’s experiences. Various kinds of triangulation

were used in this thesis to increase qualitative validity/credibility and trustworthiness (Lincoln and Guba, 2000).

Triangulation is described as a means of verification, which allows the researcher to be more confident of the research conclusions (Denzin, 1994). Therefore in order to ensure valid, credible and trustworthy data in this study, the data was collected by multiple methods and generated from multiple sources. These sources were the young people, carers and professionals. In addition both focus group discussion and open-ended interview methods were used among bereaved young people.

### **2.8.2 External validity/generalisability/transferability**

In conventional research generalisability is one of the most common tests used to determine the validity and reliability of a particular study (Lincoln and Guba, 1985). Generalisability is also common because people prefer to use aggregated numbers to explain social situations (Janesick, 2000). Yet, the term is also used in qualitative research to valid research findings. Patton (2001) identifies generalisability as criteria to determine the quality of a case study, but emphasised that it depends on case selected and studied; yet Lincoln and Guba (1985) prefer to call it transferability in qualitative research.

Generalisability or transferability in qualitative research refers to the extent to which the theory developed from any particular research can be applied to other people in a different setting at a particular time (Lincoln and Guba 2000). In this thesis the researcher might have helped the reader and the person who wished to transfer the findings to a different context made judgment of how sensible the transfer would be, by clearly describing the research context and the assumptions that underpinned this research. However, it is possible that findings in this thesis may go beyond the social setting within which the research was conducted, unlikely to be universally transferable (Charmaz 2000) but very unlikely to be universal owing to the unique nature of the Mandinka culture. It may be transferable to cultures similar to the one in this thesis using similar research procedures.

### **2.8.3 Objectivity to confirmability**

According to Miles and Huberman (1994) objectivity is perceived a gold standard for scientific research and it refers to a research that is free from researcher bias (p. 365). Other studies are perceived too subjective, biased (Reid, 1991), hard to generalise (Barrett et al, 1983); not scientific (Field and Morse, 1991 and Sandelowski, 1986). However, Lincoln and Guba (2000) argue that no researcher can be completely objective but Patton (1990) comments that objectivity versus subjectivity are ‘ideological ammunition in the paradigms debate’ (p.15) and instead of engaging with that, researchers should try to be non-judgemental and report findings in a balance way. Lincoln and Guba (1985) refer to ‘confirmability’ of the research as an appropriate alternative to objectivity for it can demonstrate the neutrality of the research interpretations. In other words, it refers to the level to which the findings could be verified or agreed with by other peoples. Several strategies were used to increase the confirmability of findings in this thesis.

During the planning stage and throughout the research process several precautionary measures were taken to produce reliable and valid data. Apart from presenting the overall study design to thesis supervisors, the research has been shown to an experienced qualitative researcher, a fellow PhD student and had been presented to university academic staff from whom positive responses have been received.

### **2.8.4 Reliability/dependability**

The traditional quantitative view of reliability refers to the degree to which the findings of the research remain stable or constant overtime (Denzin, 1994) and it is concerned with whether one would obtain the same result if one could observe the same thing repeatedly (Stenbacka (2001). Stenbacka (2001) object the use of the term reliability, because measurement has no relevance in qualitative research. Lincoln and Guba (1985) also comment that ‘since there can be no validity without reliability, a demonstration of the former [validity] is sufficient to establish the latter [reliability;]’ (p. 316). Patton (2001) supports this notion by stating that in qualitative study, reliability is an effect of the validity.

The purpose of reliability in qualitative research also referred to as dependability by Lincoln and Guba (1985) is not to produce steady findings overtime, but to account for changes that occurred during the research (Lincoln and Guba, 1985). In this thesis the researcher has attempted to obtain qualitative reliability or dependability using several strategies including dense descriptions of the research context and reflexivity. It was hoped that the documentation of the reflexive account of the researcher which included the procedural and personal reactivity and exposure of researcher's personal biases and the thick description of research context would enhance dependability

### **2.8.5 Data triangulation**

Triangulation was used in this thesis to help the researcher produce reliable and valid data. The constant comparative method, discussed in previous sections, has been used to analyse data which was generated from three data sources (young people, carers and professionals) and through two data collection methods (interview and FGD). The purpose of data triangulation is to offer multiple viewpoints of a phenomenon under study (Denzin, 1994); in the context of this thesis, the perspectives were of the young people, their carers, and professionals working with them. Whilst qualitative researchers agree that it is an important approach, there seems to be disagreement regarding the main purpose of triangulation. Denzin and Lincoln (1994) commented that there are qualitative researchers who use validation to confirm the truth of a research finding; Silverman (1985), however, contested this view, suggesting that the purpose of triangulation is to add depth to a study.

Other writers such as Knafl and Brietmayer (1991) used two terms which are similar to the above descriptions of triangulation by Denzin and Lincoln (1994) and Silverman (1985). Knafl and Brietmayer (1991) saw 'confirmability' as the use of different methods (for example, in the case of this thesis, the use of open-ended interviews and FGD) to investigate the same information with the intention of one method confirming the findings of the other; whilst they suggested that 'completeness' was the process of different approaches complementing each other.

Whilst Denzin and Lincoln (1994) recognised that qualitative researchers use triangulation to confirm the truth, they suggested that there is no objective reality in qualitative study that can

be accepted or rejected by another research method. The assumption underpinning their view is that the use of triangulation for the purpose of confirming the truth is closely related to the traditional concept of validity and reliability, a concept which the authors rejected because it perceives human behaviour as fixed. However, it was regarded as important to explore areas of difference and similarity between the experiences of bereaved young people and the perceptions of carers and professionals supporting them. It was felt that use of triangulation would help achieve this aim.

## **2.8.6 Reflexivity**

### 2.8.6.1 My insider role

It is often agreed that because of the subjective nature of qualitative studies, researchers need to show their level of subjective involvement with the participants for others to judge the degree to which it influences the result (Drapeau, 2002). In this section I intend to outline how I related to the research participants and the following sections will expand on these issues in a greater detail.

I am a Gambian Muslim from the tiny village of Alikali Kunda and educated in Serre-kunda town, ten minutes' drive away from where this research was conducted. Like most of these young people, I was born to uneducated poor farmers from a 'Mandinka' dominated culture. In this culture the basic needs of the children (food, shelter, clothing and education) are the priority and are the responsibility of not just the biological parents, but also uncles, aunts, grandparents, older siblings, older half-siblings and their spouses. Paternal lineage is still the most important source of material support and protection and maternal lineage provides care. Age is a prestige in this culture; the older one is the more power one holds. Men are the main decision makers, protectors and providers for women and children.

Being a Muslim dominated culture, beliefs, values and actions are influenced by the religion. Like many people in this culture, I was told that God is the ultimate answer to our problems and worshipping is the biggest source of comfort, especially in times of distress. From the age of 15 I have been obliged to pray five times a day, give charity and fast in the month of Ramadan. Like many children who goes to the Mosque, when I was young I was told adults

are more experienced and know better what children need; and as a result they are obliged to represent and protect children's interests, so children are also obliged to be completely obedient to adults especially their parents, except on issues that the adult thinks will harm them or others.

However, as a 34-year-old man, I am different from the young people in this thesis in terms of level of education, exposure to the UK culture and the proliferation of Western bereavement literature. I am fortunate to have lived in the UK for five years now. Whilst I still hold the belief that children need to give maximum respect to their parents, I tend to appreciate the British culture that promotes communication and decision making involving children. Western bereavement literature has also given me an idea of what life is like for young people in the west who have been bereaved and this is something different from what young people in the Gambia are exposed to. In the West, they emphasise that emotional expression through talking is healing, yet only adults in the Gambia seemed to be involved in such practices. Whilst I was not sure what works for whom, the exposure has helped me to understand and appreciate different views and perspectives regarding childhood bereavement and adult/ child communication in different cultures.

My high level of education, my exposure to Western culture and literature on bereavement suggests that I am not going into this thesis without a theory. However, during the interviews, when listening to the participants accounts I have attempted to partially suspend my theoretical understanding, so that I can more fully be aware of ideas, concepts and theories emerging from the participants' data. Whilst I have continually tried to suspend my own presumption about the participants' experience by considering possible sources of bias that would have an influence on the research process and the data, it has been extremely difficult to adhere to that role because both the interview process and the interpretation of data are influenced in some way by my beliefs and values.

#### 2.8.6.2 Researcher as an interpreter

There is a belief among researchers that an over-involvement with participants during the research process may lead to researcher bias (Bryman, 1988), which may partly be due to researchers' emotional involvement with the phenomenon under study. Some researchers

believe that emotions are impediments to knowing and that knowledge is best achieved through distanced and unemotional means (Jaggar, 1996 cited in Malacrida, 2007). In contrast, Jaggar (1996) suggested that emotions (e.g. respect, admiration, compassion and care) in research are capable of facilitating the production of knowledge that is passionate and beneficial to both the researcher and the participants. Oakley (1984) advised researchers to build close rapport with their research participants, as it provides them with a valuable experience and a greater understanding of the phenomenon from the participants' perspectives.

Consistent with Jaggar's (1996) view and Oakley's (1984) advice, I have been totally immersed in the data during analysis. Although it is impossible to say that I have not been touched by the emotional accounts of the participants, the impact has not been sufficient to influence my interpretations. Rather the emerging emotions have made me a keen listener and an empathiser, appreciating the experiences of bereaved young people, which I believe has enriched my understanding of the phenomenon and, in this way, enhanced my ability to interpret the accounts of the young people.

Whilst I have avoided imposing my presumptions throughout the research process, I have been fully aware that the way interviews were guided has been based on my previous knowledge of grief and experience of conducting interviews with young people. Realistically, a complete suspension of my theoretical assumptions has been impossible for me because I am not completely lacking in knowledge of the topic. Therefore my theoretical lens may have served as a source of bias in this research (Chenitz and Swanson, 1984).

#### 2.8.6.3 Researcher's view of young people

I viewed young people as the most important source of knowledge as their lived experiences are what this research is about. However, some researchers unrealistically see children as incompetent, thus disrespecting their potential and undermining their interpretations of their own experiences (James et al, 1998). Mayall (2002) suggested that such an attitude of researchers stems from our traditional view of children as dependants. I took several precautionary measures during data collection to prevent falling back to this traditional view. These precautionary measures included giving the participants the opportunity to choose

where they wanted their interviews to be held and when they wanted to participate in the interviews. Other measures to show respect for the participants' rights included: consent, autonomy, and assurance of confidentiality and anonymity. It was felt that all these approaches had helped in building a trusting relationship between the participants and the researcher.

On reflection my rapport building process seemed to contribute immensely to this trusting relationship. Prior to data collection, I was cognisant of Gambian young people liking to converge daily at one place, brew 'Ataya' (green tea) and enjoy it with friends and families. I have used this context to develop rapport. Not only did I enjoy drinking the Ataya with them but also contributed financially towards it, and on more than three occasions I offered to brew it for them. This interaction created a context where I believe I was viewed as an adult who was not only interested in their accounts but one who intended to establish a non-hierarchical position with them by doing what they do and enjoying what they enjoy as young people. This also boosted my confidence that I might be seen as an insider. Although I was aware that the young people's interpretation of situations could differ, it seemed to me that their responses during data collection were empowered through my personal approach and the use of the research method discussed earlier.

However, the young people's willingness (especially that of young people and their carers) to be listened to and their determination for their voice to be heard was undoubtedly one of the factors that facilitated the development and maintenance of the researcher-participant relationship based on power sharing. It was evident that they were emotionally involved with the research, and the intensity of their message suggested that they shared my interest in the topic. Sword (1999) suggested that sharing such personal information with the researcher might mean that the participants perceived the researcher to be credible.

#### 2.8.6.4 Effects of procedural and researcher reactivity - age and gender

Reactivity is the extent to which and ways in which the behaviour of the research participants is shaped both by the fact of them being researched in a given way (procedural reactivity) and the particular characteristics of the researcher (Personal reactivity). Having been 20 years older than the youngest participant, in a society where young people are meant to be obedient

to adults, my age might have some impact on how they viewed and reacted to my presence during data collection. In the Gambia open expression of negative emotions by young people is not always sanctioned by adults; yet during the interviews young people cried, obstructing the flow of data collection and inevitably affecting the amount of data gathered. Although the crying behaviour could be considered as an important source of data, it also indicated that I was not seen as the traditional authoritative figures, thus reducing the age-related reactivity.

During the interviews when the young people were nervous or crying, I offered them a cup of water. Since an adult offering young people water is an unusual event in the Gambia, such a move manifested a shift of power from myself to the young people that might have increased their confidence in honestly sharing their experiences. The use of appropriate language during the interviews, dress code, my student rather than professional stance, and being a local boy (as discussed earlier) were also used throughout the research process to reduce possible imbalances.

Despite my initial rapport with young people and their guardians during the recruitment process, and despite using open-ended questions and giving them the assurance of privacy and their right to withdraw when they felt the need, many young people appeared less relaxed and more tense when responding to the first few interview/FGD questions than they usually were in the community. The sensitivity of the topic and the use of the tape recorder might have contributed to the initial nervousness; yet, the open-ended methods used in this thesis allowed flexible exploration of the participants' meanings and beliefs. Since many of the questions flowed from the participant's replies rather than being entirely imposed by the interviewer's predetermined list of questions, the method gave the participants some degree of control over the research process, reducing reactivity.

In the FGD, young people hardly interacted with each other and some probes were given short answers (like a question and answer session), the initial answers were repeated by the participants or they did not respond to probing questions at all. Whilst the participants appeared largely in control of the amount of information they gave, restricted responses prevented in-depth discussion on the phenomenon. Despite these problems, the findings were similar (but in less depth) to the information gathered in the individual open-ended interviews.

Whilst the open-ended methods of data collection were flexible and allowed bereaved young people to narrate their stories openly, the constant comparative method of analysis used in this thesis made it possible for the genuine concerns of the participants to emerge from the data. Although aware that my professional and personal background, my familiarity with the literature and my preconceptions are bound to have influenced interpretations, I have not lost sight of the challenge to preserve the participants' meanings. Moreover, I was aware that preconceived ideas might prevent me from thinking imaginatively about the theories that lie beneath the situations studied (Denzin, 1994). My prior experience, discussed above, has not only given me a familiarity with relevant issues but also enhanced my ability to make sense of the data.

In this study where the majority of the participants were females and in a culture where males are seen as providers and protectors of their families, my gender as a male researcher would have an impact on the female participants. Despite ensuring confidentiality and making it clear that the research was voluntary, female participants seemed to be more expressive than their male counterparts regarding the problems they were encountering in their efforts to care for bereaved young people. Whilst the reason for this was not entirely clear, the female participants might have been over-reporting in order to get sympathy from a male researcher.

#### 2.8.6.5 Effects of researcher's religion and cultural beliefs

The OVC support group was founded by the WEC mission, suggesting that the beliefs and values driving the OVC were rooted in Christian tradition. The employees and families (almost all of whom were Muslims) benefiting directly from this project might have been impacted by Christian beliefs and values. Yet, the core beliefs and values, such as giving love and care to children, the poor and needy, as well as rejection of stigma and discrimination, are shared by both Christian and Islamic traditions.

Whilst as a Muslim I do not believe families should be blamed for their HIV/AIDS status, some fanatic Gambian Muslims believe that HIV/AIDS is a curse from God for those involved in premarital and extramarital sex. They also view young people as victims of their own parents' immoral sexual behaviour. Yet people do not always contract the virus through immoral sexual conduct.

The impact of my religious belief on the participants would be based on whether or not I was seen as an extremist religious person. During data collection I prayed five times a day regularly and attended Friday prayers with some research participants. Despite this I did not see myself as an extremist religious person, yet, I might have been suspected of being one, inducing fear among the participants. Fear of stigma and discrimination might have been the main reason why the guardians and the young people did not mention HIV/AIDS during data collection, reducing access to important data. However, silence surrounding HIV/AIDS may also be considered as important data since it indicated the presence of stigma.

## **2.9 Ethical issues**

The term 'ethics is derived from the Greek *ethos*, meaning character, nature or disposition' (Farrell, 2005 p.1). In this thesis, *ethics* are described as an 'application of the moral principles to prevent harming or wronging others, to promote the good, to be respectful, and to be fair' (Sieber, 1993, p.14). Ethical principles have not been applied to any one stage alone of this research; rather they have been recognised throughout the entire process (see section 2.8.3: Researcher role).

The choice of methodological approach to gather data from vulnerable people such as bereaved young people had to be ethically sound. Both the social circumstances of the participants and impact of the method had to be considered (Neil, 2005). As Punch (1994) suggested, there is more to research than just completing the research tool. Since the researcher is present throughout the research process (Punch, 1994), qualitative research gives the researcher the opportunity to personally see any possible harm the approach is likely to cause participants.

In this thesis, my choice to use a qualitative approach may be claimed to be ethically sound. The choice was made not only to give young people a voice but also to create an opportunity for them to be listened to, to interact/share with others who had similar experiences, and to feel valued (see sections 2.5.2 and 2.5.3 on the Rational for selecting open-ended interviews and FGD respectively). It is possible that this approach has not only prevented harm but also been beneficial to the young people who seemed to be in need of someone to listen to them.

Considering that the young people in this research came from AIDS-affected families and from one of the poorest countries in the world, it was considered important to think about eventualities.

Sikes (2004) believed that researchers who anticipate problems and prepare beforehand with confidence should not cause harm. Morrow (2005) concurred with Sikes (2004) and suggested that there is a moral obligation for researchers to protect young people during the research process.

Going into this study I was fully aware of its sensitivity and the possible effect I could have on bereaved young people. Liebling and Shah (2001) suggested that one way of reducing the negative outcome of sensitive research is to establish a relationship with participants essentially characterised with trust, respect, shared decision-making, and equal status. It was felt that the rapport built with these participants, the non-hierarchical position held and choices they were given during the research process would reduce the sensitivity of the research and encourage openness.

Apart from the institutions with which they were involved, research participants had the right to confidentiality as AIDS-bereaved young people, and my friends and family members were not told about their characteristics. When questions were raised regarding participants, I would say the research was about young people's emotional experiences. Participants were also told that they would remain anonymous; the initial letters of their names have therefore been used to conceal their identities (e.g. 'LJ' for 'Lamin Jargue') in the write-up. Data would be used mainly for academic purposes but, if it were to be used for other purposes, the participants would be informed and their identities would not be exposed.

Prior to the research, consideration was also given to young people's knowledge about their own and their parents' AIDS status. It was anticipated that young people would ask the researcher questions that might jeopardise the whole research process. For example, it would have been inappropriate to answer questions like *Did my parent die of AIDS? What killed my parent?*, even though it would have helped them by reducing doubts surrounding their parent's cause of death. To address such eventualities, the research identified a staff member

working very closely with the young people. Any incident of this nature would have been directly referred to person for action.

Although one important role has been to protect the welfare of participants, this role has not compromised their confidentiality. I feel I have helped protect participants by giving them information about possible sources of support they could access when they should feel the need. From my experience it is apparent that, with proper consideration of ethical principles, very few studies will breach confidentiality and rights to participate freely in research.

### **2.9.1 Consent**

The term 'consent' refers to the legal process whereby someone gives permission to the researcher to proceed with the intended investigation (Sieber, 1993). The process of seeking consent indicates people's value and how important their contribution would be if they should participate in the research. This can give subjects self-value and motivation to participate in research. However, failure to seek consent may also have its own legal and social consequences. Apart from subjects' feelings of being coerced which may lead to resistance, the researcher may legally be liable to prosecution if subjects should claim to have suffered any harm. In this interpretive research, to avoid these consequences, consent was sought from the three groups of participants (professionals, carers, and the young people). All three groups underwent similar processes.

The process of consenting to the research involved understanding of the research proposal. To this end, the carers, young people and professionals were first consulted informally to give a verbal explanation of the intended research. Issues discussed included why the research was needed; how it would be conducted; who the participants would be; why they would be selected as participants; where and when it would be conducted; what benefits/harm it would entail; possible sources of support; issues surrounding breach of confidentiality; issues surrounding reporting/dissemination of findings; and how autonomy, anonymity and confidentiality would be assured. This was done to ensure the subjects understood what they were consenting to if they were to participate in the research.

After the informal discussion, subjects were approached formally to seek their consent to participate in the research (see Appendices). Formal agreement was sought, in the form of a

written consent. The legal agreement (consent) form was completed by each of the carers, young people and professionals. It contained information about the nature of the risk and the benefit the participants were likely to incur if they were to participate (Fontana and Frey, 1998). This was done using language which I thought would enhance understanding of what the research was all about (Schenk and Williamson, 2005). All verbal communications were in language with which the participants would be comfortable. Consenting to this study indicated to me that participants had sufficient understanding about the research process, enabling them to use their discretion and participate in the research (Mitchell, 1984).

### **2.9.2 Conclusion**

The aim of this thesis is to understand young people's reactions to their loss from their own perspective, and the perspective of their carers and the professionals that work with them. In the context of this research, it has been assumed that the research participants in this study lived as active agents in their societies and that they actively participated in the construction of the meaning of the loss young people experienced. Therefore constructivism and its epistemological assumptions underpin this thesis. Interviews and focus group discussions were used to collect data. The data was tape recorded, transcribed and analysed using constant comparative analysis of the grounded theory method.

Several criteria were used to increase the validity and reliability of thesis. These criteria included validation of the data by a Gambian woman (researcher's guest) who was once a carer of a bereaved girl. Other methods included triangulation. The data was collected by multiple methods and generated from multiple sources. These sources were the young people, carers and professionals. In addition both focus group discussion and open-ended interview methods were used among bereaved young people.

## CHAPTER 3: FINDINGS WITH YOUNG PEOPLE

### 3.1 Introduction to the findings from the interviews and focus group with young people

#### 3.1.1 Overall aims and objectives of this study

The aim of this study has been to explore young people's emotional reactions to the loss of their parents through AIDS and to compare these findings with perceptions of carers and professionals regarding young people's emotional reactions to loss. This chapter discusses findings related to four aims and several objectives of this thesis, which are:

Aim 1: To explore young people's emotional reactions to the loss of a parent from HIV/AIDS and to compare that with the perceptions of carers and professionals. Objectives include identification of whether, and to what extent AIDS-bereaved young people:

- react to their loss emotionally
- are permitted emotional expression through crying and talking about their feelings
- react with sadness, anger, anxiety/fear, emotional loneliness
- remain emotionally connected to deceased parents
- employ denial and avoidance approaches

Aim 2: To explore young people's experiences regarding the impact of social factors, including stigma and discrimination, on their reactions and ability to cope with losing a parent from HIV/AIDS and to compare that with the perceptions of carers and professionals.

Objectives include:

- whether, and to what extent, AIDS-bereaved young people experience stigma, discrimination and poverty
- to what extent stigma, discrimination and poverty influence their coping

Aim 3: To explore how support from families, peers and agencies, particularly the Orphans and Vulnerable Children's (OVC) project, affect the young people's ability to cope with loss and to compare that with the perceptions of carers and professionals. Objectives include identifying the extent to which their ability to cope with loss is affected by:

- family care and support
- peer support and OVC support

- religious support

The aim in this section is to young people's accounts of their own experiences in relation to the three aims and the several objectives outlined above.

### **3.1.2 The young people**

This section presents the findings from 12 individual interviews and a single focus group discussion with a group of young people. The young people had on average been bereaved three to five years earlier. There were 11 girls and six boys. Their ages ranged from 15 to 18, and all were going to school at the time of the research. These AIDS-bereaved young people had lost either one or both parents to AIDS. Nine of the young people had lost a father, four had lost a mother and another four had lost both parents. In addition three of these young people had lost a brother and two had lost their father's second wife. At the time of the research the surviving parents of four and carers (in this case non-biological parents) of two young people were seriously ill.

### **3.2 Severity of the loss of a parent**

The young people generally described their reactions to their parent's death as intense, often a manifestation that they were involved in loss-oriented coping. The intensity of this reaction overshadowed the worries and sadness that many (ten) young people said they had already experienced during their parents' prolonged illness. Whilst a parent's illness was described by these young people as emotionally touching, death increased the intensity of their experience. For example one of the bereaved young people commented that despite the hardship his parent endured during his illness, he wished his father was alive so that he could at the least have a chat with him.

*It is hard to see your dad in such a condition; his body did not look good, his hair came off his head. I used to feel very sad and sympathetic towards him but I felt even worse when he died because at that time I used to chat with him but now it is different - he is not here [dead] with me.*

(LC, 15 years, boy)

And an 18-year-old girl:

*Imagine someone close to you has died - how bad you feel; my father's death was like that and maybe even worse than that because he [father] was worth everything to me and it was devastating to lose him.*

(SS, 18 years, girl)

Whilst the above excerpt suggests that the intensity of reactions might depend on young people's closeness to the deceased parent, in general reactions were seen not only as intense but also overwhelming. For many (nine) young people the overwhelming nature of their reactions was far beyond all their expectations and as such some (three) said, if they had not experienced the loss, they would not have understood their reactions; others (two) struggled to find adjectives capable of describing the intensity of their reactions. Examples of these experiences are shown by a 17-year-old girl:

*When I heard about it, at that time I was going home from school with my peers. I started shaking ... and I was weeping. It was really overwhelming. I did not know whether to sit down, stand up or walk. It was a strange feeling and ...you know I have experienced it [that I understand], otherwise no amount of explanation would have been enough.*

(HN, 17 years, girl)

And another 18-year-old girl:

*What I experienced was beyond any description. I did not have words for it, I felt that bad when I came to know about her death. It was devastating to realise that one of the most important person I have ever known is no more there [is dead]. It was really painful - my emotions were all over the place. Not much has changed since then; I sometimes feel overwhelmed.*

(HJ, 18 years, girl)

Four of the young people experienced suicidal ideation which could be seen not only as a sign of intense emotional reactions, but also a manifestation of overwhelming emotional reactions to loss. These bereaved young people went to the extent of seeing life without their deceased parent as meaningless and wished themselves dead. They experienced suicidal ideation soon after death when grief was acute and with little information available regarding their future welfare, as illustrated in the accounts of a 17-year-old girl:

*At that time I could not imagine losing a parent, so I wished myself death. ... I had no idea what life without him would be like. It was hard - I did not know what would happen to me without him. ... People were wailing but for me it was like 'what is the*

*need [to live] when you know you will suffer'. I thought 'if I had the choice I would have gone with him'. I do not think like that now but things are still hard for us, nothing has been easy.*

(ASS, 17 years, girl)

The bereaved young people experienced intense emotional reactions as soon as they became aware of their loss, and they reported that these intense and all-engulfing emotional reactions never completely went away. Many (nine) young people said they experienced episodes of intense emotional responses, often triggered by social circumstances; and the duration of the circumstances determined how long the young people would remain in that emotional state, as illustrated by this young person, who said: *'Towards the end of every month I feel like my mother will not be able to pay the rent and we will be harassed by landlords. I always feel like this until the rent is paid'* (ASS, 17 years, girl).

These loss-related experiences of the bereaved young people were often made worse by their circumstances and, in particular, poverty related discrimination.

A 15-year-old boy said:

*Some people don't care how I feel; at school they will ask me 'Where is your mum? Where is your dad'? This always happens at the beginning of the academic term when their parents attend school meetings, [or] when they are paying school fees for them. I dread these days because my parents are not there to do that for me.*

(AK, 15 years, boy)

Two respondents were constantly preoccupied with negative thoughts and feelings about their loss and what the future might hold for them, to the extent that they described their experience as strange and abnormal. One 17-year-old girl perceived such an experience as a huge challenge for her, a challenge that was overwhelming.

*... I never felt like this before. Since the death I have been occupied with all sorts of thoughts, only negative thoughts. This cannot be normal ... It is crazy going through this feeling, it is feeling abnormal.*

(HN, 17 years, girl)

Whilst the accounts of the bereaved young people showed that they experienced internalising problems, the following section presents the findings related to externalising problems.

### 3.2.1 Internalising or externalising

Despite some reported cases of anger, throughout the data there was no reported incident of fighting, stealing or any other antisocial crimes that may be associated with loss. There was no reported case of delinquency or police involvement with the bereaved young people as a result of their behaviour. The evidence therefore suggests that on the whole the young people reacted by internalising rather than externalising their grief.

#### 3.2.1.1 Sadness/ 'Suno' (in Mandinka)

This section focuses mainly on loss-oriented coping such as the psychological impact of the loss itself. Although the bereaved young people's accounts capture the varying ways in which they responded to their loss, one thing that is common among all the bereaved young people is that they all reacted to the death of the loved-one with a range of emotional reactions. These reactions included sadness, anxiety, loneliness and anger. This section focuses on sadness.

The Mandinka word in this thesis that is nearest to sadness is 'Suno' but the term also represents general emotional reactions such as grief or sad events such as death. The meaning of the term depends on the context within which it has been used; yet bereaved young people seemed to explain their experiences using all these three contexts. The focus in this section is young people's experiences of sad responses to their loss. Throughout the data the bereaved young people's accounts suggest that sadness was also described in behavioural terms. For example crying behaviour (see Emotional expression) was described as expression of sadness. Even social withdrawal (discussed in the section later on avoidance) and unusual quietness during bereavement were all used in describing sad responses to loss, as summed up by one young person not clear if the young people used the word:

*When he died I felt very sad... and I went and sat on my own privately and cried ... Many people cried too because it was a sad day ... the only family member I did not see crying was my dad [brother of biological father] but he appeared sad [Suno]. He was very quiet that day, he must have been very sad [Suno].*

(LC, 15 years, boy)

All the bereaved young people in this thesis reported experiencing sadness immediately after the loss. The account '*when he died I felt sad*' indicates bereaved young people's direct responses to the death of their loved-one. In other words, young people's immediate sad responses were mainly a manifestation of engagement with loss, suggesting that their loss and sadness were inseparable. This immediate sad response to loss was described by them as natural and intense and occurred as soon as they became aware of their loss. The perception that sadness is a natural response has been demonstrated by this 18-year-old girl: '*They knew I could not avoid that deep feeling of sadness when he died*' (HJ, 18 years, girl). A 16-year-old girl perceived that such a feeling was not only immediate but also intense, as illustrated by this account:

*It is obvious to feel sad when death occurs. ... People feel sad when they lose their parent, I was very sad too, I felt very very sad on that Saturday and even after that. Sometimes I would be thinking the whole day and that makes me feel very sad.*

(FB, 16 years, girl)

Intense feelings of sadness were also manifested by the bereaved young people's persistent crying on the day the parent died. But such crying may persist long after the loss when triggered by thoughts of the deceased, as illustrated below:

*I cried profusely on my own on that day [day father died]. When I think of him and think about my life without him and think about my mum and all the trouble she would be undertaking I used to feel very sad ... and start crying.*

(HN, 17 years, girl)

The account '*I felt sad when [he/she] died*' is not only a common response but also an indication that they experienced a loss-oriented coping as suggested by a 17-year-old girl: '*She used to do everything with me. I felt sad when she died. It's sad to lose a mother like her. I was very, very sad. Any child will feel sad about this...she was unique*' (MS, 17 years, girl); and another 17-year-old emphasised the severity of his sad feelings by saying '*I was very, very sad when I heard the news*' (MD, 17 years, boy).

The bereaved young people's sad responses were also related to secondary stressors. They still felt sad three to five years after the loss. Experiences such as stigma and discrimination (see Stigma and discriminations) led to missed opportunities and feelings of sadness. The death of the parent deprived them from several opportunities that their peers were enjoying,

causing intense feelings of sadness. The missed opportunities ranged from material deprivations (see Material deprivation) to socialisations (see Social exclusion) with significant ones. It included lacking the freedom their peers enjoyed of interacting and benefiting from their parents. The intensity of their sad experience was manifested by their accounts such as *'always feel sad'*, *'feel very sad'* or *'cry profusely'*. An 18-year-old girl commented that avoiding this intense sadness is difficult, especially when one is living with peers in the same neighbourhood and seeing them with their parents, as illustrated below:

*Whenever, I see them with their parents, I feel sad and sometimes cry. It is hard to avoid that [seeing them with their parents] because sometimes I meet them at the market place, other times we meet at ceremonies. When I see them first, I avoid them and concentrate on something else, [when I see them] it makes me feel very sad.*

(JS, 18years, girl)

Communal places such as the market and religious festivals were avenues for bereaved young people to experience such feelings of sadness and anxiety (see Anxiety). These were places where the bereaved young people frequently saw their peers with their parents. Sighting their peers with their parents reminded them of their loss and triggered feelings of sadness for missing the loved-one. *'Without doubt the most difficult thing... is to interact with peers when they are with their parent...'* Such concerns surface more during festivals, as suggested by a 15-year-old boy:

*During Tobaski prayer when I see them together, I look at them and feel very sad. They always remind me about my dad and I always feel very sad when I see them. Nobody wants to be in a situation where you will be seen as an odd one out.*

(LC, 15 years, boy)

These quotes point to the bereaved young people's internalisation of the stigma which they carried after the loss (see Self-stigma). For example, the perception *'Nobody wants to be in a situation where you will be seen as an odd one out'* indicates that the bereaved young people might have been suffering from self-stigma. They felt not good enough when compared to their peers resulting in avoidance and withdrawal (see Avoidance); consequently feeling sad.

### 3.2.1.2 Angry response to loss

Although anger as an emotional reaction to loss itself has not been reported by the bereaved young people, a closer look at the bereaved young people's accounts suggests that they might have experienced it.

The bereaved young people tended to report that their anger was associated with their economic circumstances (see Poverty) and how people treated them (see Stigma and discrimination). Poverty, stigma and discrimination, were cited as the source of anger by the bereaved young people. When they were asked whether they have experienced any anger after their loss, five of the bereaved young people reported feeling angry at some point during their bereavement. One of them indicated that:

*I was not like that before; since his death three years ago, people have told me '...you are different: little things make you angry.' I know now that I get angry so easily - I don't know why; maybe I think a lot about him.*

(SS, 18 years, girl)

Whilst the above quote demonstrates the possibility of young people experiencing chronic anger, none of these young people reported feeling angry with the dead parent for dying and leaving them behind. More than half of the bereaved young people who reported anger explained that it was caused by property grabbing and discriminatory behaviour towards surviving parents and the young people themselves. Anger relating to such treatment was embedded in the young people's memory. For example, a 16-year-old girl felt angry for being cheated by greedy land dealers in their neighbourhood, as demonstrated by this comment:

*I am angry because they have cheated us - they have taken away our plot of land. We were going to have our own home but now we are renting and our first landlord always make us feel angry.*

(SJ, 16 years, girl)

Many (eight) did not see anger as a normal reaction to death of a parent. One participant suggested that anger must not be related to death; death was more to do with sadness than anger. 'Everyone gets angry [but with] ... death I did not get angry, I felt sad.' There was a belief that bereaved young people '...cannot get angry at God for killing ... [their] parent.' 'I did not get angry with anyone, I did not have to. It is hard but I had to accept it [death]' (TS,

17 years, girl). A 17-year-old girl perceived anger as an urge to revenge, manifested through fighting: *'Anger, no. what I know is that when one is treated badly, he is expected to get angry and fight.'* She lamented that:

*Death is different; no one treats you badly, so there is no one to fight against. For me it does not make sense to say I am angry at God or my parents - that would be a step too far. Yes I felt very sad and I also had several concerns ... but that does not mean I was angry.*

(MS, 17 years, girl)

Whilst the bereaved young people reported that they were neither angry at their deceased parent nor at God, a close analysis of their accounts suggests all of them envied their peers whose parents were alive. Such a reaction was translated in the literature as anger. A 17-year-old girl lamented that *'When... [she] see[s] them with their parents... [she] sometimes... [cries]'*. For her *'It is hard to avoid... [seeing them with their parents] because sometimes... [she] meets them at market place... [and] other times... at ceremonies'* (JS, 18 years, girl), suggesting her frequent experiences of loss-related anger.

The accounts of the bereaved young people consistently seem to suggest that they wished their deceased parent was alive as they constantly compared themselves with their peers whose parents were alive. Concerning attending festivals, a 17-year-old girl clearly said *'...when it is time for festival, if... [her] friends put on their new dresses... [she] doesn't go'* (HN, 17 years, girl). Another one said: *'Since... [the] death [of her parents] ...now see myself as a... lonely child unlike most of... [her] peers who are enjoying [being] with their parents'* (JS, 18 years, girl). Regarding classmates, a young person reported that he was different from his classmates because *'they are happy with their parents... they don't understand [how he feels]'* (ET, 16 years, boy). All these accounts point to the possibility that the bereaved young people might have been experiencing loss-related anger. The next section looks at anxiety and fear.

### 3.2.1.3 'There was no way life would be the same [again]...' – 'Jomoli': Anxiety and fear

Several words were used by the bereaved young people to express their experiences of anxiety and fear. Whilst fear was described using words like 'scared', 'scary' and 'frightened', words like 'concern', 'worry' and 'unease' were used to express the young

people's state of anxiety. However, a Mandinka word 'Jomoli' was also used, which means either one or all of the above.

Where 'Jomoli' represented all of the above, all the bereaved young people in this thesis were 'Jomoli' at the awareness of their loss. Their experience was either as a direct result of loss or other factors such as stigma and discrimination (discussed later). 'Jomoli' or fears and worries directly related to the loss itself were loss-oriented. For example, the quote below shows how a young person became scared when she learnt about a parent's death:

*It was scary ['Jomoli'] to learn that my father had died. You know at my age you expect to enjoy [being] with your parents, live with them and do all that children do with their parents. But when he died I thought about so many things and became worried about all these things.*

(SJ, 16 years, girl)

The accounts of these bereaved young people suggest that they were engulfed with the perception that the world they lived in had become disarrayed, and that they feared the consequences accompanying such a situation. The feeling that their world was crashing down as they lost their sense of direction and perspective was a strong and immediate concern in the accounts of the young people when they lost one of their parents. '*...I thought about everything but there was no way life would be the same for me*' (MD, 17 years, boy). '*She was my everything; life without her is scary*'. For others their worries started when their parent was ill and remained after the loss:

*When she was ill I still thought that she would recover because she would sometimes become better and sometimes worse. ... When she died some people told me that I was lucky that my father is caring and he would take care of me. I know he is a good man but I needed them both. ... They are different people but mum was more patient and accommodating and she was very close to my heart. I was really ...worried when she died.*

(OJ, 15 years, boy)

Another young person's concern included the welfare of her siblings who were young and may have required a great deal of support from members of the extended family. The 17-year-old girl commented '*... If it was only me I would have been less worried than I was when he died but thinking about my younger siblings who were very young...*' and would need a lot of support made things much more difficult for her. The young person went on to say:

*I would look at them and start thinking about how we were going to deal with this ... She [mum] also used to think a lot about us, she was worried; we were all worried about what would happen to us. When we sat down and stopped talking I would say something or do something just for distractions.*

(ASS, 17 years, girl)

Basic survival needs as well as concerns about educational attainment were prominent throughout the bereaved young people's accounts. The initial reaction of all these young people was that their surviving parents/guardians would be incapable of meeting their needs which included food, shelter, clothing, and at the same time take care of their educational expenses. Their concern about food was centred on the daily three meals, whilst their concerns about clothing centred mainly on their ability to attend festivals and ceremonies dressed up like their peers.

*I thought about all the things they (mum and dad) used to provide for us [siblings]. I thought it would be too much for one person to pay the school and do all the things we used to do. I was really worried we may no longer have our daily meals like we used to... [or even] get to wear the clothes they wear during the prayer [Tobaski]... When I thought about all these things I became worried.*

(AJ, 17 years, girl)

Concerns driven by poverty, stigma and discrimination, especially during festivals, led to negative feelings of one's worth (see Self-stigma) and subsequent withdrawal from peer relationships, increasing bereaved young peoples' isolation. A young person who feared being singled out said: *'Even during festivals I don't ask my sister because I feared it would be difficult so we just have to leave it. So when it is time for the festival, if my friends put on their dresses I don't go'* (HN, 17 years, girl).

In addition there were initial fears and concerns regarding payment of school fees. The bereaved young people wondered whether or not their school fees would be paid; and there were fears that they might drop out from school, as indicated by this excerpt:

*When he died the very first thought that came into my mind was: 'I am out' - I mean dropping out from school because I was worried [Jomoli] that my mum would not be able to meet all my needs ...and also pay for my school fees. I knew people may help but again they have their own problems ...It was not that easy for me and I don't think it would be for anyone else...*

(TS, 17 years, girl)

Despite all the bereaved young people reporting that their school fees had been paid for them by the OVC project, the accounts of some (six) of them suggest that paying directly to the school had further isolated them and exposed them to stigma and discrimination (see Stigma and discrimination). They reported their fears being aroused at the beginning of every semester. Not only were they worried to see their peers with their mums and dads, but also they feared that their peers would be asking them ‘*Who is paying for you?*’ In his words, a 16-year-old said his ‘...[peers] are happy with their parents and keep on asking [him] “*who is paying for you?*”...*They don’t understand*’ (ET, 16 years, boy). This account seemed to suggest that the bereaved young person envied his peers, an indication of harbouring anger for the loss (see Anger).

However, apart from school fees a few (five) of the bereaved young people reported having concern about shelter as part of their immediate response to loss. They were worried that their guardians may not be able to pay the rent. This concern led to the fear of homelessness, as one of the boys put it: ‘*I thought of my schooling. Who will pay the rent? I thought it would be hard to get food on the table; and, who will take care of my needs? It was scary*’ (LC, 16 years, boy). Another girl commented that their family had been struggling with the finance well before the death of her parent, but the death exposed them to the risk of harsh treatment from their landlords. Concerns of possible eviction had lived with the young person since the loss, as suggested by this account:

*...it was my dad and mum who used to share the responsibility of paying the rent and the other provisions. I knew about all that. Even before he died they used to complain how expensive things were. So when he died I thought of ... and the rent. When he died I thought we [family] may not be able to pay and we would be evicted. Where would we go? It was a real anxiety for me.*

(SS, 18 years, girl)

Fears and concerns relating to the payment of rent continued long after the loss. Responses from some (four) of the bereaved young people suggested that concerns were triggered as they approached *the end of the month*. They continued to be concerned knowing that failure would lead to homelessness, as demonstrated below:

*Our landlord is harsh; he doesn’t care whether somebody died. We are always worried whether my mother will pay the next rent. We are not sure whether we will be here next month, let’s see.*

(AJ, 17 years, girl)

The death of the loved-one left some (four) bereaved young people with a persistent fear for their own mortality : *'I always feel like maybe one day both of us will die'* (AK, 17 years, girl); the safety of their siblings: *'I was very concerned about what would happen to me and my siblings ...'* (ASS, 17 years, girl) as well as for the safety of their primary carers. Death reminded the bereaved young people of the potential impending death of the primary carer; such a concern was commonly manifested during the surviving parent's period of illness. Their concerns about safety were affected by their perceptions about the health status of their surviving parent, and whether they too displayed the signs and symptoms that caused death, as suggested by this excerpt:

*I always pray that she lives forever but I know that is not possible because my father died of general body pain and headache and now my mother is always falling ill and complaining about the same problem. I am feeling worried about all these things.*

(TS, 17 years, girl)

Whilst anxiety and fear was persistently reported by the bereaved young people, emotional loneliness was another common experience. The following section presents bereaved young people's experience of emotional loneliness.

#### 3.2.1.4 Emotional loneliness

Emotional loneliness was described by the bereaved young people as the absence of warmth and the special relationship they used to enjoy with their loved-one. Phrases like *'feeling empty'*; *'missed him'*; *'is unique'*; and *'had a special relationship'* were used to describe this reaction to loss.

The bereaved young people's consistent descriptions of their relationship with their parent (now deceased) as *special*, indicates the emotional vacuum left by the parent would be hard to fill. For example a girl who felt such a special relationship commented that: *'She used to do everything with me...she was unique'* (MS, 17 years, girl). A similar relationship was reflected upon by an 18-year-old girl: *'My mother who used to be my closest friend no more exists, she is no longer here ...'* (JS, 18 years, girl), indicating not only that the deceased was important to her but also that there appeared to be a shortage of caring adults who really understood and were willing to interact with the bereaved young people in ways desirable to them. One young person said:

*Since her death, I now see myself as a sad and lonely child unlike most of my peers who are enjoying [being] with their parents. My mother who used to be my closest friend no more exists, she is no longer here ...*

(JS, 18 years, girl)

In the past, the bereaved young people had shared with their parent(s) and had interacted with them in various circumstances before the loss. Important events that had characterised their relationships ranged from attending festivals together to routine daily interactions occurring within the household such as during cooking, chatting, singing, storytelling, gardening and farming. Interactions with the special person during these activities had been missed. An example of these experiences is illustrated below:

*She used to do everything with me...she was unique; I missed her and all the things we used to do together. As I said, I used to spend the night on her bed. We were very close and at night she used to tell me stories and give me some advice... We sometimes used to go for shopping and I used to help her with cooking and laundry. Still I do cooking but not with her, I cook with others. I do really miss her...*

(MS, 17 years, girl)

The above excerpt clearly suggests that for some bereaved young people their intense loneliness had never really gone away. It was events and festivals that presented them with a mammoth challenge by triggering episodes of intense emotional loneliness. For many (eight), the absence of the deceased parent at religious festivals and school activities (see Self-stigma and anxiety), when parents were expected to be involved (e.g. payment of school fees, parents and teachers meetings) was associated with feelings of emotional loneliness, as indicated in these quotations:

*You know when it is time to pay school fees you miss your parent because your peers come with their parent and they will say 'Who is paying for you?' That is kind of difficult to answer.*

(SS, 18 years, girl)

The bereaved young people who were already feeling lonely might also be isolated by the discriminatory behaviour of others towards them. The consequences of stigma, poverty or lack of material support seemed to further marginalise the bereaved young people. For example, lack of provision of new clothes to attend religious festivals - which used to make

them feel special - now reminded bereaved young people that they were lonely, as illustrated by this excerpt:

*I think it was special to be going out with dad ... It used to make me feel happy and comfortable ...but to be honest it is not until he died that I realised how valuable that relationship was to me... I remember on Tobaski days he would put on his new clothes and he would ask me to put on mine and he would hold on my hand and go with me to the mosque for the prayer. Now, I missed all that. After his death I attended the Tobaski prayer ...I kind of feel lonely when I see other people with their parents. I don't go now.*

(TS, 17 years, girl)

Their sense of loneliness was not only connected with special events. Some (three) indicated that they missed interactions with their deceased parent during the evenings, nights and weekends when they used to enjoy their warmth. These times of the day were connected with specific interactions such as sleeping in the same bed, speaking to them and having a chat/joke at bedtime. For example one of them said: *'From time to time I feel lonely at night especially the time in the night he used to call us for a chat and provoke jokes. I feel it more at those times'* (SS, 18 years, girl).

Whilst the bereaved young people felt lonely as a result of their loss, they did not discard the memories of their deceased parent. The next section discusses the bereaved young people's continuous emotional bond with their deceased parents.

#### 3.2.1.5 'I always pray for her' - Continuous emotional bond

There is evidence in the previous sections that bereaved young people continued to engage with and feel their loss. 'Continuous bond' is another way of actively engaging with loss (loss-oriented coping). This term represents an existing emotional relationship or bonding between the bereaved and deceased parents. In spite of the emotional pain caused by engaging with loss, as discussed earlier (see Emotional intensity), the young people *always think or remember ... [their] mum [and] dad*. Statements like *how can I forget? I think about her; and he is always remembered* suggest that many of the young people perceived their relationship with the deceased as permanent and did not let go the memories of their parent.

The bereaved young people's reminiscence about their deceased parent during interviews with the researcher suggested that all of them still retained emotional connection. Three to

five years after the death of the parent, all the young people who participated in the data collection still talked not only about their deceased parent (see Emotional expression 3.2.2), but also about activities and interactions they had shared with their loved-ones as if they were still fresh in their minds. These activities included *cooking, shopping, laundry, storytelling, singing, going to farm together, sleeping on the same bed, and attending school meetings*. For example, one of the young people said: *'I used to do everything with her; we went to the farm together'* (JS, 18 years, girl); another said:

*... everything was normal, we sometimes used to do shopping, and she used to make me laugh with her song and stories. There was this special story, I will always remember that. I will narrate that to my kids [when I become a grown-up].*

(HN, 17 years, girl)

Apart from reminiscences observed during interviews, many (12) of the bereaved young people seemed to engage with their loss by retaining connection through intangible resources such as prayer, and tangible materials such as objects left behind by their deceased parent. While the objects inherited might also have been used for material benefit, the main benefit, as far as many (ten) young people were concerned, was for retaining emotional connection with the deceased. Objects they found helpful in this way were mainly *clothing, books, pictures, radio and diaries*. One girl said:

*I remembered that day when she told me to go with her for shopping. ... She bought me a nice dress and gave me some pieces of advice. When I put on my dress I always remember what she told me [advice].*

(MS, 17 years, girl)

For this young person, the special item (dress) from the deceased had gone beyond retaining emotional connections with the deceased to serving her as a symbol of guidance. Visual presentations of the deceased parent served similar functions for one young boy, as shown below:

*I think it was after the 40 days, when my uncle called me and gave me the radio. He said to me: 'This is yours now, it is left behind by your mother and now you can take it.' I cannot forget her because I have her picture in my room. I look at it at night when I am alone and sometimes I weep after that and go to bed.*

(AK, 15 years, boy)

Alongside such objects, daily prayers also emerged as a powerful way of retaining a meaningful sense of emotional connection with a deceased parent for many young people (ten). It is not just that the bereaved young people remembered their loved-ones during prayers. For example:

*...we [bereaved family] cannot forget her. When I am praying I always pray for her. It makes me feel that we are doing something worthy because she did not stay long enough to benefit from us. It is funny, when I am praying I use her praying mat and sometimes wear her long gown she used to wear when praying; this way I remember her even more and it gives me a sense of comfort. I feel like my prayers are accepted and I want to do more and more prayers for her.*

(JS, 18 years, girl)

The satisfaction and comfort derived from knowing that they and their deceased parent were part and parcel of each other is clearly manifested in the account above. Not only did the bereaved young people gain comfort in remembering their deceased parent through prayers, but they also believed that prayer helped their parents to be granted ‘Jannah’ paradise, which all Muslims strive to achieve.

### **3.3 Restoration-oriented coping**

#### **3.3.1 ‘*I could not imagine it*’ – Denial response to loss**

As opposed to loss-oriented coping which is the active engagement with loss, restoration-oriented coping is a temporary disengagement with loss and reminders of loss. One aspect of restoration-oriented coping is ‘Denial’. The account that they ‘*did not expect*’ one of their parents to die so soon despite serious prolonged illness (see Severity of reactions) is an indication of the presence of denial well before death.

Despite loss being perceived as natural and avoidable and despite several emotional reactions, such as sadness, anxiety and anger, there were instances when loss was perceived as *unreal* by the bereaved young people, being described by them in terms such as ‘unreal’ or ‘*disbelief*’. Perceiving death as unreal or to be disbelieving is often seen in the literature as a way of temporarily protecting the bereaved from the full reality which their loss potentially represents for them; an attempt to bring overwhelming emotional pain under some form of control or reduce its impact, at least temporarily, as suggested by this excerpt:

*Sometimes when death occurs you wonder whether it is real, especially when you do not see the corpse. That was what happened in my case. I wanted to see the corpse to convince myself but they would not let me. Even if I had seen the corpse at that time it would still have been hard to believe that he was dead. I could not imagine it.*

(JS, 18 years, girl)

‘I could not believe’, ‘It was not true’ and ‘It was unrealistic’ were statements used suggesting that these young people were struggling to convince themselves that loss had actually occurred. Their accounts suggest that denial was early reaction that caused them temporarily to deny their awareness of loss and temporarily prevented them from experiencing emotional reactions, as illustrated by the following account:

*The doctor told us that he would be fine but he died. So after the death I was still asking people whether it was actually true; it was difficult - I could not believe that such a thing could happen to me.*

(ASS, 17 years, girl)

Information discrimination or lack of adequate information regarding a parent’s impending death, as suggested by the quote above, may influence a young person’s denial reactions. It appears that discrimination such as denial of access to information (see Secrecy) and social isolation (see Isolation) experienced by the bereaved young people may have further reinforced their denial reactions. Exclusion of a bereaved young person from seeing the corpse may sometimes lead to denial of loss, as one young person, already quoted above, suggested: ‘*Sometimes when death occurs you wonder whether it is real, especially when you do not see the corpse...*’ (JS, 18 years, girl).

Only a few (five) reported that they had at some point experienced disbelief or perceived the death as unreal. Apart from the few exceptions above, death was generally accepted by the young people. They felt they should not disbelieve in the loss that was evident to them. ‘*The very day she died, I saw people wailing, I knew, and I always accepted that she was gone [dead]*’ (MD, 17 years, boy); ‘*When I heard the news I believed in it*’ (FB, 16 years, girl); ‘*Although I had not seen the corpse I knew that he was dead*’ (AJ, 17 years, girl).

*People have seen the dead body, so I have accepted that she is dead, normally people don’t joke with loss. They only say, ‘so and so is dead’ when death occurs. Even though I did not see the corpse I believed in them and I have accepted it. I have no reason to pretend that it did not occur.*

(MD, 17 years, boy)

It may be that their society did not permit some young people to deny loss. Four accounts suggest that they were expected not to disbelieve in the loss. For example, when young people were asked whether they felt that their loss was unreal, one of them said: *'I am not expected to say "no he is not [dead]"... it was real'* (SJ, 16 years, girl). One of the bereaved young people was concerned about the religious consequences of their reactions and would do everything not to go against religious dogma, which prohibits disbelieving in death (considered the will of God).

*I am not expected to disbelieve in his death: disbelieving would be a sin. I was aware of his illness and I believed he was dead. It is against my religion to pretend when I know for sure he is dead ... We all knew he was dead; why would I say I disbelieved - it doesn't make sense, does it?*

(AJ, 17 years, girl)

In addition to psychological denial responses, bereaved young people experienced avoidance approaches. The following section presents findings related to avoidance.

### **3.3.2 Avoidance**

#### 3.3.2.1 'Some people prefer to be alone' – Creating a breathing space

As opposed to denial response, which some saw as irrational, avoidance was a strategy voluntarily employed by young people to disengage from loss and memories of loss.

This restoration-oriented based coping can be described as creating room, breathing space, distancing, withdrawing oneself from emotionally charged situations. An example of such strategies is illustrated below:

*When death occurs... some people would prefer to be alone because they do not want to hurt others... I don't like hurting people's feelings, that's the reason, even if I am feeling sad, I don't let mum know about it ... Even with my siblings I don't cry when they are there. They expect me to cope; they look up to me... I am their role model; so when I cry they will feel sad and cry. I don't know how to console them, so I don't want to hurt them.*

(SS, 18 years, girl)

All the bereaved young people who took part in this research were involved in avoidance approach as one strategy they used in responding to their loss. The excerpt above suggests

that they indulged in two kinds of avoidance. One that was triggered by external influences such as coming to terms with social or religious expectations or avoiding the impact of one's distress on others (see the following section); the other one which is the focus of this section being voluntary withdrawal from any forms of reminder of loss. They considered that coming into contact with situations that triggered intense emotions could be overwhelming (see Intense emotional reactions 3.2.1), but when such situations arose they tended to suppress their emotional behaviours (for example through crying), even when they felt the need to express them. Typical responses included: *I keep my feelings in secret; I prefer to stay indoors and cry; I do not cry in her presence.* One of the bereaved young people said it was sometimes better to keep feelings to oneself:

*It is impossible to say I do not cry; yes, for them [adults] they have not seen me crying. When I am sitting with them I try as much as I can; I keep my feelings to myself but I do cry privately. Sometimes I will withdraw, go somewhere quiet and cry.*

(ASS, 17 years, girl)

For about three-quarters (13) of the bereaved young people, being involved in emotionally charged situations all the time was not helpful. They tended to distance themselves from the people and places that were likely to trigger, reinforce or intensify their emotions. The bereaved people, people on the funeral ground, the funeral home and the room of the deceased parent were all viewed as potential areas for avoidance. To illustrate this, young people said:

*The day my father died [at first] I did not go home; I went and sat at our school alone. That was better because it was too difficult ...It helped me to calm down and in the evening I went home.*

(LC, 15 years, boy)

*I have stayed away from home for part of the day or so. I stayed in my uncle's home for some time because I felt I would not stop crying, if I should stay at home. I needed that.*

(SS, 18 years, girl)

Whilst the pain of confronting the memories of the deceased parent remained, creating breathing space was viewed by some (four) of the young people as an opportunity to digest their experience in a way that was convenient to them. At a certain point in their bereavement, they said they had found the pain of confronting the loss too much and they needed to distance themselves from emotionally charged situations to be able to make sense of their loss.

*When I am coming from school, as I approach home I feel sad. At home I am reminded about the loss that is the reason I sometimes stay away from home ... Sitting at the park alone was helpful; the place was peaceful and lonely and helped me to think properly. Whenever I feel bad I just go and sit alone, think and cry quietly on my own. It helps me to calm down quickly.*

(FB, 16 years, girl)

The above quote suggests that the voluntary creation of breathing space had not only provided the bereaved young person the opportunity to dwell on her loss in a manner appropriate for her but also facilitated emotional expression that was free from social pressure. The following section discusses the silences surrounding the loss.

### 3.3.2.2 'You know I cannot be angry... that is not acceptable' – Emotional suppression

Apart from protecting oneself from the impact of engaging with loss as discussed above, central to the avoidance approach was the pressure for many (13) bereaved young people to suppress their emotions for the purpose of protecting others or coming into conformity with social expectations. Emotions were restrained '*...because ... [the young people] do not want them [bereaved family] to feel bad.*' Illustrating efforts to protect family members, especially the surviving parent, one of the participants said: '*I do avoid feeling bad in her [surviving mother's] presence and I do pretend as if everything is fine because I don't want anybody to feel bad too*' (SJ, 16 years, girl). Another one said: '*I know she is feeling bad about the death; I will make it worse for her if I cry. I do not want that*' (AJ, 17 years, girl). These accounts clearly show how bereaved young people perceived open expression of emotions might impact on the psychological functioning of the family members, as discussed in a later section (see Psychological functioning of the primary carer).

Whilst the above avoidance approach was engineered by voluntary choices made by the bereaved young people, such avoidance was sometimes enforced on them by external agents exerting social pressure on them to react in certain ways. In this case the reason for restraining or suppressing their emotional expression was the desire to meet social expectations, as there seemed to be an unwritten rule that determined how bereaved young people should react. By suppressing their emotions, bereaved young people met the expectations and came into conformity with the social rules. Such expectations and pressures were echoed in their personal accounts, as one of them said: '*You are expected to support her*

*at this time; crying may upset her and that is not helpful'* (AJ, 17 years, girl). Any form of emotional expression in response to death which is against the social or religious norm may be considered inappropriate. This applies, in particular, to anger, which may be discouraged because of the perception that it would have a negative impact on other members of the family, as indicated by this excerpt:

*You know I cannot be angry with Allah or my mother - that is not acceptable ... You are expected to support them [the bereaved family] and not to make difficulty for them. All the time showing them that you are sad may not help them: it can make them feel bad. In the end it would only make things worse for all of us.*

(MD, 17 years, girl)

The account '*You are expected to support them [the bereaved family] and not to make it difficult for them*' suggests that, by not obeying the social rule, the bereaved young people perceived that they were making life or coping difficult for other bereaved members of the family, forcing them to suppress their emotions. Consequently the bereaved young people's need for open expression of emotion was compromised by the need to protect social and religious norms by obeying the social order. They were expected to put up brave faces whilst underneath they may have been full of sadness and anxieties, as shown by this quote:

*They expect me to cope; they look up to me... I am their role model; so when I cry they will feel sad and cry. I don't know how to console them, so I don't want to hurt them.*

(SS, 18 years, girl)

The quote above epitomised the bereaved young person's commitment to protecting her siblings. In the process, she saw herself as a role model whose behaviour and reactions to loss may have direct effects on her siblings. Seeing oneself as a role model may well have placed extra pressure on the bereaved young people to further suppress their emotions.

### **3.4. Social factors influencing bereaved young people's experiences**

#### **3.4.1 Stigma, discrimination and poverty**

The DPM model suggested that there are two stressors the bereaved would experience: major stressors are the loss of a loved-one; and minor or secondary stressors are the other stressors the bereaved experienced as a consequence of loss. Stigma, discrimination and poverty in this

thesis are considered secondary stressors. This section shows that a range of emotional reactions encountered during the period of bereavement were not always related directly to the loss itself but rather to stressors such as stigma, discrimination and poverty. The following sections present data related to these stressors.

#### 3.4.1.1 ‘...it was “Sutomolu” (Witchcraft)’: Secrecy surrounding the cause of parental death

The researcher did not ask the bereaved young people their parent’s cause of death, as it was felt that they would voluntarily mention it if they wished to discuss it. There was no evidence to suggest that the bereaved young people in this thesis were told either by a parent or guardian that illness and death of their loved-one was caused by HIV/AIDS. In short, their parents’ death was shrouded in secrecy.

The terms ‘HIV’ and ‘AIDS’ were not mentioned throughout the interviews, suggesting they might have been associated with fear of stigma or lack of knowledge about parents’ HIV-status. As the bereaved young people reflected on their parents’ illness and struggles before death the common symptoms identified from their accounts included skin conditions, chest pain, stomach-aches, headache, and swollen limbs, as suggested by this excerpt:

*It is hard to see your dad in such a condition; his body did not look good, his hair came off his head. I used to feel very sad and sympathetic towards him but I felt even worse when he died because at that time I used to chat with him but now it is different - he is not here [dead] with me.*

(LC, 15 years, boy)

Three of the participants named their parents cause of death as something else, whilst one of the bereaved young people perceived that ‘Sutomolu’ (witchcraft) was the source of parental death, with the other two identifying chronic illnesses such as Tuberculosis (TB) or diabetes. The accounts of these young people suggest that they were either given false information by the ill parent before death or they relied on rumours surrounding the illness. For example, this young person said:

*I used to have a chat with him. He told me that he had diabetics; it was very painful. He was taking the medication from Hands on Care to reduce the pain. That helped a bit but it was not enough.*

(TS, 17 years, girl)

Another was given the impression that even the doctors could not diagnose the illness. The rumour spread by 'Marabouts' (witch doctors) was that some form of supernatural power such as witchcraft was responsible for the loss. The young person seemed to direct his anger and frustration to the person responsible for the death, as suggested by this account:

*Before she passed away, I heard people saying that the 'Marabouts' said it was 'Sutomolu' ['Suto' – means 'night', 'molu' – means 'people'- literally means witchcraft] because even the hospital did not know what happened to her. I believed it was 'Sutomolu' and that hurts.*

(MD, 17 years, boy)

However, despite the bereaved young people's awareness of their parent's illness, when death occurred they were not even told that their parent had died, they often found it out by themselves (see Emotional expression). The bereaved young people in this thesis seemed deprived of their right to information about their parents' death. The following quote suggests anger and anxiety as a result of the lack of information: '*You expect to be told "sorry, your father has died" but that did not happen... you kind of feel bad and things like that*' (MB, 17 years, boy). One young person, who had been denied information about death, perceived that such behaviour by the adults caused isolation and was unfair treatment, as shown below:

*...they talked about it [death], but for us [siblings] we did not ... it's like we are not part of the family ... You expect them to tell you that so and so has died. In this case they did not tell me and I heard it from other people.*

(MD, 17 years, girl)

As the quote shows, the young person perceived that the adults shared information among themselves, acknowledged and consoled each other, whilst depriving them the same opportunity. This situation frustrated, angered and forced the young person to see herself as an outsider, a situation that might not be favourable to her coping. The next section discusses verbal stigma.

#### 3.4.1.2 'Where is your dad?' – Verbal stigma or 'Bayoh'

In the context of this thesis verbal stigma means using words or making derogatory comments about the bereaved young people and their families as a result of their loss or living conditions.

Since there was secrecy surrounding deceased parents' HIV-status, there was no direct evidence as to whether or not the bereaved young people received derogatory comments as a result of their parents' cause of death being AIDS. However, orphan status referred to as 'Bayoh' in Mandinka was a stigmatising condition as it was described here as a bereaved young person perceived to have been abandoned by his/her paternal lineage, as suggested by this account:

*I know it is hard – he [my father] has three children, but that should not have prevented him from buying things for me. Last year he promised to give me some stuff, every single year he would promise but he never fulfilled his promise. I cannot say he has abandoned me or my mum but it looks like it.*

(TS, 17 years, girl)

All the male members of a bereaved young person's paternal lineage were referred to as father, because they were perceived to be the natural successor of the deceased father in providing livelihood for the bereaved young people. In the following quote, an 18-year-old young person challenged her paternal lineage to stop discrimination and start taking its responsibilities:

*When your dad died you kind of expect his brother to take care of you and your mum, you think he will go on and meet your needs, in your mind you will be fine, you have little to worry about. But when he does not take care of you, you know, you say to yourself 'that is it'. It is like someone telling you, you do not belong here anymore. It is unfair; he is not taking his responsibilities.*

(SS, 18 years, girl)

When the bereaved young people or the society they lived in perceived that the young people had been abandoned by members of this lineage, stigmatising names such as 'Bayoh' or 'orphan' instead of 'son/daughter' were used to describe their identity. However, only a few (three) of the bereaved young people said they had been described in this manner. Two of the bereaved young people commented that, despite their classmates' awareness of their parent's death, they were still asked 'where is your dad?' which caused worries and concerns among them. The anger and frustration as a result of this calling is evident in the following account:

*Some people don't care how I feel; at school they will ask me... 'Where is your dad?' This always happens at the beginning of the academic term.... I dread these days...*

(AK, 15 years, boy)

One of the bereaved young people said her classmates went to the extent of wanting to know how her school fees were to be paid, something she found distressing, as suggested by this account:

*...when it is time to pay school fees you... your peers come with their parent and they will say 'Who is paying for you?' That is kind of difficult to answer.*

(SS, 18 years, girl)

Calling a bereaved young person a 'Bayoh' reaffirmed social grouping which categorised bereaved young people as somewhat different from normal young people whose parents were alive. One of the bereaved young people was frustrated by people who pretended to empathetic with her when in reality they were stigmatising and discriminating against her, calling her names such as a 'Bayoh', as suggested by this account:

*Some people have the habit of looking at you and they will be saying oh! His father is dead; oh he is a 'Bayoh' orphan. They do not care - they just want to provoke and laugh at you.*

(TS, 17 years, girl)

Whilst these bereaved young people found 'Bayoh' to be offensive, they did not want to be seen as deviant, and be pitied by others. However, the following section focuses on the bereaved young people who already perceived themselves as deviant.

#### 3.4.1.3 'I felt different from them' - Self-stigma/shame

Clearly the evidence so far suggests that the bereaved young people in this thesis were sensitive to the difference between their own circumstances and those of their peers whose parents were alive. They tended to constantly compare themselves with their peers in terms of material possessions and interpersonal relationships with significant others, which left them feeling worried. The account '*they have their parents; we don't*' also points to the bereaved young people's own perceptions of 'them' (bereaved young people) being different from 'others' (non-bereaved young people).

The bereaved young people were asked how different they felt when their parent died. In addition to their experiences of several emotional reactions, they all felt their circumstances were different from their peers' whose parents were alive. The consistent account was '*I felt*

*different from them*', confirming perception of their own inferiority when compared to their peers subsequently affecting interactions with them.

It was evident in their accounts that many (see Emotional loneliness) of them found it hard to engage with their peers whose parents were alive. One described such a relationship as '*the most difficult thing*' to be engaged in (see Anxiety). They either had to withdraw from their relationships or avoid interacting with them at some point during their bereavement. For example, an 18-year-old girl avoided her peers due to what may be described as shame associated with seeing peers with their parents. She commented that: '*When I see them with their parents... when I see them first. I avoid them and concentrate on something else* (JS, 18 years, girl).

Another girl's concern was associated with being different from peers in terms of material possession (see Poverty) as she lamented: '*For me it is different - my dad is not alive and my mother would not be able to buy [clothes] for my siblings and me. When I think of all this, I hide in mum's room and cry* (TS, 17 years, girl).

*When it is festival, when my peers go, I don't go because we are seen differently - even with the things they wear you could tell who is who. It will be hard for me to take.*  
(AK, 15 years, boy)

The above accounts suggest a feeling of humiliation interacting with peers who were perceived by the bereaved young people as better off. This feeling of shame was largely associated with material possessions or the social circumstances in which they lived. Embarrassment about being without proper clothing seemed to interfere with young people's interactions with their peers. Feeling of shame on these grounds was commonly associated with certain events such as the beginning of the school year or during annual festivals where parental participation was required. For example:

*Even during festivals I don't ask my sister because I feared it would be difficult so we just have to leave it. So when it is time for the festival, if my friends put on their dresses I don't go.*  
(HN, 17 years, girl)

Bereaved young people's withdrawal from social relationships as a result of shame (self-stigma) is evident in the above accounts, yet name calling at school and in the neighbourhood

as indicated in the above section (see Verbal stigma) might have forced young people to internalise negative perceptions about themselves and their families, causing shame and isolation. For example, one bereaved young person used ‘*dread*’ to describe his feelings about going back to school after the school holiday:

*Some people don't care how I feel; ...their parents ... are paying school fees for them. I dread these days because my parents are not there to do that for me.*

(AK, 15 years, boy)

In summary, the bereaved young people’s feelings of shame were triggered by their own perception of self and how they thought other people were viewing them, resulting in anger, frustration, secrecy and withdrawal from social relationships. The following section presents findings related to bereaved young people’s social exclusion.

#### 3.4.1.4 ‘I would prefer to be treated the same way as his kids’: Social exclusion

Concern related to isolation and minimal contact with significant others as in the case of social exclusions are restoration-oriented distress. It must be noted that whilst the focus of this thesis is on bereaved young people, there was evidence that the social exclusion they experienced during bereavement started well before the death of the parent. There were two incidents of a parent travelling abroad in search of cure for their ailment, leaving their children behind, causing worries and anxieties. For example, one of the bereaved young people commented:

*I hardly saw or heard from her when she was ill. She used to go to Senegal [the neighbouring country] to her parents for treatment. Sometimes she would stay there for a year and then come home. She hardly communicated with us. When I made enquiries about her, I didn't get anything. My dad would not tell me. Sometimes I would ask him whether she was dead. He would smile and say ‘No’ but he would not tell me anything more. When mum died dad also got ill, at first he started travelling, searching for treatment, but now he does not go anywhere - the hospital is giving him the medication.*

(HJ, 18years, girl)

However, when death occurred, one of the earliest reactions was temporary relocation of bereaved young people from the funeral ground (home) to other compounds in the community. Some (three) of the bereaved young people who were forcefully removed from the funeral home lamented that their temporary relocations prevented them from having any

sort of contact with their bereaved parent in this acute stage of their bereavement. The quote below suggests that this kind of isolation was perceived as unfair and seemed to lead to sadness and anger.

*Okay maybe they have made a mistake for not telling me but even when I got home they did not let me stay, I did not even see my mum [surviving parent] or the corpse. I was escorted to a neighbour's house - for what? I don't know - that is hard for any child. That was really unhelpful and it made me sad. Even now when I think about it I feel sad.*  
(MD, 17 years, girl)

The statement above clearly suggests that the young person perceived that sharing information and social interaction with significant others was her right as a member of the extended family. None of the bereaved identified a member of the family who either shared information about their loss (see Emotional expression or Secrecy) or visited them regularly. Whilst blaming adults other than their guardians, young people (six) felt that some of their family members failed to fulfil the social obligation of socialising with them [young people]. For example, the following excerpts suggest that aunts and uncles were isolating them: '*He [father's brother] is not visiting us now, he only cares about his own children*' (ASS, 17years, girl); '*When we met, she [father's sister] said to me "I will come there" but, you know, she has already abandoned us [siblings]*' (SJ, 16years, girl).

Members of the extended family, who used to be very close to the family and visit on a regular basis, no longer visited bereaved young people and their guardians as they used to do - something that was perceived as unfair, as shown below:

*He [father's brother] used to come home frequently when father was alive. He knows it is his responsibility [to take care of me] now that my father [biological father] is gone [dead] ... Now he is not coming [home] and not doing what my father [biological] used to do. ... It is kind of unfair; I would prefer to be treated the same way as his kids.*  
(SS, 18 years, girl)

One of the bereaved young people went to the extent of describing herself and her guardian as outcasts, a perception that led to their further withdrawal from significant people in their lives. Whilst the 16-year-old girl showed her desire to reunite with her paternal lineage, she remained occupied with the thought that she would still be subjected to rejection and would remain as an outcast from the family to which she naturally belonged as child. The girl said: *I don't visit him or talk to him about my father*, the reason being:

*...because I don't know what to expect ... I may go there or call him and he may put me down. I don't want to take that risk. I am already struggling with my loss, if he puts me down that would be devastating for me. I know we need him but I don't know how to tell him because even my mother had stopped talking to us about him. I am not quite sure what is going on or what to do.*

(SJ, 16 years, girl)

Although social exclusion within a household (extended family members living together in the same compound and sharing family resources) was not a common practice, there is evidence that bereaved young people and their primary carers might have experienced it. A young person reported that death of a breadwinner had led to complete family breakdown and isolation of vulnerable bereaved young people and their primary carers.

*...one family - when the head of the household died, the household split into two. Instead of continuing sharing the household responsibilities and eating from the same basin as they used to do, the household split into two with each fending for itself. I don't think they sit together or chat any more... We do not have such problems in our family because it is only me, my mum and my sisters, we have a small household but...*

(AJ, 18 years, girl)

However, fear of stigma and discrimination consistently seemed to force bereaved young people to withdraw from social relationships. Such fears have been reported at school (see Self-stigma for details), during festivals (see Emotional loneliness or Economic deprivations for details) as well as in their neighbourhood when the bereaved young people avoided seeing their peers with their parents, as indicated in the previous sections (see Emotional loneliness; Avoidance, and Self-stigma for details).

#### 3.4.1.5 'There should not be any favouritism' - Material deprivation

All the bereaved young people in this thesis were at some point preoccupied with thoughts and feelings related to material deprivation. Such a restoration-oriented distress was associated with poverty (see the following section), families' failure to take up their responsibility in caring for the bereaved young people and property grabbing by greedy people. Whilst the latter was uncommon and reported by only a few (two), the first two were not only inter-related but also experienced by all the bereaved young people in this thesis.

The bereaved young people's accounts consistently show that both their extended families' refusal to support them and their loss had led to their feeling of being deprived materially. Since the deceased parents were reported to be economically productive, the loss deprived them the opportunity to continue enjoying such a livelihood. As a result there were worries and concerns regarding the maintenance and upkeep of the household (see Anxiety). For example:

*I thought about all the things they (mum and dad) used to provide for us [siblings]... I was really worried we may no longer have our daily meals like we used to... When I thought about all these things I became worried.*

(AJ, 17 years, girl)

Whilst all the bereaved young people reported feelings of being deprived access to material possession by members of the extended family, not all family members were discriminatory. Non-guardians were perceived to be more discriminatory than the guardians. There was only one incident where a bereaved young person claimed a stepmother (with whom she was living) was favouring her own biological children at the expense of herself and her younger siblings. The bereaved young person's half-siblings had better access to material support than herself and her siblings. This happened when the biological father of the 16-year-old girl was away from home, as suggested by the following account:

*I felt I should have been treated by my step-mum like her own children. Dad gave her everything so that she would take care of me and my younger siblings but she is giving them to her own children. When dad is not here, me and my siblings sometimes sleep in darkness and she would buy some candles for her own children and also give them school lunch. It is sad, she wants us to feel miserable all the time. It keeps me thinking about mum ...that is hard.*

(FB, 16 years, girl)

Apart from the above situation, all the bereaved young people's sources of deprivation were members of the extended family, such as uncles and aunts who were not living with the young people in the same home. The accounts of the bereaved young people suggest that they viewed material support from their extended family members as their right and failure to provide such support led to anger and frustration, as could be clearly seen in this account:

*...he is not taking his responsibilities. I kind of think that we should all be treated the same; there should not be any favouritism. ... He [father's brother] used to come home frequently when father was alive. He knows it is his responsibility [to take care of me] now that my father [biological father] is gone [dead] ... Now he is not coming [home] and not doing what my father [biological] used to do. ... It is kind of unfair; I would prefer to be treated the same way as his kids.*

(SS, 18 years, girl)

The quote above clearly suggests that feelings of being deprived - especially by the paternal lineage - led to anger and a sense of injustice. The lack of support from these significant others impacted upon the primary carers' ability to provide a livelihood for the bereaved young people on a daily basis (see Poverty).

Whilst property grabbing is uncommon and hardly experienced by any, there is evidence of cheating or corruption involving members of the community and state officials. Two of the bereaved young people lost their future home and were left with no option other than renting, as their primary carer could not afford to buy a plot of land, let alone to build a house. Such greed left the young people angry, as indicated in this account:

*I am angry because they have cheated us - they have taken away our plot of land. We were going to have our own home but now we are renting and our first landlord always make us feel angry.*

(SJ, 16 years, girl)

It appears that bereaved young people generally did not have material support equal to that of their peers whose parents were alive; and that such deprivation may have led to poverty (see next section). The following excerpts present the bereaved young people's perception of their loss and poverty:

*Since my mother died I have received lots of support but sometimes I feel like I have not been treated like the ones whose parents are there [alive]. Maybe it's me but that is how I feel, I feel that we are not treated equal. They seem to get all the things they wanted. By looking at the clothes they wear or even the uniform they wear, you could tell, you could tell that they have no problem. For me... and some of my colleagues it is different, we don't have the chance and you know that is not right.*

(JS, 18 years, girl)

*I know it is hard – he [my father] has three children, but that should not have prevented him from buying things for me. Last year he promised to give me some stuff, every*

*single year he would promise but he never fulfilled his promise. I cannot say he has abandoned me or my mum but it looks like it.*

(TS, 17 years, girl)

#### 3.4.1.6 'Worried whether... [her] mother will pay the next rent' – Poverty

Some of the bereaved were preoccupied about securing a livelihood. The accounts of all the bereaved young people suggest that, before the loss, their deceased parent was one of the main breadwinners (see Anxiety) whose death had a negative impact on family resources. It weakened their family income and there were consistent concerns about the scarcity of resources to meet their needs. Perhaps the clearest indications of poverty were concerns surrounding the bereaved young people's basic needs such as food, shelter, clothing and access to education. Such a position is illustrated by the following account:

*... I know it is easier for men to provide food, rent and things like that. This is a new responsibility for her [surviving mother]; it is hard - she knows that.*

(ASS, 17 years, girl)

The loss not only put the bereaved young people and their bereaved families under immense economic pressure but it also caused widespread worries and anxieties among the bereaved young people (see Anxiety).

The bereaved young people's worries and anxiety relating to lack of adequate material possession started immediately after the loss and continued right through their period of bereavement (see Anxiety). One of the earliest concerns that was addressed later by the OVC support project related to schooling. There were fears that the death of a parent meant the family would no longer be able to pay school fees and other school expenses, which would lead to school dropout (see Anxiety), as illustrated by a girl who said '*...I mean dropping out from school because I was worried that my mum would not be able to meet all my needs... and also pay for my school fees*' (TS, 17 years, girl). There was no evidence of the extended families' involvement in paying school fees, suggesting they might not have had the capacity to help.

Whilst the financial aspects of schooling was no more a concern thanks to the OVC project, other worries such as food, clothing and shelter remained a problem for the bereaved young people and their primary carers/guardians. At the time of data collection, families were still struggling to meet these needs (see Anxiety and Economic deprivation for more detail). As one of the bereaved young people points out, she is: *'Worried whether... [her] mother will pay the next rent. We are not sure we will be here next month...'* (AJ, 17 years, girl).

Scarcity of resources and worries surrounding the uncertainty of a secure livelihood forced some (three) of the bereaved young people to commit time in helping the primary carer meet some of their needs. These young people reported that they worked harder in order to reduce the impact of material loss but they had to admit that life was still tough for them. One of them said:

*We are working hard as a family to survive, my mother fetches firewood and sells it and my brother does brickwork and the money is used to buy food, clothes and to pay rent. Without him [brother] it would be too hard for me.*

(SJ, 16 years, girl)

There seemed to be inter-relationships between poverty, stigma and discrimination, especially when considering livelihood. The bereaved young people who perceived they were deprived (see Economic deprivation) were not only poor (see the quote below), but also humiliated (see Self-stigma) by their poverty, leading to withdrawal from peers and some members of the extended families who could have been important sources of support for them. For example, one of the bereaved young people who perceived that she had been deprived commented that she felt different and moreover she had been humiliated and marginalised by adults due to her poverty, as shown in this excerpt:

*People look at me and know that my father has died; and it [unfair treatment] made me believe that we are different ...before you know that you are different from other young people, there is a ceremony or festival and you see how they are embraced by people ... They would talk about their dresses and their look but for you no one would be bothered to have a look at what you wear. Even if they have you they would make you feel bad with yourself.*

(AJ, 17 years, girl)

Another young person's account seemed to suggest an association between poverty, social exclusion and material deprivation:

*I know it is hard – he [my father] has three children, but that should not have prevented him from buying things for me. Last year he promised to give me some stuff, every single year he would promise but he never fulfilled his promise. I cannot say he has abandoned me or my mum but it looks like it.*

(TS, 17 years, girl)

The earlier sections such as Economic deprivation, Self-stigma and Social exclusion all suggest scarcity of valuable resources for bereaved young people, as well as fears and worries related to this experience. Despite all these negative experiences, the bereaved young people either continued to live with a surviving parent or were taken in by a member of the extended family. The next sections discuss the support and the capacity of the members of these families in providing care and support to bereaved young people.

### **3.4.2 Social support and its impact on bereaved young people's coping**

The sections on Discrimination, Stigma and Poverty clearly indicate that in general the bereaved young people tended to be lonely and lack love and care from their families. Despite the widespread lack of emotional support during bereavement, the young people's accounts suggest that it is not all negative and that a few of the adults were helpful. The sections that follow will discuss the nature of the support they received and from whom in the family it was received. The next section will look into primary carer factors which will be followed by other sources of support.

#### **3.4.2.1 Primary carer factor**

##### **3.4.2.1.1 Carer / bereaved young person's relationship**

Whilst guardians have their own limitations, familiarity was not an issue. The majority (12) of the bereaved young people were biological children of their present primary carer. The remaining young people (5) had their uncle (4) or a member of the paternal lineage (one) as their primary carers. Since the five bereaved young people lived in the same small town with their recent carers, they might have known each other before the loss especially as the young

people were members of a network of the extended family system, as suggested by this account:

*We have family members all over because my dad was originally from Guinea and my mother from Senegal. Even in the Gambia we have many family members...*

(HJ, 18 years, girl)

Since all the bereaved young people were living with their primary carers at the time of data collection, the latter are referred to as guardians in this thesis. Despite the difficult circumstances of the young people (see Poverty, Stigma and discrimination), none of them reported anything negative about their guardian, except one - as seen in this excerpt:

*I felt I should have been treated by my step-mum like her own children... When dad is not here, me and my siblings sometimes sleep in darkness.... It keeps me thinking about mum ...that is hard.*

(FB, 16 years, girl)

Lack of negative information about their carers may be a sign of a cordial relationship. One of the young people acknowledged love and care shown to him both by his former guardian and his most recent guardian, suggesting a cordial relationship between him and his guardians as shown below:

*When he died, my mother took care of me. She did what she could for me. She does petty trading, goes to market to buy garden stuff, fruits and vegetables and take them to the market to sell them and with the profit she gains she buys from it some clothes for me. She is very nice to me ... When you know your mother can take care of you, you are not very worried about some other things ... Now I am presently living with my uncle and his wife; they are very nice to me. My aunt is like my mum, she is very helpful and friendly.*

(LC, 15 years, boy)

Another one reported that, although her guardian was enduring considerable pain trying to meet their (her and her siblings) needs, she maintained a very good relationship with them and did her best to make them feel happy:

*My father has died but, with my mother alive, life can be much rewarding in the future ... I know it is easier for men to provide food, rent and things like that. This is a new responsibility for her [surviving mother]; it is hard - she knows that - but at least she chats with us to make us feel happy ... My mother is so caring. It is helpful.*

(ASS, 17 years, girl)

Closer analysis of the above excerpts suggests that the little they received was useful support which helped the young people to cope better with their loss. For example, the following account: *'My mother is so caring. It is helpful'* (ASS, 17 years, girl) suggests a good and supportive relationship. It also seemed to encourage acceptance of death and create hope for the future, as suggested by this excerpt: *'My father has died but, with my mother alive, life can be much rewarding in the future'* (ASS, 17 years, girl). Both the availability and perceived availability of a caring family after the death of a parent seemed to reduce the anxiety that they would lack someone to care for them when needed, as suggested by this young person: *'When you know your mother can take care of you, you are not very worried'* (LC, 15 years, boy).

The persistent effort of the bereaved young people to protect their primary carer from being hurt by their own reactions (see Avoidance) was a clear indication of the sacrifices they were making. Such sacrifices may have been the result of a valuable relationship with their guardian, as suggested by this account: *'I don't like hurting people's feelings... even if I am feeling sad, I don't let mum know about it ...'* (SS, 18 years, girl).

Despite a close relationship with primary carers and what appeared to be empathy towards them, secrecy surrounding the illness and circumstances of the death remained. There were no signs of discussion about the nature of reactions and there was no encouragement for open expression of emotions from the side of the guardians (see Emotional expression). The following section discusses extended family support.

#### 3.4.2.1.2 Social support for young people from primary carers

Despite widespread discrimination experienced by the bereaved young people, it was clear that they all received some form of material support from their primary carers. For example, in terms of shelter, none of the young people interviewed was living alone or living on the street and none of them claimed to be the primary breadwinner of their family. All of the young people were either living with a surviving parent or a close relative referred to in this thesis as guardians. For example one of them said:

*Now I am presently living with my father [biological father's brother] and his wife; they are very nice to me. My aunt is like my mum, she is very helpful and friendly.*

(LC, 15 years, boy)

Despite widespread poverty, social exclusion and material deprivation, apart from the OVC (see OVC support) and a few other people (see Extended family support) the primary carer/guardian remained the only provider of support to the bereaved young people. They depended on these guardians for their day-to-day living. Support included food and clothing. Whilst the bereaved young people were far from happy about their circumstances, they seemed to appreciate the effort their guardians were making to minimise the impact of material loss, as indicated by this excerpt:

*When he died, my mother took care of me. She did what she could for me. She does petty trading, goes to market to buy garden stuff, fruits and vegetables and take them to the market to sell them and with the profit she gains she buys from it some clothes for me. She is very nice to me ... When you know your mother can take care of you, you are not very worried about some other things.*

(LC, 15 years, boy)

However, the bereaved young people were worried about the poverty and material deprivation they found themselves experiencing since their loss and all of them perceived that their guardians might not be able to change that. The clearest message was that the guardians were incapable of meeting their needs without the support of other members of the family, especially members of the paternal lineage. This message is clearly illustrated by a 16-year-old girl:

*I thought it would be too much for one person to pay the school and do all the things we used to do... we may no longer have our daily meals like we used to... [or even] get to wear the clothes... When I thought about all these things I became worried.*

(AJ, 17 years, girl)

Some (3) of the bereaved young people had to undertake extra fundraising activities to reduce the economic impact of loss on their guardians as their only breadwinner. For example, one of the young people raised funds by bricklaying and fetching firewood, as seen in the quote below:

*We are working hard as a family to survive, my mother fetches firewood and sells it and my brother does brickwork and the money is used to buy food, clothes and to pay rent. Without him [brother] it would be too hard for me.*

(SJ, 16 years, girl)

In addition to difficulty in meeting their material needs, lack of emotional support, in terms of giving or sharing information regarding circumstances surrounding the death and the consequences of death on the life of family members, echoed in all the bereaved young people's accounts (see Emotional expression). The primary carers' lack of capacity to share information was evident in this account:

*...they talked about it [death], but for us [siblings] we did not... You expect them to tell you that so and so has died. In this case they did not tell me and I heard it from other people... That was really unhelpful and it made me sad.*

(MD, 17 years, girl)

### 3.4.2.2 The role and capacity of the extended family

#### 3.4.2.2.1 Capacity/lack of capacity of the extended family

In this study, young people's accounts suggest the existence of a family system that is extensive. The term 'family' was applied by the young people to both paternal and maternal lineage and all the members of these lineages were referred to as relatives. Whether this structure is functional or helpful is entirely a different story.

Despite widespread stigma and discrimination from members of the extended family and apart from the biological parents, members of the extended families remained the main providers of support. The roles played by some (five) guardians who were not the biological parents has already been mentioned in the previous section. Although they were the main providers they lacked the capacity to adequately meet bereaved young people's needs.

The accounts of the bereaved young people consistently suggest that, whilst living with these guardians, they and their carers were the responsibility of the larger extended family in which they lived (see Social exclusion, Deprivation and Poverty), not the government. They expected the members of the extended family to play significant roles in their caregiving in the event of parental death; yet no significant support from the extended family was reported

to have been received by the bereaved young people and their guardians following the loss. Material support, such as payment of school fees, was not received; nor were regular visits conducted. Apart from their siblings (to be discussed later) there was no evidence of affection and protection. The bereaved young people and their guardians seemed to be enduring considerable hardship, as suggested by the account below:

*My father has died but... I know it is easier for men to provide food, rent and things like that. This is a new responsibility for her [surviving mother]; it is hard - she knows that...*

(ASS, 17 years, girl)

The accounts of the bereaved young people suggest that very few sources of support were accessed by the bereaved young people and their guardians. Only a minority (three) of the bereaved young people received support from elsewhere within the family. All the support young people received, which included finance, food, clothing and shelter, was from their siblings living in the same household. This support tended to be short-term and just sufficient to avoid serious livelihood crises, as suggested by this account:

*We are working hard as a family to survive, my mother fetches firewood and sells it and my brother does brickwork and the money is used to buy food, clothes and to pay rent. Without him [brother] it would be too hard for me.*

(SJ, 16 years, girl)

Despite lack of informational support from the members of the extended families, it appears that a minority (two) of the bereaved young people were engaged in what may be perceived as a form of emotional support rendered to them by their siblings. Living with siblings in the same household and interacting with them was cherished by the young people as helpful because it retained the bond and helped to reduce loneliness. One 17-year-old girl said her brother had taken a parental role which was found to be helpful. She commented that:

*When I wake up in the morning I go to my brother and tell him 'good morning', as we used to do when my father was alive. He prays for me and the entire family including my [deceased] father. It is as if my father was here. It makes me feel so much better.*

(ASS, 17 years, girl)

Another girl seemed to suggest that it was because of her brother they were still living together and this was found to be helpful, as suggested by this account:

*Although things are hard with us, at least we are living together. Had we been separated we would have felt it more. They did try to separate us but my brother said 'No, we are better staying together'. Since then we have been living together.*

(SJ, 16 years, girl)

The accounts of the bereaved young people suggest their sources of support from the extended family were their guardians and the siblings with whom they were living in the same household. Other members of the extended family not only refused to help but they also stigmatised and discriminated against them (see Stigma and discrimination). The next section looked at living arrangements.

#### 3.4.2.2.2 Bereaved young people's living arrangements and their impact – sibling dispersion

When death occurred, the bereaved young people and their bereaved family members also suffered from a decline in household resources. Movement of the bereaved young people between households was one of the strategies they used to cope with the economic impact of loss on the bereaved households. However, the decision as to who would be relocated to another household seemed to depend on the gender of the deceased parent. The bereaved young people whose mothers died were found to be living with their surviving fathers. These bereaved young people had always lived in this household since the death and they depended on their fathers and stepmothers as their main sources of support (see Primary carer support). The influence of paternal lineage regarding relocation of the bereaved young people was only effective when the biological father was the surviving parent. Apart from one of the bereaved young people who remained with the paternal lineage after the loss of the biological father, young people who lost a father and those who lost both parents lived with their maternal lineage. The surviving mothers served as the guardians for those who lost a father and the rest lived with their uncles (mother's brother) and aunts from the maternal lineage.

From the above section, it is clear that one important role of the extended families was to protect bereaved young people from being homeless, as well as reducing economic pressure on the bereaved family. However, there is evidence that the bereaved young people who lost both parents and one who lost a father had moved from one household to another after the loss, as shown in this excerpt: *'Now I am presently living with my uncle [father's brother]*

*and his wife; they are very nice to me. My aunt is like my mum, she is very helpful and friendly'* (LC, 15 years, boy).

Whilst a majority of the bereaved young people lived in the same household as their siblings, a few (three) of them lived elsewhere with one of the extended family members. However, since these bereaved young people lived in one small town, there did not seem to be any complaints regarding separations, suggesting close proximity and possible exchange visits.

The only complaint made by the bereaved young people regarding living arrangements had to do with their temporary relocation from the funeral ground against their will. Some (four) of them showed their anger and frustration for not being allowed to stay on the ground, as suggested by this account:

*I was escorted to a neighbour's house - for what? I don't know - that is hard for any child. That was really unhelpful and it made me sad. Even now when I think about it I feel sad.*

(MD, 17 years, girl)

#### 3.4.2.2.3 '*... for sure we all cry when someone dies*' - Common emotional expression

From the accounts of the young people emotional expressions were mainly discussed in the context of behaviours such as crying and talking about loss and feelings. Crying was described by the bereaved young people as a common reaction to their loss, but there is no report of a bereaved young person participating in wailing, epic chanting, or talking about loss, or of their having participated in any kind of ritual that could be categorised as a form of emotional expression. Crying was the only behaviour used by all the bereaved young people in this study to express their emotions. They saw it as a natural reaction that they could not completely avoid. Such an experience was demonstrated in the following account by a young man who also commented on the crying and wailing of his mother:

*Crying was the only thing to do; the way I was feeling I needed that. I don't know of anybody who can avoid that. They may not cry in the presence of other people but for sure we all cry when someone dies. For me I cried but it was mum who cried more, she was wailing and talking at the same time, other women were wailing too ... When the new guest came she would talk to them about the loss and they would all start wailing again. She spent the whole day wailing.*

(ET, 16 years, boy)

Crying was experienced as an immediate response to loss, with all the bereaved young people reporting that they cried immediately on becoming aware of their loss. Apart from two young people who heard about their parent's death a day after, all initial crying response to loss occurred on the same day the parent died, as illustrated in the following:

*When I heard about it I started weeping. My mother and all our neighbours were wailing... and our compound looked chaotic and it was like people were confused. ...When I look at my mum and think about dad I start crying again – primary carer psychological impact.*

(LC, 15 years, boy)

As this quotation also illustrates, crying behaviour is not limited to the immediate responses to loss because all the bereaved young people cried sometimes after the loss. The memories of the deceased were a key factor in triggering the crying behaviour of the young people. Whilst all the bereaved young people had cried when they remembered their loved-one, the majority (13) said they cried because of missed-opportunities. These included their lack of affectionate relationship they saw their peers enjoying with their parents; and their surviving parent no longer being able to afford some of the things their peers had. All these behaviours were commonly manifested during 'Tobaski' (Muslim annual gathering) period as demonstrated below:

*When Tobaski [Muslim festival] approaches I feel bad because those [young people] whose parents are there would be bought new clothes ...and they will put on nice clothes and go with their father to the prayer ground. For me it is different - my dad is not alive and my mother would not be able to buy [clothes] for my siblings and me. When I think of all this, I hide in mum's room and cry.*

(TS, 17 years, girl)

#### 3.4.2.2.4 '...have patience and stop crying' - Denial of emotional expression

Whilst crying remained the channel through which all young people expressed their emotions, these behaviours were commonly experience in privacy. Almost all (13) the young people in this thesis had at one point withdrawn from their peers and family members to cry in quiet places such as in bedrooms and school buildings (see Avoidance approach 3.2.4). None of these young people said they were forced to withdraw but their account suggests that the environment was not conducive for them to cry openly. For example one young person explained:

*When I cry in public some people ... may get upset. ...I don't want to remind him about the loss. I don't want to hurt him, that's why I go into my room and cry.*

(JS, 18 years, girl)

Another boy said:

*I am not expected to be crying for every little thing. Even if I want to cry for something different, people will say he is crying because he is an orphan. That will make me remember [the loss] in a certain way. Even if it is something different they will say this and that just makes you feel bad. That is why it is good to cry in private. – Self-stigma.*

(OJ, 15 years, boy)

In the very first day they became aware of their loss, all the young people in this study cried in the public but many (seven) of them were requested by adults to stop crying. The reason given by the adults for this was that too much of it was bad and might cause some health problems. These young people accepted this adult point of view, and responded positively to their request as one boy explained:

*When I heard about it [death], I started crying. I just kept on crying, I did not know what else to do. I cried for almost maybe 10 minutes. I thought crying was the only option I had on that day. So I cried but then an old woman told me to have patience and stop crying because I may develop a headache. I stopped when she told me that because I didn't want to have any problems.*

(AK, 15 years, boy)

There is evidence to suggest that the young people were positively deterred from confronting and expressing their loss. None of them reported being told by their surviving parent that death had occurred in the family. A majority (nine) of them only became aware of their parent's death when they heard people wailing or overheard people talking about their parent's death. In five of these incidents, when bereaved the young people showed their desire to discuss their loss and when they asked questions, they were denied the information as one girl described:

*I wanted to go and see her before she died but that day early in the morning my brother was told that my mum had died. And then my brother told me that my mother's sickness was critical and he was going to see her. I suspected and asked him whether mum was dead; he said no. ... He did not want me to know.*

(FB, 16 years, girl)

Despite lack of opportunity to verbalise their own emotions, wailing and talking about death (verbalisation) among adults was seen as a common practice and one that was observed by

almost all (14) of the young people in this thesis. Although much of this practice of wailing and talking by the adults occurred the same day the parent died, it was not confined to that day alone. Late comers or guests who visited the family after the funeral also participated in these rituals as indicated by this young person:

*People have been coming and going for weeks after the loss. Any time a guest visited. I mean when women visited mum they would wail and talk about my dad, things like his death. When we see guests [visiting mum] we leave her room and go into our room, but even there I can hear them wailing and talking about things like his death. For us we do not talk about stuff like that, that is only talked about when mum has visitors, even with that we are not involved.*

(SS, 18 years, girl)

#### 3.4.2.2.5 The value of emotional expression

Despite the difficulty young people had in being allowed to express their emotions openly there was a strong desire to express their emotions through verbalisation and crying, as was shown throughout the interview process. For example, despite their own acknowledgement of difficulty in discussing their parent's death and crying during the interviews, all the bereaved young people somehow showed their appreciation for being allowed to express their feelings to the interviewer:

*It is great that there is someone who is interested in listening to us.*

(AK, 15 years, boy)

*Before, I did not think or talk about death the way I did during the interviews.*

(ASS, 17 years, girl)

Such comments suggest the need to provide a suitable environment for bereaved young people's emotional verbalisation. Having someone to listen helped them express their feelings in a manner they saw as helpful to them. One of them said:

*I wish all the group members have this opportunity because if it is not you no one will think about this. Though I cried, now I feel comfortable; my heart is lighter.*

(SJ, 16 years, girl)

One important benefit that came out of this interviews was that they seemed to have increased some (five) young people's confidence and reduced their anxiety in discussing their

loss with loved-ones. As illustrated below, they felt prepared by the interview to confront and talk about their loss with their carers and loved-ones.

*I have surprised myself... Now I think I will be able to discuss with mum and hopefully I will ask her some questions*

(ET, 16 years, boy)

*It is good to have a talk like this, especially with someone like you who did not know my dad. I felt if you had known my dad it would have been very difficult for me to talk to you because it would be too painful for both of us. Even in this interview the beginning was very difficult for me as you can imagine. ... Coming this far, I am starting to believe that I can discuss some of my concerns in the future with my mum and siblings.*

(SS, 18 years, girl)

#### 3.4.2.3 Peer support and its influence on ability to cope with loss

The bereaved young people in this thesis were from OVC projects that support orphans and vulnerable children. The OVC members are brought together quarterly to socialise with their peers in the same group. They play, sing, chat and interact with each other during this period. The peers in this section were from this support group and their accounts suggested that they made very few friends. The term 'friend' was used only twice by the young people and that was for members of their OVC support group. Such a situation reflects that the bereaved young people were lonely, as indicated earlier when discussing isolation and discrimination. Being a peer was not determined by age or sex but by whether or not the person was a member of the OVC support group, made up of young people (5-20 years of age) whose parents were chronically ill or had died of chronic conditions, as described by this young person:

*I am in this group with my siblings and others are here with their siblings too. In this group not all of us lost our parents like... some of their parents are ill.*

(HJ, 18 years, girl)

All the bereaved young people in this study associated themselves with this group and were involved in some form of conversation and socialisation, and half of them suggested that members of the group were helpful to them. They identified peer relationship as one that provided them with an environment conducive for interactions and conversation of some sort.

Whilst all these young people were involved in chatting during their meetings or gatherings, which they found useful, the topic of loss was generally avoided. There appear to have been two reasons for this: two of the bereaved young people thought the purpose of the gathering was to get away from their home, which always reminded them about their loss; and discussion on death would compromise the purpose of the gathering.

*It is nice to come here at least for a break. At home you would be thinking about stuff. You know, you are always reminded about things. We are here to chat and have fun and not to think about things like that.*

(HJ, 18 years, girl)

Some (three) thought initiating and going ahead with a discussion about death would be hard, especially at a gathering as big as theirs. Clearly they did not have the understanding and there is no indication that they had been prepared to tackle discussions like this. Examples of their lack of preparedness are shown in the following excerpts:

*We got together and chatted; that was nice, but we did not talk about death or things like that ... If we are told to, then it would be hard. Where would I start? I may not even know what to say. Talking about it here requires a lot more thinking.*

(ASS, 17 years, girl)

The account '*talking about it here requires a lot more thinking*' suggests that the bereaved young people may either lack confidence to discuss such a personal issue or did not have the trust to share such an experience with their peers. However, the young people who felt their peers were helpful also identified socialising with them as helpful to their coping because it reduced anxiety and feelings of isolation. The accounts '*socialising with them [peers] is helpful ... [because] it [socialising] makes you feel that you are not alone ... It is a relief to know others have a similar problem*' (ASS, 17yrs girl) imply that the bereaved young people's interactions with peers not only had a positive influence on feelings of loneliness but also created comfort and temporarily reduced fears and anxiety related to their loss.

*With them I don't feel too bad; I don't think about that [death]... so I don't feel worried ... When I am chatting or listening to someone singing my focus is all on that. I totally engage with them ...and at least I have managed to make a friend, we both have similar problems and he is also living with his aunt*

(LC, 15 years, boy)

Whilst the phrase ‘*when with them*’ suggests that the bereaved young people were not always interacting with peers and therefore the impact of such support was sporadic, the above excerpts suggest that peers were viewed as a source of respite, as indicated by this account: ‘*With them I don’t... think about that [death] and that is helpful*’. They were used as a distraction for the young people to temporarily escape from the intense emotions caused by actively engaging with loss. The reason seems to have been that peers engaged them with talk and activities as an alternative to them focusing on death.

#### 3.4.2.4 OVC project support

All the young people in this study were recruited from the OVC support project and all of them recognised the contributions made by the support group in their efforts to cope with their loss. The project was defined by the role it is playing in their lives. For example, it was viewed as the provider of educational support as well as creating opportunities for socialising among members of the OVC group, as is explained in this account below:

*When my father died, the OVC project coordinators came home and told my mother that they will take care of my schooling. Since then they pay for my schooling and also organise meetings for us at the centre. I know I still have so many problems unsolved, I still think about him a lot but things like this [activities of the organisation] helps. It kind of reduces your worries because school fees would have been a big problem.*

(AJ, 17 years, girl)

All the bereaved young people said they attended the OVC project meeting at least once, and for half of them it was helpful (see the previous section). The meeting provided them with the opportunity to have a chat and helped them form acquaintances and some (two) forming friendship with their peers. One of the young people said: ‘*After the meetings I am becoming friends with some; that is nice*’ (ASS, 17yrs girl). These relationships were helpful because it has at least temporarily addressed their feeling of loneliness as suggested below:

*I think coming to the meeting and meeting other young people of your age and they have similar problem with you - when you spend some time with them is good because then you don’t have time to think too much about your mother anyway.*

(OJ, 15 years, boy)

The role of the project in providing material support, especially in relation to education, was reported by all the bereaved young people. The benefit of the support in reducing their earlier fears and anxiety regarding who would pay for their schooling and whether or not the support would last, was also acknowledged. The account '*Now I am not worried about the school fees*' suggests that the material support prevented young people from being preoccupied with school fees and provided them with an avenue to focus on other aspects of their lives, as demonstrated in this excerpt:

*Now I am thinking of other things, not school fees... The project [OVC] is paying for my school fees, so that has been sorted out. It used to be my main worries but as I said, I am no longer worried about that any more.*

(FB, 16 years, girl)

### **3.5 The DPM**

To conclude it appears that the finding in this thesis is in conformity with the dimensions of the DPM. The findings seemed to suggest that bereaved young people experienced loss- and restoration-oriented coping and that these dimensions alternate. Sometimes bereaved young people focuses on their loss (see sections on Loss-oriented coping) and sometimes they avoid the memories of the deceased (see sections on restoration-oriented coping). In terms of loss-oriented coping young people felt overwhelmed by their loss, with a minority experiencing suicidal ideation. They have experienced a range of emotional reactions such as sadness, fear and emotional loneliness as both immediate and as a long term reactions to loss, with sadness and anxiety more likely to be predominant in the early stage of the loss. After these early reactions, young people's response seemed to be characterised with episodes of sadness and anxiety accompanied by loneliness and continuous bond with the deceased.

The expressive emotional behaviour the bereaved young people talked about was crying and emotional verbalisation (i.e. talking about loss and loss-related feelings). They perceived both crying and talking about loss as important and there was a strong desire to verbalise their emotions, but they were neither told that their parent had died nor was there any discussion regarding loss or the consequences of loss.

However, in terms of restoration-oriented coping, for some young people their earliest reaction seems to be denial response. For them it is the gradual realisation of loss that led to a

range of emotional reactions. Bereaved young people' data also suggest young people's avoidance approach, a strategy they use throughout bereavement to reduce the emotional impact of loss. Where the emotions were likely to be intense, bereaved young people sometimes distanced themselves from anything that was likely to trigger their emotions. Other aspects of restoration-oriented coping which seemed to have influence on the coping process of the young people included interactions with peers, living together with siblings and talking about loss, which were all perceived to be helpful to bereaved young people's coping. Their belief encouraged them to accept and confront loss and their prayers created for them some comfort and also helped them to retain connection with the deceased parent. Material support such as paying for school fees and buying clothes for them was also seen as helpful and assisted in addressing anxieties associated with lack of material possessions.

Stressors such as stigma, discrimination and poverty were experienced, but young people had their own ways of dealing with them. For example they concealed the HIV-AIDS status of their deceased parent as a way of protecting enacted stigma. They also withdrew and avoided potential perpetrators throughout bereavement.

The following chapter presents carer and professionals' perspectives of bereaved young people's emotional reactions to loss.

## CHAPTER 4: FINDINGS WITH CARERS AND PROFESSIONALS

### 4.1 Introduction to findings of the interviews with carers and professionals

This section presents the findings from interviews with 16 adults who either served as carers to the young people or worked as professionals with them. A total of ten carers and six professionals were included in this study.

#### 4.1.1 The carers

The ten carers were either the surviving parents or close relatives (see Figure 4.1.1) to the young people and were living in the same compound during the data collection. Some (five) of the carers interviewed were known to be HIV-positive by the professionals and were taking free HIV antiviral drug treatment from Brikama Health Centre's Hands on Care Project. There is no evidence from the carers as to whether or not bereaved young people knew the HIV/AIDS status of the deceased or the surviving parent.

Adult carer's initials	Young person's initials	Relationship	Young people's knowledge about HIV/AIDS in the family
FC	ASS	Mother	No evidence
SS	TS	Mother	No evidence
JC	MD	Mother	No evidence
JJ	OJ	Father	No evidence
LB	FB	Father	No evidence
AS	MS	Aunt	No evidence
SR	AJ	Mother	No evidence
MJ	AK	Uncle	No evidence
MD	LC	Uncle (father's brother)	No evidence
AC	ET	Mother	No evidence

**Figure 4.1.1 Carers and young people's relationships**

### **4.1.2 The professionals**

The data presented in this section was also from professionals working closely with these families. The participating professionals were from the OVC support project in Brikama and the Santayalla Support Society in Serrekunda and consisted of nurses, a doctor and a counsellor. They provided support to both the HIV-positive adults and bereaved young people.

### **4.1.3 Aims and structure of the chapter**

Review of literature suggests that young people's bereavement does not occur in isolation. They are surrounded by family members whose knowledge, attitude and behaviour towards them may have influence on the way they cope with loss. In addition to the family members, professionals have also initiated programs targeting bereaved young people. Whilst their intention may be to help, their attempts to do so could backfire through lack of experience of bereaved young people. Therefore it is important to understand the perspectives of these adults regarding AIDS-bereaved young people's emotional reactions to their loss and the influence of social factors on their coping.

Whilst the aim of this study has been to explore young people's emotional reactions to the loss of their parents through AIDS, and to compare findings with perceptions of carers and professionals regarding young people's emotional reactions to loss, this chapter presents only the findings related to carers' and professionals' perceptions of young people's emotional reactions to their loss. These findings from the carers and professionals relate to the four main aims and several objectives outlined in the previous chapter (see Overall aims and objectives of this study – Section 3.1.1).

### **4.1.4 Interviews**

The findings presented here are based upon 16 individual interviews with adults who were involved with AIDS-bereaved young people during their bereavement. The purpose of the chapter is to present their observations and perceptions regarding bereaved young people's

emotional reactions to the loss of one of their parents and the social factors that were perceived by them as helpful or unhelpful to their coping.

#### **4.2 Loss-oriented coping: severity of loss**

As shown in the previous chapter (see Section 3.2.1), internalising problems falls under loss-oriented coping because it is a manifestation that bereaved young people have engaged with their loss. The evidence here is gathered from the carers and professionals as shown below.

##### *Carers*

One such perception related to what death itself meant to carers. A common description was that the carers saw it as the end of a journey that began at birth. For example, statements like ‘... he should know that we live and die; this world is about life and death,’ show death is unavoidable. ‘I am here today: who knows what tomorrow may bring - I may be dead ...’ and ‘...we are not in control of our lives - when it is time to go we have no choice’. It seemed that the carers felt that death was predetermined: predetermined in the sense that there may not be any warning before death. Such descriptions appeared to be closely related to the adults’ religious beliefs as suggested by ASS’s mother:

*The difficult bit about planning is that you do not know when you will die. You can go to sleep and wake up dead, so we are not in control. No one except God knows when your time is up [when you will die] because he decides how long you will live for; so it is important to look after orphans because one day [when you are dead] people will look after your children...*

(FC)

Bereaved young people’s engagement with loss (i.e. loss-oriented coping) was observed by the carers immediately after the event. There was a strong belief among the carers that young people would react to the loss because emotional reactions to loss were perceived as a natural response that no one could avoid. MS’s aunt said that ‘When a child’s father died she felt it because that was part of the whole experience’ (AS). Similarly a girl’s (TS) mother said:

*That day she felt it differently. She felt his death because she was close to him and they used to do a lot of things together. It was not a surprise that she was emotional that day but that is natural. We tend to feel it when someone so special to us has died, so it was not a surprise that she was feeling like that.*

(SS)

Apart from this initial reaction discussed above, the majority (six) of the carers seemed to perceive that emotional reaction was not a long-term issue for bereaved young people. There was a strong perception that the bereaved young people had moved on three to five years since their loss. It was typical for carers in this research to use words like *'they have recovered quickly'*, *'... has forgotten about it and is not crying now'* to describe the emotional reactions of the young people. AK's uncle (MJ) thought his nephew was brave enough to cope with loss as suggested by this quote: *'At first he cried; that did not last long, he is a brave boy ... difficult at the start but after three days he was okay but sometimes he feels it a bit'*, but further material support was perceived by ASS's mother to make her bereaved children cope even better: *'Maybe the first days they were a bit uneasy, you could see that on their faces but after that nothing major ... there is no problem; the only thing they need is more [financial] support; if they get that they will be fine'* (FC). This account is supported by AJ's mother who commented that:

*When her dad died it was hard for her because it used to be him buying things for her. She cried because she was thinking about problems we were going to face – trying to pay for school fees, clothing and the rent. She was thinking 'my mother is the only provider,' so it is hard for her. School fees have been sorted out by the project, she only needed other things to be sorted out and she would be fine.*

(SR)

### *Professionals*

Consistent with the views of the carers, the professionals seemed to hold the belief that death and emotional reactions were inseparable. Permanent escape from emotional reactions was perceived to be impossible to achieve because *'it will be hard to imagine that a child will not feel different when a parent dies'* (RC). Bereaved young people who knew their parent and were close to their parent would be bound to feel the death of that parent as suggested by this professional:

*I have no doubt in my mind that the bereaved young people we worked with have felt differently when death occurred. How could they not feel the loss or cry? It would be impossible to imagine that, especially when they were close to their parents. No young person would be that emotionless.*

(BB)

Despite the widespread belief that bereaved young people react to their loss with emotions, only one professional seemed aware of the intensity of emotion experienced by the young people, saying that:

*[AIDS-related] death of a parent is always going to be a traumatic experience that may have an everlasting effect on them [young people].*

(RC)

Apart from this, no professionals or carers reported emotions at the level of intensity suggested by the young people in the previous chapter. However, the first few days of the loss were described by some (six) of them as the period when bereaved young people experienced powerful emotions. This was owing to the acuteness of their loss and uncertainty about the future.

*Normally the first few days were more difficult – at that time the emotions were high, the death was fresh and it was not clear what would happen next. Things were far from clear, in situations like that even adults will find it hard.*

(DS)

In general apart from the one professional who recognised the intensity of bereaved young people's emotional reactions, there was no evidence either from the carers discussed above or the professionals to suggest that young people's experience might be the equivalent of adults'. Even when young people's emotional reactions were perceived as powerful, as in the case of the few days after loss, two of the professionals perceived that their reactions were still less intense than their surviving parents' (see the quote below). The reason for their belief that surviving parents experienced more intense and powerful emotional reactions to loss was the years of attachment relationship with the deceased and because the surviving parent was in charge of taking care of the children, a responsibility that used to be shared by two. Neither such a long-term relationship nor the responsibility was applicable to young people, as indicated by this excerpt:

*The emotional impact of death is on the entire family, especially when related to AIDS. Without doubt the children undergo emotional pain but I am not convinced that they experience the same level of pain as their surviving parent, especially when they are quiet young ... the parents lived together for a long time and the change of circumstances, especially the new responsibility, is huge.*

(BK)

Consistent with the perception of the carers, a majority (five) of the professionals said their interactions with AIDS-bereaved young people over time had given them the impression that they (i.e. bereaved young people) were doing well.

*From what I have seen so far the bereaved young people ... are coping well, they are receiving support [from OVC] and did not show any concern to us during our visits.*  
(BK)

*... [In] OVC meetings, they do not show any particular problem that is worrying.*  
(BR)

Also:

*[The professionals] did not receive any complaint from the carers relating to emotional issues. It felt as if they were doing well.*  
(DS)

In contrast to the carers, the professionals seemed to believe that neither the carers nor the bereaved young people had told them the whole story and they held the belief that young people were discriminated against, stigmatised and isolated (see Stigma, discrimination and poverty 4.4.1), which they believed would have an impact on their coping.

Loss-oriented coping is a core category that entails many sub-categories, which will be discussed in the following sections. These describe various aspects of emotional reactions including how bereaved young people expressed their emotions and various types of emotional reactions to loss including denial, avoidance, sadness, anger, anxiety, fear and emotional loneliness and continuous emotional bond.

#### **4.2.1 Internalising or externalising behaviour**

Whilst the accounts of the primary carers and the professionals may have suggested that bereaved young people experienced anger after the loss, there was no evidence to show that they experienced externalising behaviour. There was no evidence of fighting or any other forms of antisocial behaviour. The evidence therefore suggests that the young people reacted by internalising rather than externalising their grief.

#### 4.2.1.1 Sadness

##### *Carers*

One early emotional reaction observed by all the carers in this study was ‘sadness’. As with the young people in the previous chapter, three meanings of sadness, as an emotion, as grief and as a death event, emerged from the carers’ accounts. In general the carers in this thesis used words like ‘sadness’, ‘unhappy’ and ‘unease’ to represent bereaved young people’s experiences of sad responses to loss. Emotional behaviours such as crying were also seen as manifestations of emotional reactions to loss, as shown by FB’s dad:

*He was very sad that day and he kept on crying. It was a very sad day for all of us - for the entire family, not for just HN. It was a very big loss: that was the reason for the crying because people were feeling very sad.*

(LB)

Not only did all the carers in this study perceive sadness as an immediate response to loss, as suggested in the above quote, but they also perceived that sadness was inherently related to the loss of a parent, suggesting that it was mostly a manifestation of loss-oriented coping. MS’s aunty said that she was not surprised that MS felt sad about the loss because no one could escape from it: ‘*She was like anyone who lost a parent - she could not avoid feeling sad*’. LB thought that his daughter’s (FB) ‘*crying is absolutely understandable because she could not help it*’ and TS’s mother observed that ‘*sometimes she feels unease even to sit with people*’ (SS).

Episodes of sad feelings after the initial response were perceived by six of the carers to occur among bereaved young people. This experience was perceived as not being intense or directly related with loss itself, as suggested by OJ’s father: ‘*...he is not crying any longer. Obviously he is not happy that his parent died but he is not showing any sign of sadness due to the death now ... that was a long time ago [the showed sadness]*’ (JJ). One mother commented that:

*[The] death of a parent may not be easily forgotten but I thank God that they are coping well. They are not crying, they are great lads – even though we are still juggling they don’t seem to be that sad. Maybe they now have some confidence that the future could be different.*

(FC)

The episodes of sadness were not perceived to be directly related to loss; rather, they were related to missed opportunities, as clearly described in the section on discrimination and isolations. For example MD's mother said that:

*...sometimes she feels sad when her friends get things that I could not get for her but that has nothing to do with the death; even when her dad was alive we could not provide all the things she wanted but maybe things are worse now than before. In this generation things are changing and people are not supporting.*

(JC)

OJ's dad also seemed to suggest that he was feeling sad because of missed opportunities:

*He is normally very calm but he feels sad when he sees other young people with their parent during Tobaski time buying new clothes for them and we could not afford them for her.*

(JJ)

### *Professionals*

Using the same description of sadness as carers and consistent with carers, all the professionals perceived sadness as a natural human response that all young people who lost a parent experienced immediately after the loss, suggesting loss-oriented coping. One professional said:

*... they felt sad. When loss occurs the first thing that comes to your mind is sadness. As I said if you ask anyone about how he/she feels, whether he/she has cried or not, the first thing he/she will tell you is 'I feel sad' ... As far as I am concerned, death and sadness have a strong link.*

(BR)

Another professional commented: 'In the Mandinka culture, death nearly means sadness, which means bereaved young people had experienced sadness' (BR). One professional believed that, whether or not bereaved young people's sad emotions were recognised, they tended to experience sadness after the loss:

*Generally young people experience sadness when loss occurs. Even if they are not crying, sadness is written all over their face. But that is expected even if they do not show it out for some reason. Sometimes they mask their emotions but that would not stop them from experiencing sadness. It is always there after the loss whether it is noticed by us or not.*

(DS)

Although the professionals were working with the young people, they claimed to know very little about details of young people's responses because they were not living with them. *'It is hard to know their sadness especially if you rarely see them as I am doing now'* (BK). However, unlike the carers, all the professionals seemed aware that sadness could last for some time, and that bereaved young people would continue to experience sadness responses to loss as long as they saw their peers interacting with their parents. For example, one of the professionals said:

*It's not only about loneliness; when they see their peers with their parents they will feel sad. Whether they tell their parents or not, that cannot be avoided because young people have the tendency of wanting to be like their peers. As long as this continues they are likely to feel sad and lonely.*

(BK)

Consistent with the carers, all the professionals agreed that unfair treatment of young people also triggered episodes of sadness. Again in this context young people's attention may have shifted from the loss itself to the problems of discrimination and isolation discussed later. An example of such a response is suggested by this quote:

*Obviously there are instances when they [bereaved young people] will be told off or be treated as second class family members. They may receive less support than their peers and that alone can make them feel sad and cry. Things like this are bound to happen to some bereaved young people.*

(DS)

#### 4.2.1.2 Anger

##### *Carers*

Descriptions of anger in the literature as an early and normal reaction to the loss of a parent can be seen as loss-oriented coping. In the context of this study, of all the emotions discussed in this section, anger was the least reported with only three carers claiming to have witnessed an expression of anger by bereaved young people. The angry behaviours reported were neither immediate response, nor directly related to loss itself. They were in response to unfair treatment by other people, a reaction that may be seen as restoration-oriented as opposed to loss-oriented coping. An aunt commented:

*After all the funeral stuff, at one point she became angry at my husband for treating her badly ... she has never been like this before. I am not sure what actually happened; maybe my husband has done something to her.*

(AS)

Yelling at step-parents was found to be another way of showing anger, yet such anger could be triggered by an embarrassing situation, ‘... for instance failure to afford what she [TS] needed’ (SS). However, the carers did not perceive this to be associated with loss; it was seen as the consequence of the failure to meet the needs of a young person, as suggested by TS’s mother:

*I can see why a young person would get angry; there are certain things they always need, that is for all young people. If they want it and they cannot get it, they get angry; that is not only for bereaved young people - it applies to all young people.*

(SS)

### *Professionals*

Anger was the emotion least reported by the professionals (as with the carers) and one related to restoration-oriented coping. Only one professional seemed to suggest that anger is experienced by bereaved young people. However, unlike carers, the professional suggested that the anger they witnessed was directly related to the parent’s AIDS-related death and the failure to be told the cause of death.

*He was angry because he suspected that their parent died of AIDS. He has been coming to Santayalla Support Society but all along he suspected about it but no one told him. People gossip about it and he became more and more angry. He should have been told by their relative so that his doubts would be cleared.*

(RC)

None of the other professionals perceived anger as a normal response to loss. Like the carers, some (four) of the professionals thought that discrimination and isolation experienced by bereaved young people might lead to anger; but no connection seemed to be established between loss and anger. One of the professionals commented that:

*For sadness, I am aware that it is a common reaction to loss. I know when they are unfairly treated they will get angry; but to say they were angry for the death - I am not so sure of that.*

(BK)

Another professional said:

*We all get angry, it is normal to get angry but getting angry for death is not common. I have not heard about it yet - it may be possible but I am not aware of it yet. If something happens that is perceived unfair, maybe it is possible to show anger; but I am not sure whether young people will perceive their loss as unfair.*

(BB)

#### 4.2.1.3 Anxiety and fear

##### *Carers*

Unlike anger, which the young people reported but about which the carers were largely unaware, carers' descriptions of fear and anxiety were generally similar to those of the bereaved young people themselves. They perceived that death had raised young people's concerns about what the future held for them. Fear and anxiety were seen as a common experience among bereaved young people (shown later).

All the carers perceived that young people experienced fear and anxiety at various times during their bereavement. Fears and concerns about what the future held were observed immediately after the death. Whilst there was a perception among the professionals that some of the young people's fear and anxiety was directly related to loss (loss-oriented coping), the carers were not aware of such fears (discussed later in this section). Carers' accounts suggested that young people's experiences of fear and anxiety were related to restoration-oriented coping. One central source of fear was thought to be the fear of poverty and its consequences. These fears were thought to centre on the immediate needs of the young people, such as someone to look after them by providing school fees and clothing. Since their parents were often responsible for paying their school fees, the death of a parent created worries among bereaved young people, as demonstrated by this excerpt from the account of MD's mother:

*Her father was directly responsible for her schooling and, when she needed things like clothing, her father used to provide all those things for her - that was why we were worried ... She was worried too that her schooling would be terminated and that no one would be able to help us to cope financially ... but the OVC project has helped.*

(JC)

Consistent with the experiences of bereaved young people discussed in the previous section, the carers believed that young people would have concerns about food and clothing, and that death had reduced the economic power of the family and left them struggling to maintain their (family) upkeep. Whilst such a difficult position for the family might not actually have been the case, the carers still perceived that immediately after death young people were worried that the family (i.e. adults) would be unable to provide enough food and clothing for them. TS's mother commented that:

*Of course all the kids were thinking 'who will pay school?' That is scary ... before death much of their life was predictable - they knew when it is time to pay school fees we will pay for them, we will buy new clothes for them when they need them but you know most of these things cannot be done by one person; that was why they got worried.*

(SS)

Apart from school fees that were paid by the OVC project, there remained fears and anxiety about the upkeep of the family. The carers perceived that they and the young people they were looking after needed some form of economic support to help them cope with their fears. These points of view held by the carers have been explained by MD's mother:

*The problem of school fees has been addressed but now that some people have refused to give support as we used to do when crises occur, food and clothing, especially food, is something that is not guaranteed. It keeps them thinking whether mummy will have enough for them tomorrow.*

(JC)

### *Professionals*

Consistent with the carers, all the professionals perceived that young people experienced fear and anxiety both immediately after the death and during the aftermath of death. Among the reactions the professionals believed the young people experienced when they first heard about the loss was the fear of uncertainty because the lost one was seen not only as a loved-one but also a provider of some form of security. The idea that the young people might feel fear for the safety of the surviving parent emerged from the accounts of one of the professionals. This professional, commenting on the experience of a girl who lost both her younger sister and her father to AIDS, said:

*Young people had all sorts of thoughts ... at one point a child thought both her surviving parent and herself would die because she witnessed both her sister's and her dad's death. Her mother was not feeling well and because of all these things that were going on she became very disturbed.*

(RC)

Apart from this single account, neither the professionals nor the carers mentioned anything to do with such experiences and none of the carers seemed to be aware that young people might have felt such an intense fear. Whilst the account of this professional seemed to suggest that young people were involved in loss-oriented coping, accounts from the remaining professionals (like carers) suggested that the fear and anxiety they experienced may have been related to their restoration-oriented coping. For example, it was perceived that bereaved young people feared the future regarding access to school fees, clothing, food and shelter. Such a shift of attention from loss-related fear to fear associated with living in the absence of the deceased may be perceived as restoration-oriented coping. An example of such a fear is given by one of the professionals in this thesis who perceived the young people:

*... feared that ... schooling would be terminated due to lack of income that used to come from the deceased parent.*

(BR)

Such a concern was made explicit in another of the accounts of one professional:

*The immediate impact is feeling insecure; before the loss, the bereaved young people knew that their parents together would provide for them the things they needed. They were often responsible for their schooling, food, clothing and shelter and they would buy for them things to make them feel good. What death does is to take away the security and they become worried because their security is dead.*

(DS)

Although professionals said young people did not show intense anxiety and worries during their meetings with them (see Emotional Expression – permission to express), they were aware that the young people might be worried about their families' ability to maintain tenancy and the general upkeep of the families:

*The ones [young people] I have worked with were like non-bereaved young people. They did not show any special concern but, knowing HIV/AIDS and its impact, I believe that they may have been worried with things like their parent's ability to pay rent and buy them things, especially during Tobaski [Muslim festival] prayer.*

(BB)

#### 4.2.1.4 Emotional loneliness associated with loss

##### *Carers*

Whilst fear and anxiety were related to a concern about the future, in the accounts of the carers, loneliness was viewed as an emotional reaction focused on interpersonal relations with the loved-one. It was viewed as the loss of an internal relationship that could not be replaced by anyone, no matter how special the person. The void or sense of emptiness created by the loss was suggested in the accounts of AK's uncle:

*It is very natural to miss a loved-one. All the children felt lonely when their mother died. It was hard for them that day because they used to have a very good relationship with her.*

(MJ)

Clearly the above account of the carer focused on loss itself and how much the deceased person was missed, suggesting the association between emotional loneliness and loss-oriented coping. Emotional loneliness was seen as a common experience among bereaved young people by the carers in this study. There seemed to be a perception among the majority (seven) of the carers that death of a parent had deprived bereaved young people not only of their parent's love but also their daily routine interactions. A majority (six) of the carers recognised the close relationship between the bereaved young people and their parents, suggesting that the young people had a special place in their heart for their parent, whose death left a void that would be hard to fill. An example of such a close relationship, between OJ and his mother, was given by his dad:

*He was close to his mother and for sure he must have missed her. He is one of those children who love their parents and recognise each parent's uniqueness. We are all unique in our own ways and he needs both of us in his development. I believe whoever is absent would be greatly missed. He must have missed his mother because she had been a great mother ... it was obvious that he had missed her in every aspect.*

(JJ)

Special activities that brought young people and their parents together (including domestic chores such as cooking and outdoor activities such as farming), which used to create that special interaction, were perceived by some carers (four) to have been missed by the young people. They felt that this was likely to occur when the young people were reminded either by the people or the situation in which they found themselves. For example, OJ's father said:

*I have no doubt that when he visits his peers, he would be reminded about the great time we used to have here. His dad was great, with great social skill and had a good sense of humour; he used to entertain us a lot, especially when we were doing our weekly cleaning. He used to do a lot of things with him; he used to enjoy a walk to the farm with him. They were as close as friends. Now we are not doing a lot of the things we used to do because it used to be two of us, now it is only me but I think he understood that.*

(JJ)

Some of the carers recognised that emotional loneliness was commonly manifested when events took place such as festivals and ceremonies that brought together young people and their parents. It was not the event itself that served as a reminder but ‘*seeing other non-bereaved young people sharing great moments with their parents makes them feel lonely*’ (FC). Carers (three) perceived that events like Tobaski that brought all Muslims together might not have provided an environment conducive for bereaved young people’s social interaction with peers, because the event triggered and increased young people’s sense of emotional loneliness. AJ’s mother commented that:

*Tobaski day is supposed to be a day of enjoyment; it used to be for many of us but things are different now. I think it reminds her [about the loved-one] because she sees other children with their parents but I always try my best to make sure that I buy new clothes for her so that she would not feel his absence too much.*

(SR)

Whilst the interaction was perceived by carers as very important for the bereaved young people, the gift, which included buying them new clothes during these events and festivals, was also recognised as a problem for bereaved young people. According to some of the carers (four) in this study, the absence of gifts triggered and reinforced the young peoples’ sense of loneliness because it was a clear manifestation of the absence of the deceased person who was responsible for making those provisions, a point of view expressed in the account of MS’s aunty:

*It feels lonely to see other young people being provided with new clothes by their parents. She does not feel comfortable if her peers have been and she has not. I think that is normal among peers but Tobaski day is very important, so I do everything to make kids happy on that day. That is very important because they tend to look at other children and feel bad.*

(AS)

This account suggests that bereaved young people are viewed as lonely, especially during annual events. It is apparent that the professionals believed that bereaved young people's emotional loneliness would continue for as long as their peers continued to enjoy these privileges.

Although most of the instances of emotional loneliness reported by the carers appeared to take place during the day, one carer's observation seemed different. She found bereaved young people showing their feeling of loneliness at night, when many would be thinking of going to bed. She felt that activities such as storytelling were greatly missed during this time, as shown by ASS's mother:

*All my children were very close to their father, he used to chat with them and joke with them. I am trying to do all these things but it is difficult, I am struggling ... but I am trying my best but one thing he used to do I could not do was storytelling. They used to enjoy it like during the night, before they [siblings] go to bed, their father would narrate to them stories; they must have missed that.*

(FC)

### *Professionals*

Consistent with the accounts of carers in this thesis, those of the professionals suggested that loneliness was a feeling of emptiness bereaved young people felt when they lost a loved-one. As shown in the case of carers, this perception of the professionals appeared to be associated with loss-oriented coping. An example of such a reaction was suggested by this professional:

*In a family both parents have their specific roles and no one can completely replace the other... Their children suffer after death because the deceased always leave a void that could not be replaced. In this sense every bereaved young person is lonely because of that missing relationship.*

(DS)

Emotional loneliness was seen by the professionals as being a common experience among bereaved young people by professionals in this study. All the professionals perceived that the death of a parent had deprived bereaved young people not only of their parent's love but also their daily routine interactions. The professionals were aware that bereaved young people felt lonely both immediately after the loss and later in the bereavement, and that this loneliness was presented in the form of episodes, as suggested by this account:

*They sometimes feel empty immediately after the loss because at that time it [death] is acute and their emotions are all over the place. They tend to miss this special attachment figure.*

(RC)

Consistent with the carers, all the professionals perceived that young people's emotional loneliness was not only an immediate response but was also experienced later during bereavement. Episodes of this emotion were common during Muslim festivals when bereaved young people either saw their non-bereaved peers interacting with their parents or being bought new clothes by their parents.

*This feeling does not confine itself to immediate responses but some young people experience it for a long time, often occurring in the form of episodes. It is a common reaction during ceremonies and festival times when other young people are bought clothes and bereaved young people have no one to buy for them. In situations like this they feel lonely.*

(DS)

In line with the carers, many (four) of the professionals perceived that, although the Muslim festival was supposed to be a joyous occasion for bereaved young people, because it brought families and peers together, Tobaski might not have provided an environment conducive for bereaved young people's social interaction with peers, because it triggered and increased their sense of emotional loneliness. For example:

*Every child wants to be with his parent during such festivals, he wants his hand to be held by his parent. Seeing other young people that close with their parent and having a great time is hard to tolerate. That is why parents are missed by young people, but this is not unique to bereaved young people alone; it is common across the board. ... Maybe the only difference is bereaved young people know for sure that there would never come back a time when they would be holding the hands of their deceased parent. That makes it worse for them.*

(BK)

*During their annual festivals they find it lonely because other young people will be there with their parents and they will wear new clothes given to them by their parents. Sometimes bereaved young people do not have all those privileges and that clearly reminds them about their loved-ones.*

(DS)

This account suggests that bereaved young people are viewed as lonely, especially during annual events. It is apparent that bereaved young people's emotional loneliness would continue for as long as their peers continued to enjoy these privileges.

#### 4.2.1.5 Continuous bonding relationship with the deceased

##### *Carers*

The carers' accounts suggested that a bonding relationship between bereaved young people and their deceased parent existed. Although this implies that young people were engaged in loss-oriented coping, only a minority of the carers perceived that young people continued to retain emotional ties with their deceased parent after the loss. In contrast to the bereaved young people in the previous section who showed this relationship important to them, only three of the carers recognised that young people retained important emotional connections with the deceased through material objects and daily prayers, as illustrated by MD's mother

*...she did not forget about his loss. She has got his pictures on the walls and also got some of the things her father left behind.*

(JC)

Material objects such as pictures, radios and clothes left behind by the deceased parent were perceived important by six of the carers. Although four of them tended to focus on the practical and the monetary values of the objects, the remaining carers recognised the importance of the objects in terms of creating and retaining emotional connection with the deceased parent. ASS's mother commented on her siblings, saying:

*They [siblings] use pictures to remember their father; it helps them to replace his physical presence with his spiritual presence.*

(FC)

In addition to the inheritance, prayers for deceased family members are a religious obligation among the Muslim population in the Gambia. These private prayers are offered to the deceased on a daily or weekly (e.g. on Fridays) basis so that their souls will rest in perfect peace. In this study all the bereaved young people were Muslims, suggesting that they were involved in observing prayers for their deceased parent; and appreciation that prayer could be a means of retaining emotional connection was shown by AJ's mother.

*... it [death] was difficult for her but she knows what she wants. I remembered a month after her father's death, she started going to the mosque sometimes with candles, other times with white paper and asking people to pray for her. That was a bit unusual but I think she was trying to pray for her dad because sometimes I do hear her dad's name when she is praying in her room. I think she is pious, and praying for her dad makes her feel good, after all there is a huge blessing, she knows that.*

(SR)

### *Professionals*

Consistent with the carers in this thesis, all the professionals were aware that young people did not forget about their deceased parents and as a result they tended to retain connection with them. One of the professionals working with the young people said:

*... I have the feeling that some carers will think that their children have forgotten about the loss. They may not be aware that children have various ways of remembering their deceased parents. It is normal that many of them use clothes, pictures, things like that to retain the memories. ... In fact sometimes they are involved in certain activities simply because they once participated in such activities with the deceased. It reminds them about their parent, so it is important to know that they may distance themselves from memories but they do not forget about their loss.*

(RC)

Another one said:

*I think it connects them and also helps them to cry sometimes when they need to.*

(DS)

One professional observed that, despite the age difference, bereaved young people were not much different from adults in terms of connecting with their deceased parent:

*I don't think young people are any different from us: there are things that will live with us forever, and we can never get rid of them. ... We all passed through childhood and people like me have lost my father when I was of their age, but I still have some of his possessions and I remember him every day. In fact it is easier for me to remember him than forget because he had occupied a great part of my life.*

(BK)

### **4.3 Restoration-oriented coping response to the loss of a parent**

#### **4.3.1 Denial response to the loss of a parent**

In the literature restoration-oriented coping refers to the temporary shifting of attention away from loss and circumstances of loss. Loss-oriented coping includes psychological denial which is used in mitigating the impact of loss. Evidence from the carers and professionals suggested very rare occurrence of denial response among bereaved young people.

##### *Carers*

One of the early reactions identified by a single carer was denial response (discussed later). Consistent with the accounts of the bereaved young people in the previous chapter where death was perceived by some as unreal, one carer thought confronting death immediately after the loss was too powerful for her daughter. A mother had observed her bereaved daughter in a state of denial after the loss, which she said had occurred immediately after the loss as shown in this quote:

*It is against our religion [to disbelieve that death has occurred] but when her father died she was asking whether it was real. She was with the belief that her dad would recover from the illness. It was because during one of her visits at the hospital, she asked ... [doctor] about her dad's survival chance and the response was he would recover one day. She kept that in her mind since then and when she saw the doctor the day her father died she asked him again.*

(FC)

The account that the bereaved young person 'was asking whether [father's death] was real' suggested that she had temporarily shut down her awareness of the loss, suggesting restoration-oriented coping. Although another carer did not seem to discount the possibility that bereaved young people might have experienced denial response, she perceived that if young people expressed a sense of disbelief that meant they were not accepting the death as predetermined by Allah. MD's mother said:

*It is Allah who determines who will die, no one can challenge that. She cannot pretend that her father is alive. She has accepted the death.*

(JC)

This perception of the adult seemed to suggest that, even if young people felt their loss was unreal, they were unlikely to show it because it was not religiously sanctioned. However, five other carers were not only unaware of bereaved young people's feelings of disbelief, but also felt that bereaved young people could not have disbelieved in the loss. They based their reasons on the availability of evidence (see below) to suggest that bereaved young people accepted their loss. This evidence included bereaved young people's crying behaviour as suggested by TS's mother who said that *'If she had not accepted the loss, she would not have cried'* (SS); and LB said that his daughter (FB) *'...had accepted the loss, there was nothing like feeling unreal, she had accepted it'*.

### *Professionals*

Consistent with carers' data discussed above, only one professional perceived that bereaved young people experienced denial responses to their loss. As in the case of the carers, 'perceiving death as unreal' was viewed by this single professional as a psychological mechanism that temporarily protected young people from absorbing and digesting the potentially overwhelming information that in reality loss represented for them. The professional (who was also a counsellor) gave a detailed account of why and how she believed the bereaved young person expressed this response, which included unrealistic expectations that the parent would live forever:

*... Growing up comes with lots of optimism about the future because it does not normally come across their mind that one day mother and dad will not be here. Unlike adults they place all their eggs in one basket, so when death occurs, it becomes so devastating that inside their head it is unreal. It sometimes becomes too much for them to handle and they will engage themselves with things that in normal circumstance they would not have. They may leave the funeral ground to watch TV and do silly things, then parents would be thinking and saying he is brave, he did not even feel it, that's how they react but many do not know. Even adults do [experience denial response] so it would be normal for bereaved young people to experience denial response to their loss, it is a way of controlling the pain.*

(RC)

Unlike the majority of carers, who stated clearly that bereaved young people did not experience denial response but rather accepted their loss, the majority (five) of the professionals claimed that bereaved young people accepted their loss but gave very little substantial evidence to demonstrate their understanding of young people's denial response, as suggested by one professional:

*Whether they perceived their loss unreal at one point during bereavement is a tough call for me to answer. Honestly I don't think I know that; what I know is that they do feel the death of their parent. Disbelief, I am not quite sure about that.*

(BB)

#### **4.3.2 Avoidance approach**

##### *Carers*

Unlike denial which is mostly irrational, in this thesis avoidance, which falls under restoration-oriented coping, has been defined as a voluntary strategy to minimise the impact of death by distancing oneself from people and situations that are likely to trigger an intense emotional response. Some carers were aware of this response. Creating space and suppressing emotion were two common attributes of the avoidance approach to loss shown in the adults' accounts, and a manifestation that young people may be involved in restoration-oriented coping. For example creating space involved physically distancing oneself from emotionally charged situations (which included people and places). AJ's mother commented that her daughter:

*... did not come in until after the funeral, so I did not see much of her, but I know it is normal for young people to sometimes distance themselves from people. As I said, this might have been because there were many people in the compound and things might have been too much for her. So it was not a surprise that she isolated herself.*

(SR)

The avoidance approach was observed the same day as death occurred. Some (three) of the carers observed or might have observed bereaved young people distancing themselves from people - an action that was perceived by the carers as an avoidance approach. For example AJ's mother said that:

*... it might have been too much for her [to sit in the house] because there were many people in the house wailing. She sat there [veranda] for hours and did not come in until after the funeral... [that occurred the same day]*

(SR)

And OJ's dad also observed his son's avoidance approach and commented that:

*When it [death] occurred he was at school; he was not here and by the time he came from school our compound was packed full with people wailing. He came past all of us*

*and went straight into his room and locked the door. He completely ignored me - maybe it was too hard for him to see me in such a state. That was the first time he saw me wailing, maybe that was the reason. If it were not his half-brother he would not have come out that day.*

(JJ)

In general the carers thought that young people coped well with their loss; as a result, little was reported about their emotional suppression. Only two of the carers seemed to observe young people suppressing their own emotions which happened immediately after the loss. In their view young people's emotional suppression was motivated by their desire to protect others. By suppressing emotions one avoided hurting other people's feelings, as suggested by MD's mother:

*She knew if she cried now her younger sibling would cry too, that was why she was not crying. I am not sure whether she still cries on her own but we all know that her younger children are fragile and they need to be protected, so she doesn't cry openly.*

(JC)

One carer perceived that the reason young people were involved in avoidance approach was because it helped them to calm down. LC's uncle (MD) said that his nephew '*...went and sat on his own and after some time he came back and started talking with his brother ... he was much calmer*'.

### *Professionals*

In contrast to the carers, who seemed relatively unaware of the avoidance strategies of young people, the majority (four) of the professionals were aware that bereaved young people were involved in the avoidance approach. The strategies they observed the young people practising included distancing themselves from people such as the bereaved family members and places that were likely to remind them about their loss. The professionals perceived that bereaved young people did not always want to remember loss; they wanted to have a break from emotions that were triggered by these memories.

*They are like adults; they don't want to be feeling sad all the time. There are instances they will go away from home to have a break from all these emotions. Here it is not strange to see young people spending hours playing football. During one of our support visits, one widow told me that since her husband's death her son was spending more and more time playing football, she was a little bit worried about this...*

(BR)

*...some of them will not go [to festivals] because it will remind them about their loss. Even if their peers are nice to them, they will still feel jealous and in their mind it will be like 'they are with their parents so they have got all they wanted'. It will be really hard for them to enjoy such events because they are constantly preoccupied with these thoughts. For sure some of them will avoid such interactions.*

(DS)

Four professionals recognised that young people used the avoidance approach: they perceived that bereaved young people had the natural instinct of protecting their parents and their siblings from being hurt by anything. Two such examples have been shown below:

*Sometimes the young people feel like crying but they keep their emotions inside; when they know that crying will trigger others' emotion, they avoid doing it in public. This seems to be common among young people whose father died. They don't want to do anything that will make their mother feel the absence of their father.*

(BR)

*It is our responsibility to protect our children but many don't realise that children also make a lot of effort to protect us from what they perceive as harmful. They neither want to see us feeling low nor do they want to be the cause of the negative feelings. Their protective behaviour becomes apparent when death occurs. In fact some of them, instead of crying and being consoled, will be consoling their mother, trying to make sure that she is okay.*

(RC)

Whilst suppressing emotions was seen as a strategy by which the young people protected a family member from what young people perceived to be negative emotions, distancing oneself from loss-related reminders was perceived to be more than just having a break from intense emotions. A professional thought it would give a young person the opportunity to '*...create for themselves time and space to think and try to understand their experience*' (RC).

#### **4.4 Social factors influencing young people's coping**

##### **4.4.1 Stigma, discrimination and poverty**

The evidence so far suggests that the bereaved young people's thoughts and feelings oscillated between loss-orientation and restoration-orientation during the course of bereavement. They sometimes focused their energy, thoughts and feelings on the deceased

such as their loss, and sometimes they psychologically denied any awareness of these feelings.

In the previous chapter the bereaved young people showed that the stigma and discrimination they experienced had a negative impact on their ability to cope with their loss. This section presents the findings on this topic from the perspectives of the adult participants. Both the carers' and professionals' descriptions of stigma and discrimination were centred on comparing bereaved and non-bereaved young people's access to care and support within the extended family set-up and a clear manifestation that attention was shifted away from loss itself to dealing with the secondary consequences of loss. Traditionally extended families were obliged to meet the needs of all the children within that set-up without any segregation. Within this context some people were more fairly treated than others as clearly shown in the accounts of both guardians and professionals below.

#### *Guardians*

All the guardians in this thesis suggested that the situations of bereaved and non-bereaved young people were different owing to the death of one or both parents. They perceived that material discrimination and social exclusion were the main problems young people encountered from the members of the extended families. AK's uncle commented that in a big social set up like the Gambia loss of a parent may be associated with negative attitudes and behaviours from adults:

*It is hard; things are not the same any more. Any child whose parent dies will suffer because they are likely to be treated unfairly. Even if the intention is to help, the economic situation may force them [carers] to make certain decisions that may be discriminatory.*

(MJ)

More than half of the carers (six) in this research viewed death of a parent, especially a father, as a forerunner to material discrimination within an extended family set-up. A mother observed that '*... [her daughter's] peers have more privilege ... I cannot afford [to buy for her] what her peers wear*' (FC). Whilst the primary carers identified both isolation and discrimination as a problem bereaved young people experienced, they blamed other members of the extended family (but not the primary carers) for being responsible for such treatment.

In other words they saw themselves as innocent when it came to discrimination and isolation of bereaved young people, as suggested in this account of LC's uncle:

*Since his father died I have done my best to buy things for him. I have been struggling since then [the death]; only a few family members want to know what we are up to, many have important things in their mind for their [biological] children, but not for us. His uncles [father's brother] and half-brothers are all well enough off to help but no, they are not interested. I work hard to make sure I buy something for him but I can only give what I have...*

(MD)

Professionals did not physically see young people being isolated by members of their families (but believed that they were); however, there is evidence - though weak - to suggest that bereaved young people were isolated. Two carers suggested there were incidents when a family member 'stopped visiting because he was avoiding taking the responsibility of caring [for] them [bereaved young people]' (FC). One such account has been demonstrated by ASS's mother:

*...my children were very close to him because he was all along seen as the successor of their dad. He used to come and visit his brother several times in a week, have lunch with us. Generally he was a good man ... He is no longer close to us; he is not visiting them anymore. He stopped visiting because he was avoiding taking the responsibility of caring for them. It is hard but we are still living.*

(FC)

Despite the obvious evidence shown above that bereaved young people and their guardians were stigmatised and discriminated against, none of the guardians mentioned the terms 'AIDS' or 'stigma' throughout the interviews. Whilst guardians' failure to mention these words may have been a result of the interviewer's deliberate attempt not to use leading words of this nature, their lack of comment may simply suggest the presence of both stigma and discrimination surrounding the topic. In general the loss was shrouded in secrecy; there was no evidence of discussion within the family about a parent's cause of death as AIDS. Whilst there was evidence that adults openly expressed their emotions through wailing, consoled, and talked to each other about the loss, young people were denied all of this (see Emotional expression).

Whilst evidence suggests that young people were deprived access to information and material support, consistent with the professionals, four of the carers seemed to agree that both stigma and discrimination were exacerbated by poor economic climate and increased dependency. This evidence suggests stigma, discrimination and poverty, as suggested by TS's mother:

*I understand that things are hard, financially things have been very hard recently but things are always hard anyway. There was never a time when money was enough but we always used to manage and cope with situations by supporting each other. Yes, I admit poverty is making things more difficult for bereaved young people, because some families have to prioritise their small resources and that sometimes goes against the newcomers in the family. But all these are happening because only a few are ready to come together and help people like me and my children.*

(SS)

Another consequence of stigma and discrimination was that it was not helpful to bereaved young people who were trying to cope with their loss. It was perceived that young people's experiences of discrimination had led to their emotional reactions being intensified. TS's mother commented that: '*...generally when children like her are treated unfairly, it makes them feel worse; things like associating with other young people become hard*' (SS).

### *Professionals*

In contrast to the accounts of the carers, all the professionals held the view that many primary carers who were not biological parents were not innocent; they were more likely than others to isolate and discriminate against bereaved young people. '*In general I think they are isolated but not often by their carers*'; but half of these professionals perceived that the worst forms of discrimination and stigmatisation were from the primary carers [non-biological parents], especially non-biological carers living with their own children. One professional believed that even though such a practice was subtle, it was common among the guardians.

*I am not saying carers are not trying but there are a lot of things happening that will never be reported either by the carers who sometimes maltreat them or the young people who have been maltreated. They want to protect their carers even though some may struggle to get single word of praise no matter how hard they work. When you meet some of them on the street you feel that something is going wrong but they would not tell you. I believe some are not treated the same way as others in the same family; that's unfortunate.*

(BB)

Moreover, professionals viewed stigma and discrimination as a common experience. Unlike the guardians, they were comfortable talking about stigma and HIV/AIDS throughout the interviews. There was a consistent view that people had a negative attitude towards young people whose parent had died of AIDS, and this was thought to be a result of their parent's AIDS status. It was shown either by negatively labelling the person or calling one or both parents names and it was considered unhelpful to their coping with loss:

*Stigma is subtle but it is there and young people whose parents have died of AIDS are likely to experience it. When they see their parents getting thinner, people would start labelling them and saying 'So-and-so's parent has AIDS...'*

(DS)

As the above quote suggests, stigma and discrimination might not be openly admitted but it will always be experienced by AIDS-bereaved young people. Although only one professional saw a young person who had claimed to be stigmatised, all the professionals were convinced that AIDS-bereaved young people were stigmatised and discriminated against by their peers and family members. These accounts: 'When they know they will call them [parents] names' (DS); 'They will say you have AIDS' (RC), and 'They will remind their children about their parent's death' (BK), suggest that the professionals believed young people and their guardians were to suffer from stigma and discrimination. One of them said:

*To be honest with you, no one has ever come to me to say that she and her family have been labelled because of their AIDS illness. I have not come across a single case yet, but I am convinced that it happens and I believe some carers will certainly stigmatise bereaved young people.*

(BR)

The professionals perceived that stigma and discrimination led to increased social exclusion, which was accompanied by poverty and humiliations. 'Often when you are stigmatised ... they will have very little to do with you' (RC), and '[it] denies them support' (BR) but one of the biggest impacts according to two of the professionals was the feeling of unimportance or worthlessness, all of which are unhelpful to young people's coping with their loss. For example one professional said:

*Stigma is belittling, you belittle someone for what - contracting HIV? Here the intention is clear, it is just to tarnish your reputation and make life worthless for you. That's*

*exactly what they do to young people; they kill their confidence. As a result they cannot function properly in their towns ... makes them feel they and their parents are bad.*

(RC)

Despite this difference in opinion, there seems to be agreement between the professionals and the guardians regarding the socio-economic impact of stigma and discrimination. All the professionals seemed to perceive that both poor economic climate and increased dependency exacerbated the discrimination and isolation bereaved young people experienced. For example: *'Families are taking in more than they can afford to adequately cater for'* (DS) and as a result *'they are forced to make choices'* (BR). It is apparent that *'things are no more the same because families have to prioritise their scarce resources to survive'* (BK). *'In many families the biological child is the first priority to spend the scarce resources on and the bereaved child may only benefit when there are enough resources'* (DS).

There was also an agreement between the professionals and the guardians in this thesis that stigma and discrimination were not helpful to the bereaved young people who were trying to cope with their loss. The impact of stigma and discrimination on their ability to cope with their loss was thought to include intensification of the feeling of loneliness as they were directly denied not only physical contact, for example through visiting, with people who mattered to them but also access to gifts that these people might have provided for them:

*...I don't think that kind of behaviour from carers should be accepted because young people need their support to cope, they rely on them. Discrimination would only isolate them further and make them lonelier and vulnerable. In future they may not even have the guts to seek for help because they may be intimidated [into thinking] that they would receive a negative response from adults.*

(RC)

Two of the professionals felt that, whilst discrimination and stigma directly led to an increased level of loneliness, indirectly it could also lead to humiliation and consequently social withdrawal. One of the participants said:

*The problem [of stigma and discrimination] is that it damages their [young people's] confidence and as a result they become anxious even to receive support from people that they would normally appreciate it from.*

(RC)

Also:

*It becomes difficult because they no more trust them. Some may withdraw from important relationships completely because they are no more comfortable...*

(DS)

The above quotation seems to suggest that young people's negative experiences such as discrimination and stigma led to distrust of their significant others, a low level of confidence, and anxiety in accessing support that might be useful to their coping. One professional commented that:

*If you thought someone was going to care for you and all of a sudden you are maltreated, then you will lose trust in that person. That is what happens to some young people - they don't have anyone to trust and ... [they] do not bother asking for help.*

(DS)

Another consequence of stigma reported by the six professionals was that it forced information on a parent's illness and death to be kept in secrecy out of fear that, if it were known, young people would be stigmatised. Their account suggested young people were engulfed in persistent fear and secrecy as they tried to protect themselves and their families from the embarrassing information about their loss:

*Many young people themselves do not know their parent's cause of death. They may suspect but they are not told but even if they know it is very unlikely that they will tell others. Normally it is a top secret in the family because they are likely to be stigmatised when other people know about it.*

(BK)

There was agreement among professionals that secrecy surrounding a parent's death was not helpful to young people's coping. Two commented as follows:

*Denying young people information they desired increased speculation and doubts about their parent's cause of death.*

(DS)

*Most of them [AIDS-affected young people] remain in doubt because they were denied so much important information.*

(RC)

This suggests that secrecy may have reinforced the young people's sense of denial that death had occurred and consequently prevented them from actively engaging with their loss.

#### **4.4.2 The family, peer and OVC support**

##### 4.4.2.1 Primary carers' support and capacity

###### *Guardians*

Whilst guardians had their own limitations, familiarity was not an issue. The majority (seven out of ten) of the carers were surviving parents providing care for their own children. More than half of the surviving parents were biological mothers (five) with the remaining two consisting of biological fathers. Known biological parents included father's brother (one), uncle (one) and aunt (one). The relationships shown above highlighted familiarity between bereaved young people and their primary carers who might have known each other well before death.

Despite the stigma, discrimination and poverty as discussed earlier, none of the primary carers reported anything negative about their relationship with the young people they were caring for and there was no sign of altercation between the carers and the young people they cared for. Lack of negative information may be a sign of a cordial relationship between them.

The primary carers were the main providers of food, shelter and clothing for the bereaved young people and they worked very hard to place food on the table for them. Their persistent effort to meet young people's material needs was a clear manifestation of the caring nature of the primary carers. Such efforts may have been the result of a valuable relationship with the young people they were looking after, as suggested by this account:

*Since his father died I have done my best to buy things for him... I work hard to make sure I buy something for him but I can only give what I have...*

(MD)

Despite being the main provider of support to bereaved young people, all the primary carers complained about scarcity of basic needs such as food, clothing and payment of rent. They

perceived themselves as poor and not having the capacity to meet these basic needs, as suggested by this excerpt:

*I understand that things are hard, financially things have been very hard recently but things are always hard anyway. There was never a time when money was enough... I admit poverty is making things more difficult for bereaved young people... But all this is happening because only a few are ready to come together and help people like me and my children.*

(SS)

What made it worse for the bereaved young people was the lack of support from the members of the extended family members as shown by this extract:

*...my children were very close to him because he was all along seen as the successor of their dad. He used to come and visit his brother several times in a week, have lunch with us. Generally he was a good man ... He is no longer close to us; he is not visiting them anymore. He stopped visiting because he was avoiding taking the responsibility of caring for them. It is hard but we are still living.*

(FC)

Another one clearly showed the distress guardian's encountered when they felt deprived and unsupported to meet the needs of the young people they were caring for, as indicated below:

*Since his father died I have done my best to buy things for him. I have been struggling since then [the death]; only a few family members want to know what we are up to, many have important things in their mind for their [biological] children, but not for us. His uncles [father's brother] and half-brothers are all well enough off to help but no, they are not interested. I work hard to make sure I buy something for him but I can only give what I have...*

(MD)

The primary carers perceived that with more material support bereaved young people would cope better with their loss, as shown by ASS's mother who said that: *When they [her children] have enough food and live in a better place than this they will be much better* (FC) and OJ's father who perceived that:

*All what is needed is support, support to maintain our daily upkeep. Food is important for the children; all other things come second to food. They will cope better when they are provided enough food and things like clothing.*

(JJ)

There was disagreement between carers and professionals regarding the impact of protective behaviour of adults towards young people's coping with loss. Carers perceived that removing bereaved young people temporarily/permanently from the funeral ground and asking them to stop crying was helpful in protecting them from intense emotions.

*She was crying bitterly and needed our protection at the time; that was why she was relocated.*

(JC)

*...she needed to be told that. She didn't stop immediately but at least she knew we care*

(SS)

Yet, neither professionals nor the families discussed such a topic because of lack of expertise (see Emotional expression – permission to express 4.4.2.2).

### *Professionals*

All the professionals maintained that the primary carers were the closest family members to the young people. Where the surviving parent was alive, a bereaved young person was often looked after by the biological parent. Otherwise they were often looked after by their uncles and aunts. None of the professionals observed or reported any altercation between the bereaved young people and their primary carers but they believed that if the bereaved young person was not a biological child, he/she might be stigmatised and discriminated against by the same person who should have been supporting him/her as discussed in the previous section, suggesting that their relationship might not be cordial:

*I believe some are not treated the same way as others in the same family; that's unfortunate.*

(BB)

However, the professionals maintained that the primary carers were the main providers of support to bereaved young people, because they housed, clothed and fed the bereaved young people on a daily basis; but they were unable to meet these needs adequately and they believed that more material support '*...would [provide] some form of security and [reduce] bereaved young people's worries, especially in relation to food and shelter*' (BK). In addition all the professionals believed that material support should be backed up by psychological support. One of them said:

*Material support alone is not enough; sharing information about death is necessary, it reduces doubts about the loss and makes them feel confident to talk about it.*

(RC)

Yet, neither professionals nor the families discussed such a topic because of lack of expertise (see Emotional expression – permission to express 4.4.2.2).

In contrast to the carers' position that strong emotions and highly charged emotional situations were bad for young people, professionals perceived that emotional expression should not be discouraged. The professionals perceived that adults often discouraged bereaved young people from crying - a culture that needed to be changed, as it may not have been in the best interests of the young people:

*Young people should be encouraged rather than discouraged from engaging with their loss. ... I think they need that [to cry]; it will reduce tension. Stopping them completely might not be helpful to them. Adults need to be told that, because it appears that whenever a young person starts crying they stop him/her.*

(RC)

#### 4.4.2.2 Emotional expression - permission to express

##### *Carers*

We have seen the young people reported that one of their immediate emotional reactions to loss was manifested through behavioural expressions such as crying. Their crying behaviour in the early stages of bereavement was reported by all the carers in this study. From the perspective of both the carers and professionals, crying behaviour of the bereaved young people immediately after the loss was associated with the loss itself, suggesting their involvement in loss-oriented coping as described in the previous section. Crying was viewed as a normal reaction to loss that all bereaved young people experienced when they lost a significant relationship, as suggested by FB's dad:

*She cried just like any other children who lost a parent. That was not a surprise, it was normal for bereaved people including myself. I think I cried even more than she did, so it was normal for us to cry. She was expected to cry.*

(LB)

Young people's initial emotional expression of their loss, typically crying behaviour, was first observed by the majority (seven) of the carers the day the death occurred, which was also the same day as the funeral. This, for example, is what AJ's mother said:

*...it was a very sad day, children were crying and women were wailing. It was really chaotic as many people came to pay their last respect.*

(RS)

The crying behaviour of the young people was expected and perceived as a normal reaction but, when crying was perceived to be endless, then it was seen as abnormal by some (three) carers. In line with this, one carer in the study had to ask her child to stop crying because it was perceived to be going on forever. MD's mother commented:

*... I was worried because she was not screaming but anytime I see her she would be weeping. That had been going on for most of the day. I was worried for her because if she cry, especially as a child of her age, if she cry for long it would not be good for her. It is not bad to cry but you cannot cry forever - it gives you headache.*

(JC)

Despite bereaved young people being seen crying the day their parent died by their carers above, none of the carers claimed to have seen them crying in response to their loss after that first few days.

*She had stopped crying: crying, no, not after that day (day parent died), I did not see her crying. That day was different because even adults were wailing so it was not a surprise to see her and her younger siblings crying.*

(SR)

Another mother said, '*She sometimes cries but that has nothing to do with the loss, it is a children thing*' (JC). The above extract suggested that carers may not be observant of young people's expressive behaviour in their response to death, but the accounts of some of the professionals (see next section) suggested that they did cry.

The concern for the majority (six) of the carers was the difficulty of discussing such a painful subject with bereaved young people '*because it would intensify their emotions*'. For example, ASS's mother, who found it hard even to tell her own children that their father had died, said:

*When you are sitting talking you think that it is easy, but when you look at them you are lost for words ... I could not even tell them that their father was dead - that should have been the easiest thing to do but we never discuss death. Right now it will be too painful for them; I have to wait until they ask me about it. It will be hard for them to tolerate right now.*

(FC)

### *Professionals*

Consistent with the carers, the professionals also perceived that the most common form of behavioural expression of emotions was crying. All the professionals observed crying behaviour in the first few days after the loss; and they perceived it as normal. It was described as the one:

*We all ... [do] when we lose someone significant, young people do too.*

(DS)

*I think crying is the single thing all young people do when they experience loss.*

(BR)

*[It]... is common among them.*

(BK)

*When death occurs, it does not matter whether you are an adult or a youngster, we all feel the pain. We may be able to tolerate the pain differently but for crying and sadness we all experience whether it is in private or public. Children are no exception to this rule. Since time immemorial death comes with crying, it is all part of the same thing, so I expect children to feel sad and cry.*

(RC)

Although all the professionals observed crying behaviour in the first few days after the loss, only one of them claimed to have observed it after that. Despite this, unlike the carers - who were not sure whether bereaved young people continued to cry months and years after their loss - all the professionals in this study were aware they did.

*[I am convinced that bereaved] ...young people would cry when they came to realise that one of their parents was dead ... they may cry even after that.*

(BR)

*It is obvious that they would cry... even adults cry so what is the big deal?*

(DS)

*In our society children cry when death occurs, I don't see any difference. They may even cry when they are reminded about their loss.*

(BB)

Only one professional had actually witnessed crying, suggesting that professionals had limited contact with the bereaved young people and might have minimal understanding of their experience. However, the only professional who witnessed crying behaviour saw ‘... *siblings crying during their father's funeral and one of them was found crying in ... subsequent visit*’ (RC). She continued by saying that:

*It is hard to go for a support visit and find them crying, as I said it happened to me only once. Even if they are crying, when they hear the car, I am sure they will stop, so it will be hard for you to find one. One thing I am sure of is that they do feel sad and cry, whether the crying is directly associated with death or not. That is the difficult bit, you don't know whether the crying is because of the death or some other things. Unless they tell you, it would be hard to know what they are crying for but for sure they do cry especially when certain things happen to them that remind them about their parent.*

(RC)

Consistent with the perceptions of the carers, all the professionals reported there were wailing and talking about death among the adults involved but there was no report of such behaviour among the bereaved young people in this study. For example one of the professionals said:

*When you observe people immediately after the loss, you realise that children, men and women don't react exactly the same way because it is only the women who wail and are allowed to wail and they also talk more about their loss among themselves than the men do. Their children just cry and they do not talk about their loss. All the people coming to pay their last respects go to the deceased spouse, not to the children; so they do not have an opportunity to talk about their loss.*

(BK)

However, in contrast to the carers, all the professionals were more concerned that they did not have the knowledge, skill and permission to engage with young people to the level of sharing such sensitive and emotionally touching information about their deceased parent. There was agreement among the majority (five) of the professionals that they lacked the necessary training and skills to initiate verbalisation of emotions with bereaved young people. The following excerpt demonstrates the professionals' view about their capacity to facilitate young people's emotional expressions.

*We have not started talking about death yet; we need to group them in different age categories first. We are not sure how to go about it yet.*

(DS)

*We felt that it is the responsibility of the family, we are not prepared for it.*

(BR)

*I suggested we borrow ideas from abroad but my idea was rejected.*

(RC)

One of them clearly said:

*We said we do provide emotional support but I am not sure we are doing that right now. I think we need to engage with them more and talk about issues like this [death], because some of them want to know more about it. Some may even want to know whether their father died of AIDS, many of them still do not know but we cannot tell them unless the parents want us to do, it is a bit difficult but I think we should work closer with the parents to start talking about their loss – it is high time, but we would need technical help for that.*

(BK)

#### **4.4.3 OVC project**

##### *Carers*

Where families were unsuccessful in giving adequate support to bereaved young people, support rendered by the OVC project was recognised by all the carers and it included: educational funding, nutritional supplements, workshops and seminars for bereaved young people. Provision of educational support by paying school fees for the young people seemed to be the main goal of the project, as indicated by MS's aunty, who said:

*They go to the centre for meetings and training but, as far as we are concerned, the main thing the project is doing for us is paying for the school fees. In some families babies are given milk powder but funding for education is the key work they do.*

(AS)

However, all the carers seemed to suggest that educational support from the OVC project was helpful for bereaved young people and their families because it came at a time when it was badly needed. Such a support may be perceived as restoration-oriented coping because it reduced the worries of young people and their families regarding their dropping out from school, as suggested by a mother to ASS:

*The school fees were paid for them at the time we were preoccupied with thoughts about schooling. We were very worried at the time: they thought they would be drop-outs; but the payment had lifted all the loss-related worries.*

(FC)

The accounts of both the carers and professionals (discussed later) clearly suggest that young people struggled to deal effectively with all these worries whilst at the same time continuing in their grieving process without support. Therefore the perception of the professionals and carers seemed to indicate that bereaved young people required others (as with restoration-orientation) to cope effectively with their loss.

### *Professionals*

Consistent with the carers, the professionals perceived that support rendered by the OVC project included nutritional supplements; workshops and seminars; educational support in the form of paying school fees; and provision of bicycles and school lunches for bereaved young people. However educational support seemed to be the main goal of the project, as indicated by this professional:

*... I mean even those who are not part of this program they struggle to pay [school fees] for their children but children from these families are generally better off and they stand a better chance of completing their school than orphans. So from the start we knew orphans and children whose parents are chronically ill, which of course includes HIV/AIDS, diabetes and TB, would need our support. But to be honest at the beginning the main focus of the project was to ensure that children's school fees were paid for them. We have done a great job in that respect.*

(BK)

The nutritional supplement provided by the project was only for younger children and babies, the purpose of which was to discourage breast feeding and reduce the chances of HIV transmission from mother to child. Two of the professionals said that at the time of the interview a few bicycles were purchased for young people who had to travel a long distance to school and plans were in place to make them available for all the young people experiencing a similar (travelling) situation. One of the professionals explained:

*Right now we have purchased a few new bicycles and we will be distributing them to those who are travelling long distances to school. Our intention is to purchase as many as possible and make them available to many young people who may be willing to ride to school. It is not possible to provide them for all the young people - only those who travel a long distance to school and are capable of riding will be given a bicycle. (BR)*

However, participants seemed to agree that *'support for education addressed one of the biggest stressors for the young people. The funding addressed the worries associated with availability of educational support'* (BR). There is a strong belief that the availability of this support improved the young people's confidence that they would at least complete their schooling without a major financial burden, as suggested by this account: *'They now know that with our support at least they will complete their schooling'* (DS). This suggests that the material support from the OVC improved young people's sense of security, as suggested by this professional:

*One of the things they [young people] were extremely worried about was schooling. In fact most of the time it is the surviving parent who would be complaining to us that they are worried about their children's schooling but we know these worries are shared by the children themselves. So, we wanted to give them hope and make them feel secure; at least to show them that despite their loss they have an equal or even better opportunity to complete their school than their peer [non-OVC members].*

(DS)

Although both the carers and the professionals said the young people attended workshops and met regularly, only the professionals suggested that such meetings helped the young people's coping with their loss. According to the professionals, bringing the young people together was helpful because: *'it resulted in acquaintances and friendship that might continue beyond the meeting'* (BK). Interaction was perceived as addressing the feelings of isolation among bereaved young people, because it makes them feel that they are not alone in their problem, as demonstrated below:

*We organised meetings for them quarterly; we pay their school fees and give some nutritional support to their families. That is helpful for them because it reduces their worries.*

(BR)

Another professional said:

*Normally children from AIDS-affected families are stigmatised and discriminated against and because of this they are isolated from people. I felt that bringing these young people into one big group had at least temporarily addressed isolation; especially since many of them have similar experiences.*

(DS)

Some of the professionals (three) perceived that gatherings temporarily removed them from their emotionally charged environment and their interaction with their peers allowed them to temporarily forget about their loss: *'...they need meetings like this regularly because it makes them forget about the troubles at home. It appears like they have a temporary escape from these feelings'* (BK).

Some (three) of the professionals were eyeing for improvement in several aspects of their service delivery but also identified initiatives that seemed useful for young people. One aspect of the project they felt was helpful to young people was their life skill programs which included training on tie and dying, batik and soap making. The purpose of this was to ensure that young people would be able to provide for themselves when the funding from the project ceased. One of the professionals explained:

*We thought of sustenance because we could not guarantee that funding will always be available. It was a good idea we trained them on Batik, soap making and tie and dying. We also gave them the tools they needed and the money to start the business with. Funding is available for our training so we will continue with the training.*

(BK)

Two of the professionals talked about plans in place to give extra responsibilities to some of the members of the OVC's existing executive committee members who themselves were young people. The new initiative required at least ten members of this committee to be visiting at least 12 young members of the OVC group. The purpose of the visit was to consolidate the relationship, create friendship and trust among young people themselves.

*In this project we have two types of membership: general membership and executive membership. The executive members are also young people; in the near future they will be running the project. They are not yet prepared for that. For now we help them organise executive meetings, and come up with an agenda for the general membership meeting. As I said they will need training to fully function in all these areas.*

(DS)

The professional was also eyeing for a better relationship between young people in the project, a relationship that would bring trust and friendship:

*We are looking for ways to improve communication and interactions between the OVC members in the project. One of the ways of doing that is introducing home visit scheme. That is ten of the executive members would be allocated 12 of the younger members of the large group. It will be like a team with a team leader being an executive member. He/she would be visiting them at home. They may be visiting each other as well. This plan can help bring friendship between them.*

(BR)

#### **4.5 The DPM**

The evidence emerging from the carers' and the professionals' data presented above seemed to be in conformity with the proposal made by the Dual Process Model of coping that the bereaved experience both loss- and restoration-oriented coping. The accounts of the carers and the professionals indicated bereaved young people's thoughts and feelings about their loss. Such thoughts and feelings commonly appeared immediately after the loss. Their thoughts and feelings were manifested by a range of emotional reactions to loss which included sadness, emotional loneliness, fear/anxiety (see previous sections for quotes). The carers and professionals also perceived that bereaved young people were involved in expressive behaviours such as crying immediately after the loss, all of which were manifestations of bereaved young people's loss-oriented coping.

However, according to the professionals' and carers' account, bereaved young people did not always engage in loss-oriented coping, they sometimes disengaged with thoughts and feelings related to their loss. This process, which is referred to as restoration-oriented coping, includes both denial and avoidance approach to the loss. They also experienced minor stressors such as stigma, discrimination and poverty. Interpersonal relationships with the primary carer, material support such as paying for school fees and buying clothes for them helped address some of the anxieties associated with these stressors. The following chapter discusses these issues.

## CHAPTER 5: DISCUSSIONS AND CONCLUSIONS

### **5.1 Introduction: the aims of the thesis**

This thesis has had three main aims and several objectives as shown below:

Aim 1: To explore young people's emotional reactions to the loss of a parent from HIV/AIDS and to compare that with the perceptions of carers and professionals. Objectives include identification of whether, and to what extent AIDS-bereaved young people:

- react to their loss emotionally
- are permitted emotional expression through crying and talking about their feelings
- react with sadness, anger, anxiety/fear, emotional loneliness
- remain emotionally connected to deceased parents
- employ denial and avoidance approaches

Aim 2: To explore young people's experiences regarding the impact of social factors, including stigma and discrimination, on their reactions and ability to cope with losing a parent from HIV/AIDS and to compare that with the perceptions of carers and professionals.

Objectives include:

- whether, and to what extent, AIDS-bereaved young people experience stigma, discrimination and poverty
- to what extent stigma and discriminations influence their coping ability

Aim 3: To explore how support from families, peers and agencies, particularly the Orphans and Vulnerable Children's (OVC) project, affect the young people's ability to cope with loss and to compare that with the perceptions of carers and professionals. Objectives include identifying the extent to which their ability to cope with loss is affected by:

- family care and support
- religious support
- peer support and OVC support

The discussions on findings related to the aims and objectives in this chapter will be explored as aspects of the two dimensions of the DPM. The section on loss-oriented coping discusses young people's engagement with loss manifested by several emotions such as sadness and anger, whilst the one on restoration-oriented coping contains discussions on denial responses, avoidance approaches and the use of supports. Social factors such as discrimination and stigma will also be discussed and how young people attempt to cope with them. These sections will be followed by a discussion on a proposed African model of bereavement. This is followed by a discussion on key messages to people and NGOs working with them. The chapter is concluded by a section on reflection and limitations.

## **5.2 Young people's emotional reactions to loss**

### **5.2.1 The emotions young people experienced and the order in which they experienced them**

Internalising seems to be a common experience among bereaved young people. All three groups (young people, carers and professionals) reported that when young people became aware of their loss they all reacted to the death of the loved-one with a range of emotional reactions. These reactions included sadness, anxiety; loneliness and anger. Although the participants thought that they could not stop death from happening, they perceived young people's reactions to be natural. A similar concept was reflected in the work of Bowlby (1980) who claimed that even some higher animals experience grief. Some cultures may not show their grief openly (Wikan, 1988), but that does not mean grief is not a natural response to loss. This evidence is consistent with the assumption underpinning the loss-oriented dimension of the Dual Process Model (DPM) of Stroebe and Schut (1999) which implies active engagement of loss as one of the essential component of the coping process,

The young peoples' initial and most obvious emotional reaction to loss was evident in the early part of bereavement when it was acute and the environment highly charged emotionally. Young people were openly involved in a number of overt emotional behaviours such as crying and withdrawal, signifying the importance of their loss to them. Although crying as a behavioural response seemed to dominate other behaviours that might be indicative of their response, basic emotional reactions such as sadness, anxiety,

anger and denial were experienced by the young people as soon as they became aware of their loss. This evidence is consistent with Worden's (1996) findings that emotional expression through crying occurred in 91% of the sample immediately (within the day) news was heard, whilst other emotions such as sadness, anxiety, anger and denial were also experienced.

The traditional phase model by Bowlby (1980) proposed that the bereaved must go through four stages of grief work (numbness/disbelief, yearning and searching accompanied by anxiety and periods of anger, despair, and recovery), and in a rough chronological order. As we have seen, the idea of 'stages' and chronology has largely now been superseded by models such as the DPM which proposes two processes. One is loss-orientation, involving the emotional aspects of loss and reminiscence discussed earlier and the other process is restoration-orientation, which includes both secondary consequences of loss (multiple stressors) and coping with the new situation independently or with support from others. The central tenet of this model is alternation (oscillation) between loss- and restoration-orientations throughout the bereavement period (Stroebe and Schut, 1999). Therefore, this model does not discard Bowlby or Silverman and Worden's ideas of grief work; rather, it has added 'restoration-orientation', not covered by these models.

In this thesis, there was evidence that denial was experienced by a few participants as an early reaction. Where it was experienced, it was very brief in nature. Most of the young people experienced a range of initial emotional reactions, and in particular sadness and anxiety as the predominant emotional reactions in the early stage of bereaved young people's reactions. Emotional loneliness and continuous bond were least likely to occur in the early stages, and to be experienced later.

There is consistent evidence from all three groups of participants that, whilst the earlier part of young people's reactions may have been dominated by loss-oriented coping such as preoccupation with thoughts and feelings about the death itself, their reactions at later stages were mostly associated with anger and anxiety over poverty, stigma and discrimination. However, there were periods of sadness, anxiety, anger and avoidance throughout the period of bereavement. It was therefore hard to see any strongly marked chronological order relating to all the participants, especially since the majority of them seemed to

accept death immediately they received the news. This lack of clear 'stages' is consistent with more recent models of bereavement, such as the DPM. According to the DPM (Stroebe and Schut, 1999), at times the bereaved confront their loss, at other times they avoid memories, are distracted or seek relief by concentration on other things (e.g. managing household chores) or engaging with other people. Several alternations may take place within a short period of time. For example, a child may wake up feeling sad (loss-orientation), and then feel better and able to focus on her homework (restoration-orientation); then sink back to loss (loss-orientation) when she watches a particular TV programme which brings on a wave of emotion.

There was no evidence from the three groups of the participants that young people were involved in externalising behaviours, such as fighting, stealing or any other antisocial crimes that may be associated with loss. There was no reported case of delinquency or police involvement with the bereaved young people as a result of their behaviour. The evidence therefore suggested a lack of externalising behaviours among the bereaved young people. However, poverty related discriminations had led to quarrelling between a young person and their landlord. Consistent with this evidence Bray (2003) notes that loss is not generally related to externalising behaviour, saying that even young people that lack an adult guidance are not prone to externalising behaviour, unless they live in communities where people stigmatise and discriminate against them there are usually no behavioural problems.

In summary the young people, the carers and professionals all perceived that internalising emotional reactions were a natural response to loss, with denial seen as an occasional and early response which, if experienced at all, gave way to a range of emotional reactions. These reactions shifted in balance gradually over time, with a major focus on sadness at the start, through a sense of loneliness and continuous bond with the deceased, into a sense of anger and injustice at how they were treated in their life after the loss. Anxiety was a common thread running through the whole experience.

### **5.2.2 Severity of loss: intensity and longevity of feelings**

This section discusses the perceptions of the three groups of participants regarding the extent and intensity of young people's emotional experiences.

There appeared to be differences in perceptions between the young people, carers and professionals regarding the intensity of bereaved young people's reactions to loss. From the perspective of the bereaved young people, the journey leading to death came with many emotions relating to a parent's years of illness and deteriorating health conditions, but they reported that their feelings of loss when their parent actually died superseded all those earlier reactions in terms of intensity.

Indeed most of the phrases and sentences about intense emotions emerged from accounts of the bereaved young people. They perceived their reactions as overwhelming and that its overwhelming nature was far beyond all their expectations. Whilst for some if they had not experienced loss no amount of explanation would have made them understand the pain involved in it; others struggled to find adjectives capable of describing their reactions. For some death made them feel as part of themselves was missing. These intense feelings seemed to be compounded by their experiences of stigma and discriminations they encountered throughout bereavement.

Although the carers and the professionals showed understanding that bereaved young people react with feeling to their loss, apart from one professional who was aware that their experience would be traumatic, neither the professionals nor the carers appeared to be aware of the degree to which young people were impacted by their loss. The carers believed that the young people were mostly in control of their reactions and the professionals perceived that in their immediate response to loss, the surviving parent experienced more intense reactions than their children. The reason for this assumption appeared to be based on the cultural belief that the adults had stronger attachment relationships with their partners and had taken up further unfamiliar responsibilities which increased their level of emotional reaction. This suggested that the professionals had limited knowledge about the importance of the parent-child relationship and the impact of such a relationship on young people.

Evidence from Tanzania suggested that bereaved young people's intense reactions may not be confined to the immediate aftermath of their loss. For up to a year after their loss bereaved young people in Makame et al's (2002) Tanzanian study were still experiencing strong emotions. The young people interviewed in this present research (thesis) reported that their intense and all-engulfing emotional reactions never completely went away. They continued to experience episodes of emotional intensity as they came into contact with reminders in their society. For example there is evidence that certain social circumstances (e.g. annual Muslim festivals) and issues surrounding the death constantly reminded them about their loss and triggered intense emotional reactions. Similarly Worden (1996) found American bereaved young people saying graduation reminded them about their deceased parent and made them feel lonely.

In contrast neither the professionals nor the carers were aware of the longevity of bereaved young people's emotional reactions to their loss. Both the professionals and the carers perceived that young people's emotional reactions to loss lasted only for a few days and that young people moved on rapidly after the death. In the case of the professionals this may be understandable as they were not living with the families and were not visiting them regularly, but it also suggested their limited understanding of bereaved young people's reactions.

These findings about the lack of awareness by professionals and carers of the intensity of feeling the young people experienced and the longevity of their experience raise the question as to whether young people received the support they required from their carers. Bereaved young people need to know that adults are there for them especially in times of crises like this. Giving them the necessary information about their loss they may require and giving them the opportunity to engage with their loss in ways suitable for them may be needed. Yet, creating a conducive environment for young people requires understanding of their needs, which is mostly lacking.

To summarise, whilst it is clear that important similarities were identified between the young people, their carers and the professionals, in terms of recognising that the young people felt the immediate loss acutely, important differences were also shown by the ways in terms of

neither the professionals nor the carers recognising the intensity of these feelings and the length of time for which they lasted.

### **5.2.3 Suicidal ideation**

The complexity and intensity of young people's emotional reactions has also manifested itself through suicidal thoughts or ideation; yet there seemed to be differences in perception between the young people, the professionals and carers regarding this phenomenon.

A minority of the young people experienced suicidal ideation which occurred soon after death when grief was acute. With little information available to young people regarding their future welfare, it is not surprising that some of the bereaved young people went so far as to see their life without their deceased parent as meaningless and wished themselves dead. Perhaps these bereaved young people's suicidal ideation and perception of their reactions as being abnormal arose from the fact that none of the adults recognised their loss, discussed it with them or told them that their reactions were okay. On the contrary, they were often stigmatised and discriminated against and told to stop crying and 'be brave'. Clearly, the feeling that 'part of oneself is missing', 'wishing oneself dead' and perceiving their reactions as abnormal all suggested that young people were overwhelmed by the emotional intensity; yet clearly carers and professionals were not aware of these intense responses.

Consistent with the accounts of the young people, evidence from Rwanda (Brown et al, 2005) and Tanzania (Makame et al, 2002), shows the presence of suicidal ideation among AIDS-bereaved young people slightly younger than the participants in this thesis. In Tanzania, a year after death there was still high prevalence (34%) of suicidal ideation among AIDS-bereaved young people, suggesting that young people's feeling of suicidal ideation might have been reinforced by social factors such as stigma and discrimination.

However, it is important to note that adults have the duty to protect the interests of young people. This requires an adequate understanding of their thoughts and feelings, yet what is evident in this thesis is that their emotions were considered shallow and not requiring the same level of attention as that needed by adults. A similar assumption used to be held in the West but research has now made it clear that young people experience emotions as deeply as adults.

In summary, whilst Makame et al's (2002) Tanzanian study reported a high prevalence of suicidal ideation, only a minority of young people reported suicidal thoughts, and none of the professionals and carers were aware of these experiences at all, suggesting the need for further research in this area.

#### **5.2.4 Anger in response to loss**

Anger, for example with the loved-one for dying, or with oneself for being in some irrational way 'to blame' is normally portrayed in the West as a normal and fairly common reaction to loss (Jewett, 1994) and so it might be expected that African young people would experience this kind of anger too. However the bereaved young people, their carers and the professionals did not appear to see anger as a normal reaction to loss and it was not identified by anyone as one of the immediate responses of young people to loss.

Perhaps part of the problem of not seeing anger as a response to loss may be related to the understanding of what anger is or is not in Africa. My understanding about anger in the Gambia is that it is a response to injustice which may be shown through verbal/physical aggression or withdrawal from the person perceived as causing injustice. Since God is believed to be just, natural death caused by God is not often associated with anger among Muslims. This mirrors Bowlby's (1980) belief that not all cultures were likely to recognise 'anger' as either a natural response to loss or beneficial to mourning, because they seemed to differ in the way they perceived anger which is reflected in their mourning practices.

Anger reported in this thesis was associated with stigma and discrimination rather than with the death itself. It was experienced later in the bereavement process as a response to unfair treatment and as such cannot be categorised as loss-oriented coping. Whilst anger was perceived as a common reaction to loss in the West, it must be noted that, in the African context, only a small portion of participants reported that young people experienced anger, and it was associated with the consequences of loss rather than a reaction to the loss itself.

However, socio-religious belief that life and death are predetermined by God and that no one can live beyond what is prescribed by God seemed to have some influence on the

participants' responses. The claim by the young people in this thesis that they could not get angry with their parent/God and the adults' persistent avoidance of linking death with anger seemed to be a testimony to that. It may be that young people and their carers perceived protest against death as disobedience towards God, and therefore not a feeling to be admitted, even to oneself. For socio-religious reasons, it would be hard to draw any realistic conclusions about whether or not anger was present as a response to loss.

However, it may be that the young people experienced anger inwardly as a feeling but were not able to express it openly during bereavement, or even name it for themselves, because their beliefs prevented them from expressing their anger and they may also have masked their anger so that the adults around them would not have been able to recognise it, let alone offer them support.

The few bereaved young people, carers and professionals who suggested young people's experiences of anger reported that it was not directly related to death. Being deprived of their properties and discriminatory behaviours from people in their neighbourhood were the main factors resulting in their anger. So although bereaved young people did not report anger as a response to the loss itself, applying Schiemen's (2000) Western definition of anger in this study would suggest that a majority of the bereaved young people would be considered to have experienced an anger response. This definition views both torment and envy as an indication of anger, which is in contrast to the position held by the participants and the understanding of anger in traditional African culture. However this experience of the bereaved young people seems to be consistent with some research literature in an African context which suggested that anger after loss may not be directly related to loss itself. Whilst Atwine et al (2005) found AIDS-bereaved young people's anger was related to household chores, Sengendo and Nambi (1997) reported living arrangements as the cause.

In summary, there was no difference between the perceptions of bereaved young people, their carers and professionals regarding young people's response of anger to loss. Stigma and discrimination were reported to be the cause of young people's anger. Anger was not seen as a normal reaction to loss and in consequence it was not identified by anyone as one of the immediate responses of young people to loss. However, defining anger using Schiemen's (2000) definition suggests that a majority of the Gambian young people might in fact have

been experiencing loss-related anger. As there is no scientific evidence from African literature clearly suggesting that young people perceived anger as a normal reaction to loss of a parent, there may be a need for further research in this area and for this issue to be explored sensitively with young people in order that their needs may be better met. Meanwhile, whatever its origins, the anger young people feel about their living circumstances needs to be recognised lest the bereaved young people continued to internalise, which in the long run could harm them (Thomas et al, 1970).

### **5.2.5 Sadness as an emotion**

Unlike anger, sadness as an emotional response to loss was perhaps one of the most consistent findings from the three groups of participants. Whilst sadness in the Gambian context may have several meanings, the discussion in this thesis centred on sadness as an emotion. This sadness may be manifested by crying, withdrawal and sometimes by unusual quietness during bereavement. When in response to loss, it is seen as loss-oriented coping.

From the perspective of the young people, professionals and carers, sadness and loss were inseparable. Their consistent description suggested that they viewed sadness and loss in terms of cause effect relations. Not only was it perceived as natural but also an emotion that was experienced immediately after the loss of a loved-one.

Reasons for the young people's feelings of sadness being easily recognised in the acute stage of bereavement included the crying and withdrawal behaviours with which they often engaged. Such behaviour may not only have shown an underlying emotion of sadness, but also communicated a signal that they needed someone to console them, show them love and care. Whilst adults may have needed to give them support, it was important that this did not turn into pressure to act or feel in a certain way.

There is consistent evidence that young people's sadness was reinforced by several factors including poverty, stigma and discrimination. The impact of these factors was likely to be experienced after bereaved young people's immediate responses to their loss. These factors led to missed opportunities such as material deprivation, social isolation and the lack of freedom, enjoyed by their peers, to interact and benefit from their parents.

In summary, there are similarities in perception between the bereaved young people, the carers and the professionals regarding young people's experiences of sadness, suggesting that perhaps sadness and loss were considered inseparable.

### **5.2.6 Anxiety and fear**

Whilst 'sadness' was found to be associated with the loss itself and 'anger' found to be associated with unfair treatment, 'fear' and 'anxiety' were concerned with the consequences of loss. In the West fear has been described as a powerful biological experience of an unpleasant risk or danger, either real or imagined (Payne, 1999), while anxiety has been described as fear of uncertainty or a state of being troubled in the mind about an uncertain event (Dunant, 1996). The fear and anxiety young people experienced was not only as a result of loss, but also as a result of poverty, stigma and discriminations.

Fear and worries were observed among young people immediately after the loss and seemed to be experienced intermittently throughout the period of bereavement. For all three groups, parents were not only seen as loved-ones but also as a source of security. They helped to place young people's world in order by meeting their developmental needs, such as love and material provisions. The evidence from the three groups of participants suggested that death threatened these provisions and placed young people's world in disarray. The evidence from the young people suggested that they felt their world was crashing down as they lost their sense of direction, perspective and a clear future. This finding that young people felt insecure following their bereavement is in line with previous studies conducted in Africa (Clacherty, 2001; Strode and Barrett-Grant, 2001; Atwine et al, 2005; Cluver and Gardner, 2006; Cluver et al, 2007; Atwine et al, 2005) that found bereaved young people's sense of security being threatened by their parent's HIV/AIDS illness and death.

The above fears and anxieties the bereaved young people experienced immediately after loss showed their active engagement with loss, thus their experience was loss-oriented. However, not all their anxieties and fears were as a result of loss-orientations; some were outcomes of the effects of the bereavement, such as poverty, stigma and discrimination. There is agreement between the accounts of the young people, carers and professionals that fear and anxiety was sometimes experienced as a result of shifting the focus of attention from loss to

other factors that may be stressful. For example evidence from the three groups of the participants suggested that bereaved young people were predominantly concerned with losing material support immediately after the loss. The reason behind this fear and anxiety was the belief that their surviving parent might not be capable of meeting their needs, such as payment of schooling, clothing, shelter and food. There was agreement among the three groups of participants that when young people lost their parent, and before they received sponsorship from the OVC project, they were preoccupied with thinking about who would pay their school fees and whether they would have to drop out from school; similarly some young people were worried that they would be evicted from the house they and their parents were renting because they might not be able to afford it. Clearly young people at this particular time were distracted from loss by other stressors. Addressing issues of school fees (a cause for concern) without delay seemed to address young people's anxiety in this respect and gave them hope about completing school, which appears to have been helpful in their coping.

There was agreement between the bereaved young people, professionals and the adults that, when the end of month (for those renting their accommodation) and festivals were approaching, bereaved young people's sense of anxiety and fear became more prominent. Whilst the end of month was concerned with doubts about ability to pay the rent and fear that they would be asked to leave the house; festivals were associated with doubts about the affordability of new clothes and fear of seeing oneself as the odd one out when they were at the festival with their surviving parents. The extent to which this specific fear and concern lasted is likely to have depended on how well the adults engaged with them and understood their concerns. Whereas issues associated with affordability may have been easy to address, fears and anxieties about seeing peers with their parents may have lasted for a very long time.

It seems that the fears and anxiety prevalent amongst young people induced secrecy and encouraged social isolation (see Stigma and Secrecy). As indicated above, fear and worries about seeing peers interacting with their parents prevented some young people from attending festivals, which removed them from people and places that reminded them about their loss. Such fears encouraged social isolation and reinforced emotional loneliness. There is also evidence that fears of stigma and discrimination led to secrecy and social isolation among bereaved young people (see Stigma and Isolation). Consistent with this, Strode and Barrett-

Grant (2001) in their study with young people found that fear intensified secrecy surrounding their parents' cause of death and young people's worries about their future.

In contrast with their general lack of awareness of the intensity and longevity of the young people's feelings of sadness it seems that the carers and professionals were aware of the young peoples' feelings of fear and anxiety. However there were differences in detail between the three groups in terms of what they felt the young people were afraid and anxious about. One early fear that the young people reported was a fear for their own safety and safety of the surviving parent. The death of the parent seemed to threaten some of the young people to the extent that they viewed themselves and their surviving parent as unsafe. Such concerns and fear were more prominent when the surviving parent fell ill, especially when the illness resembled the deceased parent's cause of death. This finding is consistent with another African study (Sengendo and Nambi, 2005) in Uganda, which found that, when the young people's parents were seriously sick, they responded to it with fear of the impending death. A parents' looming death was also found to be frightening and separation from their significant others such as grandparents at this time provoked more fear and anxiety for young people.

However, neither the professionals nor the carers seem to have been aware of this particular cause for fear and anxiety, indeed only one professional reported having observed such an experience.

Even when their need for education funding has been met and the general perception that their fear of dropping out from school had been addressed, young people specifically identified the beginning of school semesters as difficult times for them. It was neither the educational support nor the academic pressure they were worried about, but rather seeing their peers with their parents interacting and paying school fees for them. They generally feared that their peers would ask them about their parents which seems to have reinforced their sense of loneliness. Neither the carers, nor the professionals were aware of these concerns of the bereaved young people suggesting a lack of communication between adults and the young people they were meant to be supporting.

In summary, there was agreement between bereaved, carers and professionals that fear and anxiety were common experiences for bereaved young people and that bereavement brought with it a sense of insecurity and destabilisation. However, carers and professionals were not aware that AIDS-bereaved young people were concerned about their own and their surviving parents' safety, nor that they found particular times in the school year and events such as festivals to be anxiety provoking. Again it suggested limited understanding of bereaved young people's reactions and a lack of ability to talk to them effectively about their feelings (see emotional expression).

### **5.2.7 Emotional loneliness**

There were similarities in the perceptions of bereaved young people, carers and professionals regarding the extent to which young people felt emotionally lonely as a result of their loss.

It is clear from the accounts of the young people and the carers that the relationship between deceased parents and their children was special and characterised by love and routine daily interactions (including domestic chores such as cooking and outdoor activities like farming). Bowlby's (1980) attachment theory suggested that the intensity of one's emotional loneliness depended on the strength of one's relationship with a primary carer; it is therefore not a surprise that the unique and loving relationships described by the three groups of research participants had led to a lonely experience for the bereaved young people. The young people described themselves as feeling hollow/empty and they thought about their loss, dwelling extensively on how much they missed their deceased parent, and reminiscing about the interactions and activities they used to enjoy with them, suggesting their feeling of loneliness. Evidence from Africa (Brown et al, 2005, Sengendo and Nambi, 1998 and Wood et al, 2006) suggested that it is natural for bereaved young people to miss a special relationship with a loved-one.

One would have thought that, since there was an extensive family network and many of the young people were living in a compound, emotional loneliness would not be an issue for them. This suggests that the network might not necessarily be addressing issues of emotional loneliness either due to the uniqueness of the missing relationship or stigma and discrimination encountered. However, Ponzetti (1990; p.336) reminded us that emotional

'loneliness reflects an interpersonal deficit that exists as a result of... less satisfying relationships than a person desires', suggesting young people's emotional loneliness is loss-oriented and the presence of others might not completely address their feelings of loneliness.

The poverty, stigma and discrimination the bereaved young people endured further isolated them from individuals who might have been helpful to them. There seems to be agreement between the three groups of participants that bereaved young people continued to experience emotional loneliness long after their loss. There were episodes of emotional loneliness triggered by people, circumstances or events, suggesting that some emotional loneliness was caused by factors other than loss itself. The most common event that triggered emotional loneliness was the 'Tobaski', (the biggest Muslim festival) when young people's deprivation and isolation became particularly evident. Emotional loneliness was commonly manifested at events like this that brought together young people and their parents. Tobaski was perhaps the most important event young people longed to celebrate with their parents.

There seem to be two main reasons why such an event was significant to bereaved young people. Firstly in the past it used to be a positive emotional event that created venues for interaction with their parents beyond the ordinary. It was an event when love was shown openly and parents and their children were both physically and emotionally closer than usual. Secondly, it was a day of jubilation and for young people a day of showing off the new clothes bought by their parents. The absence of gifts like new clothes triggered and reinforced their sense of loneliness because it was a clear manifestation of the absence of the deceased person who had been responsible for making those provisions. It is therefore not a surprise that bereaved young people felt lonely when they saw their peers with their parents or when their peers were showing off their new clothes. Whilst this annual event and occasional ceremonies were bound to occur, the implication was that bereaved young people's emotional loneliness would continue for as long as their peers continued to enjoy these privileges. It may be true to say events like Tobaski, bringing Muslims together, may not provide an environment that is conducive for bereaved young people's social interaction with peers, because they are likely to trigger and increase their sense of emotional loneliness.

In addition to special occasions, everyday events that took place during the evenings, weekends and nights could also trigger emotional loneliness. The evidence from young

people and carers suggested that young people used to have special interactions with their parents at these times. After death occurred, they missed this closeness with their deceased parent at these times of the day or night which used to be characterised by specific interactions such as sleeping in the same bed, speaking to them, storytelling or having a chat/joke at bedtime. Professionals did not appear to be aware of this.

In summary, evidence from the carers and professionals was consistent with the young people, that the latter experienced emotional loneliness as part of their immediate response. Events like 'Tobaski' were also perceived as one event that triggered young people's emotional loneliness. However, whilst the carers and the young people were aware that bereaved young people missed their parents more in the evenings and at nights, the professionals were not aware of that. Again important sources of potential support are being missed.

#### **5.2.8 Continuous bonding relationship with the deceased**

Whilst emotional loneliness seemed to show that death of a parent left a vacuum in the hearts of the bereaved young people, this section discusses whether they remained emotionally connected to the deceased after the loss.

There was a degree of agreement between the young people, carers and professionals that bereaved young people retained emotional connections with their deceased parent years after their loss. Whilst the carers and professionals in this study recognised that bereaved young people sometimes remembered their parents, it was the bereaved young people who strongly emphasised their need to retain emotional connection with their deceased parent. The young people made it clear that they had no intention of letting go the memories of their deceased parent. Their view that they would live with their experience and not forget their loved-one suggested that, although their relationship might be transformed, in a way it would remain permanent.

The young people reported that death did not terminate the existing emotional relationship between them and their deceased parents. In spite of the pain involved in engaging with loss, they continued to retain emotional connection with the deceased parent. The recurrent

question they posed ‘how can I ever forget her?’ is an indication of continuous emotional relationship between the bereaved and the deceased. Retention of this emotional connection with the deceased suggested that young people engaged with loss-oriented coping for years after their loss.

Worden (1996) suggested that in the West one way of knowing that the bereaved young people retained emotional connection with the deceased was through their reminiscence. During the interviews in this thesis, bereaved young people’s open talking about their deceased parent could be seen as a sign of emotional connection with their loved-one. Their recollection of important interactions with their deceased parent, including activities they used to share, suggested that the deceased were still fresh in their minds. Such a recollection strongly suggested that young people remained connected with their deceased parent, despite all that might have been going on in their lives. Worden (1996) claimed that retaining connection with the deceased helped one to accept the permanence of loss and was sometimes comforting, but it neither prevented the experience of pain nor did it mitigate emotional problems.

The bereaved young people’s emotional connections with the deceased parent occurred in various ways, with some more tangible than others. Evidence from the young people’s data suggested that intangible resources such as prayer were commonly used to retain connection with the deceased parent. Writing from the Western perspective, Becvar (2003) maintained that the holding on process helped the bereaved to ‘maintain an inner representation of the deceased [which in itself] is normal and helpful’ (Becvar, 2003; p.254). Although prayer in Islam means fulfilment of one’s obligation, from the perspective of the majority of the young people and a minority of the carers, bereaved young people’s prayer was beyond obligation. It had a special meaning to them because it not only connected them to their Lord but was also a means through which they were emotionally connected with their deceased parent by remembering them in their prayers. Several daily prayers meant several avenues to celebrate their internal relationships with their loved-ones. Yet the bereaved young people viewed prayer as beneficial to them because it created comfort for them. This thesis is the first study known to the writer claiming that some Gambian bereaved young people are likely to remain connected with their deceased parent through their daily prayers.

Also there seems to be growing literature in the West suggesting that some people are more likely than not to retain emotional connection with their deceased parents. For example, Becvar (2003) comments that people 'maintain an inner representation of the deceased [which in itself] is normal rather than abnormal' (Becvar, 2003; p.254) and Klass et al (1996) also suggested that continuous bond is a function of how people cope more generally with their lives or coming to terms with loss.

Whilst the carers and the bereaved young people acknowledged the importance of objects (materials) left behind by the deceased, it was the material benefits of this object that the carers emphasised. However, for the young people, these objects were meaningful rather than materially useful. For example, several objects (e.g. clothes, books, pictures and diaries) were used by the bereaved young people as a powerful means of retaining a meaningful sense of connection with a deceased parent. Using objects to retain connection with the deceased has been identified in Harvard Bereavement study (Worden, 1996). However, no African study recognised that young people's emotional connection would last for a long time. However, these people are still young; it is hard to know how many of them will remain connected in this way in the future.

In summary, the evidence from the young people showed that they retained emotional connection with the deceased people, but the carers and professionals were largely unaware of this. Again it suggested limited understanding of bereaved young people's reactions and a lack of ability to talk to them effectively about their feelings. The extent to which bereaved young people maintain a continuous emotional relationship with the deceased parent as permanent would appear to be a new finding in the African context. The extent of this bond was not uncovered in previous African studies. In the literature, young people's engagement in prayer was mentioned in the studies of Worden (1996) and Wood et al (2006), and the latter recognised that bereaved young people in their study found comfort in praying, although none of these studies suggested that young people used prayer to retain emotional connection with their deceased parent. The experience of the bereaved young people would however seem to be supported by wider literature, which suggests that Africans encourage retaining strong connection between living and dead (Kilonzo and Hogan, 1999), and so could be an interesting topic for further investigation.

### **5.2.9 Denial and acceptance of loss**

Bereaved young people's reactions were not only restricted to loss-oriented copings as discussed in the preceding sections, but also included restoration-oriented copings. Restoration-oriented coping refers to any transaction of the bereaved other than active engagement with the loss, for example temporary avoidance of the memories of the deceased, distraction from focusing on loss, seeking relief by engaging with people and things. 'Denial response' in this thesis can be seen as one aspect of restoration-oriented coping because it involves temporary shifting of attention away from the deceased or the circumstances surrounding the dead. According to Kubler-Ross (1969), the earliest reactions of a bereaved person are likely to include denial, which was described by Jewett (1994) as one's 'natural defence mechanism [that] may allow us to shutdown our emotional awareness and screen out potentially overwhelming or devastating information' (Jewett, 1994; p.66).

The evidence from bereaved young people's accounts indicates that a few of them experienced a denial response to loss, shifting their attention away from loss and denying consciousness of it and perceiving their loss was unreal. Such a reaction seemed to occur immediately after the loss. This is manifested by bereaved young people's questioning of people as to whether death has actually occurred, making statements such as 'it was not true', and in some cases wanting to see the corpse to convince themselves.

The young people's reports suggested that denial may have been reinforced by exclusion and secrecy surrounding the death. In some cases the young people had experienced refusal of access to information on parent's impending death, lack of information, and exclusion of a bereaved young person from seeing the corps as part of adult rituals. .

There is support for denial responses amongst bereaved young people in a previous African study. Evidence from Zimbabwe suggested that bereaved young people had difficulty in accepting their loss, which was mainly influenced by lack of communication within the family (Wood et al, 2006).

Despite denial reactions, the general perception of most of the bereaved young people was that they accepted their loss. Whilst denial is an unconscious decision, many of the bereaved

young people who claimed to have accepted the loss immediately after the incident might not have been aware of their denial responses in the first place. Whilst the majority of the carers suggested that bereaved young people did not experience denial but rather accepted their loss, it appeared as if the majority of the professionals were not quite sure of the presence of either denial or acceptance of loss among bereaved young people.

However, in Zimbabwe, Wood et al (2006) found that, where there was no communication regarding death, the bereaved young people experienced denial response. Taking Wood et al's (2006) finding into consideration, one may assume a widespread denial response to loss in the Gambia because of poor communication (regarding death of a parent) between young people and the adults surrounding them (see Emotional expression 5.2.2). The low levels of denial response reported in the Gambia may be due to several factors including socio-religious influence on young people.

Young people, the professionals and carers seemed to be holding the belief that life and death are predetermined by God and accepting death as the will of God is a religious obligation. An expression of disbelief or denial may therefore be perceived as one being disobedient towards God and a violation of socio-religious order and therefore not a feeling to be admitted, even to oneself. This may be the reason the low levels of denial response reported. It may be that the young people experienced denial inwardly as a feeling but were not able to express it openly during bereavement, or even name it for themselves, because their cultural and religious beliefs dictated what should be or should not be expressed or felt.

Another possible reason for the low level of denial is associated with its brief nature. The carers' perception that bereaved young people had accepted death seemed to be influenced by their interpretation of the crying behaviour which dominated the early part of bereavement. Since immediate denial response after the loss might be brief and elusive to the adults; it is possible that bereaved young people had already experienced denial response before accepting loss or engaging with intense emotions, as suggested by Kubler-Ross's (1969) model. However, in the 'Task of Grief' model Worden (1996) made it clear that at some point the bereaved accept the loss and move on. Some people do not accept it and get stuck; and for some it is hard, such as when someone is missing, presumed dead. However, there was no previous African study that supported or rejected evidence regarding acceptance of

loss; but evidence from Africa (see the internalising behaviour) that bereaved young people reacted to their loss with a range of emotions may be an indication that they have accepted their loss at some point during their bereavement.

In summary, only a minority in each of the three groups of participants perceived that bereaved young people experienced denial response. The general perception of most the young people and the majority of the carers was that bereaved young people accepted their loss. It also appears that the majority of professionals were not sure of the presence of either denial or acceptance of loss among bereaved young people. As with denial, there may be a need for further investigation of this issue, as well as more sensitive discussion with young people on the issue of denial.

### **5.2.10 Avoidance**

In the previous section denial was largely discussed as an involuntary response, in this section the discussion was centred on what might be seen as voluntary responses such as avoidance.

Worden (1996) in his study in the US found that avoidance is a common experience among bereaved young people. In this study, avoidance was reported by all of the young people. Many of the professionals and a minority of the carers were aware that young people used this strategy. The evidence in this thesis is that whilst young people may not have control over their feelings of grief (see Emotional reactions, 5.2), there were choices to be made about how they behaved during the grieving process. In particular, they negotiated and made choices that enabled them to distance themselves from emotionally charged situations, such an approach which shifted their focus from the loss itself suggesting that avoidance approach can best be seen as a part of the restoration-oriented coping. This is consistent with Jewett's (1994) conceptualisation of avoidance which suggested that it is a defence mechanism consisting of a refusal to deal with situations, objects and activities as a means of either complying with social expectations or preventing further painful emotional experiences (Jewett, 1994).

All the bereaved young people were involved in two kinds of avoidance. The first strategy involved voluntary withdrawing from the situation that formed any reminder of the loss, in a conscious effort to create breathing spaces, avoiding situations such as festivals, people and places that would trigger memories of the lost one or intensify emotions. The second strategy was suppressing one's own emotions to avoid the impact of one's distress on others, which was a means of establishing a sense of control over an imagined or real threat, which also helped to fulfil social, cultural and religious norms and expectations.

These strategies were connected. They considered that coming into contact with situations that triggered intense emotions could be overwhelming (see Intense Emotional reactions 3.2.1), but when such situations arose they tended to suppress their emotional behaviours (for example through crying), even when they felt the need to express them.

However, whilst decisions to distance oneself from festivals might be seen as a conscious decision, there is evidence that this decision may also be influenced by poverty, stigma and discriminations as the bereaved young people did not have the clothes that their peers wear and feel ashamed to be part of what used to be an important occasion for them (see, poverty, economic deprivation and shame).

An awareness of the social pressures and expectations on bereaved young to protect other people and the norms of their society by suppressing their own emotions was evident in their accounts and the accounts of the professionals, yet their primary carers were not aware of this despite living with them in the same compound. This finding suggested not only poor communication between bereaved young people and their carers, but also that apart from the obvious reactions, such as crying, carers were unable to observe many of the young people's bereavement related symptoms. This is worrying especially because, as we have seen earlier, young people in this study reported that they often felt overwhelmed by their emotions.

There appear to have been two main reasons for avoidance and for the consequent suppression of public displays of emotion by young people. The first reason was to protect the bereaved adults, especially the surviving parent whose emotional state seemed to be more of a concern to bereaved young people than their own. There was a burning desire among bereaved young people that their emotional reactions should not impact on others, even if it

meant compromising their own emotional needs, or making false pretence as if they were okay. Young people appeared to be made to believe that any form of emotional expression, such as anger, which suggested a lack of acceptance of death which is against social or religious norm may be considered inappropriate, and may not be encouraged because of the perceptions that it will have a negative impact on other members of the family.

Bereaved young people in the USA were also found to be protective towards their surviving parent (Worden, 1996). In Harvard Bereavement Study Worden (1996), reports that the bereaved young people acted as grown-ups and tried to be good to their surviving parents (trying to take care of them) in order to please them. They protected their surviving parent by behaving differently so that their emotional response and behaviour would not be considered a burden. Voluntary avoidance of potentially difficult situations that created temporary respite for bereaved young people was seen by bereaved young people as a strategy well worth taking in dealing with highly emotionally charged events/situations. The fact that bereaved young people said it helped them to digest their experience in a way that was convenient to them seems to suggest that avoidance had psychological consequences similar to the denial responses presented above.

Many of the professionals were aware that bereaved young people did not always want to remember loss, they wanted to have a break from emotions that were triggered by the memories of their loss and, as a result, they distanced themselves from bereaved family members and places that were likely to remind them about their loss. However only a minority of the carers were aware of this, and of those that were aware, their observation was limited to young people's withdrawal immediately after the loss had occurred. The majority of the carers were unaware that the avoidance approach was a choice that many young people had taken and were involved in throughout their bereavement. When bereaved young people masked their reactions, their reactions were misinterpreted by the carers as coping.

Evidence from Wood et al's (2006) ethnographic case study conducted among AIDS affected families in Zimbabwe found avoidance amongst both adult members of the family and the young people. Adults were found to avoid informing young people that a parent had died or talking to them about loss in general. Bereaved young people were also found to be withdrawn and not talking about their loss. A more general failure to communicate within

and outside the family about issues surrounding parents' AIDS-related deaths was reported to be a common experience among AIDS-bereaved families in Africa (Clacherty, 2001; Strode and Barrett-Grant, 2001; Cluver and Gardner, 2007). Whilst in the above two studies the main reason for lack of communication was the fear of stigma and discrimination, Wood et al (2006) suggested that young people's lack of talking about their loss in their research was wrongly perceived by the adults as coping.

Whilst all the young people and many of professionals suggested that bereaved young people suppressed their emotions and distanced themselves from people and places likely to trigger and intensify their reactions, the majority of the carers were not aware of such reactions. Only one previous African study was found that discussed the avoidance approach (Wood et al, 2006), yet this study neither linked it with the grieving process, nor showed it as an active part of the grieving process. It appears therefore that this study has the potential to offer something to existing knowledge in this field, and to point to the need for further discussion with young people to uncover what may be suppressed needs and meet them more effectively.

### **5.3 Coping with stigma, discrimination and poverty**

The DPM suggested that bereaved people experience two types of stressors: major stressors, related to the loss itself; and minor stressors, related to the secondary consequences of loss (Stroebe and Schut, 1999). This section discusses these secondary stressors and how young people tried to cope with them.

The stress and misery created for bereaved young people by poverty, stigma and discrimination were perhaps one of the most consistent findings in this thesis. Evidence from the young people, carers and professionals suggested that they were common experience among bereaved young people. The following sections discuss various types of stigma and ways young people try to cope with them.

#### **5.3.1 Felt stigma and secrecy**

With felt stigma, the stigmatising condition does not need to be overt and known for people to feel it. Even though others may not be aware, young people may suffer as a result of their

stigma. However, in this thesis the prevalence of stigma has been observed by all the three groups. There is evidence that the thoughts and feelings of the bereaved young people were coloured by both felt and enacted (discussed later) stigma. Yet felt stigma was characterised by a constant fear of negative societal attitude and behaviour towards bereaved young people.

Perhaps secrecy surrounding parental death and lack of disclosure were among the clearest indicators of the presence of felt stigma, because the underpinning reason for such a silence was fear of stigma (enacted stigma) and discrimination. Young people's evidence suggested that, in spite of their experience of the trauma of witnessing their parent's illness and death and holding their own perception about the illness (e.g. they might have recognised the signs and symptoms of the illness as AIDS), there was consistent silence surrounding parental illness, and there seemed to be continuous denial that the illness and death was related to AIDS.

Consistent with young people's experiences, evidence from both the professionals and carers suggested secrecy surrounding the deceased parent's illness and loss. The carers and young people avoided talking about AIDS during the interviews with the researcher in this thesis, suggesting they might have been experiencing felt stigma. Professionals believed that young people and their carers would not be able to avoid being stigmatised in their society if people knew their HIV/AIDS status.

However, one would have expected the professionals supporting bereaved young people to lead the way in advocating that society should change its attitude towards AIDS-affected families. Yet, in this thesis the professionals as well as the primary carers made it clear they did not discuss HIV or death with the bereaved young people they worked with and they seemed to be reluctant to begin doing so; again depriving the young people their right to support and care.

The bereaved young people in this thesis showed the desire to cope with their felt stigma. Although largely unsuccessfully, there is evidence that bereaved young people consciously approached adults seeking information about their loss. The mere attempt and the desire to get information about their parent's death and the issues surrounding the death may suggest that young people were avoiding internalising stigma or were dealing with felt stigma. Young

people want to be told the truth (Wood et al, 2006), so giving them clear information about a parent's death may reduce their anxiety and give them more confidence to confront their loss and the secondary consequences of their loss.

The fact that bereaved young people conquered their fears and volunteered to participate in this thesis and discuss issues that were personal and capable of exposing them to further stigma and discrimination shows that one coping strategy young people used was engagement in discussion about their worries. The fact that the bereaved young people themselves said the interviews reduced their anxieties was a clear manifestation of this.

It is important to note that bereaved young people's reactions are temporary measures and they require support. So we must break the silence and start listening to young people talk about their stigma. One way of supporting them is to help them acknowledge their existing personal and social problems associated with the HIV-related death of a parent and together discuss strategies to deal with it. This may help to reveal young people's hidden fears of what they may perceive as potential perpetrators of stigma. Specific strategies such as counselling of young people and awareness campaigns targeting the potential perpetrators could be developed to address the situation.

In summary, all the groups of participants recognised young people's experiences of felt stigma and secrecy surrounding the loss. Neither professionals nor carers discussed the cause of a parent's death being AIDS. Although young people were largely unsuccessful in their attempts to discuss their loss with adults, they successfully conquered their fear by sharing their feelings and thoughts with the interviewer in this thesis, suggesting the need to permit them to share their thoughts and feelings about their loss.

### **5.3.2 Verbal and self-stigma (shame)**

Derogatory comments/name calling, shame and humiliation were, according to the young people and professionals, a significant aspect of bereaved young people's experience, with both groups suggesting that bereaved young people received comments they found derogatory. The professionals believed that young people were teased at school; carers seemed to be unaware of this. Although the professionals did not personally witness any

name calling, they believed that young people were shamed by their peers and other members of the family because their parent's cause of death was AIDS. Consistent with this, Clacherty (2001) reported that in South Africa, at community level, HIV-positive young people were laughed at and gossiped about in churches and at school, because of their own HIV/AIDS status and that of their parents.

Whilst their parents' cause of death being AIDS had not been mentioned by the bereaved young people at all, they took offence at the name 'Bayoh' (which may be more or less translated in English as 'orphan'). 'Bayoh' is a bereaved young person abandoned by the paternal lineage, which is culturally obliged to provide for his or her needs. The stigmatising of young people as 'Bayoh', though uncommon, occurred within the community reaffirming the social grouping which categorised bereaved young people as different from normal young people whose parents were alive. Whilst the literature did not cover 'Bayoh' at all, it is a unique feature of the Mandinka culture and seemed to explain why some bereaved young people persistently longed for closeness to their paternal lineage as their coping strategy and others felt ashamed of themselves (discussed later). This is new and may be a significant contribution to literature.

Similar evidence that involved school was also found in the accounts of the bereaved young people. At the time of paying school fees, parents (especially members of paternal lineage) were absent because the fees had been paid by the OVC project. This caused isolation and fuelled speculation on the cause of the parents' absence, reinforcing the sense of the young person as a 'Bayoh' or an outcast. The OVC involvement may also have confirmed to their classmates the possibility of their parents having died from AIDS. However, carers were not aware of these derogatory comments young people experienced both at school and in the community.

There is evidence in this thesis of the several strategies bereaved young people used to cope with their shame or to avoid being further stigmatised. They consistently showed that they assessed, identified, perceived or preconceived potentially stigmatising situations and avoided them. Such situations included avoiding (see Avoidance) situations where their non-bereaved peers, whom they sometimes perceived as better than themselves, were likely to be

seen interacting with their parents. Avoiding such situations may have reduced the chances of reinforcing their existing stigma or prevented them from internalising stigma.

At other times, bereaved young people engaged with a stigmatising situation and then realised that it was either increasing their shame or they just could not cope. In such situations they sometimes withdrew. Perhaps embarrassment through lack of proper clothing and seeing others with their parents, especially during annual festivals and school events, made interactions difficult for bereaved young people and they consequently withdrew from these situations. Sometimes the bereaved young people had no option other than to 'act normal' and 'put on a brave face'. For example despite feeling ashamed, the bereaved young people interacted with their classmates at school, suggesting that they might either be acting normal or putting on a brave face whilst in the same class as a potential source of stigma.

Felt stigma may also be considered as one of the strategies bereaved young people used to reduce their exposure to enacted stigma. For example, if their classmates were unaware of their loss, it was possible that bereaved young people would not have received verbal stigma from them. However, this is not to suggest that young people should keep their information to themselves. It might be more useful to share information, especially if we are to be successful in demystifying stigma and AIDS.

It is important to note that, whilst the carers and professionals seemed not to know the importance of the presence of a father figure - especially from the paternal lineage - at festivals and school activities, evidence from young people's data seemed to suggest that their presence would have reduced the stigma associated with being a 'Bayoh'. This suggests the need for members of the paternal family's active participation in young people's school activities.

In summary, whilst bereaved young people and the professionals realised that young people experienced verbal stigma and may have felt ashamed of themselves, the carers were not aware of these humiliations young people experienced. Despite all participants knowing the importance of paternal lineage, the impact of the absence of a father figure on young people's feelings of shame had not been noticed by the primary carers and professionals. What this

shows is lack of communication between bereaved young people and the adults surrounding them. There is a need for this problem to be further investigated.

### **5.3.3 Social exclusion**

The distress and anger created by social exclusion were consistent findings in this thesis. Travelling away from home in search of treatment, leaving young people behind and temporary relocation of bereaved young people from home when the funeral took place to neighbours' compounds were some of the actions adult took to exclude bereaved young people. In addition, evidence from young people suggested a reduction in the frequency of visits from close relatives, especially those perceived to have an obligation to provide their needs, provoking anger among the bereaved young people.

Consistent with the accounts of the bereaved young people, the carers felt that they themselves and the young people they were caring for had been abandoned by the members of extended families, while the professionals thought that HIV/AIDS-related loss was always associated with stigma and social exclusion. It appears, therefore, that the experiences of the young people and their carers might have been associated with the view that their loss was AIDS-related; hence a reduction in the frequency of visits from close relatives.

However, the bereaved young people in this thesis seemed to be coping with their social exclusion using several strategies, often geared towards building solidarity between family members. Whilst many of them had this burning desire to re-unite with their paternal lineage, such efforts were often unsuccessful. They generally seemed to cope with social exclusion either by retaining what seemed to be a positive relationship with the primary carers and their siblings or by socialising with peers who had a similar problem. Professionals seemed to understand the importance of peer supportive networks for bereaved young people and they suggested that the OVC project was putting in place a plan that would allow young people to socialise more, to support and visit each other at home.

In summary, there was agreement between the participants that bereaved young people experienced social exclusion. They also maintained positive relationships with their primary carers and siblings and socialised with their peers in their efforts to reduce social exclusion.

### **5.3.4 Material discrimination and poverty**

There is a saying that ‘there is no orphan in Africa’, implying that the burden of caring for bereaved young people does not fall on the biological parents alone but is shouldered by the whole society. In other words it is children’s right to be fed, clothed, sheltered, protected, schooled and loved by members of the extended family. So it is the recognition that they have been deprived of these rights which has led the young people, carers and professionals to see young people as victims of stigma and discrimination.

The evidence from bereaved young people was that they wanted to regain their lives by having equal access to food, clothes and shelter, and enjoy the things their peers were enjoying and live like their peers in a society where care for young people was supposed to be a collective responsibility. Consistent evidence from all three groups suggested that non-primary carers (such as stepfamilies and other relatives), often members of the paternal lineage, only focused on providing support for their own biological children. Even people who used to be active in providing support when the parent was alive ceased contributing towards the bereaved young people after the death. Consistent with this evidence, in South Africa, Cluver and Gardner (2007) reported that in terms of material support bereaved young people who had been taken in by extended families were not always treated equally with the foster parents’ biological children. The latter were more likely to be bought clothes and given school lunches than the former.

Social exclusion and shame seemed to reinforce young people’s economic deprivation. Where the bereaved young people ceased to receive regular visits from members of their paternal lineage, it was very unlikely that material support could be acquired from these people. Similar support may have been lacking if they felt ashamed of themselves, leading to poverty and discrimination.

Bereaved young people seemed to develop strategies to cope with material discrimination and poverty. Evidence from the young people and their carers suggested that the former did not always give in; they actively confronted and dealt with potentially stigmatising situations or people. There was evidence of young people (a minority) showing anger to their landlords for trying to discredit them and their carers. Such attempts showed the young people’s refusal to

compromise family dignity. Even if the family had already been stigmatised, such confrontations may have helped young people to change their perceptions about self and others that were initially seen as potential sources of stigma. It may also have given them confidence to confront similar situations in the future.

Considering primary carers' inability to provide adequate material support for bereaved young people and the fact that they experienced material discrimination, it was not a surprise that evidence from young people, carers and professionals suggested that some of the young people had taken up additional income generating activities to reduce the economic impact of loss on their carers. They, their siblings and primary carers supported each other for their daily sustenance. This mutual support reduced their exposure to potential sources of material discrimination and may have reduced the impact of poverty on them.

According to the professionals, there were plans in place to train bereaved young people with some income generating skills so that they would be able to help their carers to meet their needs more adequately. Although adequate income may have reduced poverty and materially-related discrimination, bereaved young people's commitment to such tasks may have meant losing valuable time in their development. When they should be have been playing and interacting with their peers, they were either preoccupied with thoughts about their circumstances or occupied with income generating activities.

In summary all the participants agreed that bereaved young people had experienced material discrimination and that their carers were unable to meet their material needs adequately. Young people employed strategies to cope with these situations, including mutual support for siblings and the primary carers they were living with, which may have reduced their exposure to material discrimination. Another strategy was to take up additional income generating activities to reduce the economic impact of loss on their carers and siblings and their exposure to potential sources of material discrimination. And finally, strategies included refusal to accept stigmatising attitudes and behaviour from others by directly showing anger at their attempts to discredit the affected families.

### **5.3.5 Summary – coping with stigma**

In general, young people cope with their stigma, discrimination and poverty using five main strategies: they confront, act normal, avoid, withdraw or seek/engage with support. ‘Confronting stigma and related conditions’ includes: rejecting stigmatising attitudes/behaviour, refusing to internalise stigma and engaging in discussing stigma. ‘Acting normal in the presence of stigma’ includes: putting on a brave face, trying to connect with paternal lineage and engaging with classmates despite their stigmatising attitude. ‘Seeking/engaging with support and defying stigma and poverty’ includes: strengthening supportive relationships with primary carers, siblings and peer support groups (e.g. OVC). ‘Avoiding potential sources of stigma’ includes: distancing from people, places and situations that may incite stigma; avoiding the discussion of family HIV-positive status. And ‘withdrawing from stigmatisers’ includes: leaving places, people and situations because of the stigma experienced or perceived.

However, whilst these were coping mechanisms which young people used when confronted by or perceiving stigma, they appeared to be temporary measures. More comprehensive approaches may be required. Giving young people and their affected family members counselling may help them to protect themselves from the impact of stigma they anticipate or encounter. Support groups like OVC may minimise vulnerability of their members and enhance their resilience in response to stigma and loss. The behaviour of perpetrators of stigma needs to change. Information, Education and Communication (IEC) campaigns, which aim at giving correct information and addressing baseless fears and anxieties about the dangers of AIDS-bereaved young people, will help in this pursuit.

## **5.4 Supporting bereaved young people**

### **5.4.1 Support and its impact on bereaved young people’s coping**

The previous sections have shown that bereaved young people and their carers endured considerable hardship. In general they tended to be lonely and lack love and care from their families. Despite stigma, discriminations and poverty, young people’s accounts suggested that it is not all negative and that some of the adults were helpful. The sections that follow

will discuss the restoration-oriented coping in the light of the support some of the young people access to survive their loss and its consequences. DPM suggested that several substantial sources of stress (e.g. stigma and discrimination) and secondary consequences (e.g. communication problems) must also be confronted. The bereaved must find ways of addressing these problems, either directly or in cooperation with others. Attending to these multiple stressors means temporarily shifting attention away from the loss itself. In summary, shifting of attention away from the loss (or from loss-orientation) is referred to as 'restoration-orientation'.

## **5.4.2 Family as a protective factor for bereaved young people**

### 5.4.2.1 Capacity to provide care and support

The DPM proposed that, for optimal coping to occur, the bereaved also need to handle what Stroebe and Schut (1999) called minor stressors. The process of handling or dealing with these stressors is referred to as restoration-oriented coping. Since a family is considered as fundamentally the most useful unit that provides young people security, sense of belonging and identity (Mallmann 2001), it is not a surprise that all three groups of the participants named family as the primary source of care and protection for young people. There was also consistent evidence from these three groups that the main providers of care and support for young people within the family are their primary carers, who are often supported by siblings.

Consistent with this finding, Ankrah (1993) suggested that African families are capable of adapting to social adversities. Several studies (Heymann et al, 2007; Hillhorst, 2006 and UNICEF, 2004) have also shown that African families remain the primary source of support for bereaved young people. A study on the situational analysis of orphans and vulnerable people in the Gambia reported that although families are struggling to cope with poverty, they remain the main providers of various types of material support to orphans and vulnerable children (UNICEF, 2004).

Despite the widespread prevalence of poverty among the fostering families, young people, professionals and carers provided evidence that the bereaved young people depended on their primary carers for their day-to-day living. Whilst siblings helped in providing material

support, the primary carers were by far the main providers of food, shelter and clothing for the bereaved young people. Active participation of young people towards the upkeep of the family is not a new thing in Africa. Mallmann (2001) commented that ‘teenagers have for many years looked after households in rural areas whilst mothers migrate on weekly basis... to work as domestic workers in nearby cities’ (p.18).

However, mutual contributions of primary carers and siblings in maintaining the upkeep of the family is clearer in studies that focus on child-headed households (Nelson Mandela Children’s Fund, 2001; Naicker and Tshenase, 2002; Masondo, 2006; Malinga, 2002; Sengendo and Nambi, 1997); yet, even in these studies the head of the household remained the main provider (USAID/Zimbabwe/SCOPE, 2004).

In the absence of established social welfare services in the Gambia capable of taking care of bereaved young people and in an environment where adult mortality is likely to continue, the care and support provided by the primary carers contributed immensely to bereaved young people’s restoration-oriented coping. They were not only protected from hunger and homelessness, but at least provision of casual clothing may have reduced their exposure to verbal stigma.

The importance of adequate material support has been highlighted by all three groups of the participants. They felt that adequate material support was a form of security that would reduce worries centred on food and shelter. Evidence from the professionals indicated that the OVC had introduced a new initiative that intended to reduce child poverty. This initiative included income generating life skill training for bereaved young people. This was intended to reduce child poverty and probably place them at the same level as their non-bereaved peers, thus potentially reducing poverty-related stigma and discrimination. However, whilst the carers believed that when young people had material support they would live better, the professionals and the young people’s accounts seemed to suggest that although material support would be helpful, it was not perceived as enough on its own for adequate coping.

Although all the participants recognised that the material support young people received was inadequate and they may require external support, the fact that young people were not fending exclusively for themselves and there was at least someone who sheltered, clothed and

fed them was encouraging and seemed to give them the feeling that at least someone cared. There is evidence that appreciation (Stinnett and DeFrain, 1985), committed carer (Garmezy, 1984), and stable family environment (Wyman et al, 1992) serve as qualities of a helpful/protective family in an adverse social condition. Since family is the first environment in which a child experiences love, affection and makes discoveries (Mallmann, 2001, p.6), it was important that the primary carers, a majority of whom were the biological parents and siblings of the bereaved young people, remained central to the support young people received.

In summary all three groups recognised the importance of family support and viewed primary carers as the main source of support; but they were unable to meet the needs of the bereaved young people adequately and they may require external support to do that. However, carers differed from the professionals and adults in that they felt adequate material support was enough for optimal coping to occur; suggesting lack of carers' understanding of the psychological aspects of young people's coping.

#### 5.4.2.2 Positive relationship with the primary carer and siblings

One of the ways the bereaved young people dealt with their distress (i.e. secondary consequences of loss) was to establish/maintain positive relationships with the primary carers, a majority of whom were biological parents and their biological siblings. Although the professionals felt that a few non-biological primary carers might be discriminatory, evidence from all three groups of the participants in general suggested that, despite widespread stigma, bereaved young people had cordial and close relationships with their primary carers. Neither the primary carers nor the bereaved young people gave any negative comment about a primary carer or siblings of bereaved young people. There was evidence of young people describing a primary carer and siblings as caring and lovely.

This finding is consistent with other African studies. In Botswana (Tsheko et al, 2007), bereaved young people were found to get along with their carers. Their positive relationships with their carers were manifested by their feelings of happiness living in their new households. In Zimbabwe, 40% of the OVC reported that their guardians treated them with care and more than half reported that they were treated the same as biological children, while

the majority did not want their guardians to change anything. Studies have shown that positive relationships lead to more emotional support from the primary carers in terms of giving assurance, advice and caring for the bereaved young people (Tsheko et al, 2007) and more openness (69%) between the bereaved and their primary carers (Rusakaniko et al, 2006). (Issues of openness will be discussed later.)

The importance of a positive parent-child relationship was highlighted in the work of Bowlby (1980) when he introduced the attachment theory. It is now becoming common knowledge, at least in the West, that young people who have secured a positive attachment relationship with a caring adult are better equipped with psychological resources to deal with stressful life events than those without such an attachment. Richter et al (2004), suggested that positive parenting provides young people with resourcefulness and resilience to cope with parental bereavement; and that it can be a predictor of bereaved children's ability to cope with mental health problems, suggesting that this relationship was an important aspect of the bereaved young people's restoration-oriented coping processes.

In summary, whilst professionals felt that the bereaved young people may have been stigmatised by primary carers who were not their biological parents, in general the primary carers, a majority of whom were biological parents, and the bereaved young people showed positive relationships with one another - relationships that may help them cope with their loss.

#### 5.4.2.3 Influence of living arrangement on restoration-oriented coping

Another aspect of restoration-oriented coping is associated with living arrangement. Living arrangement concerns those with whom young people lived after the loss and how that influenced their coping. Evidence in this thesis shows that whilst African tradition provides bereaved young people an option to live with a member of the extended family, the majority of them lived with their remaining biological parent and their siblings. Consistent with this finding, several African studies (Gilborn et al, 2001; Rusakaniko et al, 2006 and Tsheko et al, 2007) showed that the majority of the young people knew their guardians well before they moved into their house. Such a familiarity seemed to contribute to young people's restoration-oriented coping, as living with a primary carer with whom one is familiar is

associated with feelings of happiness, comfort and relief (Gilborn et al, 2001) and a greater emotional well-being among bereaved young people (Nampanya-Serpell 1998).

However, familiarity is not limited to biological parents alone; Foster and William (2000) suggested that in the past, the sense of duty and responsibility of extended families in Africa towards other members was almost without limits. Consistent with the findings of this thesis, research shows that even though a family did not have sufficient resources to care for existing members, orphans were taken in and it was based on this assertion that traditionally 'there is no such thing as an orphan in Africa' (Van Den Berg, 2006; p.44). Considering the impact of HIV/AIDS on bereaved young people and their families, in many African societies the assumption that 'there is no such thing as an orphan in Africa' may be considered a myth.

In this thesis, although extended family members had often not lived up to their expectations, as clearly shown by young people's experience of stigma and discrimination, there was nevertheless evidence from all three groups of participants that when death occurred some (bereaved young people) were taken in by members of their extended families as a measure to reduce the economic burden on the bereaved family. Whilst these are customary measures in place to facilitate coping, they should only be encouraged when the psychological benefit of such a move for bereaved young people is obvious or outstanding.

Whether or not young people were living with a biological parent, the majority of them lived with their siblings in the same compound. The young people reported that continuing to live with siblings in the same household and interacting with them in special ways, as they used to with their deceased parent, was cherished by a young person because it made her feel as if the deceased was there and helped to reduce the feeling of loneliness. Consistent with these findings, in Zimbabwe, Nampanya-Serpell (2001) found that, when extended families kept bereaved young people together in the same household, fewer emotional problems existed than when they separated them from each other, suggesting the need to leave bereaved young people in the same household.

The evidence from the young people suggested that a few of them were living in different households from their siblings. The majority of these young people had lost both parents. In support, the carers and the professionals perceived that these bereaved young people (who

had lost both parents) had little chance of living together in the same household/compound. Yet, it is pleasing to note that all the bereaved young people in this research always lived in the same small town suggesting close proximity and possible visits. Consequently, none of the bereaved young people talked about missing a sibling. In Zimbabwe, Hirasawa (2007) found love, affection and appreciation between the siblings, despite hardship; and feeling of been loved, cared for and respected was found by Cluver and Gardner's (2007) South African study to enhance bereaved young people's ability to cope.

In summary, there was consistent evidence from the young people, carers and the professionals that bereaved young people mostly lived with their biological parents and those who lost both parents tended to live with members of their extended family. However, it was the bereaved young people who emphasised the emotional benefits such as their siblings' contributions that may have served as an important factor in their coping.

### **5.4.3 Family's influence on young people's emotional expressions**

#### 5.4.3.1 Behavioural expression of emotions

Emotional expression in this thesis is an observable behaviour that communicates and/or symbolises a strong feeling with/without the awareness of the person experiencing it. To some extent an individual may control such an expression or may have deliberate intent in displaying it (Kennedy-Moore and Watson, 1999).

Emotional expression in the West is the heart and soul of healing in bereavement. There is a widely held belief among laypeople and professionals in Western culture that expression of feelings is healing and bottling them up is a danger to health (Bowlby, 1980). The idea of bottling up suggests that emotions build up inside us like steam in an engine. This suggests that unpleasant experiences bottled up create discomfort and may be dangerous (Solomon, 2003). In the West, it is not uncommon to hear expressions such as 'letting off steam', 'releasing emotion', 'let it all out' and 'release pent up emotions'. All these show how culturally ingrained hydraulic philosophy is.

Africans seem to share a similar belief with the West but the African model of emotional expression was centred on adults and it is often manifested as part of the mourning process. When death occurs, adults are involved with a range of rituals which include crying, wailing, chanting, and talking to each other about loss, prayers for the deceased, seeing the deceased. However, emotional expression common to all the bereaved young people in this thesis was crying and there was no evidence of young people being involved in any of the other behaviours manifested in the above African model.

There was some similarity between the experiences of bereaved young people and the perceptions of the carers and professionals regarding the presence of crying behaviour. Crying was viewed by all three groups as a common behavioural expression of the immediate emotional reaction to loss.

It was generally perceived as a natural reaction to a stressful situation and it is unlikely to be avoidable when death occurs. The crying behaviour occurred as soon as bereaved young people became aware of their loss and, in a majority of the cases, it occurred the same day as the parent died. This finding is consistent with previous African studies conducted by Poulter (1996), Segendo and Nambi (1997), and an American study reported by Worden (1996). A study in France by Van Eerdewegh et al (1982) suggested that bereaved young people cried as an immediate response to their loss.

The following sections discuss whether bereaved young people were permitted to express their emotions, for example through talking and crying.

#### 5.4.3.2 Were bereaved young people permitted to express their emotions, for example through crying?

Although the bereaved young people's initial crying behaviour which mostly took place in public was expected by the carers and professionals, such an expression of emotion was not always welcome by the adults. Evidence from both young people and the carers suggested that, on the very day the parent died, some of the bereaved young people were requested by the adults to stop crying, even though they had desire to cry. One reason underpinning this request was that too much of it might cause ill health. The previous African studies reviewed

do not show whether or not adults supporting bereaved young people stopped them crying at the funeral ground, which was usually on the day their parent died. Moreover, Jewett (1994) suggested that, even in the West, rather than validating children's loss and supporting them, adults sometimes encouraged them 'to act as if what has happened to them is unimportant or [is a] relief' (Jewett, 1994, p.107). Indeed the only verbal communication that was reported as occurring between the bereaved young people and adults was to ask them to stop crying and be brave. Whilst this behaviour of adults may be culturally sanctioned, it may not be helpful to young people who want to express their emotion openly.

Whilst the initial crying of young people was reported by all three groups, it appeared that there were differences in opinion as to whether they continued to cry years after their loss. The bereaved young people said that they still cried three to five years after their loss, which is also consistent with the perceptions of the professionals. In France, Van Eerdewegh et al (1982) showed that such crying behaviour among their young research participants was not restricted to only that period immediately after loss: they observed intense crying among bereaved young people in France within the first 13 months after the death.

However the carers were unaware that the bereaved young people continued to express their emotions through crying behaviour. One explanation of their possible lack of awareness of young people's ongoing crying behaviour was that the young people engaged in the avoidance by crying privately, partly to avoid upsetting the adults, which may be the reason they were perceived by adults to be coping, when young people themselves perceived their experiences as overwhelming.

Evidence from the bereaved young people suggested that memories of the deceased were a key factor in triggering their crying behaviour. Other factors such as missing the affectionate relationship with the deceased and lacking what peers got were associated with crying. Bereaved young people also tended to cry privately after seeing their peers either interacting with their parents, especially during ceremonies, or the parents of their peers buying things for their children which they could not have. Such behaviour in the later part of bereavement suggested that young people required more support from their carers.

To summarise, there is evidence that bereaved young people were denied the ability to openly express their emotions through crying. Whilst young people said they still cried in private when confronted with circumstances that reminded them about their loss, their carers and professionals were not aware of such behaviour and they thought young people had recovered. Again it appeared that neither the professionals nor the carers were aware that young people continued to cry over their loss some time after the event. Moreover, it suggested limited understanding of bereaved young people's reactions and a lack of ability to talk to them effectively about their feelings.

#### 5.4.3.3 Were bereaved young people permitted to verbalise their emotions through talking?

Although no previous African study has discussed the importance of talking about loss for bereaved young people, talking about loss is the entire thrust of Western talking therapy. Many Western psychologists and bereavement scholars emphasise the therapeutic importance of talking, and there is some good evidence for this. For example, evidence from the Netherlands suggested that when people talk about their distress, they feel relieved; and when they feel they have been listened to, they are comforted (Zech and Rime, 2005). It also helps them to better understand their stress, which may attenuate some of the negative psychological distress associated with the event (Lepore et al, 2004).

In relation to talking and loss, Bowlby's (1980) theory suggested that adequate coping cannot be achieved without active engagement with loss, and talking facilitate this engagement. Jewett (1994) also advised carers to talk about loss about loss with the bereaved young people they were looking after, or at least allow them to show their thoughts and feelings, because talking would help them to get what was bothering them off their chest and enable them to be heard. It would release some stress and make them feel better.

Talking about loss is a manifestation that the bereaved is engaged with loss which, in the context of this thesis, falls under the DPM's loss-oriented coping.

Talking about loss and its related feelings as a form of emotional expression is not alien to Africans. There is evidence that bereaved adults in Africa shares their thoughts and feelings about their loss with their fellow adults (Kilonzo and Hogan, 1999). For example according

to Kilonzo and Hogan (1999) in Kenya it is a cultural practice for the bereaved adults to talk openly about their loss to those adults paying their last respect to the deceased. However there is no research evidence to show that African young people are encouraged to talk in this way. Whilst it appears that talking is allowed and culturally sanctioned ways of expressing feelings about loss, it appears that it is restricted to adults only. The evidence from the bereaved young people, carers and professionals in this thesis seemed to support this view. For example the evidence from young people suggested that they were often deprived of the information that death had occurred in the family. They often came to be aware of the loss when they heard people wailing or overheard people talking about it. In spite of their desire to talk about loss and efforts to initiate verbalisation by asking questions about their deceased parent, adults discouraged and refused to talk with them about their loss. Consistent with this evidence, the data from the carers and the professionals suggested that there was no talking about loss either between bereaved young people and their family members or professionals supporting them. This evidence with Wood et al's (2006) ethnographic case study in Zimbabwe found problems of verbal communication between the young people and their carers regarding the cause of parental illness, death and general matters relating to their parents' loss. In their study they found that, even though some of the young people wished to be told about their loss, they were not informed of their parent's death, let alone given the opportunity them to discuss their loss-related feelings. The reasons for this appeared to be that the adults hoped by doing this they would protect young people against distress. However in some cases they could not even identify young people's reactions.

The evidence from this thesis suggested that Gambian bereaved young people needed to talk about their loss as part of their coping process, an opportunity that had not been created for them in the past but one they desired. Despite their own acknowledgement of difficulty in discussing their parent's death and crying during the interviews, all the bereaved young people somehow showed their appreciation for being allowed to express their feelings to the interviewer. Having someone who listen to them and allow them to express their feelings was a new experience for young people, but one that they perceived has facilitated their safe expression of emotions during the interviews. Young people's comments on the interviews carried out for this research suggested that they found them helpful, and in some cases formed the first time they had been able to talk about their feelings. These accounts seemed to suggest that because of secure interview environment they were able to cry and talk about

their loss in a way that met their needs and suited them. It may be that the bereaved young people perceived the researcher as non-judgemental and therefore one who is safe to speak to. The discussions between the researcher and young people appeared to have a positive impact on young people's confidence. It increased their confidence in their ability to share their thoughts and feelings about their loss with their family members, thus reducing their anxiety related to talking about one's loss. This finding is a new contribution to African bereavement literature.

In summary, even though bereaved young people showed their desire to talk about their loss, which could facilitate their emotional expression, there was agreement between the young people, professionals and carers that their loss was shrouded with secrecy. Young people were neither told that death had occurred in the family nor involved in discussions about their loss after the event. Again it would appear that their needs are not being met in this context.

#### **5.4.4 Relationship with supernatural being (Religion and bereaved young people)**

In addition to the support and relationship with some family members, evidence from the young people suggested that they also established a relationship with a supernatural being. This relationship was built on the assumption that, since their own situation was hard to change by themselves and the people around them, they could always sustain the belief that all would not be lost since God remains firmly in control and explicitly supports them (Pargament, 2002). Their frequent mentioning of God during the interviews was a manifestation of their assumption. It suggested their belief in a power superior to their own and one that may help them to overcome difficulty they were encountering. This was shown when a majority of them engaged in prayers not only for the retention of connection with the deceased parent but also to gain closeness to their deity.

Apart from retaining connection with the deceased parent through prayers, the bereaved young people viewed their relationship with their deity as comforting as they knew someone out there was watching over them. McIntosh and Ladd (2008) suggested that prayer by its nature facilitates engagement in care taking behaviours (e.g. intercessory prayer) and as such it 'has the ability to meet human's built in needs to provide and receive care taking (p. 34)

and it may help to ‘keep a person’s perceptions of internal or external stress well under control’ (p.34).

The influence of young people’s belief about what is perceived as acceptable or not acceptable by their religion was crucial to how they reacted to their loss. Evidence from both the carers and young people was that religious belief influenced many young people to accept loss immediately after the event (presumably after the initial denial). The evidence that their religion encourages the acceptance of loss as opposed to disbelief may be a good thing. McIntosh (1995) suggested that a religious network with an explicit belief system ‘may facilitate integration of stressful or traumatic events into one’s beliefs about the world and oneself that leads to more positive post crises outcome’ (Ladd and McIntosh, 2008, p.28).

An explicit religious belief system creates a social network as a readymade resource to be tapped when needed (McIntosh, 1995). The sharing of an explicit worldview with others in the society may enhance interpersonal support (Hackney and Sanders, 2003), as people living in a society that supports their faith are likely to get most benefit from their religion (Pargament, 2002). Ankrah (1993) suggested that spiritual leaders have important roles in traditional African society because they serve as psychologist and counsellors, yet there is no evidence in this thesis that such religious supports were available to bereaved young people. Whilst a majority of these spiritual leaders may focus on adults, paying more attention to young people and engaging with them will show them that they care.

Despite the influence of religious belief on their reactions and despite living within a network of people who share the same worldview with them, there is no evidence that adults prayed together with them. A majority of the carers were not even aware of young people’s engagement with prayers.

#### **5.4.5 OVC and peer support**

##### 5.4.5.1 OVC support

UNAIDS and USAID (2002) called upon governments and agencies to provide support for bereaved or stressed children through the existing family and community structures. One

such agency in the Gambia is the Orphans and Vulnerable Children (OVC) project which focuses on children and young people whose parents are chronically ill or have died of a chronic illness including AIDS. The goals of the OVC project are provision of life skills to meet the material demands of young people such as school fees, food rations and free medication, as well as supporting their parents during illness and providing psychological help.

It appears that this project goes some way to help bereaved young people to cope with their loss. However, whilst the project is supportive, the accounts of the young people, carers and professionals suggested that its goals have not yet been fully achieved. All three groups of participants suggested that the project was helpful in providing material support, with school funding being the aspect of support most talked about. Evidence from the young people, carers and professionals suggested that financial rewards in terms of school fees has addressed many of the earlier fears and anxieties experienced by the bereaved young people and their families. The young people and their carers' initial fear of not being able to pay their school fees, and consequently their having to drop out of school, had been addressed.

Similar financial support was also found useful in Tanzania but it was perceived to create economic dependency, such that, when the funding stopped, children would not be able to continue schooling (UNAIDS, 2001). To avoid or reduce dependency, professionals working for the OVC project in the Gambia have developed and implemented life skills programs which included tie and die, batik and soap making (which are profitable local businesses in Gambia) so that when the funding was stopped, young people and their families could pay for the school fees. Although the young participants in the study were not yet involved at the time of data collection, the professionals felt that training and the provision of capital to start businesses would help the young people and their families to raise the much needed finance to run their day-to-day affairs. However, with many people already involved in similar businesses, it was not clear how the organisation was helping the young people to market their products, or how they would survive in such a competitive environment let alone make a profit to support themselves, their surviving ill parent and pay school fees when the sponsorship stopped.

There is also strong evidence that the project was trying to strengthen the relationship between the young people of different ethnic origin, age and gender sponsored by the project by bringing them together to socialise. Whilst the general members of the support group met quarterly, the executive members (who were also the young people) met twice more. The meetings were mainly to create an avenue for young people to interact and discuss issues affecting them. Although they were meant to set their own agenda for the meetings, according to the professionals that was not yet happening. This intervention was similar to HUMULIZA's innovative peer counselling in Tanzania (UNAIDS, 2001). According to young people, during the meetings they engaged in activities such as chatting but, as we have seen, there was no discussion on loss and coping.

Group meetings were generally found to be useful in providing a platform to interact and chat; however, the carers did not recognise the importance of the social aspects of such meetings. The data suggested that bringing young people who had similar experience under the same roof created acquaintances and friendship and reduced feelings of loneliness. Yet, as in Masiye Camp, the members of the OVC project received 'low dose' psychological support from the project by attending quarterly meetings (Bantaba) which lasted for a few hours. It is therefore not a surprise that, despite regular meetings, neither the professionals nor the members of the group in this thesis were confident enough to discuss issues concerning a parent's death.

In summary it appears that all three groups of participants agreed that the OVC project was supportive in providing material support and teaching life skills which might enable the young people to make a living. The bereaved young people and professionals also felt that the OVC project was useful for bereaved young people in helping them feel less alone and less different from other young people. These useful aspects of the OVC project need to be respected and retained, but it could usefully be developed to provide an avenue for young people to discuss their loss.

#### 5.4.5.2 Peer support

A Western research study by Worden (1996), the Harvard Bereavement Study, suggested that peer support for bereaved young people can create an environment conducive for discussion about death and sharing of emotion.

Although the young people reported that their peers in the OVC kept them company, which suggested their involvement in restoration-oriented coping, these peers met only occasionally at their OVC support project. Bereaved young people identified themselves with these peers not only because they are age mates but because they shared the common problem of losing their parent to AIDS or other chronic illnesses. However whilst it might seem likely that bereaved young people should find such a group useful, in fact only half of them thought it was useful.

Evidence from the bereaved young people and the professionals showed that there was no discussion on loss during OVC support meetings among bereaved young people, suggesting that the environment was not sufficiently conducive for such a discussion. Half of the bereaved young people perceived the peer group as useful, saying that their relationship with peers in this group provided an environment in which to interact and talk with others in the same situation. However, the topic of loss was generally avoided. This appears to be because of their understanding of the purpose of the gathering which seem to be avoidance through getting away from home, and thus to talk about death would remind them of their loss and compromise the purpose of the gathering. Secondly there was a belief that initiating and going ahead with a discussion about death would be hard, especially at the OVC meeting. Clearly they did not have the understanding and there is no indication that they had been prepared to tackle discussions about loss especially that the carers and the professionals themselves appeared to be avoiding discussions on death.

However the group was useful to some. Half of the bereaved young people reported feeling that, at some point, they had benefited from being with their peers, who provided them with an environment that comforted them and allowed them to chat and interact with one another. The interactions and chatting created comfort that helped the young people to make friends and to understand that there were other young people with similar experiences in their own

neighbourhood. It not only reduced bereaved young people's loneliness but also the worries associated with feelings of being different from other people. The professionals were also aware that bringing peers together as a group reduced loneliness and created an environment within which they could make friends.

The general comforting nature of the peer group, even in the absence of any discussion of loss and bereavement, is supported by the findings of other previous African studies. In Cluver and Gardner's (2007) study peer support helped protect bereaved young people from psychological problems. Atwine et al (1997) also found that peer support reduced anxiety and depression. It is not clear whether bereaved young people in this research experienced stigma; however, if they did, Atwine et al's (1997) findings suggested that interaction with their peers may have diminished their feelings of stigma and shame.

Peer support also seemed to be related with the avoidance approach. From the data of the young people, it appears that engaging and interacting with peers temporarily helped bereaved young people to escape from intense emotions that may have been caused by the active engagement with loss. The reason seems to have been that peers engaged them with talk and activities during their socialisation as an alternative to them focusing on death, suggesting their involvement in restoration-oriented coping.

Evidence from the professionals suggested that plans were in place to consolidate relationships and improve trust between the group members through embarking on peer home visits in order to help them optimise their coping. The project proposed initiating interventions similar to youth-run projects such as YOCIC in Zimbabwe and Vijana Simama Imara VSI organisation in Tanzania which were found to be giving young people the voice they needed to change their own circumstances (UNAIDS 2001). Generally it was not clear how this project would facilitate peer support or the benefit of peer support.

In summary, evidence from the young people and the professionals suggested that peer support helps in reducing isolation. The young people also perceived that it served as a temporary respite from intense emotions, suggesting the need to encourage interaction with each other. Such interaction may have reduced the feeling that they were different from them. However it was clear that no opportunity was taken to help the young people talk about death

with one another, and help one another to find comfort and support in their mutual experiences of loss.

### **5.5 A proposed West African model of bereavement**

The purpose of using the DPM has been to guide this research in exploring young people's emotional reactions to loss and uncover a selection of social factors that influenced their coping in a West African context.

The findings of this thesis support Stroebe and Schut's (1999) proposed DPM model which suggested that loss- and restoration-oriented coping are integral and important parts of young people's reactions to loss. The term loss-oriented coping refers to the bereaved young people's engagement with or paying attention to the deceased parent and expression of reactions related to death. Restoration-orientation refers to avoidance of loss experience and focusing attention on living which includes thinking or engaging with secondary stressors. For optimum coping to occur, the bereaved (e.g. bereaved young) people have to oscillate between loss and restoration orientations. Stroebe and Schut (1999) emphasised that focusing on one does not result in the absence of the other but only its temporary avoidance.

The present West African bereavement model suggests that coping with AIDS-related death is complex because young people have to cope with loss on one hand and also cope with stigma, discrimination and poverty that come with AIDS on the other hand. It is evident that young people do not wait until they completely recover from their loss before they start dealing with poverty and material discrimination. The two processes seemed to alternate throughout the duration of the bereavement. The evidence in this thesis clearly suggested that bereaved young people sometimes confront their loss especially at the immediate aftermath of the loss itself, at other times they avoid memories, are distracted by trying to cope with poverty and stigma or seek relief by socialising with peers and primary carers. Several alternations may take place in a day, and over months or years: for example, a young person who wakes up feeling sad because of the loss (loss-orientation) becomes lively again and able to focus on her income generating activity for the family sustenance (restoration-orientation),

then sinks back to loss (loss-orientation) when she comes in contact with the belongings of the deceased which bring on a wave of emotion.

This model is an improvement on the traditional Western stage model which focuses only on loss-oriented coping as a coping strategy to loss. Although the original DPM was developed from research on adults in the West and, as far as the researcher is concerned, there is no evidence that it has been used in Africa or on AIDS-bereaved young people, the evidence in this thesis suggests that it is a useful framework in West African AIDS-bereavement research. Being the first of its kind, it may increase our understanding of how bereaved young people from West Africa cope with death and poverty, stigma and discrimination during bereavement.

The following model is a West African version of DPM and it intends to show the complexity of bereaved young people's reactions to AIDS-related death. This model intends to be both descriptive and prescriptive.

### **5.5.1 Coming to grips with acceptance and denial of loss**

This model proposes that when African bereaved young people are confronted with or have experienced loss, they do not immediately process the full information about the loss. The loss-related threat might be identified by their natural defence mechanism which may allow them to shutdown their emotional awareness and 'screen out potentially overwhelming or devastating information' about the loss (Jewett, 1994; p.66). Processing the information that 'a parent has died' could be difficult for anyone, let alone young people who often have stable, caring and nurturing relationships with their parents.

Although denial responses were reported, because of what appears to be their socio-religious beliefs, only a minority of people perceived its prevalence among young people in the Gambia. They seemed to be holding the belief that life and death are predetermined by God and accepting death as the will of God is a religious obligation. An expression of disbelief or denial may therefore be perceived a violation of socio-religious order and therefore not a feeling to be admitted, even to oneself. However, it may be that the young people experienced denial inwardly as a feeling but were not able to express it openly during

bereavement, or even name it for themselves, because of their cultural and religious beliefs. In addition it might have been a common experience but carers and professionals might not have noticed it, owing to the dominance of crying often in the acute stage of bereavement.

Whilst a minority might have perceived the presence of denial and a majority perceived acceptance of loss, in reality many young people might have experienced denial at the acute stage of bereavement before they finally accepted their loss. When the environment is emotionally charged as it is at the acute stage of bereavement, African young people may not be psychologically prepared to deal with such powerful emotions as yet; they need to process them in 'smaller manageable doses' (Ankrah, 1999, p.69), allowing them to avoid being too overwhelmed by their loss. Temporarily allowing them to selectively deny threatening information of their loss may help them to have a break from intense emotions and regain their strength to confront their loss.

It would appear that in this context denial and acceptance are like a continuum with two extremes, denial at one extreme end and acceptance at the other (e.g. denial---acceptance). At first contact with the information on loss, young people may experience denial and gradually move towards acceptance. When they come to the stage of acceptance, the full realisation of their loss becomes evident. Many of them are likely to explode at this stage, as was clearly seen in this thesis when bereaved young people burst into tears. Although acceptance is the end of the continuum, young people may not have the capacity to permanently engage with these strong emotions, suggesting the continuation of the 'denial --- acceptance' cycle. This process may go on for several times in a day, month or year. The beginning and ending of the continuum may differ between individuals and some may never experience one or the other. There is even a possibility that one may get stuck at one end of the continuum making coping difficult for them.

As adults we must not only rely on our beliefs, we must try to have an open mind. We must understand that denial response is a psychological process and it is not a confirmation that one has lost faith in God or one is challenging the powers of God in any way. It is important for adults to share this view with their children, so that they may feel that it is normal to deny loss.

### **5.5.2 Engaging in emotional expression**

Emotional expression viewed as both a communicative signal (e.g. that one needs a help) as well as an underlying symptom of an emotional state (Parkinson, 2005) is a universal need, as it was found in this thesis. Therefore it is not a coincidence that when young people become aware of their loss they express their sadness, anger, fears and loneliness through several behaviours including crying. Their crying often occurs at the acute stage of bereavement, and in a majority of the cases it occurs the same day as the parent died and in the presence of the adults. After this initial emotional expression, they are more likely to cry privately and in private places, largely due to social pressure to inhibit their emotions.

However, there is much evidence to suggest that emotional expression may be helpful to bereaved young people, as it is associated with less illness (Pennebaker 1988), reduction of distress and depression, improved physical and mental health (Pennebaker, 1997; Greenberg and Stone, 1992 and Greenberg et al, 1996) and immune functioning (Pennebaker, 1988). The evidence suggests that young people's emotional expression should be encouraged as it is a healthy option in coping with loss.

Despite the evidence that emotional expression is helpful and despite young people's desire to express their emotions openly, they are likely to be discouraged by adults. On the very day their parent died they may not even have been informed of the death, they may have overheard it from secondary sources, there may not be any discussion about loss, they may even be told to stop crying and be brave. Even in the later part of bereavement when young people feel the need to express emotion in public so that they can receive support, they may resort to private expression of emotions, denying carers the opportunity to know how they are feeling and what needs they may have.

Adults must understand that bereaved young people feel as deeply as they do and they need to express these feelings in the same way as adults. Therefore the current African way of expecting young people not to talk, and seeing them as simple, empty vessels, emotionally shallow, forgetful and easily distracted needs to be replaced with a more sophisticated understanding of the need for young people to express themselves and of their having complex feelings. Current expectations need to be replaced with an improved African model

which draws on elements of Western thinking, but also uses current African models which are only applied to adults (e.g. talking, expressing, wailing, rituals etc) at present.

In the West, emotional expression is the entire thrust of talking therapy. There is a widely held belief among laypeople and professionals in Western culture that expression of feelings is healing, and bottling them up is a danger to health (Bowlby, 1980). The idea of bottling up suggests that emotions build up inside us like steam in an engine and that the steam or emotions need to be let off, released or vent out before causing any damage (Solomon, 2003). Clearly Western thinking is that the more one expresses emotions, the greater the immediate relief and the beneficial effects of such an expression (Kennedy-Moore and Watson, 1999).

The current African model for adults' bereavement seems to draw extensively on Western thinking, especially in relation to talking and expression of emotions. Emotional expression through talking, chanting and wailing are a few of the characteristics of African adults' ways of demonstrating openly the intensity of their sorrow and remorse (Kilonzo and Hogan, 1999). As regards talking, the spouse of the deceased often narrates a story about events that led to the death to late comers in highly emotionally charged language; which is often followed by sobbing and consolation of each other. Several other behavioural rituals include: viewing the corpse, praying for the corpse and special black cloth for the widow to wear. All these rituals show the intense engagement and expressing of emotions adults embark on, a model that can also be revisited and improved upon to integrate the complex needs of bereaved young people.

AIDS-bereaved young people in this thesis had the urge to talk about loss, and hence to ask adults about it. Their right to be heard must be recognised by adults. Allowing their voices to be heard indirectly shows that they would not experience their loss in isolation, but rather as part of the family. Recognising their voice may give them the impression that they are valued members of the family, suggesting that they can rely on family members when needed. In addition adults can provide relief for bereaved young people by listening and by simply allowing them to talk, even if one doesn't have all the answers (Zech and Rime, 2005). Having someone who listens to them and allows them to express their feelings, especially at the acute stage of their bereavement, may facilitate their safe expression of emotions and it

may in the later part of the bereavement give them the courage to share their thoughts and feelings about their loss with their family members, thus reducing the anxiety related to talking about their loss.

As adults we have a duty of care, we must stop telling young people not to cry and instead we should recognise their need to talk and cry. They should be told that it is okay for them to openly express their thoughts and feelings when they feel the need to, but they must not be pressurised to ‘express it all’ or ‘tell all’, even if that is what is perceived by the adults as the right way to do things. We must now clarify our thoughts about their loss and console them as we console our fellow adults. In this way we may be validating their loss and preparing them to deal more effectively with situations that are challenging to them.

### **5.5.3 Apprehension over survival**

The DPM suggested that when death occurs the bereaved have to deal with the secondary consequences of it. Young people need not completely recover from loss to be able to shift their attention to other things. Dealing with the secondary consequences of loss such as the quest for survival requires shifting of attention temporarily away from the loss itself; hence it is not possible for young people to be completely focused on loss and at the same time pay one hundred percent attention to the survival hunt.

African young people may realise or perceive that the deceased parent was their only source of livelihood and security. They may start feeling that their world is crashing down, when they realise that their surviving parents may not be able to meet their needs such as paying for school fees and, at the same time, providing them with food, shelter and clothing. They may be preoccupied with thoughts and feelings and asking themselves who would pay their school fees and whether they would have to drop out from school. They ask themselves whether their carers would be able to pay rent and whether they would be evicted if they failed to do so. Stigma and discrimination may aggravate these concerns.

Considering widespread poverty and the fact that parents are the main breadwinners, young people’s apprehension over survival appears to be an experience many African people will encounter (Atwine et al, 2005; Nkomo, 2006; Cluver and Gardner, 2007;

Sengendo and Nambi, 1997; and Chatterji et al, 2005). Adults must therefore reassure bereaved young people who may be holding these thoughts and feelings that it is okay for them to feel that way but that they must also make conscious efforts to reduce these apprehensions. In helping young people, truth about the situation must not be concealed or compromised; adults need to be realistic regarding the message they convey to the young people. Giving the impression that everything will be fine, especially in this poor community of Brikama, may raise unrealistic hopes that would later be shattered. Ignoring the realities and keeping quiet as if one is not bothered about young people's concerns is not helpful because it will only put doubts into their minds. Even if the adults' intention is to protect them, bereaved young people may interpret this as lack of support or discrimination. Adults must understand that their well-intended care may be perceived by the bereaved young people as unhelpful, which suggests the need to understand young peoples' problems from their own perspectives.

Although African young people's concerns and worries appear to continue throughout their bereavement, there are specific periods of the year or day when their worries and concerns are likely to be elevated. They include bedtime when the deceased parent may be particularly missed, the end of the month when rents are due to be paid, just before and during annual Muslim festivals when new clothes and the presence of parents are required, and the beginning of a new academic year when parents are required to pay school fees and attend parent-teachers' meetings. All these times are associated with anxiety and fear among bereaved young people.

Unfortunately adults in the Gambia did not know these important periods. Knowing them would have enabled carers to engage with bereaved young people, share certain information with them and give them assurance that not all hope was lost. The extent to which this specific fear and concern lasted is likely to have depended on how well the adults engaged with them and understood their concerns. Whereas issues associated with affordability may have been easy to address, fears and anxieties about seeing peers with their parents may last for a very long time if they are not addressed.

#### **5.5.4 Sense of helplessness and uncertainty**

Parents are the protectors of their children and their death shakes the personal safety of bereaved young people. Not only do African young people feel powerless over the death of the loved-one and the emotions it comes with, they will also be concerned with what exactly the future holds for them, their carer and siblings. They are not only likely to see their surviving parent's deteriorating health condition but may also learn to live with the stigma associated with it.

Lack of control means African young people are pre-occupied with the consequences of their loss, and concerned about personal safety and the safety of their carers and siblings. Where the surviving parent/carer, sibling or self is ill, especially when the signs and symptoms are similar to those of the deceased parent, there will be particular safety concerns. Young people are worried that the person concerned will die and they have no control or power to prevent this.

When the future is uncertain for African young people in the aftermath of death, there may be conscious efforts to prevent family disintegration or abandonment. As the paternal family is supposed to be the main source of support and protection for bereaved young people in Africa, young people may make conscious efforts to reunite and retain connection with their paternal lineage; as it is evident in this research. Here it is shown that they were seriously worried about family disintegration, abandonment and the associated consequences. Such consequences included anger and humiliation.

Adults must realise that young people are afraid of family disintegration and as such all efforts should be made to sort out relationship issues and place the interests of young people first. In pursuing this, better communication between family members would be of benefit. It is important to discuss the future with the young people as they are often preoccupied about the uncertainty of the future.

### **5.5.5 Creating breathing space – avoidance**

At some point in their bereavement African young people need to make a conscious decision to create a breathing space for themselves. Creating this space involves distancing themselves from places, people, events and activities that may serve as potential reminders to their loss. They may temporarily withdraw physically to go and sit on their own away from the funeral ground or they may even go to a football match when other people are at the funeral. It is not that young people do not care, but these are some of the strategies they use to minimise the impact of loss on them.

Although the pain of confronting the memories of the deceased parent may remain, creating breathing space may serve as an opportunity for African young people to digest their experience in a way that is convenient to them. They sometimes need a breath of fresh air so that they will be able to deal with their loss in an appropriate manner.

Adults must not assume that young people do not feel their loss when they are not acting sad; neither should it be interpreted as the loss being irrelevant to young people. They may escape the weight of their loss by engaging in behaviours at moments that seem inappropriate to adults, but adults must understand that bereaved young people do not always engage with their loss. They should also be in a position to reassure young people that it is normal for them to temporarily avoid their loss experience (restoration-oriented coping) either by having fun with their peers or being preoccupied with thoughts about their schooling. Although optimum coping may be achieved by the movement of bereaved people between focusing on the person who has died, the need to express emotions and the desire to find a respite from grieving and get on with living (Stroebe and Schut, 1999), adults must take extra care not to put pressure (e.g. telling them not to cry etc.) that will further reinforce young people's denial responses.

### **5.5.6 Withdrawing and avoiding stigma**

Stigma and discrimination seemed to compound the experiences of young people throughout their bereavement and they need to find ways of coping with them. They seemed to be using several strategies to cope with stigma and discrimination. Common strategies likely to be

used include avoidance and withdrawal. Bereaved young people may first assess, identify, perceive or preconceive potentially stigmatising situations and avoid them. Such situations may include avoiding (see Avoidance) places such as market areas or festival events where the bereaved young people may see their peers (non-bereaved young people) interacting with their parents. If the bereaved young people perceived they would not be able to cope with further stigma, such avoidance may reduce their exposure to enacted stigma. Avoidance may also prevent further internalisation of stigma and reinforcement of the shame young people may already be experiencing. Secrecy surrounding a parent's HIV-positive status and AIDS-related death may be a deliberate attempt to avoid enacted stigma.

Young people who are already experiencing stigma may also withdraw from stigmatising situations if they feel they are not strong enough to confront them (see next section). Bereaved young people's use of one or several of these strategies may depend on their perception of self and people around them, the degree of the threat, feasibility of a strategy and the opportunity to use it. For example, they may experience stigma at school, yet they have to interact with their classmates who are stigmatising them, because there may be very limited opportunity to avoid such an interaction. In situations like this to avoid further stigma or reinforcement of the existing stigma, they may choose to 'put on a brave face' and 'act normal' as if nothing happens.

It is important that adults understand and appreciate the complexity of young people's coping processes in order to avoid reinforcing behaviours that may not be helpful. Although avoidance and withdrawal may be a temporary relief of emotional discomfort that results from stigma, it may become unhelpful when it is prolonged and interferes with potential sources of support. The distress associated with a stigmatising condition may force young people to ignore or mask it and sacrifice help that they might readily recognise as useful if someone else was affected. Whilst continuous withdrawal from interpersonal relationships needs to be discouraged, adults must be careful not to place young people in relationships that may reinforce their existing stigma. Adequate communication with young people may equip adults with the necessary tools vital in helping young people to cope better with their situation. However, although the above coping strategies of bereaved young people may be helpful, the attitude of members of society also needs to change to allow young people to

function as children of their age should. There should be a community stigma awareness campaign to challenge the very core beliefs that underpin AIDS-related stigma.

### **5.5.7 Confronting stigma – anger and disclosure**

Bereaved young people may not always withdraw or avoid stigmatising situations; they may confront and reject what they perceive as negative attitudes and behaviour from others. This section of the model focuses on confronting felt/enacted stigma or stigmatising situations.

It appears that anger and disclosure are two strategies young people may choose to use in confronting real or perceived stigma. Anger in the Gambia is often used in response to injustice which may be shown through verbal or physical aggression towards the person causing injustice. Bowlby (1998) suggested that anger is an intense emotional reaction associated with a fight against what is perceived to be undesirable; and may be directed at someone perceived as responsible for the loss or those reminders and people who bring home the reality of loss (Parkes, 1970).

Since stigma is perceived by young people as undesirable and people stigmatising are considered to be involved in unjust acts, young people may direct their anger at them. The anger towards people perceived to be belittling or trying to belittle young people may be a deliberate attempt to protect their dignity and minimise their internalisation of negative perception about themselves. Young people may verbally tell off people who are trying to stigmatise them; and yell at them for their attempts to degrade their carers for not paying rent in time or for not having the money to pay rent. Such outward expression of anger may stop stigma and discriminations and force the perpetrators to change their attitude and behaviour towards bereaved young people, at least for a while.

Although adults should not deny bereaved young people confronting a potential source of stigma with anger, adults must not always assume that every angry response is as a result of a real or potential source of stigma. There is a need to engage with young people to better understand what exactly they are angry about, as there may be a tendency to displace anger making coping difficult for them.

Although the outward expression of anger is perceived to be directed at stigma and discrimination, it is important to note that bereaved young people may experience loss-related anger inwardly as a feeling whilst unable to express it openly during bereavement, or even name it for themselves, because their cultural and religious beliefs dictate that one should not get angry at God or at a deceased parent. There is therefore a possibility that loss-related anger may be redirected towards other people in the family perceived to be perpetrators; which may lead to distorted communication and difficulty in coming to terms with their loss (Jewett, 1994).

Another way young people may confront their loss and stigma is by talking about them. The evidence that the bereaved young people in this thesis shared their thoughts and feelings regarding stigma or potential sources of stigma with the researcher was an indication that, in the right environment, they might share some of these issues with family members. Whilst sharing their problems with people they perceive as potential perpetrators is a risky business, information sharing often addresses anxiety and may turn out to be an important source of support for young people.

Whilst it may be a volatile situation to disclose family concerns to others, it may be important for adults to help young people share their thoughts and feelings on issues surrounding their loss. In addition, addressing stigma and discrimination in the Gambia requires a public awareness campaign that educates people on the impact of these stressors on bereaved young people, and the best possible ways of helping them, using traditional methods of communication such as singing, dramatisation, storytelling and visual presentations.

#### **5.5.8 Strengthening social connectedness – real sense of unity between siblings and peers**

Whilst bereaved young people live in a society where traditionally every child is perceived to have several carers looking after them, AIDS seems to have altered that structure. Family members tend to isolate them, resulting in social exclusion. To deal and cope with enacted stigma like social exclusion, bereaved young people may strengthen their relationship with the few members of the family that are accessible to them. On the other hand they may establish new/ reinforce existing relationships with peers who have similar problems to their own.

Bereaved young people may make conscious efforts to re-unite with members of their traditional paternal lineage but such efforts are often unsuccessful. They generally seemed to cope with social exclusion by retaining what seemed to be a positive relationship with primary carers and their siblings. This secured attachment relationship with a primary carer may not only have reduced isolation but also better equipped them with psychological resources to deal with stressful life events (Bowlby, 1980), including death and social exclusion. Whilst young people's efforts to bring family members together should be supported as long as it is not detrimental to their coping processes, it is important for the adults to recognise and maintain the existing positive relationships with young people.

Adults should be aware that their presence at the time of death would make little difference if they were not caring, because bereaved young people at this point need adults to show them additional love and reassurance that someone will look after them, despite the loss. Showing them love (e.g. by interacting with them, rubbing hand on their head/shoulder or hugging them) at the time when most Gambians may be focusing their attention on bereaved adults would give them the impression that the adults were caring. Although, this may not replace the love they had for their deceased parent, it may validate their loss and give them hope that someone out there was caring, thus minimising their worries about access to care from family members. Care for bereaved young people should not be limited to this period; it should be throughout their bereavement. Adults may give them a gentle stroke and cuddle more frequently now than before because things like that show that you care.

It also appears that bereaved young people valued their relationship with peers in similar situations. Establishing and strengthening existing positive relationships and socialising with them may have reduced isolation. The fact that they shared the same misfortune indicated that they may understand each other's concerns and interact better. The idea that the OVC project in the Gambia is trying to strengthen this very relationship between OVC members may be a step in the right direction and it may even help to demystify stigma related to social exclusion.

Adults must advocate relationship building and encourage their children to visit other children who may have similar experiences. Children should also be allowed to visit anyone they wish to visit, not only their peers who share the same experience. Bereaved young

people in this thesis wanted to be treated on equal terms with non-bereaved young people and also found family visits, engagement with peers with similar problems and material support from the OVC project helpful to them. This suggests that bereaved young people also need more such support in a consistent and continuous manner.

#### **5.5.9 Reaching out for tangible social support – material support**

Before the advent of HIV/AIDS, the sense of duty and responsibility of extended families towards other members was almost without limits (Foster and William 2000). Even though a family did not have sufficient resources to care for existing members, orphans were taken in (Van Den Berg, 2006). This was the basis of the assertion that traditionally ‘there is no such thing as an orphan in Africa’ (Van Den Berg, 2006; p.44). Today, poverty, stigma and discrimination seem to have made this claim a myth for many bereaved young people. Many young people are in need of the sort of things their peers have and feel materially deprived.

However, young people seemed to reach out for tangible social support to reduce the impact of poverty and material discrimination against them. They appear to use two strategies: consolidation of family effort to meet material needs, and engagement with support of the OVC project. Both strategies appear to be useful in mitigating the impact of these stressors. Where parents used to be the only providers of material support, many young people may now take up additional income generating activities to reduce the economic impact of loss on them and their carers. Where paying for school fees and school expenses was a problem, many of them may seek assistance from the OVC project for such support. There are also plans to give bereaved young people necessary income generating skills, so that they can operate their own small businesses.

Adequate material provision for bereaved young people may mitigate poverty. At least if young people have as much as their peers, this will go a long way in addressing some of their bigger concerns. These concerns include peers having better clothes than them. With material possessions equal to their peers, some young people may start socialising with their peers and the general public, reducing their felt stigma and stigma driven by poverty and material discrimination. It is therefore important for such material support to continue as far as possible, but in the long term it needs to be replaced with a traditional system that is

permanent and has the ability to distribute communities' resources equally among bereaved young people.

#### **5.5.10 Strengthening/reaching out for supernatural support**

Many young people may establish/strengthen their relationship with a supernatural being as a way of coping with their AIDS-related loss and its consequences. Young people may feel they have lost control of their lives and that adults around them can only make little impact to change their situations. As a result of their perceived loss of control, they may always sustain the belief that all will not be lost since God remains firmly in control and explicitly supports them (Pargament, 2002). They may turn to this supernatural power they believe is capable of rescuing them from their troubles. A belief that when people fail you there is someone out there more powerful watching over you may be comforting for many bereaved young people.

Bereaved young people may physically engage in religious rituals such as prayers that help them to establish or maintain existing relationships and gain closeness with their deity. For young people, prayer seems to be important because it 'has the ability to meet human's built in needs to provide and receive care taking' (McIntosh and Ladd, 2008, p. 34) and it may help to 'keep a person's perceptions of internal or external stress well under control' (McIntosh and Ladd, 2008; p.34). So their prayers may be used not only to retain connection with the deceased person (see next section) but also to seek support from their deity.

In addition to their prayers, young people's religious belief seems to dictate how they should react to loss. According to McIntosh, a religious network with an explicit belief system 'may facilitate integration of stressful or traumatic events into one's beliefs about the world and oneself that leads to more positive post crises outcome' (Ladd and McIntosh, 2008, p.28). Despite the difficulty associated with confronting the news that one's parent is dead, young people's religious belief encourages acceptance rather than disbelieving in such news. It may be that their initial emotional expressions on the very day the death occurred were influenced by this belief.

An explicit religious belief system creates a social network as a readymade resource to be tapped when needed (McIntosh, 1995). Ankrah (1993) suggested that spiritual leaders have

important roles in traditional African society because they serve as both psychologist and counsellors. Greater involvement of religious leaders, including institutions such as churches and mosques, may be helpful. Since the Gambia is a multi-religious country, bereaved young people should know that their religious leaders care for them. Such a care should be demonstrated right from the first day the religious leader comes into contact with the bereaved family. Their loss should be recognised and validated by giving them the choice to engage in rituals with the rest of the family and if wished talk about the loss and their feelings. The religious leaders and the mosque should take the greatest responsibility in the society and they should 'be there' for bereaved young people. If bereaved young people know that people do not forget about their loss and pray for them regularly, and encourage them to openly perform regular prayers for their deceased parent it will make them strong and give them the impression that they are not dealing with their loss in isolation and they will be able to retain connection with both their deity and with their deceased parent.

#### **5.5.11 Maintaining inner representation of the deceased**

Although West African young people's relationships with their deceased parents might be transformed, they remain connected to them. The death is not very likely to terminate the relationship, nor will the intensity of the emotional reactions be able to force young people to discard the memory of the loved-one, hence the dead parent remains a member of the family.

Despite lack of permission to talk about the deceased person, memories of the deceased clearly remain fresh in the minds of West African young people for a long time. When they are given a chance many will still recollect important interactions and activities they shared with their deceased parent. Retaining such a connection signals that young people may be finally accepting the loss; and they may be internalising the memories of the deceased person in a manner possible for them. Relationships of this nature may be comforting for young people. It is important that carers are aware of this and understand that bereaved young people need to retain this connection rather than expecting them to forget about their loss and move on.

There are different ways which show that young people retain a connection with their deceased parents. Perhaps the most common one is special items left behind by their

deceased parents that carry important memories. Carers may need to identify these items and make them available to bereaved young people. Some of these items include pictures, story books, diaries and clothes.

The OVC support project may help families and bereaved young people to choose some of these deceased person's belongings which they can treasure because it may help them to get in touch with their feelings. In other parts of Africa a memory box is used to this effect (UNAIDS, 2001). The idea of a memory box seemed to be appealing especially because all these items may be kept together in the same box. The box containing vital information about the deceased and the family, important dates, as well as visual images and objects may facilitate both verbalisation of emotion and retention of emotional connection with the deceased. Also information about the date the parent died is important because that allows the day to be used in sharing memories and addressing recurring grief. Imagine how a young person will feel when she receives a note of encouragement from friends, school and the mosque, especially if she assumed that they had forgotten.

Young people may also retain connection with their deceased parent through the spiritual world. Some believe the ancestral powers will channel their emotional energy to retain connection not only with the deceased parent but also with the ancestral world. Young people who believe in God retain emotional connection with their deceased parent through their daily prayers. Churches and mosques should join young people in their prayers, as it will not only give reassurance that they care, but also indicate that prayer is a way of remembering and retaining the previous relationship with both God and the deceased parent.

## **5.6 Conclusions and recommendations**

### **5.6.1. Key messages for those who live and work with bereaved young people in the Gambia, Africa**

#### **5.6.1.1 Key messages for family members**

It is important for adults to know that the current African way of expecting young people not to talk, and seeing them as empty vessels, needs replacing with a more sophisticated

understanding of the need for young people, because they feel as deeply as adults and they need to express these feelings in the same way as adults.

Allowing them to talk may provide relief and reduce anxiety, make them feel assured, give them the confidence to share their thoughts and feelings in the future. They need to be:

- Told that their parent has died. Their questions about their parent's death should be answered as accurately as possible, preferably by the surviving parent.
- Told what might happen to them and their siblings next, and who may take care of them. Re-assure and discuss with them their fears and anxieties as much as possible. This may include discussing potential sources of stigma.
- Allowed to express their emotions - through crying, wailing, chanting, talking. They may need to be told that it is 'okay' to express emotion but they should not be forced to do so.
- Consoled in the same way adults are consoled (if required). Showing them love (e.g. by interacting with them, rubbing hand on their head/shoulder or hugging them) at the time when most Gambians may be focusing their attention on bereaved adults would give them the impression that the adults are caring.
- Engaged or may be sat by the surviving parent who may be narrating how the whole event unfolded to the late comers.
- Allowed to distance themselves from places, people, events and activities that may serve as potential reminders of their loss or serve as a potential source of stigma. This must not be interpreted as recovery from loss.
- Allowed and encouraged to build a secure attachment relationship with a primary carer.
- Given the opportunity to live with their siblings in the same compound and they should not be relocated when death occurs.
- Allowed to grow the same way as other children are growing without the burden of adult responsibility.
- Given the opportunity and courage to build positive relationships with people who matter to them.
- Their religious belief and practice should be recognised and encouraged.

- Permitted to retain emotional connection with the deceased parent in any form or kind.

#### 5.6.1.2 Key messages for the OVC and other supportive projects

The OVC support project that brought bereaved young people together reduced isolation but it did not address discrimination or stigma, nor did it encourage sharing of emotions with peers. Adequate information sharing between the members of the OVC support group may minimise the vulnerability of their members and enhance their resilience in response to stigma and loss. For example, giving young people and their affected family members stigma-related counselling may help them to protect themselves from the impact of stigma they anticipate or encounter. With Information, Education and Communication (IEC) campaigns that aim at giving correct information and addressing baseless fears and anxieties about the dangers of AIDS-bereaved young people, attitudes and behaviour of perpetrators of stigma may change.

However, the OVC is doing a good job that needs to be encouraged. The future project of the OVC that would permit bereaved young people to visit each other regularly in their homes may facilitate friendship and building of trust between young people themselves. In consequence, bereaved young people may start sharing their feelings among themselves. Professionals supporting them also need training in order to be able to adequately identify the support needs of both the bereaved young people and their families.

One of the things the OVC project identified that was helpful to the bereaved young people was their educational fund. Whilst the economic support such as providing educational funding to bereaved young people was helpful because it reduced their worries and fears regarding their schooling, the way school fees were paid for the young people needs to be reviewed. The surviving parent/carer not the official of the sponsorship body should be given the opportunity to pay the school fees to the school. This may reduce bereaved young people's feelings of sadness and loneliness caused by seeing other young people with their parents paying school fees for them.

### 5.6.1.3 Key messages for religious leaders

For young people, prayer helps them to retain connection with both God and their deceased parent. This gives them comfort and helps them to reduce their distress. Greater involvement of religious leaders, including institutions such as churches and mosques, may be helpful. Since the Gambia is a multi-religious country, bereaved young people should know that their religious leaders care for them. Such a care should be demonstrated right from the first day the religious leader comes into contact with the bereaved family. Their loss should be recognised and validated by giving them the choice to engage in rituals with the rest of the family and, if wished, to talk about the loss and their feelings. The religious leaders and the mosque should take the greatest responsibility in society and they should 'be there' for bereaved young people. If bereaved young people know that people do not forget about their loss and pray for them regularly, and encourage them to openly perform prayers for their deceased parent regularly, it will make them strong and give them the impression that they are not dealing with their loss in isolation and they will be able to retain connection with both their deity and with their deceased parent. Religious leaders should:

- Encourage young people's active participation in mourning prayers that are observed in the mosque/church to bless the deceased just before the final burial.
- If possible, encourage them to attend the burial to pay their last respects to the loved-one.
- Encourage young people' participation in the seven day and 40 day ritual prayers, which allows them to reflect on the loved-one.

## **5.6.2 Reflexivity**

### 5.6.2.1 Effects of researcher's age and gender – personal reactivity

Having been 20 years older than the youngest participant, in a society where young people are meant to be obedient to adults, my age might have some impact on how they viewed and reacted to my presence during data collection. In the Gambia open expression of negative emotions by young people is not always sanctioned by adults; yet during the interviews young people cried, obstructing the flow of data collection and inevitably affecting the

amount of data gathered. Although the crying behaviour could be considered as an important source of data, it also indicated that I was not seen as the traditional authoritative figures, thus reducing the age-related reactivity.

During the interviews when the young people were nervous or crying, I offered them a cup of water. Since an adult offering young people water is an unusual event in the Gambia, such a move manifested a shift of power from myself to the young people that might have increased their confidence in honestly sharing their experiences. The use of appropriate language during the interviews, dress code, my student rather than professional stance, and being a local boy (as discussed earlier) were also used throughout the research process to reduce possible imbalances.

Despite my initial rapport with young people and their guardians during the recruitment process, and despite using open-ended questions and giving them the assurance of privacy and their right to withdraw when they felt the need, many young people appeared less relaxed and more tense when responding to the first few interview/FGD questions than they usually were in the community. The sensitivity of the topic and the use of the tape recorder might have contributed to the initial nervousness; yet, the open-ended methods used in this thesis allowed flexible exploration of the participants' meanings and beliefs. Since many of the questions flowed from the participant's replies rather than being entirely imposed by the interviewer's predetermined list of questions, the method gave the participants some degree of control over the research process, reducing reactivity.

In the FGD, young people hardly interacted with each other and some probes were given short answers (like a question and answer session), the initial answers were repeated by the participants or they did not respond to probing questions at all. Whilst the participants appeared largely in control of the amount of information they gave, restricted responses prevented in-depth discussion on the phenomenon. Despite these problems, the findings were similar (but in less depth) to the information gathered in the individual open-ended interviews.

Whilst the open-ended methods of data collection were flexible and allowed bereaved young people to narrate their stories openly, the constant comparative method of analysis used in

this thesis made it possible for the genuine concerns of the participants to emerge from the data. Although aware that my professional and personal background, my familiarity with the literature and my preconceptions are bound to have influenced interpretations, I have not lost sight of the challenge to preserve the participants' meanings. Moreover, I was aware that preconceived ideas might prevent me from thinking imaginatively about the theories that lie beneath the situations studied (Denzin, 1994). My prior experience, discussed above, has not only given me a familiarity with relevant issues but also enhanced my ability to make sense of the data.

In this study where the majority of the participants were females and in a culture where males are seen as providers and protectors of their families, my gender as a male researcher would have an impact on the female participants. Despite ensuring confidentiality and making it clear that the research was voluntary, female participants seemed to be more expressive than their male counterparts regarding the problems they were encountering in their efforts to care for bereaved young people. Whilst the reason for this was not entirely clear, the female participants might have been over-reporting in order to get sympathy from a male researcher.

#### 5.6.2.2 Effects of researcher's religion and cultural beliefs

The OVC support group was founded by the WEC mission, suggesting that the beliefs and values driving the OVC were rooted in Christian tradition. The employees and families (almost all of whom were Muslims) benefiting directly from this project might have been impacted by Christian beliefs and values. Yet, the core beliefs and values, such as giving love and care to children, the poor and needy, as well as rejection of stigma and discrimination, are shared by both Christian and Islamic traditions.

Whilst as a Muslim I do not believe families should be blamed for their HIV/AIDS status, some fanatic Gambian Muslims believe that HIV/AIDS is a curse from God for those involved in premarital and extramarital sex. They also view young people as victims of their own parents' immoral sexual behaviour. Yet people do not always contract the virus through immoral sexual conduct.

The impact of my religious belief on the participants would be based on whether or not I was seen as an extremist religious person. During data collection I prayed five times a day

regularly and attended Friday prayers with some research participants. Despite this I did not see myself as an extremist religious person, yet, I might have been suspected of being one, inducing fear among the participants. Fear of stigma and discrimination might have been the main reason why the guardians and the young people did not mention HIV/AIDS during data collection, reducing access to important data. However, silence surrounding HIV/AIDS may also be considered as important data since it indicated the presence of stigma.

#### 5.6.2.3 Limitations

Several limitations can be observed in this study. The most important issue lies in the different methods used in the data collection. The two methods that were used were open-ended interviews and a focus group discussion. These two methods differed in the quality of data produced. The evidence suggested that bereaved young people found it hard to open up and discuss sensitive issues relating to their loss in front of one another, which undoubtedly affected the quality of data from the focus group. However, the one-to-one interviews with them generated good quality data. In addition, whilst the interviews with the carers took place at home and professionals in their offices, these sites were not favourable and led to interruptions of the interviews which may have jeopardised their quality somewhat.

Although the findings may not be generalised owing to the small sample size and difference in the socio-environmental context from other settings, they do support previous research and have raised new questions about the knowledge and practice of families and health workers regarding bereaved young people in the Gambian context.

#### 5.6.2.4 Recommendations for future research

The study has possibly provided more questions than answers, which should lead to further research and enhanced understanding of emotional reactions of AIDS-bereaved young people and social factors that have an influence on their coping in an African context. A number of further research studies are indicated by this thesis. In terms of models, a range of studies are required aimed at testing the DPM model on AIDS-bereaved young people in the African context in general and the Gambia in particular. Such research is essential, especially since this is the latest comprehensive model on bereavement research known to the researcher and

has not been tested on AIDS-bereaved young people in Africa. The number of AIDS-bereaved young people in Africa is increasing and there is a paucity of African research in this area. It is apparent that African professionals and families need to be informed about the existing challenges with which bereaved young people are confronted. Many studies of this nature are required to inform the professionals and families of the emotional needs of AIDS-bereaved young people.

Ultimately an important goal would be to further study the differences and similarities between the perceptions of AIDS-bereaved young people, their carers and professionals regarding the extent to which bereaved young people react to their loss. This may be necessary, especially since these two groups of adults are the ones supporting the bereaved young people and there is no previous African study that has examined this perspective in bereavement research. The underlying factors that brought about differences in opinion between the three groups of participants also require further attention.

Whilst it was clear from the perspectives of the young people, carers and professionals that AIDS-bereaved young people experienced ranges of emotional reactions, little evidence seems to exist regarding their experiences of denial and anger response to loss in this thesis. The evidence that young people may feel they cannot be angry with their parent or God suggested religious and cultural reasoning underpinning their view about anger. Similar reasoning seemed to underpin their view about denial responses to loss because perceiving death as unrealistic may have suggested disobedience to God. It may be that they experienced anger and denial but showing it openly would be against their religious beliefs. As there is no scientific evidence from African literature clearly suggesting that young people perceived anger as a normal reaction to loss of a parent, it is therefore necessary for a further study that may use a different population to explore this phenomenon.

There is a paucity of research on how African bereaved young people continued to retain emotional connection with their deceased parent. In this thesis several ways were identified as to how they retained this relationship with their loved-one. Apart from material objects left behind by the deceased, prayer was perceived as one of the most important media of emotional connection with the deceased parent, the one that should be encouraged. Since young people are young, it is necessary to examine how long they would continue to be

actively engaged in retaining emotional connection with the deceased through prayers and how much impact over time prayer would have on their coping. Further research is also required as to the best possible ways of encouraging young people to be involved in such prayers as part of family ritual.

Emotional expression in the form of talking about death and crying is generally seen in the West as an essential element in coping with loss. Despite its possible therapeutic effects as suggested by Western literature, talking about death among bereaved young people, between the bereaved young people and adults was not reported. Due to the scarcity of evidence from previous African studies, it is important that further study is conducted on this area, and in particular their reasons for not talking about loss. Even if the Gambian carers and professionals wish to talk about death, they might not know what to say or what is best for the child. It is therefore necessary to conduct further research on the best way for those supporting bereaved young people to discuss loss with them. Further research is needed on who should share the information with bereaved young people and what information is required for what age.

Although crying behaviour is common among bereaved young people in this thesis, it was openly shown only on the very day loss occurred. Much of the time young people were either told to stop crying or they avoided crying to prevent hurting people. Because of the paucity of previous African studies that clearly described this emotional behaviour in the same way as this thesis, further research is needed to examine these issues as well as adults' reactions to young people's crying behaviour and the impact of their reactions on young people's expression of emotion.

One objective of the study was to examine the impact of stigma and discrimination on bereaved young people's coping. Whilst there was evidence that these factors might have been unhelpful to bereaved young people, there was little evidence in previous African studies in this area. These studies were not specifically on AIDS-bereaved young people, suggesting the need for further studies. Whilst literature on stigma in general is growing, little is known how bereaved young people cope with both stigma and death at the same time during bereavement. Although this thesis shows how that might happen in Africa, the model developed here is the first of its kind and therefore similar researches may be required.

## APPENDIX 1

### THE INTERVIEW GUIDES DEDUCED FROM THE LITERATURE REVIEWED

#### 1 Young people's interview and focus group guide

The young people's interview guide is based on four broad questions, with each question having a list of concepts for possible discussion as indicated below:

- How different did you feel when your parent died?

(Probing on: the nature of sadness, loneliness, anxiety, fear, anger, denial)

If you felt any different, how intense were these feelings?

- What social factors help you to cope with your loss?

(Probing on: the nature of family, peer and OVC support, and its importance for their coping)

- What social factors hinder your coping?

(Probing on: the nature and impact of discrimination, isolation, secrecy and stigma)

- How do you feel about this interview?

(Probing on: the benefit of being heard and opportunity of telling their stories)

## **2 Carers' interview guide**

The interview guides for carers and professionals are similar to that of the young people, except they do not contain the question on how they feel about the interview (see 1 above: Young people's interview guide). The guide for the carers is as follows:

- How different did... (name of the child) feel when his/her parent died?

(Probing on: the nature of sadness, loneliness, anxiety, fear, anger, denial)

If she/he felt any different, how intense were these feelings?

- What social factors help him/her cope with the loss?

(Probing on: the nature of family, peer and OVC support and its importance for their coping)

- What social factors hinder his/her coping?

(Probing on: the nature and impact of discrimination, isolation, secrecy and stigma)

### **3. Professional' interview guide**

The interview guides for the carers and professionals are similar to that of the young people except they do not contain the question on how they feel about the interview (see 1 above: Young people's interview guide). The guide for the professionals is as follows:

- How different does a bereaved young person feel when his/her parent dies?

(Probing on: the nature of sadness, loneliness, anxiety, fear, anger, denial)

If she/he felt any different, how intense were these feelings?

- What social factors help a bereaved young person to cope with the loss?

(Probing on: the nature of family, peer and OVC support and its importance for their coping)

- What social factors hinder a young person's coping?

(Probing on: the nature and impact of discriminations, isolation, secrecy and stigma)

## APPENDIX 2

### PARENTS' CONSENT FORM

Dear Parent of .....,

#### **Re: consent for your child to participate in research**

My name is Abdoulie Sanneh. I am a Gambian student presently interested in conducting a research on bereaved young people in the Gambia. I have already spoken to Dr. Sabally and Mr. Saikou Ceesay and been granted permission to speak to you about my intentions.

This research covers two major areas:

- (1) Young people's emotional reactions to their parents' death
- (2) Social factors that help or hinder young people's coping with their loss

I am aware that discussing this topic could be difficult, especially for young people. I have therefore arranged for a professional to be available for your child, in the event of distress and emotional help being requested. Allowing your child to participate in this research could be rewarding for both you and your child. Their accounts would help to raise a whole new consciousness about how young people's emotional experiences are conceptualised and what locally available social factors can be tapped to facilitate their coping with loss experiences. Giving them a chance to participate would mean you are indirectly participating with the production of new knowledge that can only help to tailor interventions to address the mental health needs of bereaved young people.

Those to be included in this research include:

- (a) Young people aged 15 to 18 years
- (b) Young people who lost one or both parents a year ago
- (c) Young people supported by the OVC project of Hands on Care

Since your child has met all three criteria I am wondering whether you would allow him/her to participate in this research. With your permission, your child would be contacted directly by the researcher for the completion of a consent form.

Please sign below if you grant me permission to approach your child.

..... signature

Yours sincerely,  
Abdoulie Sanneh.

### APPENDIX 3

#### YOUNG PEOPLE'S CONSENT FORM

Dear.....(read to them)

#### **Re: consent to participate in research**

My name is Abdoulie Sanneh. I am a Gambian student presently interested in conducting a research on bereaved young people in the Gambia. I have already been given permission by Dr. Sabally and your carer to ask for your consent to participate in research.

This research covers two major areas:

- (1) Young people's emotional reactions to their parents' death
- (2) Social factors that help or hinder young people's coping with their loss

I am aware that discussing this topic could be difficult for you. I have therefore arranged for a professional to be available to you, in the event of your being distressed and wanting help. Your participation in this research could be rewarding for you and beneficial for many children who have lost their parents. Your accounts would help to raise a whole new consciousness about how young people's emotional experiences are conceptualised and what locally available social factors could be tapped to facilitate their coping with their loss experiences. Your participation would mean you are indirectly contributing to the production of new knowledge that can only help to tailor interventions to address the mental health needs of bereaved young people.

If you agree to participate in this research, please sign below:

..... signature

You are assured that any information you provide would remain between you and the researcher. In the case of any intention to disseminate this information, you would be consulted and this information would only be shared with others with your consent. You have the power not to participate and to withdraw during the research. The day and the place for the interview/focus group interviews would be based on our mutual agreement. Upon receiving your consent, I will consult you as soon as I can.

Please, if you agree to participate in this research, I would like you to identify one of your carers who is aware of your experience to participate in this research. When you have done this, a letter will be sent to him/her asking for his/her participation in this research. Remember, none of the information you share with us would be shared with them. Thank you for your cooperation.

Yours sincerely,

Abdoulie Sanneh

## APPENDIX 4

### CARERS' CONSENT FORM

Dear Carer of .....

#### **Re: consent to participate in research**

My name is Abdoulie Sanneh. I am a Gambian student presently interested in conducting a research on bereaved young people in the Gambia. Your child (name) has identified you as a potential participant for this study and Dr. Sabally has also given me permission to seek your consent to participate in the research.

This research covers two major areas:

- (1) Young people's emotional reactions to their parents' death
- (2) Social factors that help or hinder young people's coping with their loss

I am aware that discussing this topic could be difficult for you. I have therefore arranged for a professional to be available to you, in the event of your being distressed and wanting help. Your participation in this research could be rewarding for you and beneficial for many children who have lost their parents. Your accounts would help to raise a whole new consciousness about how young people's emotional reactions are conceptualised and what locally available social factors can be tapped to facilitate their coping with their loss experiences. Your participation would mean you were indirectly contributing to the production of new knowledge that could only help to tailor interventions to address the mental health needs of bereaved young people.

If you agree to participate in this research, please sign below:

..... signature

You are assured that any information you might provide would remain between you and the researcher. In the case of any intention to disseminate this information, you would be consulted and this information would only be shared with others with your consent. You have the power not to participate and to withdraw during the research. The day and the place for the interview/focus group interviews would be your decision. Upon receiving your consent, I will consult you as soon as I can.

Yours sincerely,

Abdoulie Sanneh

## APPENDIX 5

### CONSENT FORM – PERMISSION FOR YOUR CHILD’S PARTICIPATION

Dear Carer of .....

#### **Re: consent to participate in research**

My name is Abdoulie Sanneh. I am a Gambian student presently interested in conducting a research on bereaved young people in the Gambia. Dr. Sabally has also given me permission to contact you. Since I have identified your child as a potential candidate for the research, I am writing to seek for your permission to recruit him/her for this purpose.

This research covers two major areas:

- (1) Young people’s emotional reactions to their parents’ death
- (2) Social factors that help or hinder young people’s coping with their loss

I am aware that discussing this topic could be difficult for her/him. I have therefore arranged for a professional to be available to him/her, in the event that she/he is distressed and wants help. His/her participation in this research could be rewarding for her/him and beneficial for many children who have lost their parents. His/her accounts would help to raise a whole new consciousness about how young people’s emotional reactions are conceptualised and what locally available social factors can be tapped to facilitate their coping with their loss experiences. His/her participation would mean he/she is indirectly contributing to the production of new knowledge that can only help to tailor interventions to address the mental health needs of bereaved young people.

If you agree to participate in this research, please sign below:

..... signature

By signing this consent form you are giving permission to include your child in the research. The child has the power not to participate and to withdraw during the research. The day and the place for the interview/focus group interviews would be mutually agreed. Upon receiving your consent, I will consult you as soon as I can.

Yours sincerely,

Abdoulie Sanneh

## APPENDIX 6

### PROFESSIONALS' CONSENT FORM

Dear .....

#### **Re: consent to participate in the research**

My name is Abdoulie Sanneh. I am a Gambian student and a health worker presently interested in conducting a research on bereaved young people in the Gambia. I have already been given permission by Dr. Sabally and Mr. Saikou Ceesay of the National AIDS Secretariat to ask for your consent to participate in the research.

This research covers two major areas:

- (1) Young people's emotional reactions to their parents' death
- (2) Social factors that help or hinder young people's coping with their loss

I am aware that discussing this topic could be difficult for you. As a consequence I have arranged for a professional to be available, in the event of your being distressed and wanting help. Your participation in this research could be rewarding for you and beneficial for many children who have lost their parents. Your accounts would help to raise a whole new consciousness about how young people's emotional experiences are conceptualised and what locally available social factors can be tapped to facilitate their coping with their loss experiences. Your participation would mean you are indirectly contributing to the production of new knowledge that can only help to tailor interventions to address the mental health needs of the bereaved young people.

If you agree to participate in this research, please sign below:

..... signature

You are assured that any information you may provide would remain between you and the researcher. In case of any intention to disseminate this information, you would be consulted and this information would only be shared with others with your consent. You have the power not to participate and to withdraw during the research. The day and the place for the interview/focus group interviews would be your decision. Upon receiving your consent, I will consult you as soon as I can.

Yours sincerely,

Abdoulie Sanneh

## APPENDIX 7

### CODES AND THEIR DEFINITIONS

Category	Definition
<b>Emotional loneliness</b>	The feeling of being alone. Includes feeling empty, missing a special relationship - the company and warmth.
<b>Sadness</b>	A human reaction to a painful circumstance, described as unhappiness, sorrow, melancholy, feeling down, mood change, crying, depression.
<b>Fear</b>	An experience of unpleasant risk or danger that results in one reacting to the situation by either confronting the threat or fleeing. Includes racing heart, fast breathing, moving away from the event, panic and alarm reactions in the form of perspiration and nightmares.
<b>Anger</b>	Uncomfortable feelings and thoughts expressed in the form of resentment, irritation, annoyance, rage, exasperation, disgust, envy, torment; includes: yelling, sarcasm, glaring, hitting and cutting.
<b>Worry/anxiety</b>	A state of being troubled in the mind about an uncertain event. Includes perceived feelings of apprehension, concern, worry, uneasiness, nervousness, dread. Difficulty with concentration and decision making, frequent headaches, restlessness, and sleeplessness.
<b>Continuous bond</b>	An existing emotional relationship between the bereaved and the deceased persons. Includes: use of material objects (radio, books, diaries, clothes), non-material mediums such as storytelling and prayers.
<b>Denial</b>	A 'mechanism [that] allows us to shut down our emotional awareness and screen out potentially overwhelming or devastating information' (Jewett, 1984, p.68). It includes: disbelief, numbness, any psychological effort to undermine emotional state.
<b>Avoidance</b>	A defence mechanism consisting of a refusal to deal with situations, objects and activities as either a means of complying with social expectations or preventing further painful emotional experiences. Includes suppressing emotions, distancing oneself from reminders of loss.

<b>Family support</b>	The parents, siblings, grandparents and their families; includes all those who have close ties with these members. They are the protectors, and providers of material support, love and affection.
<b>Peer support</b>	The support coming from young people in the same age group or people sharing similar concerns. Social interaction and information sharing within this group; includes members of the OVC group.
<b>Agency support</b>	Non-governmental organisation that provides support services for bereaved young people and their families. Includes group work, sharing information on their loss experiences, socialisation, material support: money, school fees, clothing, and school lunch.
<b>Stigma</b>	An attitude that is underpinned by a severe disapproval of behaviour that is not within cultural norms. Includes: negative labels, intention to disgrace. Impact on their bereavement.
<b>Secrecy</b>	Keeping information related to the loss of a parent away from the young person. Includes information that parent has died, talking and discussing the death. Impact on their bereavement.
<b>Discrimination</b>	An action based on prejudice resulting in unfair treatment of other people. Includes: denying access to ill parent, permanent relocation without consent, withdrawal from relationship, sharing information on parental death, consequences of death, access to clothing, adequate shelter, and money. Impact on their bereavement.
<b>Isolation</b>	Interpersonal deficit that exists as a result of a less satisfying relationship than a person desires. In the context of loss, it remains even when the bereaved appears to be surrounded by others. Missing the loved-one, feeling empty.

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