

**EXPLORING COMMUNITY VOLUNTEERS' USE OF THE  
MEMORY BOX MAKING TECHNIQUE TO SUPPORT  
COPING WITH HIV AND AIDS.**

*by*

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*Submitted in partial fulfilment of the requirements for the degree*

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PRETORIA

## **DEDICATION**

**I DEDICATED MY WORK TO MY BELOVED BROTHER  
WHO LOST HIS LIFE DUE TO A TERMINAL ILLNESS,  
LEUKAEMIA:**

“We love you Jacques, thank you for leaving us with such precious memories of you. You will forever remain part of our hearts”

## DECLARATIONS

**I, Ancois Swanepoel (99044910), hereby declare that all the resources that were consulted are included in the reference list and that this study is my original work.**

.....

A Swanepoel

October 2005



I, Rika Opper, hereby declare that I undertook the editing of the grammatical and language aspects of this dissertation.

.....

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Koos and Elize Swanepoel (Parents)

Family, friends and colleagues

***Their support and encouragement guided me through the tough times, and remains an unforgettable memory***

## SUMMARY

# EXPLORING COMMUNITY VOLUNTEERS' USE OF THE MEMORY BOX MAKING TECHNIQUE TO SUPPORT COPING WITH HIV AND AIDS

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The HIV and AIDS pandemic have already impacted considerably on the South African society. Volunteers play a pivotal role in mitigating the impact of HIV and AIDS in three spheres, namely prevention, care and support. The aim of the study was to explore community volunteers' use of the Memory Box Making technique to support coping with HIV and AIDS. Research was done by using an interpretive paradigm through means of qualitative research. Data was primarily collected through interviews with the community volunteers who acted as participants in the study. Findings of the study suggest that volunteers were able to acquire, apply and adapt the Memory Box Making technique in both their personal and professional lives.

### KEYWORDS

- Community volunteers
- Memory Box Making technique
- Memory box
- HIV and AIDS
- Coping with HIV and AIDS
- Support in HIV and AIDS
- Grief/bereavement
- Explore
- Describe
- Application/apply

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## CHAPTER 1 – OVERVIEW AND RATIONALE

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### 1.1 INTRODUCTION

This introductory chapter explains the rationale for and the purpose of the study. It contains a discussion of the selected paradigmatic perspective, the chosen conceptual framework, the research design, considered ethical strategies and an introduction to the preferred quality criteria to maximise trustworthiness. The concepts used are also clarified.

### 1.2 RATIONALE

***The purpose of this study is*** to explore and describe how community volunteers can apply the Memory Box Making technique to support communities coping with HIV and AIDS.

The HIV and AIDS pandemic have already impacted considerably on the South African society. The Siyam'kela Project (2003: 2) estimated that nearly 5 million South Africans are infected with HIV. If this is the number of infected people, one can only imagine the scope of people whose lives are affected by the disease. HIV and AIDS are distinctive among health problems, especially in the dynamic relationship between preventing the incidence of HIV and AIDS and supporting, caring for and treating those infected by it (De Jong, 2003: 30).

According to South African government (Akukwe, 2003), now is the time to focus on how to resolve the mechanics of providing community-based services that meet the preventive, clinical and support needs of individuals, families and communities. A comprehensive community-based approach will focus the attention of politicians, policy makers, academics, and activists on what really matters in the fight against this deadly condition (Akukwe, 2003). If a national decision is taken in this regard, volunteers will play a pivotal role in mitigating the impact of HIV and AIDS in three spheres, namely prevention, care and support.



What *are* the roles that volunteers presume? According to Christensen, Reininger, Richter, McKeown and Jones (1999), volunteers are already doing more than what can be expected of them. They provide medication, food packages and support to the most vulnerable people in their communities. In particular, they give of their time and effort in deprived conditions where the spread of HIV and AIDS have affected many members of their communities. In communities that are particularly susceptible to HIV and AIDS, there are limited opportunities to provide the necessary support a community needs in a time of desperation. It is then that volunteers tend to also take on the role of counsellors.

The focus in this study will be on: *Firstly*, what is Memory Box Making? (obtaining information by means of a literature study). *Secondly*, exploring the existing role of community volunteers (by way of unstructured focus-group interviews). *Thirdly*, how community volunteers can be trained in the Memory Box Making technique (by means of a two-day workshop), and *finally* exploring how community volunteers applied their skills in the Memory Box Making technique to support their communities in coping with HIV and AIDS (by way of unstructured focus-group interviews).

My working assumption is that volunteers will be able to apply the Memory Box Making technique to support their communities in coping with the emotional impingement of HIV and AIDS. Because volunteers are not social workers or counsellors and do not have formal training, they might not be able to make use of the different theories and techniques known to many professionals concerning grief or bereavement. Training them in making Memory Boxes could help in overcoming this gap in their knowledge systems. The making of Memory Boxes comprises many of the different strategies or techniques that can be applied to help individuals cope with death or dying. Exline, Dorrity and Wortman (1996: 14) state: 'a common element running through most of these treatments is that they are structured to help the client face the reality of the loss and to promote processing of the loss.' Memory Box Making does just this and can offer cathartic, restorative or curative support to a range of individuals who are infected with HIV or are already dying of AIDS, and to individuals who have already lost a loved-one to this disease.

### 1.3 THE PURPOSE OF THE STUDY

As the purpose of my research was to explore and describe how community volunteers can apply the Memory Box Making technique to support coping with HIV and AIDS, the question guiding my study is:

- *How do community volunteers apply the Memory Box Making technique to support people coping with HIV and AIDS?*

Carefully chosen data-collection methods (as discussed in detail in Chapter 3), will aid me in the process of exploring this question and explaining my findings.

Secondary questions to my study, as well as methods to be used in gathering data in order to be able to answer these questions, include:

**Table 1.1 Secondary research questions and methods used for data collection**

<b><i>Secondary research questions</i></b>	<b><i>Methods used for data collection</i></b>
➤ <i>What is the Memory Box Making technique?</i>	Literature study
➤ <i>What is the existing role of community volunteers?</i>	Focus group interviews and interviews with the volunteers
➤ <i>How can community volunteers be trained in the Memory Box Making technique?</i>	Development of workshops Implementation of a programme by way of a two-day workshop
➤ <i>How did the community volunteers apply the Memory Box Making technique?</i>	Follow-up focus group

Table 1.1 illustrates the data collection strategies used to address the secondary research questions. These questions are important as they set the stage for the research process. The methods for data collections will be discussed in more detail later in this chapter, as well as in Chapter 3.

#### 1.4 PARADIGMATIC PERSPECTIVE

My chosen epistemology is that of interpretivism. The aim of interpretive research is to understand and interpret the meanings and intentions that underlie everyday human action (De Vos, 2000: 240). I seek to interact closely with participants to understand the way in which volunteers apply the Memory Box Making technique to support communities coping with HIV and AIDS. I will also monitor this process by keeping a research diary of my interactions, perceptions and interpretations.

Throughout the study, by interacting with the participants and listening to what they say, I will attempt to gain a better understanding of the social world in which they live and the meaning they ascribe to their experiences. I will continuously strive to understand participants' behaviour, their lives and their views in terms of scientific ideas, since findings in interpretive research are created through the process of interaction between researcher and participants (De Vos, 2000: 240). My aim is to do this by using strategies such as keeping a researcher's journal, making reflective field notes, having informal and unstructured discussions with the participants to clarify understanding, and making use of member checking of the themes uncovered. Refer to Chapter 3 for a more detailed description.

#### 1.5 RESEARCH DESIGN AND DATA COLLECTION METHODS

Table 1.2 below serves as a visual presentation of the entire research process, as will be discussed in more detail in Chapter 3. Figure 1.1 below illustrates one of the various audio-visual methods used for data collection, as referred to in Table 1.2 below.

**Figure 1.1 Using an audio-visual method of data collection**





Table 1.2 Research design and data collection methods

Research design: Instrumental case study design				The research process related to the research questions		
				<p>What is Memory Box Making?</p> <p>↓</p> <p>Exploring the existing role of community volunteers</p> <p>↓</p> <p>Developing a program for training community volunteers in the Memory Box Making technique</p> <p>↓</p> <p>Implementation of the programme through a two-day workshop</p> <p>↓</p> <p>How could the community volunteers apply the Memory Box Making technique?</p> <p>↓</p> <p>Exploring how volunteers applied the Memory Box Making technique</p>		
Data-gathering methods				Authenticity and trustworthiness?		
<p><b>Literature study</b></p>	<p><b>Two-day workshop</b></p>	<p><b>Focus group interviewing</b></p>	<p><b>Field notes and Research Diary</b></p>	<p><b>Audio-visual methods and visual data</b></p>	<p><b>Member checks</b></p>	<p><b>Crystallization</b></p>
<ul style="list-style-type: none"> <li>⌘ What is Memory Box Making?</li> <li>⌘ Program for two-day workshop</li> </ul>	<ul style="list-style-type: none"> <li>⌘ Training volunteers in the Memory Box Making technique</li> </ul>	<ul style="list-style-type: none"> <li>⌘ For insight into perceptions of volunteers</li> <li>⌘ To establish volunteers' current roles in their communities</li> <li>⌘ To explore how volunteers applied their skills</li> </ul>	<ul style="list-style-type: none"> <li>⌘ Detailed notes on what occurred</li> <li>⌘ Recording personal experiences</li> <li>⌘ Reflecting on volunteers' ascribed meaning</li> </ul>	<ul style="list-style-type: none"> <li>⌘ Video camera, Dictaphone, photos</li> <li>⌘ For visual and auditory presentation of interaction with participants</li> <li>⌘ See Figure 1.1</li> </ul>	<p>Verify with volunteers if they agree with the themes that were uncovered during phases of data analysis</p>	<p>Obtaining a variety of perspectives on the use or application of the Memory Box Making technique</p>

Table 1.2 illustrates the research design that was selected for the purpose of this study, as well as the research process related to the various research questions. Data-gathering methods and authenticity and trustworthiness reliability are also shown.



## 1.6 ETHICAL STRATEGIES

In working with human beings, it is important to consider certain ethical aspects. Cognisance will be given to specific ethical principles during the research process (Patton, 2002; Berg, 2001; Denzin & Lincoln, 1998), as discussed in Chapter 3.

(See Appendix A for ethical principles adhered to while conducting this study, as well as the Ethics and Research statement of Faculty Education of the University of Pretoria.)

## 1.7 QUALITY CRITERIA

The basic issue of trustworthiness relates to how the inquirer can persuade his/her audiences that the findings of the inquiry is worth paying attention to, or worth talking about (Babbie & Mouton, 2001: 276). Taking cognisance of my design choices, I will aim to maximise trustworthiness in my study by using credibility, transferability, dependability and conformability. This will be discussed in more detail in Chapter 3.

## 1.8 CONCEPTUAL FRAMEWORK

Owing to the nature of this study, the conceptual framework will be informed by various bodies of literature. A discussion of the conceptual framework used in this research study follows below.

HIV and AIDS are terminal conditions, and affected and infected individuals may need to be taken through the steps of preparing for death (Visser & Moleko, 2001: 132). Partners, family members and friends will also require some form of help, either during the time of the individual's illness, or after his/her death. This forms part of the grieving process.

Elisabeth Kübler-Ross (1987) did extensive research on the reactions of terminally ill individuals to death and dying. In her book entitled *On death and dying* (Kübler-Ross, 1989), she outlines the various stages in dying, which relate to the grieving process. In my proposed study, which will involve demonstrating the Memory Box Making technique to community volunteers during a two-day workshop, I suggest that volunteers will be

able to use this activity as a form of guided bereavement therapy to support their communities in coping with the devastation caused by HIV and AIDS.

Through Memory Box Making, as a form of bereavement therapy, volunteers could support families affected by HIV and AIDS to cope with disease, death and grief, and to create a sense of hope for the future. In facilitating Memory Box Making as a process (for example, shared memories of an ill parent or family member, or of a person who has already died), memories are recorded and stored in the memory box (Siyam'kela Project, 2003; DeJong, 2003).

In addition to aiding volunteers in providing emotional support to their communities in coping with HIV and AIDS, the Memory Box also offers a level of functional support. It enables parents to leave a physical legacy to their children. It is in the Memory Box that documents such as birth certificates and testaments can be placed for safekeeping by the families. In doing this, parents and their children can rest assured that their wishes will be documented. The issue surrounding future care for children whose parents are dying of AIDS is also attended to by placing a document in the memory box, stating where the parents wish their children to go after their passing.

In using interpretivism as a backdrop to Kübler-Ross' grief and bereavement theory, I can explore how the participants (volunteers) view their own understanding of applying the Memory Box Making technique to support their communities in dealing with HIV and AIDS. Kübler-Ross (1987: 11) explains that it is only when individuals affected by HIV and AIDS receive enough support from people who accept them and give them the natural nurturing that all human beings need, that they will be able to develop the state of peace and serenity that makes the transition called death a 'quiet slipping over' into another form of existence. From an interpretive point of view, Cohen *et al.* (2000: 23) explain this as follows: 'Interpretive approach to action is viewed as behaviour-with-meaning. That people's actions are only meaningful to the degree in which individuals are willing to share their experiences.'

A comprehensive literature review is essential to provide this study with a conceptual and contextual frame. Literature will focus on the main subject matter of the study, and will include Memory Box Making, the roles of the community volunteers, the application



of the Memory Box Making technique, death, dying and bereavement, and communities coping with HIV and AIDS. Chapter 2 contains a comprehensive literature study that includes, *inter alia*, the following:

**Table 1.3 Literature to be discussed in Chapter 2**

<b>BOOKS / JOURNALS</b>		
<b>Author(s)</b>	<b>Date</b>	<b>Description</b>
Denis, P	2001	Children who remember their parents in a positive way when they become ill or when they die are in a better position to cope with the hardships of their condition
Exline, J. J., Dorrity, K. & Wortman, C. B.	1996	The authors provide an overview of how people typically respond to major losses, reviewing factors that have been shown to enhance vulnerability to the effects of loss.
Kübler-Ross, E	1987	Theories on death and dying and the ultimate challenge of HIV and AIDS.
Morgan, J	2001	A description of events relating to the establishment of a Memory Box project, which is aimed at creating a personal history of those who have died of HIV.
Velentgas, P. Bynum, C. & Zierler, S.	1990	A discussion of the buddy volunteers commitment in AIDS care.
<b>RELEVANT WEBSITES</b>		
UNICEF - HIV & AIDS - Care and support for orphans and families affected by HIV and AIDS <a href="http://www.unicef.org/aids/index_orphans.html">http://www.unicef.org/aids/index_orphans.html</a>		
SINOMLANDO PROJECT <a href="http://www.hs.unp.ac.za/theology/sinomlando/memory%20boxes.htm">http://www.hs.unp.ac.za/theology/sinomlando/memory%20boxes.htm</a>		
Community level responses to mitigate the impact of AIDS ... <a href="http://cira.med.yale.edu/law_policy_ethics/Dombo.pdf">http://cira.med.yale.edu/law_policy_ethics/Dombo.pdf</a>		
Secure the Future: <a href="#">Child bereavement counselling and memory boxes</a> <a href="http://www.securethefuture.com/grant/data/commun.html">http://www.securethefuture.com/grant/data/commun.html</a>		

Red Cross Red Crescent: Memories of the past provide hope for the future

<http://www.ifrc.org/docs/news/02/02112001/>

Table 1.3 provides an indication of some of the subject matter that formed part of the comprehensive literature study undertaken to increase the reliability and validity of the study. This will be discussed in more detail in Chapter 2. This literature study was an integral part of my research as it enabled me to explore the most recent and authoritative theorising about Memory Box Making, as well as the supportive value of this activity in dealing with grief and/or loss caused by terminal illness, or, as in this study, HIV and AIDS. It also enabled me to ascertain what the most widely accepted definitions of key concepts in Memory Box Making are, and to define the volunteers' role in supporting individuals who have to cope with HIV and AIDS (Mouton, 2001: 86-87).

## 1.9 CLARIFICATION OF CONCEPTS

Key terms such as *community volunteers* (home-based-care and youth volunteers), *Memory Box Making*, and *support in coping with HIV and AIDS* will be at the centre of this study. The clarification of these concepts is therefore essential.

**Community volunteers:** It has been made clear, at national level, that volunteers will play a pivotal role in mitigating the impact of HIV and AIDS in all spheres, namely prevention, care and support. Home-based-care volunteers are recruited and trained (at community level) to work with people who are ill. These volunteers may include people who are already HIV positive, or may be drawn from community-based, faith-based and other organisations. Home-based-care volunteers (appointed by the government) are individuals who visit AIDS sufferers at home and undertake direct care work where this is seen to be necessary. Youth volunteers (coordinated by a Non-Governmental Organisation) work with the youth in their communities. The various services provided by them include counselling, training, HIV and AIDS education, sports, and an after-school haven for all youth (Department of Health, 2005; Akukwe, 2003).

**Memory Box Making technique:** The Memory Box Making technique allows volunteers to assist individuals and families in their communities who are confronted by HIV and AIDS to tell their life stories. This technique can be used to assist people in the grieving

process, and also for crafting a personal legacy to be left behind for loved ones (Siyam'kela Project, 2003).

**Coping with HIV and AIDS:** Coping with bereavement caused by AIDS may differ from coping with the loss of loved ones to other diseases in several respects (Sikkema, Kochman, DiFranceisco, Kelly, and Hoffmann, 2003: 166). People with HIV and AIDS need to know how to cope with their condition and how to look at how they can best live each day, rather than think too far ahead into the future. However, they do need to be aware of what will happen in the future and to plan for it. This could serve as means for coping for those individuals affected by HIV and AIDS, and making a Memory Box could help them to do this. People who are themselves living with HIV and AIDS often face the unique challenge of coping with the loss of loved ones to this disease, and the physical and psychosocial losses associated with HIV disease itself. Psychosocial losses may include the pain caused by the stigma that is often attached to having HIV and the consequent discrimination against those that are infected. This may influence the individual's decision to disclose his/her HIV status, which may lead to increased anxiety as result of fear that his/her status may be discovered. Therefore AIDS-related bereavement, especially among persons who themselves are living with HIV infection, may remain a major coping challenge (Sikkema *et al.*, 2003: 167). It is against this background and the coping skills that it requires that the proposed study will be undertaken.

**Support in HIV and AIDS:** People living with HIV and AIDS may suffer many losses. They may lose their health, their independence and many years of life. Support creates a therapeutic environment in which people affected by HIV and AIDS can share their emotions and experiences, and volunteers could provide such support (Visser & Moleko, 2001). Partners, family members and friends will also require some form of support, either during the time of the individual's illness, or after his/her death. Numerous studies have found that the well-being of people living with HIV and AIDS is closely related to the quality of the support provided by care givers (McCausland & Pakenham, 2003: 854).

**Explore:** The use of this concept in the study refers to the investigation of Memory Box Making and the use of this technique by community volunteers to support communities coping with HIV and AIDS (Mouton, 2001: 54).

**Describe:** In the context of this study, the term *describe* refers to a detailed written description of how the use of Memory Box Making could enable community volunteers to support communities in coping with HIV and AIDS (Mouton, 2001: 53).

**Application/apply:** In the study these concepts are used as synonyms for the utilization or employment (or not) of the Memory Box Making technique by community volunteers to support people in their communities who are trying to cope with HIV and AIDS.

#### 1.10 OUTLINE OF CHAPTERS

Chapter 1 serves as an introduction to this study. Chapter 2 comprises of a comprehensive literature study that focuses on the main factors dealt with in this study, namely community volunteers and their role in supporting their communities to cope with HIV and AIDS, the Memory Box Making technique, and grief and loss caused by terminal illness (in this case AIDS). Chapter 3 outlines the entire research process, as well as professional and personal experiences of and reflections on the methods and process related to my study. Section A of Chapter 4 present the results obtained through my study and describe how community volunteers experienced applying the Memory Box Making technique in their communities as way of supporting bereaved individuals or families. These results are interpreted in Section B of Chapter 4. For this purpose a literature check is conducted, as set out in Chapter 2. The final chapter, Chapter 5, presents the final conclusions based on the volunteers' application of the Memory Box Making technique to support their communities, and includes a discussion of the various shortcomings and recommendations regarding possible future research on the use of this technique.

## 1.11 CONCLUSION

Chapter 1 introduced the research process and provided a brief discussion of the chapters to follow. In Chapter 2, I will commence by presenting a comprehensive literature review of subject matter that relate to the study. The subject matter, as outlined in this chapter, includes Memory Box Making and discussion of the role of community volunteers with regard to enablement, death, dying and bereavement, and assisting communities in coping with HIV and AIDS.

## CHAPTER 2 – LITERATURE REVIEW

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### 2.1 INTRODUCTION

In this chapter I will explore some of the most recent and authoritative theorising about community volunteers' role in supporting their communities to cope with HIV and AIDS, as well as Memory Box Making and the supportive value of this activity in coping with grief and/or loss caused by a terminal illness, focusing on HIV and AIDS. I will discuss the most widely accepted definitions of key concepts relating to Memory Box Making, as well as the role played by volunteers in offering support to communities coping with HIV and AIDS.

### 2.2 DEATH, BEREAVEMENT AND COPING IN THE CONTEXT OF HIV AND AIDS

Any person who suffers a loss, goes through a stage of **bereavement**. According to the Sinomlando Project (2003: 13) this term refers to 'the objective fact that a meaningful person has died'. Such an event causes a sense of grief, which is a process rather than a specific emotion such as fear or sadness (Webb, 1993). A more detailed a description of the bereavement process and aspects thereof that relate to HIV and AIDS follows below.

#### 2.2.1 The extent of the AIDS epidemic

The global picture of HIV and AIDS is that of a disease that is spreading very rapidly, creating a growing socio-economic, health and security challenge to all countries (Kelly, 2000: 10). According to Uys (2003: 271), the alarmingly high prevalence of HIV and AIDS makes this disease a potential catastrophe for population and health services. In 2003 UNAIDS (2004) estimated the number of South African children and adults aged between 0-49 years who were living with HIV and AIDS at 5.3 million. Avert.org (2005) reports that an estimated 17.5% of the population in the Limpopo Province (where my study was undertaken) are living with HIV and AIDS, whereas the national figure is estimated at 27.9%. If one considers these statistics, it becomes clear that this disease has taken its toll on the whole of South Africa, and that the community volunteers in the

Limpopo Province who support the large number of people affected by HIV and AIDS, be it physically, emotionally or spiritually, face a major challenge.

HIV and AIDS constitute much more than merely a health problem; these conditions are causing a developmental crisis. They reduce life expectancy, increase child mortality, place unendurable strains on health-care systems, and leave households impoverished. HIV and AIDS, unlike other transferable diseases, do not respect social barriers. They affect all spheres of economic life. Unfortunately, poverty creates situations of vulnerability to HIV infection; in fact, HIV and AIDS may even aggravate poverty (DeJong, 2003; Kelly, 2000). Individuals living with HIV and AIDS frequently experience social stigma, scorn or maltreatment. Social stigma, in particular, can be an obstacle to both prevention and care. It may lead to the isolation of the individual, caused by social exclusion that starts in the family and extends into the community (Siyam'kela Project, 2003; DeJong, 2003).

HIV and AIDS thus impacts on all levels of the eco-systemic model, as presented by Donald, Lazarus and Lolwana (2002: 55). HIV and AIDS affect people at the **individual level** (whether a person is ill or is dying), and impact on the personal life of the affected individual. Because of the social stigma attached to HIV infection and AIDS and the discrimination that is so often experienced, individuals suffering from these conditions are often reluctant to disclose their HIV status to family and friends for fear of being rejected. HIV and AIDS also have an impact at the **local community level** (among the affected individual's family or friends), where relatives and friends might be overcome by feelings of confusion and grief that accompany the knowledge that someone they love is dying from the disease. The impact of HIV and AIDS is also experienced at the **wider community level** (for example the individual's workplace or church), where such institutions need to work together in order to provide HIV-infected individuals with the necessary support to ensure that they will continue to feel safe in their community environments. The **social system** at large (for example the country's economy, the health system, social or welfare system) is also impacted on. Adequate funding, health care workers and community volunteers should be available in order to relieve the strain that HIV and AIDS place on our country as a whole.

If one considers the many levels of society that are affected by HIV and AIDS, it must be evident that individuals living with this disease have to face many challenges, as will be discussed in the following section.

### **2.2.2 Challenges faced by individuals living with HIV and AIDS**

One of the main challenges faced by individuals living with HIV and AIDS is perhaps the stigma attached to those who are infected and the discrimination that so often follow the disclosure of their status. This stigma might well intensify the bereavement process, since as a result of this experience the individuals affected by HIV and AIDS not only grieve about the dying process, but also about the reputation of their families. UNAIDS (2002: 8) describes stigma as a process that is reinforced by social inequality, therefore making it a definite form of discrimination against individuals who are affected by the disease and against their families. Fear of being rejected could contribute to the reluctance of individuals who are HIV positive to disclose their status to family and friends; to avoid possible rejection, they prefer to isolate themselves from the social world. One could thus say that such an individual is already grieving the loss of something over which s/he has no control.

Beverly, Wells, Goldie, DeMatteo and King (2001: 162) state that stigma, discrimination, secrecy and disclosure are significant issues for parents living with HIV and AIDS. These parents fear that their children will suffer discrimination if they tell others what their parents' status is. This often leads to HIV-positive parents keeping their status a secret from the rest of their families, which results in what Beverly *et al.* (2001:162) refer to as 'disenfranchised grief', where their loss becomes 'unspeakable'.

The *Sinosizo Home-based Care and Oral History Project* (2001) points out that it is particularly difficult for children to deal with the stigma, shame, guilt and fear related to HIV and AIDS. Dealing with the above-mentioned aspects creates anger and frustration within children whose parents are infected with HIV. For this reason the parents' decision to disclose their HIV-positive status to their children becomes extremely difficult. Parents and children who are affected by the disease should therefore be assisted in developing the coping skills required to deal with the strain that HIV and AIDS place on their lives, as will be discussed next.



### 2.2.3 Coping with HIV and AIDS

*'Who should be the judge of whether someone is coping effectively?'*

(Woznick & Goodheart, 2002: 53).

If one considers the number of people estimated to be living with HIV and AIDS, as well as the total number of AIDS-related deaths, one can begin to form some idea of the vast numbers of family members and friends who have to cope with the effects of HIV and AIDS. Sikkema, Kalichman, Hoffman, Koob, Kelly and Heckman (2000: ¶1) emphasise the fact that AIDS places strain on the psychological coping skills of both the HIV-infected individuals and those close to them. Therefore, HIV-infected individuals do not function in isolation, but are viewed as being in a dynamic and mutually reciprocal relationship with their environment.

In the above-mentioned context, Mccausland and Pakenham (2003: 855) define stress as a relationship between the individual and the environment, which is evaluated by the individual as exceeding his or her resources and threatening his or her well-being. Therefore the use of coping resources becomes an important issue to deal with the stress associated with HIV and AIDS. Mccausland and Pakenham (2003: 855) also describe coping resources as relatively stable characteristics of individuals' environments, and of the individuals themselves. These individuals then rely on their coping strategies to deal with the effects that HIV and AIDS have on their lives. Pakenham (2001) also notes an association between social support and caregiver well-being.

A study on social support conducted by Kmita *et al.* (2002: 283) illustrates that individuals who are coping with HIV and AIDS found group activities a great source of support. They also found that HIV-positive parents could share their experiences, discuss important issues and provide each other with the necessary support and respect, without being scrutinized. The above-mentioned researchers ran separate groups for children, using various therapeutic techniques such as art and drama, to create an environment in which the children would feel safe in expressing their emotions, such as fear, anxiety or a feeling of loss. In my opinion, combining the parent group with the child group could provide an opportunity for parents to safely express their concerns

to their children and vice versa. Being in groups with their parents could also provide the children with opportunities to get to know their parents at a deeper level, and to share with them their fears and feelings of anxiety associated with their parents' illness. Such a group situation could therefore provide ideal bonding opportunities for parents and children.

In her study on families as sources of support and of stress (as illustrated above), Owens (2003: ¶4) identified three primary categories of support to aid individuals to cope with the effects of HIV and AIDS, namely emotional, concrete and cognitive support. The **emotional categories** include affective support, love and concern, sympathy, commitment and acceptance by their families. Therefore, when a household begins to feel the effects of HIV and AIDS, family relationships provide the most immediate source of support (Laurie, 2004). The second category, **concrete support**, implies physical support, such as providing a place to live, assistance with parental responsibilities, including the preparation of meals, doing the laundry and providing transportation to clinics, doctor's appointments and social services offices. The third category, **cognitive support**, relates to providing families who are affected by HIV and AIDS with the information they will need in order to cope with the disease. The availability of the above-mentioned three categories of support is essential if people are to be able to cope with the effects of HIV and AIDS on the lives of HIV-infected individuals and their families.

Health care workers are intensely aware of the need for and importance of providing emotional care for families (Uys, 2003: 277). These services should therefore be made available to communities where the prevalence of HIV and AIDS is high. It becomes difficult, however, when individuals living with HIV and AIDS do not want their families to know that they are HIV positive for fear of being rejected or discriminated against. Lindsey *et al.* (2003: 498) mention the fact that stigmatisation often prevents individuals who are living with HIV and AIDS to access support services. One of the nurses interviewed by these authors suggested that health care workers should be more comfortable with an HIV diagnosis and should encourage shared confidentiality, since people are dying in secrecy. These are distressing words, as families affected by HIV and AIDS should be supported in their grief, and should be encouraged to talk freely about the past, present and future. A free exchange of thoughts and emotions could

provide families and the person who is dying of AIDS with an opportunity to share their concerns, aid them in the bereavement process and prevent them from becoming socially and emotionally isolated. Another obstacle in the way of effective support could be a lack of knowledge, particularly with regard to adequate information about HIV and AIDS care, as mentioned above.

In the next session I will discuss grief responses related to HIV and AIDS, and how these grief responses relate to coping with the losses associated with the disease.

#### **2.2.4 AIDS-related grief and coping with loss**

UNAIDS (2004) reports that in 2003 a total 370 000 AIDS-related deaths were reported among adults and children. If one considers this high figure, it should be evident that people living with HIV face unique challenges when they have to cope with the loss of loved ones to AIDS, as well as with the physical and psychosocial losses associated with HIV as such. Like people who die of other diseases, those who die of AIDS leave behind relationship partners, family members, loved ones and close friends who are left to cope with their bereavement. However, coping with bereavement caused by AIDS may, in some respects, differ from losses to other diseases (Sikkema, Kochman, DiFranceisco, Kelly and Hoffman 2003: 166) if one takes cognizance of the high number of AIDS-related deaths compared with deaths caused by other diseases. These authors also state that HIV-positive persons rank *difficulty coping with AIDS-related bereavement* as one of the most severe life stressors.

Bearing in mind how difficult it is to cope AIDS-related bereavement, Field and Behrman (2002: 170) suggest that support from friends, neighbours, employers and others in the community can make a difference in the experience of families living with an individual with a serious illness, such as HIV and AIDS. Once a person has died, care for that person ends. For those that are left behind, however, the need for emotional, spiritual and practical support continues. Parents, in particular, need support as the death of a child (which is described as one of life's most devastating experiences), not only affects the parents, but also siblings and a wider circle of relatives and friends (Field & Behrman, 2002: 171). Appropriate psychological, spiritual, and practical care for the bereaved family and friends is necessary to reduce physical and emotional health risks.

With regard to psychological care, Gisela Winkler (2003: 17), in her book *Courage to Care*, states that it is difficult for individuals who have HIV and AIDS to speak openly and honestly about the disease. Individuals living with HIV are mostly silent about the disease, possibly because they fear rejection or are embarrassed and do not want to be humiliated and discriminated against. Because they remain silent, they do not receive the sorely needed support that family and friends could offer.

In this study especially it is important to mention another reason why it might be difficult to speak of HIV and AIDS, namely *denial*. Most people who are HIV positive realise that they may develop AIDS and die, and it could be for this reason that they find it difficult to talk or even think about what might happen to them. Instead, they keep their focus on living, denying the possibility of death as a result of AIDS. The stigmatisation and discrimination associated with being HIV positive might also prevent individuals from disclosing their status to others (causing denial). Winkler (2003: 17) points out that young people in particular choose the route of denial, and Owens (2001: ¶8) states that this form of denial could block family communication, because family members might be going through a different stage in the grieving process than the individual who is infected with HIV. Cultural factors could also play a role in people's reluctance to talk about death and dying. Beverley, Wells, Goldie, DeMatteo and King (2001: 162) mention that there are some cultures where it is legitimate to not share with children aspects such as financial matters and sexual activities of parents, and as far as HIV and AIDS are concerned, strict privacy is maintained because children are considered as lacking in the level of judgement required to deal with such information. Also refer to the discussion on stigmatisation in the sections above.

In view of the difficulties that exist in talking about HIV and AIDS, it might be a challenge to build trust and acceptance in communities in order to make it easier for people affected by HIV and AIDS to talk more freely about their disease (Winkler, 2003: 19). It is in this regard that community volunteers could play a pivotal role, especially in the sphere of emotional support for families affected by HIV and AIDS. Community volunteers could provide safe channels through which community members can share their experiences and stories about how HIV and AIDS have affected their lives. As Winkler (2003: 19) points out, people with HIV and AIDS are often the victims of discrimination and prejudice. The community volunteers could therefore serve as guides

in creating a culture of acceptance of individuals coping with the consequences of HIV and AIDS.

In coping with death or dying, children especially might find it difficult to express their feelings about the death of a loved one or a parent dying of AIDS. In this regard Thompson and Rudolph (2000) state that the realisation has only recently set in that talking about death may be helpful to individuals in accepting death as a part of life and coping with the accompanying feelings. This will be particularly helpful to young children, whose understanding is limited by their level of cognitive development, as outlined by Piaget's theory of cognitive development (Louw, van Ede & Louw, 1998). Unresolved grief may lead to personal, interpersonal, or social problems in the future. An orphan's caregivers may also die of AIDS and leave the child to suffer multiple bereavements, and separation from siblings could intensify orphaned children's suffering. In this regard, UNAIDS (2004) states that people who work with orphaned children often struggle to understand the emotional suffering these children live through as they watch their parents die.

Intervention for adults and children who are grieving multiple losses often includes elements such as opportunities for emotional expression or exposure to death. Successful intervention of this nature includes elements such as a safe haven for facilitating expression of grief, the reassurance that their feelings and responses are normal, allowing sufficient time for grieving, monitoring the risk of coping failure, encouraging expression of emotions and developing the capacity to tolerate the painful emotions associated with grief (Exline, Dorrity & Wortman, 1996: 15).

According to Coovadia (in Uys 2003: 272), the provision of care, counselling and support for people living with HIV and AIDS and those close to them is one of the top 10 national priorities in South Africa, but the high workloads and skill scarcity makes this an 'ideal rather than a reality'. The application of the Memory Box Making technique by community volunteers could provide an opportunity for the expression of all the above-mentioned elements.

## **2.3 THE MEMORY BOX MAKING TECHNIQUE**

In various countries throughout Africa, health workers and community volunteers have begun to work on memory projects with families affected by HIV and AIDS (Winkler, 2003: 38). Projects such as the Memory Box Making Project, which is being implemented by researchers, health care workers, caregivers and volunteers nationwide in communities suffering from the impact of HIV and AIDS, are aimed at strengthening the bond and relationships between family members who are affected by the disease. As mentioned by Denis, Mafu and Makiwane (2003: 2), the idea of doing memory work with people affected by HIV and AIDS originated in Uganda in the mid 1990s, when an organization called NACWOLA (an organization for women living with HIV and AIDS) invited members to make a memory book in which they could preserve important information for their family and friends. Currently this model is used in various organisations in Africa to provide families with the emotional support needed to cope with HIV and AIDS. The above-mentioned authors further state that in 2002 various organisations in Gauteng and KwaZulu-Natal adopted the Memory Box Programme to train community workers and volunteers in aiding families affected by HIV and AIDS. Research done in areas as those mentioned above provided the inspiration to determine how volunteers in the Limpopo Province would apply the Memory Box Making technique came from.

Memory is the ability to bring back to consciousness past events (Sinomlando Project, 2003: 20). Therefore a memory box is a physical object created by a family for storing letters, photographs, tapes or any object that relates to the history of the family. The purpose of such a memory box is to build up resilience in families affected by HIV and AIDS to enable them to *cope* in difficult times, when loved ones become ill or die.

The Memory Box Making technique and its application by community volunteers to support communities in coping with HIV and AIDS will now be discussed in detail.

### **2.3.1 What is Memory Box Making?**

The Memory Box Making technique allows community volunteers to assist individuals and families in the community who are confronted with HIV and AIDS in telling their life

stories. This technique can be used to aid individuals and families in the bereavement process, as well as for crafting a personal legacy to be left behind for loved ones (Inger, 2002; Denis *et al.*, 2003). Therefore, the aim of Memory Box Making could be to provide community volunteers with the skills needed to help communities to take care of their basic psychosocial needs.

Theoretically, all members of communities that are affected by the HIV and AIDS pandemic (be it children or their parents) could benefit from the therapeutic value encapsulated in Memory Box Making. Since volunteers are in regular contact with their communities, the provision of physical and mental health care (as mentioned previously under the section on coping with HIV and AIDS) has also become an important aspect of their work that needs to be dealt with. However, it appears that limited time and training are allocated to development in this area. A relatively simple technique such as Memory Box Making could enable volunteers to provide emotional support to individuals affected by HIV and AIDS.

The technique of Memory Box Making is intended to help South African families affected by HIV and AIDS to cope with the disease, and with death and grief, as well as to plan their children's future. It also provides HIV-positive parents with the means to leave their children a legacy of information, memories and a warm feeling of love (UNICEF, 2005; Siyam'kela Project, 2003; Smetherham, 2002).

The memory box is a symbol, a physical object that is decorated with photos, drawings or anything that is precious to the individual or family (Sinomlando Project, 2003). This box therefore contains the story of the deceased or the dying person, as well as various objects related to the history of the family. The Memory Box Making technique also provides a dying parent with the opportunity to disclose his or her status to the child (UNICEF, 2005; Inger, 2002). As mentioned previously, this disclosure generally appears to be a difficult and traumatic decision.

The making of a memory box is a process. This process involves the sharing of memories of the ill parent or family member (or the deceased), and the recording and storing of these memories in the memory box helps family members to break the silence about disease or death (Inger, 2002). This process creates space for family members to

talk about sickness and death, thus helping them cope with the loss of their loved one. Everyone can take an active part in the creation of the memory box, because the more they contribute to the process of the retrieval of memories, the more they benefit from it. Community volunteers get an opportunity to encourage the sick parents to tell the history of the family in the presence of their children. In this way they could possibly facilitate the bereavement process of these children more efficiently.

Through making a memory box, children could be aided in building their identities and strengthening their emotional capacity. This could enable them to understand the past and be less afraid of the future. Through collecting photos, drawing family trees and writing about their lives, families become closer (see Appendix B for a description of the types of items that would be suitable for placing inside the memory box). Knowledge of what a memory box is and how it is made enables the volunteer to apply this technique as a bereavement tool to help individuals affected by HIV and AIDS to deal with their grief.

### **2.3.2 Using the Memory Box Making technique as a tool for dealing with bereavement**

By using Memory Box Making as therapeutic means of coping with bereavement, volunteers can support families affected by HIV and AIDS in coping with disease, death and grief, and in creating a sense of hope for the future. In facilitating Memory Box Making as a process (for example, shared memories of an ill parent or family member, or of a deceased person), memories are recorded and stored in the memory box (Siyam'kela Project, 2003; DeJong, 2003). This, in turn, could help members of the family and friends cope with the death of their loved one by creating space for them to break the silence and talk about sickness and death. The whole process and dynamics of Memory Box Making creates opportunities for volunteers to encourage ill parents to tell the history of their family in the presence of their children to facilitate the bereavement process for them. However, it is not only the bereavement process of the children that is facilitated, but also that of the parents and other family members or friends affected by the emotional turmoil associated with losing a loved one to AIDS.



Since bereavement has so many facets, Sikkema *et al.* (2003: 177) suggest that interventions for coping with AIDS-related loss and bereavement should be developed for the diverse populations of persons living with HIV and AIDS. That is exactly what the memory box provides: a culturally friendly intervention designed in such a way that individuals coping with death or dying have a safe way of expressing their grief. It also provides the infected individual with the opportunity to disclose his or her HIV status in the making of the memory box, therefore making it a cathartic process, freeing individuals with HIV and AIDS of the shame and fear associated with the disease (Smetherham, 2002).

The *Sinosizo Home-based Care and Oral History Project* (2001) suggests that the aim of Memory Box Making is to help families create a memento to keep alive the memories of the family, thus facilitating the bereavement process. They found that especially children who participated in the Memory Box Project, expressed gratitude for the way it has given them an understanding of their family tree and insight into their culture. As mentioned previously, children find it particularly difficult to deal with the stigma and fear related to their parents' death as a result of AIDS. Therefore, the Memory Box Making technique could help children to work through the bitterness and anger they feel towards a deceased parent. The emphasis in making a memory box is not on death and dying, but rather on stories of hope and of people's dreams.

### **2.3.3 Using the Memory Box Making technique as a form of functional support**

According to Viljoen (2005: 55), insufficient research has thus far been done on the functional aspects of the memory box, for example on what it should contain when used to offer support to individuals affected by HIV and AIDS. Therefore I will be incorporating my own ideas with ideas obtained from literature dealing with the value encapsulated in the memory box as a therapeutic technique to assist bereaved persons in my discussion of the practical use of the memory box in the context of functionality.

#### **2.3.3.1 Exclusive items**

Any materials found in the home can be used to construct a memory box. The family decides what is significant and should be used to decorate the box, and what items

should be placed inside it. These could include photographs, poems, letters, or anything else that attests to the uniqueness of a particular family's history. Morgan (2004: ¶26) mentions the possible use of a video tape recording to document memories on film, should a family have access to such means. This would enable a parent to make a video recording in which he/she talks about aspects of his/her life to leave to children and other family members. It is also suggested in literature (Morgan, 2004; Sinomlando Project, 2003; Smetherham, 2002) that items such as precious books and other objects such as jewellery and pieces of clothing could be placed in the memory box for children to admire and reflect on when their parents have passed away. In her work on Memory Box Making and vulnerable children, Viljoen (2005: 40) states that even items such as achievements and rewards received by either a parent or a child could be placed inside the box to reveal the parent's dreams and wishes for a child, thus providing the child with a sense of hope for his or her future: knowing that there is a life with possibilities for them after the death of their parents or caregivers.

### **2.3.3.2 Important documents**

In terms of the practical purpose of the memory box, Morgan (2002) points out the importance of placing in it a written document (a will) that states how the dying person would like matters to be handled after his/her death. Keeping an important document such as a last will and testament safe is of great importance, especially in communities where access to lawyers' services is a rare luxury. A document of this nature, through which they give instructions regarding their children's future can be a consolation to parents dying of AIDS. Other essential documents that could be included in a memory box are practical items such as birth and marriage certificates, identity documents, medical records, clinic charts and progress records obtained from the child's school. In their memory boxes, parents could include a written request addressed to the person who will be taking responsibility for their child after their death. The existence of such a document can provide the dying parents with the necessary peace of mind regarding their children's future. Children will also benefit from knowing in advance who their caregivers will be in the event of their parents' death. If such documents are kept together in a safe place and are accessible, the volunteer's task will also be less stressful once the parents have passed away and arrangements have to be made for the placement of the children with a caregiver.

### **2.3.3.3 Personal Information**

Personal information could include the names and addresses of close relatives or friends who can be contacted in case something happens to a child after his/her parent has passed away, as well as information about the child (e.g. health information, treatment received or required and clinic records).

In considering the documentation that goes inside the memory box, I must admit that although I understand the importance of keeping such documents safe, the true purpose of the memory box is essentially to provide emotional support to people suffering from terminal diseases and to their loved ones during the period of loss and grief. Therefore, the memory box could be used more effectively as a tool for emotional support for bereavement. I myself have made such a box in memory of my brother and have found it a great help in dealing with my loss. Could the volunteers use this tool as a means to offer emotional support? Could they possibly look past its functional value and look to its deeper meaning and supportive value, especially in the context of families who are saying their good-byes to a loved one?

The section that follows includes a discussion of the role of community volunteers who are helping communities to cope with the effects of HIV and AIDS.

## **2.4 COMMUNITY VOLUNTEERS**

### **2.4.1 Definition of the term *community volunteers***

According to Smart (2003: 9), HIV and AIDS and international human rights guidelines define the parameters of a rights-based, effective response to the epidemic in terms of generating appropriate governmental institutional responsibilities, implementing law reform and support service, as well as promoting a supportive environment for those individuals living with HIV and AIDS. Rosa and Lehnert (2003: 32) explain that the right to social security or support as a human right is widely recognised in international law as part of the body of rights collectively concerned with the well-being of individuals who are infected with and affected by HIV and AIDS. Owing to the immense impact of AIDS on the health sector, Community Home-based Care (CHBC) is seen in South Africa as a

key strategy to sharing the workload of AIDS care among hospitals, clinics, families, and the rest of the community (Lindsey, Hirschfield, Tlou & Ncube, 2003: 489). These authors provide the following comprehensive definition for CHBC:

*CHBC is defined as care given to individuals in their own natural environment, which is their home, by their families; supported by skilled welfare officers and communities to meet spiritual, material and psycho-social needs; with the individual playing a crucial role. The target group for this programme is any person with HIV related diseases/AIDS including all other chronically ill patients, social welfare officers including nurses (who will play the lead role), social workers, district health and nutrition officers and other allied health professionals.*

From the above-mentioned it becomes clear that the government also recognises the need for assistance where HIV and AIDS are concerned. They strongly acknowledge that, in addition to physical care, people affected by HIV and AIDS are in desperate need of spiritual and psychosocial care. In the sections that follow, the focus will be on defining the current role of community volunteers among people in their communities who are affected by HIV and AIDS. The type of care currently provided by volunteers, and the aim of such care, will be discussed.

#### **2.4.2 Community level home-based care**

According to a statement by the Department of Health (2005), the increase in the incidence of AIDS has made it necessary to consider what the best care provision would be for people with a chronic illness and for their families. Since South Africa has limited health care resources, and more and more individuals are becoming ill, hospitals, hospices and other care institutions will be able to admit only a small percentage of patients. This emphasises the importance of the role of community volunteers in caring for people when they become too ill to take care of themselves. Another factor, besides the lack of care facilities, that has to be considered is the cost of running such facilities and the cost to patients if they have to pay for transport to visit such facilities regularly. Home-based care volunteers are able to provide a pivotal service for ill individuals in the comfort of their own homes.

On account of the AIDS pandemic, home-based care has become an important reality in our country (Winkler, 2003: 39). One challenge is to get community volunteers involved in caring for those who are ill, not only providing in their physical needs, but also providing emotional and spiritual support. Kmita, Baranska and Niemiec (2002: 280) explain that this type of intervention diminishes the social isolation of families who are living with HIV and AIDS and plays an important role in supporting children and their families in the process of coping with this terminal illness and with the loss associated with HIV and AIDS, as mentioned earlier. It is therefore essential that attention be given to providing caregivers with some form of training to prepare them for the task of providing psychosocial intervention or support.

According to UNAIDS (2004), the large contribution of community-based initiatives is widely recognised and home-based care has become part of many countries' health campaigns. They also state that regardless of some remarkable examples of good practice, progress towards drawing these care programmes into the wider public health system has been limited. Therefore, even though such services are being implemented, they are restricted.

The Department of Health (2000) states that every community should provide individuals who are chronically ill with some form of home-based care, as well as access to community-based care. They also urge communities to establish home-based care that is comprehensive and holistic. In other words, care that does not focus only on specific aspects or needs of an individual or community, but on the whole person or community, attending to every area that is affected by living with HIV and AIDS or watching loved ones dying of the disease. Government policy documents also recommend that home-based care be person centred, placing the focus on what the individual is experiencing and not only on his/her HIV status. Sensitivity to culture, religion, values and respect for privacy and dignity and the preservation of self-esteem are also deemed important aspects that deserve special attention. Thus, providing care that is humane, care that knows no boundaries and care that does not discriminate in any way against the recipients. A non-judgemental attitude is of particular importance. People living with HIV and AIDS have such a heavy burden to carry that an attitude that causes – or increases – feelings of guilt and shame could serve no purpose.

This national programme assists all people who are in need of basic support services to continue living and/or dying in their community (Department of Health, 2005). Therefore this national programme is aimed at *healthy people*, at risk *elderly*, *terminally ill people*, persons *living with HIV and AIDS*, as well as people who are at risk owing to severe functional disabilities and any other disadvantaged group or person in need of such care. This document also takes note of the other individuals affected by HIV and AIDS, such as the caregivers of those mentioned above. These individuals include *family members*, *caregivers* from the formal system (professionals) and non-formal system (NGOs) and *caregivers* from the informal system. This is where the community volunteers, religious groups offering assistance and other health care workers fit in.

#### **2.4.3 Provision of support by community volunteers**

When the HIV and AIDS pandemic made usual work patterns impossible for hospitals, rural hospice in South Africa developed an integrated community-based home care model (see Figure 2.1) in the mid 1990s. This model provides a continuum of care for individuals living with HIV and AIDS from diagnosis to death (Uys, 2003: 272). This model also includes counselling of individuals who are relatively free of symptoms, while placing emphasis on the physical and terminal care of individuals who are dying of the disease.

**Figure 2.1 The Integrated Community-based Home Care Model (ICHC)**

(Uys, 2003: 237)

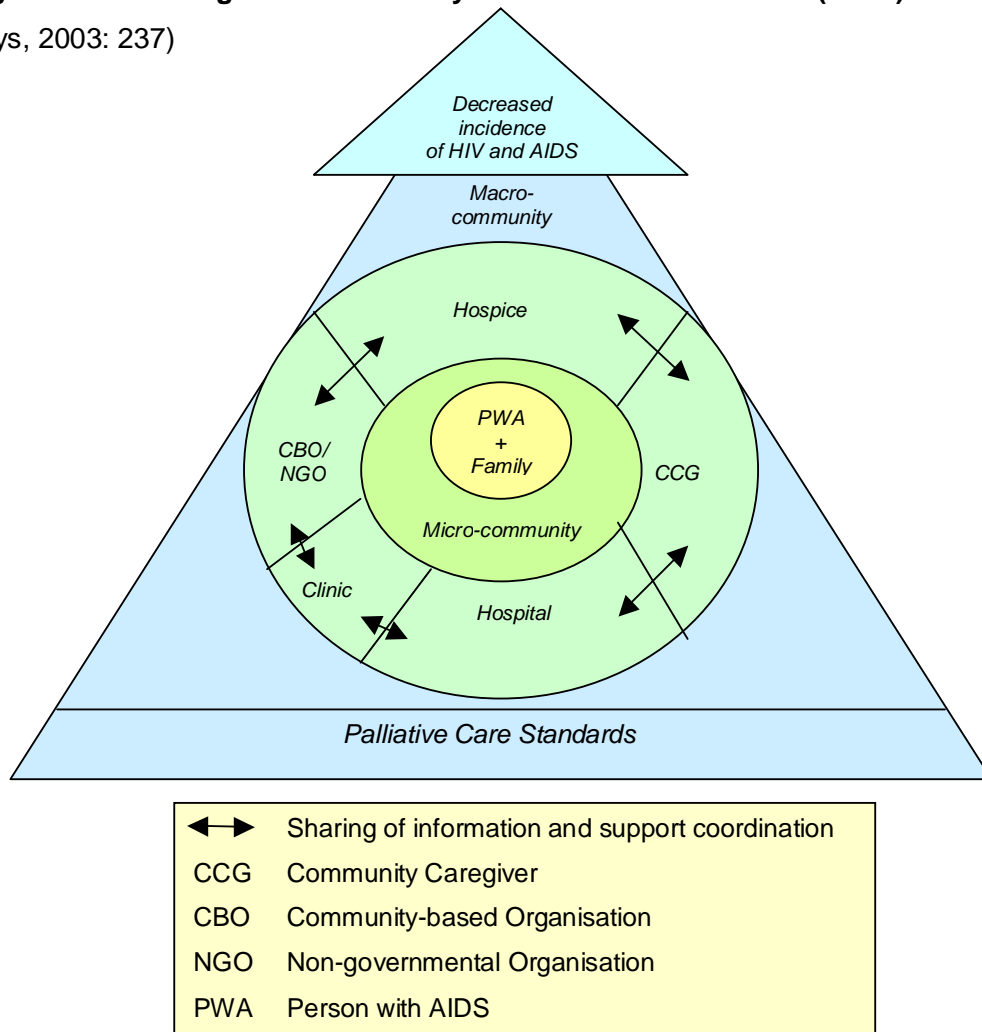


Figure 2.1 demonstrates the Integrated Community-based Home Care Model. This figure illustrates that it is important for all those concerned to realise that home-based care also improves the illness and death experience. Therefore, that the relationship between dying at home and having a 'good' death supports the notion that home-based care is the model of choice for individuals living with HIV and AIDS (Uys, 2003: 279). Uys (2003: 273) also explains that an important part of this model is the involvement of, as well as collaboration between hospital, hospice, and primary health care clinics, who, together with the community, take ownership of the ongoing process associated with helping individuals who are coping with HIV and AIDS.

Uys (2003: 272) also mentions that in terms of counselling, much attention is being given to the illness itself, and that international HIV and AIDS literature on counselling focuses mostly on pre- and post-test counselling. Coovadia (2000) states that even though provision of care, counselling and support for people living with HIV and AIDS is one of South Africa's top 10 national main concerns, high workloads and a shortage of people with the necessary skills makes this concern 'an ideal rather than a reality'. In general, emotional care and support for families who have lost a loved one to AIDS receives little attention.

Lindsey *et al.* (2003: 498) suggests that one of the needs most often identified in terms of home-based care is the need for counselling. However, the health care workers involved felt that they lacked the skills required to adequately meet this need. Literature (Lindsey *et al.*, 2003; Uys, 2003) also suggests an identified need for effective interpersonal communication and psychosocial support for individuals affected by HIV and AIDS. In particular, families indicated a need for bereavement counselling and anticipatory guidance. These families felt a need to share and talk about the effects the disease had on them and their loved ones and expressed a desire to be guided in dealing with all the associated emotions. In their study of home-based care in Botswana, which involved older women and younger girls, Lindsey *et al.* (2003: 299) found that members of the community who offered home-based care felt that they lacked the skills required to effectively provide their communities with psychosocial care. As a result, they tended to ignore the families' need for counselling. One could therefore say that because the volunteers did not have the necessary skills to provide emotional support to their community members, they opted not to become involved.

To avoid circumstances such as mentioned above, UNAIDS (2004) proposed that governments ensure that individual caregivers, or volunteers that care for HIV and AIDS-susceptible communities, receive the necessary training and support to ensure that they will not give in to hopelessness. Community volunteers need information and should be trained in how to care for individuals suffering from the effects of HIV and AIDS, specifically through providing emotional support, as they play a critical role in enabling their communities to deal with the effects this disease.



## **2.5 CONCLUSION**

In this chapter I explored the main concepts dealt with in this research study, which include the role of volunteers in helping their communities to cope with HIV and AIDS, Memory Box Making, and the supportive value of the Memory Box Making technique when applied to help those dying of AIDS and their families cope with loss and grief. In Chapter 3 the details of the research process, and the research design and methodology will be discussed in detail.

## CHAPTER 3 – RESEARCH DESIGN

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### 3.1 INTRODUCTION

This chapter contains my personal reflections on the research process, as experienced by a young, inspired researcher. It relates the story behind my experiences (personal and professional), as well as reflections on the process and methods that were utilised during the research project.

### 3.2 BACKGROUND TO THE PROJECT

I was first inspired to research this topic in 2003, when a project called 'The Memory Box Project' was born. In that year Liesel Ebersöhn and Irma Eloff determined that volunteers at Acornhoek required assistance to enable them to provide psychosocial support to families coping with HIV and AIDS. They decided to determine if volunteers could effectively use the Memory Box Making technique for this purpose. This created a lot of excitement and I, as the primary researcher, was particularly excited as I would be given a great opportunity to put my newly acquired research skills to the test.

The motivation behind my research was to explore the important role volunteers play in mitigating the impact of HIV and AIDS, particularly in three spheres. The first of these spheres is *prevention*, doing HIV and AIDS education and enhancing awareness. The second is *care*, where home-based care volunteers go out to families to provide them with the necessary medication or aid them to get to clinics for treatments. The third sphere is where my focus lies: *support*, with the emphasis on the emotional well-being of families in communities coping with HIV and AIDS, and in particular the role that volunteers play in giving such support.

***From the researcher's pen:***

*Volunteers play a significant role in supporting people affected by HIV and AIDS. They give of themselves emotionally, spiritually, and physically to help people in their communities who are affected by this terminal illness. I cannot even begin to think what I might uncover during the period of research and the study that lies ahead of me. What I do realise is that where families are trying to cope with the loss that HIV and AIDS has brought into their lives, it is the volunteers*

*who are faced with the 'responsibility' of supporting their communities in such desperate times. From my current knowledge and from conversations with various individuals, I gathered that home-based care volunteers mainly support their communities with their physical needs. Not much is being done in connection with the emotional support needs of families coping with HIV and AIDS. Even though I do believe that through offering physical support the volunteers do, to some extent, support the families emotionally, I wonder if support concerning feelings of loss and grief, as well as coping with dying and death as a result of the disease, are being adequately covered. I am looking forward to the research process and applying my newly acquired research skills!*

### 3.3 PARADIGMATIC PERSPECTIVE

According to Terre Blanche and Durrheim (2002: 36), a paradigm 'acts as a perspective that provides a rationale for the research and commits the researcher to particular methods of data collection, observation and interpretation'. In taking an interpretive stance to one's research, the aim is to understand the world of human experience by gaining a better understanding of the experiences of the participants of the study, as well as the subject matter (Cohen, Manion & Morrison, 2000; Denzin & Lincoln, 2000; Ferguson, 1993). Therefore, as Garrick (1999: ¶4) explains it, research is done *with* people, rather than *on* people.

I chose to work from an interpretive stance and found it to be of considerable value. In using this type of epistemology I am able, as a researcher, to gain insight into the volunteers' experiences surrounding Memory Box Making, that is, how they applied their knowledge, and used their skills regarding the Memory Box Making technique (Jansen in Eloff & Ebersöhn, 2004; Cohen *et al.*, 2000). According to Terre Blanche and Kelly in Terre Blanche and Durrheim (2002: 123), the interpretive approach presumes that 'people's subjective experiences are real, that we can understand others' experiences by interacting with them and listening to what they tell us, and that qualitative research techniques are best suited to this task'. They further conclude that interpretive research relies on first-hand accounts in which it attempts to portray what it sees in rich detail, and then presents its findings in engaging and sometimes indicative language. In using an interpretive paradigm, provision was made for thick and rich descriptions. As Patton (2002: 437) explains, thick and rich descriptions supply the foundation for qualitative

analysis and reporting, also providing for the reader, to be taken into the setting being described.

Since an interpretivist paradigm is being utilised for this study, the focus is on seeking to understand participants' experiences, not on the basis of my own perspectives and categories, but rather from those of the participants taking part in the study (Huberman & Miles, 2002: 48). The situation is therefore viewed from an *emic*, rather than an *etic* perspective. Throughout this study my role as the researcher and facilitator was to gain a better understanding of the perspectives of the Acornhoek community volunteers, to avoid viewing them from an 'outsider's' perspective and not to allow my different cultural background and my own personal interests in the study influence the results of the data obtained (Patton, 2002: 84). Denzin and Lincoln (2000: 194) explain this course as one where, in interpretive traditions, the researcher or interpreter should remain unaffected by and external to the interpretive process.

Garrick (1999: ¶2) states that interpretive research uses personal experience as its starting point. He further concludes that this starting point could be problematic as the researcher's subjective experiences are engrossed in and shaped by discourses, in other words, the researcher could be influenced by historically and contextually framed experiences. That is why, in my study, I chose to exercise an emic perspective, not letting my discourses influence the results of my study. Throughout the process I kept a researcher's journal that allowed me to reflect upon my own life story, and monitor my historically and contextually framed background. I did this because the interpretive argument, as outlined by Garrick (1999: ¶3), is that an individual's experience is best understood from the standpoint of the social world of *that* individual, the perspective of the volunteers.

***From the researcher's pen:***

***(Reflection on the workshop):*** My decision to work from an interpretive stance definitely did not let me down. I realise that I acquired so much more information, especially from the workshop, by taking note of the participants' experiences rather than posing specific questions. I also benefited from the fact that the volunteers actually wanted to share their experiences with me. They were quiet at times, but I think that the amount of information that they were expected to assimilate, especially during the workshop, was quite overwhelming. I was also amazed by the fact that the volunteers so readily shared with me their experiences concerning grief and loss, as

*well as their experiences concerning the communities they work in. I wondered whether I could possibly have obtained the same rich descriptions about how they view their own enablement in supporting their communities to cope with HIV and AIDS if I had chosen a paradigm other than interpretivism for my research.*

**(Reflection on the whole experience):** *I really feel that choosing an interpretive paradigm most certainly helped me to explore more widely, and not necessarily focus on just the specifics. I had an opportunity to be a researcher and a facilitator. Furthermore, I was able to obtain more detailed and enhanced descriptions of the participants' feelings and experiences. I would never have received so much information on their personal life experiences concerning grief and loss, as well as the impact of HIV and AIDS, if I had, for example, followed a more positivist mode of thinking.*

### 3.4 RESEARCH DESIGN

According to Durrheim (Terre Blanche and Durrheim, 2002: 29), a research design is 'a strategic framework for action that serves as a bridge between research questions and the execution or implementation of the research'. In this study, research was done by way of a *qualitative approach*. Qualitative research is concerned with trying to understand meaning and impact in a more multifaceted way, as described by Parker, Dalrymple and Durden (2000: 82). Denzin and Lincoln, in De Vos (1998: 240), explains qualitative research as a multiperspective approach to social interaction, aimed at describing, making sense of, interpreting or reconstructing this interaction in terms of the meanings that the subjects attach to it. Often unanticipated information can be identified through qualitative research, since the discussion is not limited by predetermined closed questions. Therefore, by using a qualitative approach in my study, information about how participants think, feel and act, as well as what they believe, could be collected.

As mentioned in Chapter 1, the ***purpose of my research*** was to explore and describe how community volunteers apply the Memory Box Making technique to support communities coping with HIV and AIDS. The focus therefore was on *explorative* and *descriptive* research. In conducting my research, this firstly implied an in-depth investigation of Memory Box Making and the use of this activity by community volunteers in their support of communities coping with HIV and AIDS, and secondly, obtaining a

detailed description of how community volunteers apply the Memory Box Making technique to support people who are learning to cope with HIV and AIDS.

Research in this study was done by means of an instrumental case study of volunteers who are supporting communities coping with HIV and AIDS in a township called Acornhoek, in the Limpopo Province.

### 3.4.1 Design

Bless and Higson-Smith (1995: 43) explain that an *instrumental case study* is a comprehensive in-depth investigation of a few cases. The purpose of such a study is to give greater insight into the subject matter (Cohen *et al.*, 2000). Stake, in Denzin and Lincoln (2000: 437), defines an instrumental case study as a particular case that is examined mainly to provide insight into an issue. It is further concluded that in an instrumental case study, the case is of secondary interest, playing a supportive role, facilitating our understanding of something else. Bergen & While (2000: ¶6) chose to define an instrumental case study as one that is chosen to answer a particular research question, which is the underlying issue that it epitomizes, rather than the case itself, which is important. Therefore, it involves dealing with the 'how' and 'why' questions. In my study I decided to use this design as it could provide a unique example of how the volunteers deal with HIV and AIDS in their everyday activities. By conducting an instrumental case study, I could explore and describe the current roles assumed by the Acornhoek community volunteers, as well as their application of the Memory Box Making technique in helping their communities to cope with the devastating consequences of HIV and AIDS.

A case may be defined as being simple or complex, a bounded or integrated system. Therefore, a case could involve an individual, a group, an organization, a city, and so forth (Berg, 2001; Denzin and Lincoln, 2000). Bergen and While (2000: ¶1) define a case as a unit of analysis. Berg (2001: 231) states that a unit of analysis defines the focus of the case study. In my study, the unit of analysis was the volunteer structure in Acornhoek. See 3.4.2.1 and 3.4.2.2 for the criteria applied for the selection of the case and of the participants.

Cohen *et al.* (2000) point out that the advantages of using an instrumental case study design are, firstly, that the participants are immediately intelligible (they can speak for themselves). There were, however, times when there was a gap in communication (understanding is in all probability always limited), but the whole group helped out in bringing across what needed to be said (as far as possible). Even though we had a scribe, he was not immediately available due to his other responsibilities. Nonetheless, gaps in communication were bridged (as far as possible). A second advantage of using an instrumental case study is that it offers opportunities to catch unique features that may otherwise be lost in larger-scale data. It was possible to interact with the group of 20 participants and allow them all to share their viewpoints and experiences concerning the required data. Much of this information might have been lost in working with a much larger group of people. A third advantage in using such a design is that it does not require the efforts of a full research team – it can be undertaken by a single researcher, as was the case in this study. Even though the research load was small enough for one person to handle, a team consisting of two co-facilitators was present during the data collection phases (as discussed in the section below). A final advantage would include that this design offers an opportunity for taking a strong stance on reality. By involving the volunteers in the whole process, making it one of close interaction, a greater sense of reality could be endorsed, enabling the researcher to gain insight into the real worlds of the participants.

Although this design has many advantages, it is not immune to weaknesses. Literature suggests that the most commonly heard objection to case study research is its low generalizability, the fact that only one or two cases are studied (Verschuren, 2003: 122; Cohen *et al.*, 2000:184). In other words, that general conclusions cannot be made of the results gathered. However, this is refuted by other literature: Berg (2001: 232) states that ‘when case studies are properly undertaken, they should not only fit the specific individual, group, or event studied, but generally provide understanding about similar individuals, groups or events’. According to Verschuren (2003: 134), the critique of low generalizability of the results obtained in a case study is based on a *reductionistic* type of reasoning. Therefore, that the results of a case study ‘are in principle generalizable to theoretical propositions, not to populations or universes’ (Verschuren, 2003: 134). Yin (2003) supports this statement by asserting that the role of theory development, prior to data gathering, is a key difference between case studies and other related approaches.

I agree with these authors in that if one has strong theory on which you can base your study, the results could be generalizable. In using an *instrumental case study* in my research, I was able to conduct a comprehensive, in-depth investigation of the Acornhoek community volunteers, and to gain insight into their experiences relating to the use and application of the Memory Box Making technique to support their communities in dealing with HIV and AIDS.

Another weakness of the design is that it is susceptible to being selective, biased, personal and subjective, as well as observer biased. From an interpretivist paradigm I acknowledge that my views and opinions as the primary researcher impacted on the themes uncovered through the research process. Therefore it was imperative for me to keep track of personal views throughout the whole process, questioning my own predispositions as the research progressed, by keeping a research diary.

However, despite the disadvantages, it would be of value to state that the aim of the *instrumental case study* is to report on and provide insight into a particular case, not the world. Furthermore that case studies, through their interpretive tradition, view situations through the eyes of participants, showing what it is like to be in a certain situation (Terre Blanche & Durrheim, 2002; Cohen *et al.*, 2000; Bless & Higson-Smith, 1995).

### **3.4.2 Methodology**

#### *3.4.2.1 Selection of case*

In my study the unit of analysis was the existing volunteer structure in Acornhoek in the region of Bothlabela in the Limpopo Province. This case was selected on the basis of existing access (research had previously been done there and a relationship had been established with a contact person in the area). I got in touch with the contact person and arranged to do my research there. There was no objection, the idea was readily accepted and I started with the first steps in the research process. Therefore, the volunteer structure in Acornhoek was readily available for research purposes. A disadvantage in selecting the existing volunteer structure in Acornhoek as the case was the distance I had to travel. Acornhoek is a five-hour drive from Pretoria, which made instant availability, as well as the observation of the volunteers applying their newly



learnt skills in Memory Box Making, virtually impossible. I therefore had to rely on the follow-up focus group for information on their application of the Memory Box Making technique in supporting their communities to cope with HIV and AIDS. Telephone calls and e-mail messages were also alternatives as the volunteers have access to these facilities at their centre. The research team gave our telephone numbers and e-mail addresses to the volunteers and suggested they contact us to discuss any possible further questions. We also obtained their telephone numbers so that we could contact them if the need arose. However, our main contact with the Acornhoek volunteers was through the contact person with whom we had already previously established a relationship, and we worked mainly through him. The case however, had to meet the criteria as set out in the purpose of this study, namely to explore and describe how community volunteers can apply the Memory Box Making technique to support people trying to cope with the consequences of HIV and AIDS.

Training was done at the community youth centre, situated in the main street in Acornhoek, which meant that most of the participants had to travel a great distance to meet us at the centre. Different shops and entrepreneurial stands surround the centre. The centre was equipped with enough chairs for the research team and the participants, and the training room was spacious enough to allow the participants sufficient room to sit comfortably while making their own memory boxes. We were also provided with a table that was big enough for the equipment we had with us. The room had a door that led outside, which provided the opportunity for the volunteers to get some fresh air during break times. Access to kitchen facilities made it possible to prepare snacks and serve lunch for the participants.

#### *3.4.2.2 Selection of participants*

Community volunteers in this area were the source of the data I needed. Approximately 20 participants were purposively selected to participate in the research process. All of the participants were involved with organisations in Bothlabela. The ages of participants ranged from 18 to 42 years. The majority of participants were female, especially those involved in home-based care, and most of the youth volunteers were young male adults. These participants were chosen on account of their being the most representative for the purpose of this study. They all work in and support communities susceptible to the

effects of HIV and AIDS. Although availability played a role in the selection of the participants, the most important criterion for selection was their knowledge and experiences of working as volunteers in a community affected by HIV and AIDS. Selection took place by way of purposeful sampling, which means that this information-rich case was selected purposefully. De Vos (1998: 252) explains that in qualitative research, purposeful sampling methods are the best to use. I therefore identified a case where the participants could be reached fairly easily and selected participants who would be able to provide me with the information I needed.

**Table 3.1 Particulars of participants involved in the study**

GENDER	AGE	YOUTH VOLUNTEERS	HOME-BASED CARE VOLUNTEERS
Male	20 – 35	10	0
Female	18 – 42	4	16

Table 3.1 indicates the number, age and gender of the participants who were involved in my research study.

***From the researcher's pen:***

***(On the location and the venue):*** When we approached Acornhoek I was astonished by the town's enthusiasm and entrepreneurial aspirations. Even the centre where we held the workshop had great potential. Initially, when the first arrangements were made, I was a bit worried that the chosen venue would be too small. I had never been to Acornhoek and had no idea of what to expect. We were privileged enough to be given access to the youth centre. It was fully equipped with enough space, as well as a photocopying machine, which we could use to make copies of the participants' ID documents, consent forms, and beneficiary forms (this was a great help, as I hadn't anticipated having to make copies of these documents!). We were allowed to use the training room, which was equipped with colourful chairs, a table-tennis table and a flipchart board that we were allowed to use. The staff at the centre were very helpful and welcoming to us as 'outsiders'. There was no running water, but water could be obtained from big containers on the premises.

***(On the research team):*** What a joy to have co-facilitators when you have 20 people sitting in front of you! It was nice working in a team while presenting the two-day workshop and having a video camera to operate, forms to hand out and take in, etc. During the interviews especially, it

was helpful to get input and feedback from a co-facilitator, and also having an extra pair of eyes and ears for observation purposes, as well as for debriefing afterwards. It would have been possible to handle the research load on my own, but I must confess that it was extremely helpful to be working together as a research team.

**(On the participants):** On arriving at the venue, I noticed only a handful of people, who turned out to be home-based care volunteers. This worried me, because we had planned the workshop specifically for these volunteers. In being flexible, we invited the youth volunteers to join the workshop, as we had enough materials for 20 people. The low attendance frustrated me at first, seeing that my specific goal had been to converse with the home-based care volunteers of this area. Surprisingly enough, what started as a disappointment turned out to be quite beneficial to my study, as I decided to change the research questions from being aimed specifically at home-based-care volunteers, to include volunteers in general. I realised that with the limited resources in this area, all volunteers play an important role in supporting the community. It was very insightful to hear what both volunteer groups had to share. However, problems arose when it became apparent that the home-based care volunteers felt that it wasn't fair for the other volunteers to join, since the workshop was intended for them. We dealt with this by suggesting that the youth volunteers nominate four people to attend the second day of the workshop, because there were 16 home-based care volunteers and only enough materials for 20 participants. Everyone was satisfied with this solution and we could continue with the workshop with happy faces.

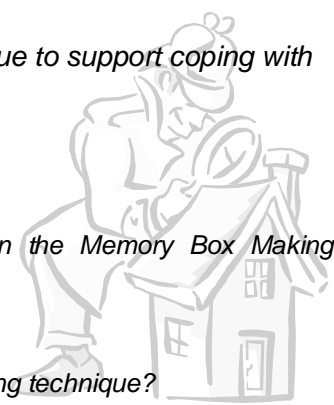


### *3.4.2.3 Data gathering*

Mouton (2001: 108) states that data come in different formats and have different properties. In this particular study I made use of mainly textual data, described by Mouton (2001: 108) as 'data that are rich in meaning' and are difficult to capture in a brief and structured manner. I therefore applied a comprehensive data-capturing process that would ensure that the data gathered would be rich in meaning. De Vos (1998: 253) describes this as essential in qualitative research and emphasises the need for the collected data to be rich in description of people and places. To ensure that I would be able to collect such data, I did purposeful sampling (as explained in section above), which allowed me to identify a case that was especially informative. The methods employed by me to collect my data included a two-day workshop, focus-group interviews and field notes, as discussed in Table 3.2 and in the section below.

In capturing the data, I used audio-visual methods (a video camera and a dictaphone) and visual methods such as using a photo camera. De Vos (1998: 329) describes data capturing through these means as 'a way of direct observation in the study of behaviour and human experiences as they occur in daily life in a variety of settings and contexts'. Through the use of these means I was able to gain a better understanding of the participants' perspectives and experiences regarding their support of their communities coping with HIV and AIDS. The figure below illustrates the different methods used, as well as the disadvantages of using them (Creswell, 2003; Patton, 2002; Denzin & Lincoln, 2000), and the measures used to correct the disadvantages specific to this study.

**Table 3.2 Methods of data collection and data capturing used during the research process**

<b>RESEARCH PROCESS:</b>		
<p><i>How do community volunteers apply the Memory Box Making technique to support coping with HIV and AIDS?</i></p> <ul style="list-style-type: none"> <li>❖ <i>What is Memory Box Making?</i></li> <li>❖ <i>Exploring the existing role of community volunteers.</i></li> <li>❖ <i>Developing a programme for training community volunteers in the Memory Box Making technique.</i></li> <li>❖ <i>Implementation of the programme through a two-day workshop.</i></li> <li>❖ <i>How could the community volunteers apply the Memory Box Making technique?</i></li> </ul> 		
<b>Data collection methods</b>	<b>Disadvantages</b>	<b>Corrective measures for this study</b>
<ul style="list-style-type: none"> <li>• <b>Two-day workshop</b></li> </ul> <p>Training in the Memory Box Making technique to establish what needed to be focused on in order for the volunteers to have the necessary means to enable their communities.</p>	Time	Conducted a workshop focused on the most-needed information on Memory Box Making.
	Cultural differences	Remained sensitive to complexities surrounding diversity, used emic rather than etic perspective.
	Language issues	A translator was present.
<ul style="list-style-type: none"> <li>• <b>Focus-group interviews</b></li> </ul> <p>Collection of data by facilitating an open group discussion.</p>	Provides information in a designated place rather than the natural field setting.	Interpretive research – gaining understanding from participants' experiences, their perspectives.
	Researcher's presence may bias responses.	I used an emic perspective, kept a reflective journal to monitor my own views.
	People are not equally articulate and perceptive.	The participants helped each other to bring their point across.
	Interview data are also subject to recall error.	Made field notes, kept a research journal and used a video.
<ul style="list-style-type: none"> <li>• <b>Field notes</b></li> </ul> <p>Recorded what occurred and kept a researcher's journal.</p>	Possible distorted descriptive information, or distorted recollection of what has been said	Made use of informal discussions to clarify specific points.

	The researcher's own feelings own insights, interpretations, initial analyses and working hypotheses.	Focus on an emic perspective and keep the focus on interpretive research. See the world through the eyes of the volunteers, also keeping a research diary.
<b>Data capturing methods</b>	<b>Disadvantages</b>	<b>Corrective measures for this study</b>
<ul style="list-style-type: none"> <li><b>Audio-visual methods</b></li> </ul> Provided visual and auditory presentation of what was missed though interaction with the participants.	May be difficult to interpret, the presence of a video camera may be disruptive and affect responses.	The participants' perspectives were taken into consideration when interpreting the audio-visual data. Employed member checking. Furthermore, participation was voluntary.
<ul style="list-style-type: none"> <li><b>Visual data</b></li> </ul> Provided a visual representation of what was done.	The presence of a photo camera may be disruptive and affect responses	Participation was voluntary. Photos were also taken during breaks so that the participants could get used to the camera.

Table 3.2 illustrates the methods used during the research process. A discussion of these methods and a description of some of the disadvantages experienced and how these were addressed follows.

- Memory Box Making training workshop**

From the exploration done by Liesel Ebersöhn and Irma Eloff in 2003, I gained better insight into the roles played by volunteers in their communities. I also conducted a literature review in order to be able to develop a workshop based on the Memory Box Making technique.

The research strategy entailed conducting a *two-day training workshop* to equip volunteers with the Memory Box Making technique. I had worked out a two-day programme with pre-established goals and outcomes (See Appendix C for a detailed layout of the programme). In short, the two-day workshop was aimed at training volunteers in the Memory Box Making technique in order to explore how the volunteers applied these skills in their work with people in communities affected by HIV and AIDS in order for them to be able to support their communities to cope with the effects of HIV

and AIDS. Even though there was a set structure to what we wanted to complete during the workshop, we remained flexible.

**From the researcher's pen:**

**(On the first day of the workshop):** *We arrived at the venue in the morning, at about 09:10, to find that only a handful of home-based care volunteers had responded to our invitation. My first thought was, 'All this effort for so few people!', but then I thought, maybe it's a good thing, because now we can work more intensely, and there will be less pressure on me as a relatively inexperienced researcher! It was all very exciting though. We started the day off with an introduction, explaining the purpose of the research and the reasons for our decision to come to Bohlabela, Acornhoek. Then suddenly people from outside the training room in the centre (the youth volunteers) started joining the group, which was fine at first, but became quite overwhelming later.*

*The first discussion was somewhat disappointing, and I was particularly disappointed that the home-based care volunteers did not join in the discussion as much as I had hoped they would. The main participants were the youth volunteers. This was a disappointment to me because my research focused mainly on the roles played by home-based care volunteers in their communities and their involvement in the community. However, as the youth volunteers spoke and shared experiences, I came to a realisation that they play just as an important role as the home-based care volunteers. Even though they work mainly with the youth, they often deal with people infected and affected by HIV and AIDS.*

*Because I had no idea of what the roles of the home-based care volunteers was in their communities, it was interesting to listen as they explained how they approach their work. I found out that they mostly refer the households to social workers for emotional support. It was then that I realised (as they spoke) that they probably do this because they do not believe that they have the skills needed to offer emotional support. After the discussion the fun began. As I introduced the 'Lifeline' activity to them, it seemed as though they were somewhat intrigued. As part of the process I also disclosed my experience of losing my brother (three months before) to a terminal illness (leukaemia), and they seemed appreciative of the fact that I shared my loss with them. They seemed very into the whole experience, and we got some beautiful results. They were really so creative and emotionally in touch with who they were.*



*I was also surprised at their willingness to participate and their acceptance of everything we had done up to this point. I realised that this is real life! That so many of the volunteers have been, and still are, affected by this awful illness called HIV and AIDS. This disease was like a creature at the back of a dark room for me, I always knew that he was there, but I never really acknowledged him, or saw his fangs. Today I saw (only a fraction) of the trail of destruction he leaves in wake, and could understand (only a fraction) of the pain the participants' experience – I had felt it through my own experience of the creature called Cancer.*

*It was pleasing to notice, with the other two activities we did, that everyone focused more on their positive experiences rather than on negative ones. This was an inspiration to me. I fall humbly at their feet, feet that have walked so many rocky paths, and yet they still manage to rise above it all with enriching experiences and positive recollections. They touch so many people's lives and inspire so many... and today they inspired yet another, a young researcher.*

**(On the second day of the workshop):** *Today's session produced a pleasant surprise: The participants offered so much positive feedback about yesterday's session. Their enthusiasm about the Memory Box is amazing, that they really are interested in using it in their communities where they work. Some of the volunteers even went home and shared their boxes with their families. One of the youth volunteers had asked his mother to share his history with him. He also mentioned that he never realised before how important the past is, and that it still influences our daily existence. Some of the home-based care volunteers brought pictures from home to put on their boxes. One even asked someone to take a picture of her child in her Grade 1 School uniform, which was something she felt she would really like to keep in her box!*



- **Focus-group interviews**

*Focus-group interviews* were held on two occasions during the research process. The first was held on the second day of the Memory Box Making training workshop, and the second about four months later.

Through the first focus-group interview I was able to establish the volunteers' current roles in their communities, that is, what they were currently doing to support their communities to cope with HIV and AIDS. The follow-up focus-group interview (four months later) gave me an opportunity to determine how the volunteers had been using the Memory Box Making technique to support communities struggling to cope with HIV and AIDS. Patton (2003: 385) describes a focus-group interview as 'an interview with a small group of people on a specific topic'. He recommends groups of six to ten people with similar backgrounds who participate in an interview lasting one to two hours. Seeing that focus groups are a form of qualitative interviewing, Herbert and Irene Rubin, in Babbie and Mouton (2001: 289), explain that focus groups are characteristically 'flexible, iterative, and continuous, rather than prepared in advance'. They describe this type of qualitative interviewing as iterative, because every time the basic process of gathering information, analysing the information, and testing it is repeated, one comes closer to a clear and compelling model of the phenomenon being studied. Therefore, the questioning is redesigned throughout the project.

My choice of focus-group interviewing above participant observation gave me the advantage of being able to observe the interaction on the topics being discussed in a limited timeframe. One disadvantage of using this type of interviewing method though is the level of control, as this means that the focus group was in a sense in an unnatural social setting, and not in the natural or 'real-life' setting, which is generally preferable (Babbie & Mouton, 1998: 292). An advantage attached to using focus groups, as Patton (2003: 385) explains, is that it is not a problem-solving session or a decision-making group; it is, first and foremost, an interview. The participants get to listen to each other's responses and make additional comments beyond their own original responses as they hear what other participants have to say. There need not be any agreement or consensus about any response. The objective, specifically within the context of this study, was to obtain high-quality data in the volunteers' social context where they could consider their own views in the context of the views of others.

**From the researcher's pen:**

*In reading up on focus groups before attempting one, I came across some useful information. I read that this type of interviewing should be carefully planned to get perceptions on a defined area of interest in a non-threatening environment, by a skilled interviewer. For me this was a major challenge, as I had never conducted a focus-group interview and could therefore not be regarded as a skilled interviewer. I then decided to rely upon the reading I had done, and on my skills as a psychologist. I figured that would be suitable for the challenge that lay ahead.*

**(On the follow-up focus group):** *Yet again, what an experience! I didn't really know what to expect from today. All I knew was that I would be asking some questions and they would be sharing their experiences. But it ended up being so much more than that. I once again joined with a group of people who have such passion for their work, people who truly give of themselves as if it is the easiest thing in the world to do. During the past four months I wondered how the volunteers were doing, if they were applying the Memory Box Making technique, or rather, if it was working for them. I got the impression from our previous visit that they were really eager to go out and use this technique ...and they were! Their enthusiasm during this visit was once again truly inspiring.*

*One of the volunteers had lost her sister to AIDS during this period. She told us how the Memory Box helped her and her family to be able to give her sister a proper burial. She had told her sister about Memory Box Making, never thinking that she would actually do it, but she did, and it had helped her family to obtain the documentation that was needed for the funeral. It was amazing listening to her story, realising how the Memory Box had made such a difference in her life. I could 'feel' with the volunteer, after having lost my brother to a terminal illness, and I have wondered how this experience would influence my study. I remember the emotions and hurt that came out when I made my own Memory Box for demonstration purposes – it was really difficult. I came to understand how precious and healing the making of the Memory Box is. I laughed, cried, reminisced and shared experiences while making my own Memory Box. It became like a little treasure of the heart.*

*The volunteers (I believed) had the same experience in making and using their Memory Boxes in their communities. They shared how, where and with whom they used it. It seemed as though the use of the Memory Box as a 'keepsake' was a great issue for them. They wanted to make it a 'sure thing', for example by involving social workers. The functional aspect, in particular, was of great help to them because they work so closely with the families and stand by them in times of loss and death. One thing I am quite disappointed about is that the second interview was attended by only about half of the volunteers that had attended the workshop. One positive*

*though is that two new volunteers joined us and were trained in Memory Box Making by our first group of volunteers. How wonderful! It seems this could in some instances become a snowball effect. Nonetheless I would have liked hearing from the rest of the volunteers, hearing their stories and finding out what they had done. I realised though that the volunteers' stories were quite similar ... they were all stories of hope, stories that inspire. I was touched by their empathic nature and moved by their dedication.*

*A pitfall in this focus group was definitely the language barrier. It was quite frustrating as we (volunteers and facilitators) at times found it difficult to understand each other. Sometimes our questions were phrased in a way that hampered understanding because of the volunteers' poor knowledge of English, and sometimes they could simply not find the right English words to express themselves effectively. We helped each other though, the volunteers translated for each other and the facilitators helped to make the questions less complicated (using more widely known terms – no jargon!). In the end the effort paid off, but I still wonder if what the participants shared was always interpreted correctly. I aim to find the answer to this by doing member checking – and in interpretive research this implies, as Garrick (1999: ¶18) explains, that by telling the participants' stories back to them with additional perspectives, I become an explorer of the subjects through re-telling their stories. This will add to the validity of my study. Member checking also allows for determining the accuracy of the qualitative findings through taking the specific descriptions or themes back to the participants and determining whether they agree that they are accurate (Creswell, 2003:196).*

*Another barrier was time. We started approximately two hours later than scheduled, and that added to the pressure to fit everything in. We therefore had very little time to really discuss everything. This especially frustrated me. I knew what I wanted to focus on, but I also kept on thinking 'We're going to run out of time!'. There were also a lot of interruptions, like noise and people passing through the room we were in. This caused general frustration.*

- **Field notes and research diary**

An additional method used for data collection was making *field notes* and keeping a *research diary*. Lofland, in Patton (2002: 302), states that field notes are 'the most important determinant of later bringing off a qualitative analysis. Field notes provide the observer's *raison d'être*. If...not doing them, [the researcher] might as well not be in the setting'. Descriptions of what has been observed are included in the field notes. It contains what the researcher, as the observer, believes to be of worth noting.

As Patton (2002: 303) further explains, field notes firstly contain *descriptive information* that will permit one to return to an observation later during analysis, in other words, the recording of basic information, such as where observation took place, who was present, what the physical setting was like, what social interactions occurred, and what activities took place. Secondly, field notes contain *what was said* during the data collection phase. If possible, they should include direct quotations of what was said during observed activities and responses obtained during interviews. Thirdly, *the researcher's own feelings*, reactions to the experience, and reflections about the personal meaning and importance of what has been observed. This entails recording feelings and reactions at the time they are experienced while in the field, as well as the intensity and nature of the researcher's own experiences (as part of the data). Finally, making field notes on your own *insights, interpretations, beginning analyses, and working hypotheses* about what is happening in the setting and what it means. (Appendix D contains examples of which of the above-mentioned methods I used when making field notes in the course of my study.)

In making field notes during this study, a detailed reproduction of what occurred during the two-day workshop and the follow-up focus group, as well as during the research process, was obtained. I preferred making notes after a session ended. In doing this, it also provided time for writing a research diary in which I could record personal experiences and evaluate the experiences of the past day. It gave me time to reflect on the meaning ascribed to the participants' experiences concerning their support of communities affected by HIV and AIDS. In making field notes, I was also monitoring my evolving assumptions and my own views in relation to my study.

- **Audio-visual methods and visual data**

*Audio-visual methods* and *visual data* were also used as part of the data collection process, but were mainly used as means of data capturing. De Vos (1998: 326) explains that these methods of qualitative research provide visual records of the daily life of the group under study and that they are creative in that they capture attention visually. According to Bottorff, in De Vos (1998: 329), videotape recording is 'a way of direct observation in the study of behaviour and human experiences as they occur in daily life in a variety of settings and contexts'. He further concludes that the key technical requirements for the recording of data for research purposes are a clear picture and

clear sound. There should also be a back-up videotape recorder, as the researcher cannot risk losing data on account of faulty equipment.

Data collection through audio-visual methods, such as taking photographs of the participants while they are making their own Memory Boxes and using a video camera, and a dictaphone to record the focus-group interviews, helped me to collect data that would not have been collected otherwise. It provided visual and auditory presentations of what might have been missed through interaction with the participants. Photos provided a visual representation of what had been done, and served as another means of interpretation. (Refer to Appendix E for examples of alternative interpretations.)

***From the researcher's pen:***

*I think using audio-visual methods to record the data was the best choice. In transcribing the data I realised how much information came across without me even realising it. It was almost like opening a treasure chest. An example of a barrier we experienced concerning the use of this method was the noise factor. The room we were in did not allow for a 100% noise-free zone. We especially had a lot of interruptions, people coming in and leaving the room, people making a noise in the corridors, as well as cellular phones ringing. It was a source of irritation for facilitators and volunteers alike. All of these distractions worried me as I knew that it would hamper the sound quality on the dictaphone as well as the video camera recordings. I evened the score by taking notes while the volunteers spoke and hoped that having the dictaphone and the video camera as well would ensure that no data would be lost. In using a camera to take pictures, the essence of the workshop could be recorded. Therefore the volunteers' boxes and their contents could be recorded, which was very useful during the data analysis phase of this study.*

### **3.5 DATA ANALYSIS**

As mentioned in Chapter 1, *thematic analysis* was used for data analysis. In identifying specific themes during the research process, I could establish the extent to which the community volunteers apply the Memory Box Making technique to support communities coping with HIV and AIDS.

Terre Blanche and Durrheim (2002) discuss the analytic steps to be followed in doing thematic analysis. I followed these steps to analyse my findings. The above-mentioned

authors explain that one *first* needs to develop ideas and theories, make notes, draw diagrams, and brainstorm to become familiar with the data. *Second*, one should induce themes that will play a big role in the process of data analysis, thus inferring general findings or rules from specific findings or instances. The *third* step involves coding. Coding is necessary for deriving themes from the data for interpretation later on. During the *fourth* step, is that of elaboration, the themes are explored more closely. The *final* step in doing thematic analysis includes interpretation and checking, making thematic categories based on the analysis.

Once the data has been analysed, the entire procedure leading up to analysis must be thoroughly reviewed to detect any errors relating to, for example bias (such as the beliefs and attitudes of the researcher) and mistakes that could have distorted the description of the aspect of social reality under study (Bless & Higson-Smith, 1995: 143). In dealing with this, as the researcher, I kept field notes and a research diary to reflect upon my own views and personal attitudes, which helped to guide me towards self-awareness. This enabled me to remain focused and keep in mind the main goals, as well as the purpose of my study.

De Vos (1998: 203) states that there is no right or wrong approach to data analysis in qualitative research. He does, however, give general guidelines for data analysis. I followed certain guidelines during the whole research process, one of them being to consider participants' responses during the workshop and the follow-up focus group. I gave special attention to specific words or phrases in their vocabularies to capture the meaning of what they said or did. This was helpful during the initial phase of the task of category integration.

The *methods of data analysis* that I used included those suggested by Tesch (in De Vos 1998: 345) and involved 1) Reading carefully through all the transcripts to get a sense of the whole; 2) Picking any transcript file and reading through it, jotting down ideas as they come to mind, asking yourself what the interview was about, while writing thoughts in the margin and identifying the major categories represented in the whole; 3) Re-reading the entire transcript file and underlining units of meaning related to the identified major categories; 4) Putting the units of meaning into major categories while at the same time identifying subcategories within the major categories, and 5) Identifying relationships

between major and subcategories and reflecting these as theories. (Also see Appendix F for examples of the transcribed text as well as data analysis.)

By taking into account interpretivist ways of thinking, the participants' meaning of the themes uncovered was explored. This was done by using member checking. I also started exploring the participants' meaning they ascribed to the information during the two-day training workshop, as well as during and after both focus-group interview sessions by keeping a diary of the events and comments made by participants. The follow-up visit also formed part of the member checking. This enabled me to check both the data and my interpretations, as it gave the participants an opportunity to confirm whether my descriptions and interpretations were accurate, based on the information provided. Subsequently, correspondence between themes was explored.

All of the above led to findings by way of interpretation, which will be discussed fully in Chapter 4.

### **3.6 ETHICAL CONSIDERATIONS**

#### **3.6.1 Informed consent**

Information about the purpose of the study, as well as the details surrounding the workshop and the follow-up focus group were communicated to the participants. They were also given information in the form of a hard copy at the onset of the two-day workshop. Furthermore, they were informed that the proceedings would be recorded. No objections were raised. Each participant personally signed a copy of the consent form handed and explained to him/her (see Appendix G for an example of the consent form). Participants were never deceived with regard to the purpose, process and consequences of the study.

### **3.6.2 Privacy**

The identities of the participants who took part in the two-day workshop and focus group interviews are *not* disclosed in this study. All information obtained from them, through the audio and video recordings and/or field notes, was managed in confidence and with their consent.

### **3.6.3 Ethical statement**

As mentioned in Chapter 1, working with human beings necessitates the consideration of other specific ethical aspects. For the purpose of this study, specific ethical principles were applied during the research process, and strict adherence to the Ethics and Research Statement of the Faculty of Education, University of Pretoria as referred to in Appendix A., was maintained throughout.

## **3.7 VALIDATION OF RESEARCH**

### **3.7.1 Trustworthiness**

The basic issue of trustworthiness relates to the inquirer's ability to persuade his/her audiences that the findings of the inquiry are worth paying attention to, or worth talking about (Babbie & Mouton, 2001: 276). An outline of how I aim to maximise trustworthiness in my study follows below.

#### *3.7.1.1 Credibility*

Credibility is related to whether the research findings capture what is really occurring in the context and whether the researcher is learning what he/she intended to learn (Pitney, 2004; Babbie & Mouton, 2001). Strong credibility in my study is ensured through the method of data analysis applied, in which multiple perspectives (by means of crystallisation) will be considered, including member checking. Member checking will be done after the themes have been uncovered by way of the process of data analysis. The process of member checking will be done via e-mail during a meeting with the volunteers who were involved in the research, organised by the contact person. Lastly,



findings will be interrelated with and supported by means of literature control, as well as a discussion with selected participants.

#### *3.7.1.2 Transferability*

This implies providing rich, descriptive information on the context or participants (Pitney, 2004). Since the paradigmatic stance is that of interpretivism, I will obtain all the different inferences of each data source, therefore providing a rich description of the data obtained (see Appendix F for examples of the transcripts). Each piece of information obtained will have its own interpretation of what has been discovered. I aim to understand and interpret the meanings and intentions that underlie these different actions.

#### *3.7.1.3 Dependability*

This depends on whether the findings would be the same if the study was replicated with the same participants or in a similar context (Pitney, 2004; Babbie & Mouton, 2001). By using 'member checks' I could check both the data and my interpretations. This allows the actual participants to clarify that my descriptions and interpretations are accurate, based on the information provided.

#### *3.7.1.4 Confirmability*

Babbie and Mouton (2001: 278) define confirmability as the degree to which the findings are the product of the focus of the inquiry and not of the biases of the researcher. Freedom from bias, however, goes against the interpretive approach where the motives and values of the researcher do play an integral part in the research process. I aim to understand and interpret the meanings and intentions that underlie different actions, recognising the role of my internal frame of reference during the research process.

### **3.8 CONCLUSION**

In this chapter I reflected upon the research process, the story behind my experiences, as well as reflections on the process and methods that were utilised during the research

project. Ethical considerations and the trustworthiness of the research were also discussed. In the following chapters I aim to give you, the reader, a better understanding of the research project by presenting you with the results obtained during the comprehensive research described above, and finally presenting you with findings, conclusions, implications and recommendations.

## **CHAPTER 4 – RESULTS AND LITERATURE CONTROL**

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Chapter 4 consists of two parts, Section A and Section B. Section A is a discussion of the results obtained through the various research methods. Section B reflects on the interpretations of those results.

### **SECTION A – RESULTS**

#### **4.1 INTRODUCTION**

In this chapter the context in which the results were obtained, as well as the resulting themes, are discussed. In the chapters that follow, the pieces of my research puzzle will start falling into place. To start with, I shall be sketching the context in which my research took place, and in which understanding emerged. I shall therefore be taking you, the reader, into the heart of Acornhoek. I will also present you with an overview of the study, thus providing you with details of the process of my study, as well as the results obtained. As mentioned in Chapter 3, research was done by way of an interpretivist paradigm. Therefore, in this chapter my aim is to demonstrate that in analysing the data (by using the interpretivist paradigm), I gained insight into the volunteers' experiences regarding the use of the Memory Box Making technique.

#### **4.2 CONTEXT AND PROCESS**

##### **4.2.1 Context where understanding emerged**

It was a cool and windy day in May 2004 when we (the facilitators and I) made our way from Pretoria in Gauteng to Acornhoek in the Limpopo Province for the first time. We were on our way to host a two-day workshop aimed at providing the volunteers with information on and training in the Memory Box Making as part of the bereavement process associated with HIV and AIDS. The research project resulted from earlier investigations conducted by focus groups and discussions with volunteers in this area (as mentioned in Chapter 3). As we drove through the mountains of the Limpopo Province, I was wondering what to expect from the research I'll be embarking on soon. As we drove, the scenery changed from level grasslands to beautiful mountains, with

peaceful towns around each and every corner - quite a change from the busy city life with tall buildings to which I am accustomed.

Acornhoek seemed to have a lively buzz to it, with shops on the sidewalks for long stretches, and people sociably walking about. I was amazed at the entrepreneurial skills of the town, as most of the shops and vendors' stalls seemed to be run by the town's residents. Apart from the shops and street stalls, there were few signs of the industrialisation I was used to, living in Gauteng. Farm animals, such as donkeys and goats, roamed freely on the outskirts of the town.

The workshops were held at a centre in the town Acornhoek near Bohlabela. When we arrived there, the volunteers greeted us with contagious enthusiasm. My enthusiasm rose as we entered the building. It was a large, colourful and spacious building, abuzz with many young people laughing and chatting away. As we walked through the reception area, we were greeted by the volunteers of the centre in a very friendly manner and felt welcome right away. The room reserved for our training was especially spacious and bright and colourful chairs and a flip chart had been put out for us. During the two-day workshop I was amazed at the volunteers' dedication to the training, as well as their eagerness to implement what they learnt. There were 14 youth volunteers and 16 home-based care volunteers that eagerly joined us in our training workshop. After completion of the two-day workshop, we informed these volunteers that we would be paying them a return visit and explained the purpose of that visit.

In October 2004 the time came for us to return to Acornhoek. As we took the same route through the mountains of the Limpopo Province, I was looking forward with great excitement to discovering what experiences and feedback the volunteers would bring with them to the focus group this time. I was somewhat disappointed when only ten volunteers showed up for this session, especially since the two-day training workshop had been so well attended and the volunteers had seemed so eager to apply what they had learnt during the workshop. Although the attendance was lower than I had expected, the focus group turned out to be of great value to my study. With feedback from these volunteers I could start putting everything together, for it was this part of the research process I had worked towards: to gain insight into how the community volunteers applied

the Memory Box Making technique to help people in their communities to deal with the effects of HIV and AIDS.

#### **4.2.2 Getting started**

The process of my research began when two researchers identified a need in a community in Acornhoek when they visited this community for other research purposes in 2002, as mentioned in Chapter 3. That was when the idea behind my research study first started developing. In May 2003 I took the first step in the research process by making contact with a contact person in Acornhoek. This was a telephonic discussion between Mr Benedict Sedibe and myself. We remained in close contact leading up to the date of our arrival on our first visit to Acornhoek for the two-day workshop. We exchanged e-mails on various logistic components such as the map to Acornhoek, the venue, and what we needed in order for our visit to be successful (also see Appendix H for a research diary outlining of the exact dates of contact that was made). Mr Sedibe informed us of the total number of the volunteers who would be attending the workshop, namely 20 home-based care volunteers who were working in the vicinity of Acornhoek. Once I knew how many volunteers would be attending, I could go out and buy the necessary materials for the workshop and organise accommodation for the time we would spend in Acornhoek. Soon everything was in place and I was ready to embark on my research.

#### **4.2.3 The two-day workshop**

On 18 and 19 May 2004, we presented the two-day workshop on the Memory Box Making technique in the centre in the main street of Acornhoek. This centre is a round, double-storey building painted in a variety of pastel colours, such as green, purple and yellow. When we arrived at the centre on the first day of the workshop, some of the volunteers were already waiting for us outside. Not all the volunteers live in Acornhoek and some had to travel to the centre by taxi, at their own expense, and arrived late. Those who were already there when we arrived seemed shy, yet as eager as to meet us as we were to meet them. When we entered the centre there were a lot of young people gathered around a pool table in the centre of the foyer, and one could also hear people chatting and laughing in the library area on the second floor.

The room made available to us for training was spacious and colourful chairs had been put out for us. There was also an old pool table. When we started the first session of the programme for the Memory Box Making workshop (see Appendix C for a breakdown of the programme, which consisted of 10 sessions held over the two days), about an hour after the scheduled time, not all of 20 the home-based care volunteers that we were expecting had arrived. We decided to invite the youth volunteers of the centre to join us in our workshop. This led to some degree of discontent among the home-based care volunteers that were present as they resented the presence of the youth volunteers at a workshop that had been arranged specifically for their benefit. We listened to their concerns and a compromise was reached, after which we could continue with seemingly satisfied participants. The next problem was that there was a shortage of materials, since instead of the 20 participants we had provided for, we now had 30. However, the participants did not mind sharing the paints, stickers, scissors, crayons and glue that we had brought for making and decorating the memory boxes. Another problem was that not everyone had a box to decorate. One of the youth volunteers found some empty condom boxes in the centre, handed them out to the participants who did not have boxes, and that problem was solved too! Another volunteer even dashed across the road to the Spar to ask for empty boxes there. To me this display of initiative was proof of their enthusiasm and commitment during the training workshop. Once each of the participants had a box, they could make and decorate their boxes.

The volunteers seemed very relaxed and comfortable during the workshop as some of them sat with their feet up, some found a sunny corner to work in, and others formed small groups and chatted away while making their memory boxes. At the end of the first day of the workshop, the sixteen home-based care volunteers voiced their disapproval of the fact that youth volunteers had been allowed to join them, stating that the Memory Box Making workshop had been intended only for them and they did not want the youth volunteers to join. We came to a compromise: it was decided that we would allow only four of the youth volunteers to attend the second day of the workshop as this would bring the number of participants to the number we had originally planned for during our preparations and there would be no need to share materials. The youth volunteers agreed to this decision and we could continue with the workshop. At the end of the second day's programme (see Appendix C) the volunteers who had attended the Memory Box Making workshop each received a certificate of attendance, which was

much appreciated. (See Appendix E for an example of the certificate, as well as photos of the certificate handout.)

#### **4.2.4 The return visit**

After completing the workshop, we returned home to Pretoria. We planned for a four-month period during which the volunteers could explore the application of the Memory Box Making technique to support people in their communities who had to cope with the consequences of HIV and AIDS. During this time, I maintained regular contact with Mr Sedibe, mostly by way of telephone calls and e-mail correspondence. When the time came for us to return for the focus group discussion, Mr Sedibe and I made the final arrangements and set the date, as well as a time for the focus group meeting. We returned to Acornhoek on 12 October 2004. This would be our last contact session with the volunteers. After we had waited for approximately two hours to start the focus group discussion, eleven volunteers had shown up. Their reason for being late was that they did not reside in Acornhoek and did not have access to reliable forms of transport. There were nine female and two male participants, ranging in age between 23 and 41 years. Of these eleven volunteers, two were newcomers who had not attended the Memory Box Making workshop in May 2004, but had been trained by their colleagues and had started applying this technique to support people coping with HIV and AIDS. This group therefore included only nine of the original 30 volunteers we had trained.

#### **4.2.5 Data analysis phase**

After the return visit in October 2004, the process of data analysis began. As mentioned in Chapter 3, these methods are explained in the data analysis. I also made use of the analytic steps for thematic analysis, as explained by Terre Blanche and Durrheim (2002). After this process, various themes emerged from all the discussions we had during our time with the volunteers, as outlined in Figure 4.1 below. After the analysis phase, Mr Sedibe was contacted once again for the final phase in the research process, namely, *member checking* (Creswell, 2003 & Garrick, 1999). A letter, together with the themes and the transcripts, were sent via e-mail to Mr Sedibe (refer to Appendix I), who then organised a meeting with the volunteers who had participated in the research process. During this meeting the volunteers discussed whether they agreed with the

uncovered themes and were given an opportunity to add to or change the themes that had emerged. After this member-checking process, Mr Sedibe confirmed the validity of the themes uncovered during my research and informed me that the volunteers had not added any statements. Member checking maximises the trustworthiness of the research data (Pitney, 2004 and Babbie & Mouton, 2001).

#### **4.3 RESULTING THEMES**

The themes uncovered during the data analysis phase of the research process are described below. These descriptions are enhanced through the inclusion of photos. The participants' written consent was obtained for the use the visual data (refer to Appendix G), and of excerpts from the participants' discussions during contact with them in May and October 2004.



Figure 4.1 Main- and sub-themes uncovered during data analysis process

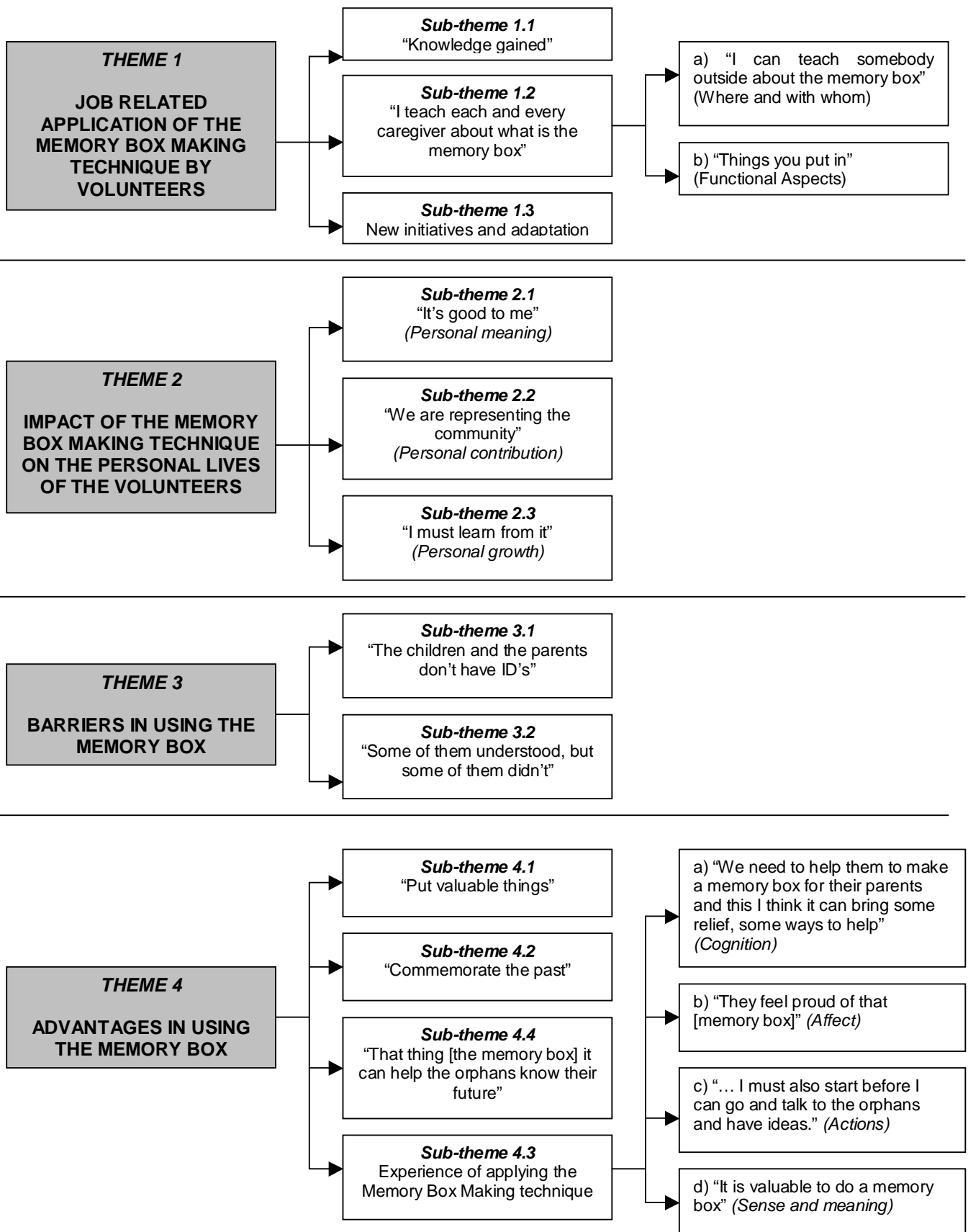


Figure 4.1 consists of the themes that emerged from my research. I will now describe each main and sub-theme uncovered during the process of analysis in more detail.

#### **4.3.1 Theme 1: Job-related application of the Memory Box Making technique by volunteers**

This main theme implies that the volunteers have, according to their reports, developed their skill in offering emotional support to their communities by applying the Memory Box Making technique. In describing this theme, the volunteers' job-related application relates to three sub-themes namely; 'knowledge gained', 'I teach each and every caregiver about what the memory box is', and new initiatives and adaptation. The volunteers stated:

<sup>1</sup>P29- F4: *'I didn't have the knowledge about it and really gained the knowledge.'*

##### **Sub-theme 1.1 'Knowledge gained'**

The volunteers reported that they had gained knowledge about the nature and purpose of a memory box is, and about the extent to which Memory Box Making can be applied. This sub-theme was uncovered especially during the first visit to Acomhoek. During and after the workshop held with volunteers they shared how enriched they felt after participating in the workshop on the Memory Box Making technique. Having learnt how to apply this technique helped them to understand its use. The following statements summarise the general response:

P13- F9: *'It's good. I've learnt something. I didn't know about memory boxes, but yesterday I learn about memory boxes. It's my first day to learn about the memory box.'*

P38- <sup>2</sup>M7: *'Yes it will work, it will work, we have to educate the people because we come across problems when we are out, and that it is difficult to us, so I think that the memory box is all right.'*

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<sup>1</sup> Throughout the rest of the document **P** refers to page number and **F** refers to female as outlined in transcripts document (see Appendix F)

<sup>2</sup> **M** refers to the participant being male (see Appendix F)

### **Sub-theme 1.2 'I teach each and every caregiver about what is the memory box is'**

This sub-theme is representative of the volunteers' reported development in the process of application. Therefore, the volunteers reported having expanded their knowledge on applying the Memory Box Making technique in their practice of offering emotional support to members of their communities who are coping with the effects of HIV and AIDS. This sub-theme relates to two particular categories, namely: 'I can teach somebody outside about the memory box' and 'Things you put in'. These two aspects relate to the volunteers' application of the Memory Box Making technique in their communities, as well as the functional value of the memory box, as will be discussed in more detail below.

#### **Category a) 'I can teach somebody outside about the memory box'**

This refers to where and with whom the Memory Box Making technique was used. Throughout the discussions with the volunteers, it became clear that the majority of volunteers used their knowledge and professional development mostly at the **centres** where they are currently working, as well as in **groups**, rather than individually. It appeared that volunteers seemingly shared their knowledge of the Memory Box Making technique with their **clients**, who comprise of caregivers, orphaned children, individuals dying of AIDS, parents of infected children, as well as with the **elderly**, to name but a few. A small number of volunteers reported that they have been applying their knowledge of the Memory Box Making technique **informally** in their communities. The volunteers also mentioned that, as part of their professional development and application, after being trained in the Memory Box Making technique, they were able to **teach others** about it. According to them, having knowledge on Memory Box Making and an example of a memory box, enabled them to **demonstrate** this technique to their clients more effectively. With regard to the above-mentioned the volunteers reported:

*P32- F2: '...when we are in support groups with the clients I teach them about memory box until the caregivers know how to use the memory boxes. Some they don't know what is the memory box and anything so I explain to them more how to do these things.'*

P32- F12: *'I just sit with the caregivers and make a memory box to show them and to give them the information and tell them how do you use it and I just sit with the clients and give them information, I just give them information, yes... In my community I gathered the children teaching them about the memory box together with the others.'*

P10- F4: *'Okay for me I experienced that I ... before I had heard about the memory box, but I didn't know much about the memory box, but yesterday I've learnt more and I can teach somebody outside about the memory box...'*

P12- F8: *'So I thought the memory box is important that we must teach our clients, maybe our orphans that they must keep the memory box''*

**Figure 4.2 An example of a memory box made by a volunteer**



Figure 4.2 above shows a memory box completed by a volunteer during the two-day workshop in Acornhoek in May 2004. This provides the volunteer with a good example to use during training and when working with clients in the community, as the clients can see for themselves how their memories could be transformed into a visual and tangible object in times of grieving.

### **Sub-theme 1.3 New initiatives and adaptation**

The volunteers also made suggestions regarding alternative uses for the memory box (related to their field of work), and shared ideas for new initiatives. On our return visit in October 2004, the volunteers were eager to share suggestions about alternative uses for memory boxes. One suggestion was that, instead of a box, one could use **a file**, particularly on the case of families who prefer to use the memory box idea solely for the purpose of keeping important documents in a safe place. Another suggestion was to use the memory box idea to make a **sketch** or to devise a simple **play** or “**drama**”. Therefore using a different format: doing a play or doing artwork to facilitate the grieving process, instead of making a memory box.

In terms of new initiatives the volunteers expressed the opinion that it could be very beneficial to Memory Box Making in **schools**. They suggested that it is in schools where the most people can be reached. The volunteers explained that through the school children, parents and family members would realise the value of making a memory box. Some volunteers also felt that **churches** need to be informed about the Memory Box Making technique for the same reason. After completion of their memory boxes, the volunteers were pleased with their newly acquired knowledge. They decided that the memory box has such functional value that the idea should be presented to the magistrate in order for the use of memory boxes to be made official. The volunteers stated that by making the memory box an **official tool**, their work with bereaved families would be less complicated, especially concerning the retrieval of important documents such as identity documents and testaments. The volunteers stated:

P15- M6: *'Yes, even to make the sketch, or a drama.'*

P43- F7: *'Would it be possible to involve the magistrate. Something of that, that this memory box should be official.'*

P44- M6: *'It is very important whenever maybe you can go to school and teach the children that they must go to their families and encourage their parents, that they must remember, always remember about the memory box whenever they are ill, because to do it in advance is very important.'*

**4.3.2 Theme 2: The impact of the Memory Box Making process on the personal lives of the volunteers.**

The volunteers reported on the impact that learning the Memory Box Making technique had had on them personally. Sub-themes that relate to this main theme include: 'It's good to me', 'We are representing our community', and 'I must learn from it'. Thus it was reported that learning the Memory Box Making technique had brought personal meaning, a personal contribution, as well as personal growth into the volunteers' own lives. These sub-themes seemed to indicate that learning the Memory Box Making technique had impacted on the lives of the volunteers themselves, as well as on the lives of (amongst others) their mothers, fathers and siblings. During the two-day workshop in May 2004, and again during the follow-up focus-group meetings, the volunteers readily shared the special impression that the memory box had made on them and their family life, as well as in their work as community volunteers.

**Sub-theme 2.1 'It's good to me'**

After completing of the two-day Memory Box Making workshop, the volunteers reported that they realised that learning this technique had made an important change to their lives. In particular the lifeline, as part of the Memory Box Making process had a significant impact on them personally as it forced them to reflect on the past, through which they realised what an important role our pasts play in our lives. While observing the volunteers, it became evident that they were enjoying making their own memory boxes and understood the value of this activity. Some were sitting together and sharing their thoughts about their own memory boxes, while others sat relaxed, with their feet up, while decorating their boxes. With regard to personal meaning in their lives the volunteers reported:

*P10- F7: '... I never thought memory boxes are important ... I never realised it's so important and like to the things I have done, what happened to my life. Like when I lost my father, I never realised that I can just put some photos of him right on the lifeline the memories.'*

P31- F11: 'It was very grateful to me and I think that this is very important and of course I really enjoy it. Thank you'

Figure 4.3 A lifeline drawn by a volunteer

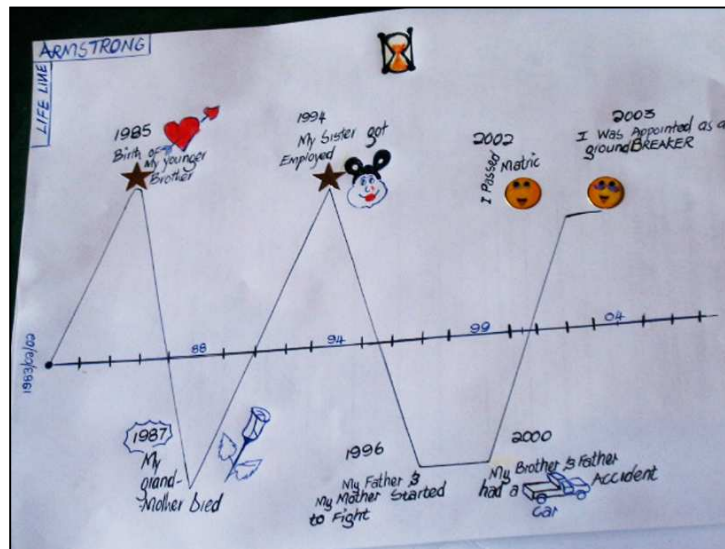


Figure 4.3 is a visual representation of the lifeline of one of the volunteers. The top half of the paper represents all the positive aspects in this volunteer's life, and the bottom half represents the negative aspects in his life.

### Sub-theme 2.2 'We are representing the community'

The volunteers reported that they experienced themselves as being the heart of their communities. They felt that by working with their communities, they provide a sense of personal contribution as in their work they give of themselves to their clients. They stated that by showing the community what they did (in making their own memory boxes) their communities, especially the caregivers or 'guardians' of individuals suffering from AIDS, could learn from them and see the value of a memory box. Therefore, on their personal contribution to the Memory Box Making process in their communities, the volunteers reported:

P11- F7: '...we are representing the community, us caregivers. We are the eyes to the community'

P36- F4: *'I told them about the memory box that I was holding ...*

P36- F7: *'I did go to the guardians of the orphans and I tried to talk with them and show them that memory box of mine, how it is like, and how do we do that box, that memory box ...'*

### **Sub-theme 2.3 'I must learn from it'**

The volunteers found great meaning in doing a lifeline as part of the Memory Box Making process. On the second day of the two-day workshop, one of the male youth volunteers also shared with the group that he had never considered the past as having any effect on the future, and how much he had learnt after realising that he had been wrong. Some of the volunteers reported that they had come to the realisation that life does not always go the way one plans, and that one will survive should unforeseen circumstances emerge. They seemed to feel that it is important to also include the negative encounters or experiences in one's memory box in order to leave a complete record for one's loved ones. Some of the volunteers reported their personal growth experiences in learning about and using the Memory Box Making technique. These volunteers stated:

P12- F8: *'It's where even in knowing that in life it will not mean you will walk in a smooth place always, sometimes life is not good, sometimes life is bad, sometimes it's where you enjoy, you are exited. Then I have learnt a lot.'*

P13- M1: *'Okay to me I was not aware that what happened in the past was still part of me. So I was used to be worried about what happened, but I must not forget it, but I must learn from it ...'*

#### **4.3.3 Theme 3: Barriers in using the memory box**

During our follow-up visit in October 2004, the volunteers reported certain barriers in using the Memory Box Making technique with their clients. Various issues surrounding important documents and levels of ignorance or insight into the process of Memory Box Making, as well as the safekeeping of the memory box, came to the fore, as will be



discussed in more detail below. The sub-themes related to the above-mentioned main theme are: 'The children and the parents don't have the IDs,' and 'Some of them they don't understand'.

### **Sub-theme 3.1 'The children and the parents don't have IDs'**

The volunteers stated that there were cases where neither the parents nor the children had Identity Documents (IDs) in their possession. This seemed to be a significant barrier in using the memory box for the purpose of keeping documents safe. Their concern seemed to relate to trying to help a client after a loved one has passed away, and not having the necessary documents to help that client bury his loved one. Another source of concern seemed to be the fact that clients did not have their birth certificates or Identity Documents at hand, especially the children who had lost their parents. The volunteers reported that the absence of such documents made it extremely difficult for them to obtain childcare grants for orphans. They indicated that if families made memory boxes, important document would be kept together in one place and would be readily accessible when needed. They were, however, frustrated by the fact that in many of the people in their communities do not possess Identity Documents.

*P10- F4: "... we caregivers to make the memory box to the clients because sometimes when we have clients we have difficulties when they parents are dead, when we ask them about IDs they don't know where are they.'*

### **Sub-theme 3.2 'Some of them understood, but some of them didn't'**

The volunteers stated that some of their clients did not understand the use and purpose of a memory box. The elderly, in particular, failed to understand the purpose of a memory box and argued, for instance, that one could not fit a large piece of clothing in such a little box. One of the volunteers mentioned that even though some her clients did not understand, others could understand why it was important to place items that had personal value to them, such as books and pictures, in a memory box that could be left behind for loved ones. One of the male community volunteers stated that he has clients who are shy, and even though they know how to make a memory box, are not interested

in making one, possibly because of a lack of knowledge. With regard to this sub-theme, the volunteers stated:

P37- F7: *'Some explained that they could not put the clothes inside that small box, it would need a big one ... So it was just a matter of the elderly people they cannot understand.'*

P40- M6: *'They've done something, we did give the box to them, but they keep that information inside that box, that's what they've done, all of them...They were having the idea of the memory box, making the memory box, but because of ignorance they decided to leave it ... some of them are shy.'*

#### **4.3.4 Theme 4: Advantages of using a memory box**

During the follow-up visit the volunteers reported certain advantages attached to applying the Memory Box Making technique to support people in their communities who are coping with the effects of HIV and AIDS. These advantages, according to the sub-themes, are: 'Put valuable things', 'Commemorate the past', 'That thing [the memory box] it can help the orphans to know their future'. They are discussed below in more detail.

##### **Sub-theme 4.1 'Put valuable things'**

The volunteers stated that the memory box had a functional advantage, especially relating to valuable items and documents that could be placed inside it for safekeeping. The volunteers were obviously very excited about the functional value of the memory box. They mentioned (as described in the theme on barriers above) that important documents such as birth certificates and Identity Documents get lost, therefore they are pleased that now there is a way for their clients to keep such important documents in a safe place for future use and reference. During the first day of the workshop the volunteers were especially concerned about the problem of obtaining legal documents from families who have lost a loved one, as such documents are often lost or misplaced. They therefore appreciated the fact that their clients could keep these important

documents in their memory boxes so that it would be easy to find them when they were needed.

The volunteers also liked the idea of keeping things in the memory box that are considered sacred and special. When we continued with making memory boxes on the second day of the workshop, one of the volunteers brought a photo of her child taken on his first day in school to put in her memory box. She felt that that had been a very important day in her life and in that of her son, so she wanted it to be in her memory box for her child. Other volunteers also felt that the memory box is ideal for keeping things in that are valuable and special. The volunteers explained that their clients also enjoyed putting valuable items in their memory boxes, in particular families who were in the process of saying good-bye to a loved one suffering from AIDS. The volunteers stated:

P31- F11: *'Some they teach for their own, they keep their certificates in, the birth certificates of their mothers and the flowers inside.'*

P33- F12: *'... the stuff that you put inside that they liked ... that they understand and enjoyed it.'*

P17- F2: *'In the memory box you need to have the ID number his last address and his telephone numbers and you have to write maybe the general policies of the child.'*

P35- F6: *'So I also told them that even things that you like so much, like jewellery you can put it there, maybe its not that you don't wear every time, sometimes you need to wear it after three months. I even told them that even if you have maybe a father that has two wives you can share things that he has at home... I also told them if they want me to show them how to make the memory box I could show them, that's what I did.'*

#### **Sub-theme 4.2 'Commemorate the past'**

As reported by the volunteers, the memory box has a 'remembering' purpose. According to them, the memory box is a way to remember and rejoice together in the past. They report experiencing how their clients (and themselves) honoured and celebrated lost loved ones' lives. The volunteers also made reference to how, when

counselling individuals who are experiencing a loss, they found that a memory box offers a way for those individuals to celebrate their passed loved one's life and experiences without needing a person to counsel them. The volunteers commented on how, even though loved ones are not there any more, one can open the memory box and remember them and their lives. On the remembrance value of the memory box the volunteers reported:

P12- F7: *'... where you can remember somebody that who you have lost ...'*

P35- F6: *'... and that your children will remember you by that memory box ...'*

P41- M6: *'So if they cry they need counselling, but with that some of them are good because they feel joy when they have the memory box. In order to commemorate the past.'*

#### **Sub-theme 4.3 'That thing [the memory box] it can help the orphans to know their future'**

The volunteers noted that the memory box offers a way to help their communities look forward to their future. They reported that the memory box could aid them in giving their clients hope for the future, particularly their young clients who are still attending school. They indicated that, in their opinion, the memory box could bring hope to the young ones, reminding them that there is still a future for them without the parents, grandparents, siblings or friends who had died of AIDS. By using memory boxes, they could therefore give their clients hope for the future. They stated:

P12- F8: *'... that thing it can help the orphans to know that their future it maybe starts where you are attending school.'*

P29- F6: *'... and they won't look at this box as a box full of other things, but look at it as their future.'*

P35- F6: *'... someone says her life then I told them memory box is their future from where you grow up until now.'*

#### **Sub-theme 4.4 Experience of application**

The volunteers experienced the application of the Memory Box Making technique in various ways; firstly, 'We need to help them to make a memory box for their parents and this I think it can bring some relief, some ways to help'; secondly, 'They feel proud of that [memory box]'; thirdly, '... I must also start before I can go and talk to the orphans and have ideas'; and lastly, 'It is valuable to do a memory box'. These sub-themes, which will be discussed below, are indicative of beneficial experiences relating to cognition, affect, actions, as well as sense and meaning in applying the Memory Box Making technique.

##### ***Category a) 'We need to help them to make a memory box for their parents and this I think it can bring some relief, some ways to help'***

The volunteers experienced that if they applied the Memory Box Making technique in their communities they could help community members to cope with the emotional impact that HIV and AIDS have on them. Especially during their discussions about their application of the Memory Box Making technique, the volunteers reported that they found it particularly enriching to explain to their clients how Memory Box Making assisted people in the healing process. According to the volunteers, if they share with their clients the value of a memory box, they are also relieved from the pressures of their work. The volunteers stated:

P34- F11: *'When teaching about this they [the caregivers] did not think it was very important but now they realise it's important and also the clients they think this is very important, because some they just died without telling someone I've got this and this, but with the memory box this is very important, yes.'*

P37- F12: *'They must get that information because someone they've got problems with the families they give us pressure ...'*

**Category b) *'They feel proud of that [memory box]'***

On an affective level the volunteers reported that, by making a memory box, their clients will have something to be proud of and cherish after a loved one has died. They also reported on various emotions experienced by their clients, which include heartache or sadness associated with the passing of a loved one, inability to cope with loss after the passing of a loved one and, as mentioned previously, looking forward to the future. The volunteers reported:

P33- F11: *'They feel very proud of that, all along they were not aware. According to our culture we think this we should throw away, but now they come along with this that is very important and always they keep on putting in ...'*

P41- M6: *'They are shy because the children after the death of the late, once they take the photos they feel, they cry in such a way...Yes, that emotion, so some of them they need even counselling, because once they didn't cope about their late or they deceased it's not good.'*

**Category c) *'... I must also start before I can go and talk to the orphans and have ideas.'***

The volunteers seemingly experienced that it is important for them to have information before they teach their clients about the Memory Box Making technique. Therefore they found it of considerable value to have their own memory boxes ready, as this enabled them to effectively share their experiences of the Memory Box Making technique. The volunteers furthermore reported that they felt that it was important for them to remind their clients of the need to prepare a will and to place it in their memory boxes for safekeeping. It is always to one's advantage if the right documentation is available when it is needed. The volunteers stated:

P28- F7: *'So it's something that makes me to remind I must also start before I can go and talk to the orphans and have ideas.'*

P34- M6: *'...so to make a will in time is very important, because you will find that once passing away without making a will or making that memory box it is difficult, because you will find that maybe our parents are having a lot of money in the bank or making a fixed deposit in the banks or insurance company, the money loose.'*

**Category d) 'It is valuable to do a memory box'**

The volunteers also reported an awareness of the significance of the process of making and filling a memory box and felt that by teaching their clients how to do this, they could also share in the special meaning of this activity. To orphans whose parents have left behind a memory box, the contents of the box will help them remember who their parents were and what special qualities they possessed. The volunteers expressed the opinion that Memory Box Making created opportunities for families to come together and share in 'the good spirit' of the terminally ill family member, discovering together what resources there are, and which of them can be accessed in the future. The volunteers disclosed:

P28- M3: *'I think it's valuable because we find what it takes to do a memory box like. And it would depend to us how we deliver or share the information to the other people so that they can understand what it is about. This memory box.'*

P35- M6: *'Okay, so with that information most of the orphans have been keep in mind, because most of their parents have been passed away without making that memory box and after that they ... what did their parents have, they failed to share in the good spirit. So they still had to find the resources of the passed one.'*

#### **4.4 CONCLUSION**

Section A mainly explored and described the context in which understanding emerged, and the themes that were uncovered during the data analysis phase of the research process. In Section B I will present the interpretation on the basis of literature consulted regarding the themes that had been uncovered.

## **SECTION B – LITERATURE CONTROL**

### **4.5 INTRODUCTION**

This section consists of a literature control of the results of this study. The following discussion explicates the results of my study in comparison with the available literature on the role played by community volunteers in supporting their communities to cope with the effects of HIV and AIDS, as well as literature on discourses related to the Memory Box Making technique as a means to guide bereavement.

### **4.6 LITERATURE CONTROL**

#### **4.6.1 Theme 1: Job-related application of the Memory Box Making technique by volunteers**

My study adds to the research that has already been done on the application of the Memory Box Making technique, as it serves as a perspective on the application of the technique by community volunteers supporting families and/or individuals in their communities who have to cope with HIV and AIDS. As mentioned previously in Section A, this theme implies that volunteers have developed their practice in supporting their communities to cope with HIV and AIDS at an emotional level by using the Memory Box Making technique. Available literature (Denis *et al.*, 2003; Winkler, 2002) states that in using memory-work with people, in this case the Memory Box Making technique, families are provided with the emotional support they need to be able to cope with HIV and AIDS-related losses.

##### **4.6.1.1 Sub-theme 1.1: 'Knowledge gained'**

My literature search revealed that to date no study has reported on Memory Box Making as a technique acquired by volunteers and used in providing emotional support to communities. However, research does show (Winkler, 2003; Kmita *et al.*, 2002), as mentioned below, that the use of knowledge of memory work as a means to provide emotional support, is an important aspect of care and support, especially with regard to individuals affected by HIV and AIDS.



The volunteers reported that they had gained knowledge about what a memory box is, and of the extent to which it could be used to offer emotional support to their clients. The knowledge they had gained regarding the application of the Memory Box Making technique helped them to understand its value. Winkler (2003: 39) states that as a result of the HIV and AIDS epidemic, home-based care, in particular, has become an important reality in our country. She states that community volunteers involved in caring for those who are ill, are expected to provide not only physical care, but also have to offer emotional and spiritual support. This type of intervention decreases the social isolation of families who are living with HIV and AIDS and supports children and families that are in the process of coping with this terminal illness, including coping with the loss associated with HIV and AIDS (Kmita *et al.*, 2002: 280).

Therefore, if volunteers have the necessary skills and knowledge in terms of guided bereavement, they will be equipped to provide the essential emotional support to their communities who are affected by HIV and AIDS.

#### **4.6.1.2 Sub-theme 1.2: 'I teach each and every caregiver about what is the memory box'**

As mentioned below, literature states (Inger, 2002; Denis *et al.*, 2003; Winkler, 2003) that the Memory Box Making technique is taught to families affected by HIV and AIDS, but does not make any specific mention of the role of community volunteers in this regard. Therefore, this emerged theme adds to the literature in terms of community volunteers who work with communities affected by HIV and AIDS and use the Memory Box Making technique as a means to offer guided bereavement.

Literature (Inger, 2002; Denis *et al.*, 2003) states that the Memory Box Making technique allows community volunteers to enable their communities confronted with HIV and AIDS to tell their life stories. Therefore, the Memory Box Making technique could be used to aid individuals in the bereavement process that is associated with HIV and AIDS. Volunteers who understand the purpose of a memory box and have acquired the skill required to make such a box are able to effectively support members of their communities who are struggling to cope with the effects of HIV and AIDS.

Winkler (2003:17) further states that it is difficult for individuals affected by the disease to talk about their status. Therefore, volunteers who have the necessary skills, could use the Memory Box Making technique to help these individuals to share their load with their families in a safe and non-threatening way.

**Category a) 'I can teach somebody outside about the memory box.'**

Volunteers are in regular contact with their communities and can provide the necessary health and mental care. As mentioned in Section A, the volunteers found that it was better to teach Memory Box Making to groups in their community rather than to individuals. A study done by Kmita *et al.* (2002: 283) revealed that individuals who are coping with HIV and AIDS find group activities to be a great source of support. They also state that groups of HIV positive parents could more easily share their experiences, discuss important issues and provide each other with the necessary support and respect, without being discriminated against. They mention, however, that separate groups should be run for children where they can feel safe in expressing their emotions. Personally I do not support this view, as groups that include both parents and children offer useful opportunities for parents and children to bond. In their book on family therapy, Becvar and Becvar (1996) state that the focus has been mainly on individual or couple therapy, but the goal should to encourage people to get know one another as they exist in the family system. They also state that this process of getting to know each other renews abandoned family relationships. Using the Memory Box Making technique with groups of families could therefore aid in the bonding relationship between parents and their children who are affected by HIV and AIDS. This relates to the theme of volunteers teaching community members (referred to by them as the '*others outside*') how to make memory boxes and explaining the purpose of this activity to them.

**4.6.1.3 Sub-theme 1.3: New initiatives and adaptation**

Currently literature (Morgan, 2004; Plusnews, 2004; Richter, Manegold & Pather, 2004) exists on various ways in which the memory box can be used (as mentioned earlier). My study adds to this body of knowledge as the volunteers with whom I worked reported that they had used the memory box in other, different ways.

The volunteers suggested alternative formats for the memory box, for example using a file, or making artwork, or even presenting memories in the form of a play. Morgan (2004) prefers to use the term 'memory-work' when referring to the tools used during the process when parents and children discuss possible death and bereavement. Ideas related to his memory-work include alternatives such as body mapping, as well as remembering books. Richter, Manegold and Pather (2004: 35) also mention the use of memorybooks in strengthening the sense of identity of children who are affected by HIV and AIDS. Morgan (2004: ¶6) states that a remembering book is a kind of Hero Book in which a child is helped to grieve and remember a lost loved one. Morgan (2004: ¶26) also mentions the value of a video tape recording for families that have access to such means. By making a video recording, a parent could leave a child with a very valuable means for keeping his/her memory alive.

In terms of new initiatives, literature refers to the fact that memory-work could be undertaken with all individuals affected by HIV and AIDS. An article in Plusnews (2004) contains a very apt definition of memory-work: 'their purpose [memory boxes] is to hold what HIV positive parents wish to leave to their children: advice, key information, sweet memories and the warm feeling of love.' They are designed to help families affected by HIV and AIDS in Africa to cope with disease, death and grief, and to plan the children's future. However, the volunteers expressed the opinion that in their communities such work could reach more individuals if training sessions in the Memory Box Making technique were to be offered to families at schools and at churches. The volunteers also believed that if an official decision were to be taken that this technique should be used by all volunteers, access to important documents, such as ID documents, would be greatly facilitated.

#### **4.6.2 Theme 2: The impact of the Memory Box Making process on the personal lives of volunteers**

##### **4.6.2.1 Sub-theme 2.1: 'It's good to me'**

Results obtained through this research study contribute to available literature on the Memory Box Making technique and process. My research therefore adds to literature in terms of the personal impact of the Memory Box Making technique on the lives of

community volunteers who work with HIV and AIDS-susceptible communities on a daily basis. These volunteers' own perspectives and their personal experience of making and using their own memory boxes before introducing the concept to their clients add value to the field of applying the Memory Box Making technique in communities affected by HIV and AIDS, as noted in this study.

The above-mentioned theme indicates the positive effect of Memory Box Making on the personal lives of the volunteers. Since the making of a memory box is a therapeutic technique, one could possibly relate the volunteers' experiences to the work done by the educational psychologist Violet Oaklander. It is important to note, however, that Oaklander's theory and applications do not represent the only therapeutic technique related to memory-work. I use her work as an example for the simple reason that in the field of Educational Psychology she adds value to the meaning of working with people (in her work the focus is more on children) who need to give expression to their emotional world in order to feel enabled and comforted in a personal and individual sense. Oaklander's aim is to help individuals to develop an awareness of their existence in their worlds. She states that the very act of drawing (without therapist intervention) is in itself a powerful expression of self that helps people to establish their identities and provides them with a way to express their feelings (Oaklander, 1988: 53). This could then possibly be related to the volunteers' experiences of the memory box as being '*good to me*'. The creation of their own memory boxes through way of drawing, painting and creating could have established a sense of expression of feelings and of self, derived from the volunteers' own personal lives.

Furthermore, one could say that the value of the memory box, in terms of past experiences, is also encapsulated in doing memory-work, especially in the making of a memory box. However, Morgan (2004: ¶2) states that the scope of memory-work is not necessarily limited to past experiences. Its purpose is also to deal with worries in the present, and the main orientation is likely towards planning, which relates to the future. This, in particular, relates to how the volunteers discovered that their past has an influence on their lives at present.

#### **4.6.2.2 Sub-theme 2.2: 'We are representing the community'**

This resulting theme is supported by literature (Department of Health, 2005; Department of Health 2003; Coovadia, 2000; Exline, 1996) in that the volunteers in our country are the representatives in the communities. They work and function within the community on a daily basis, caring and supporting those individuals and families who struggle to care for themselves. This theme therefore enriches literature in that the volunteers themselves reported a sense of making an important contribution in the environment in which they work.

The volunteers reported that they experienced themselves as being the heart of their communities. Therefore, by giving of themselves in their work, they do indeed make a very real personal contribution. The volunteers also provide their communities with a safe space in which they can give expression to their grief, therefore *they do become* the heart or the eyes in their communities. Exline *et al.* (1996: 15) maintains that the success of an intervention includes having a safe haven for facilitating the expression of grief, and having the reassurance that feelings and responses are normal. Thus, by normalizing grief, the opportunity for emotional expression to death is facilitated.

As mentioned previously, the volunteers feel that they represent their communities. Coovadia (2000: 272) states that the provision of care, counselling and support for individuals affected by HIV and AIDS remains one of the top 10 national priorities in our country. The volunteers provide care and support to their communities in desperate times.

#### **4.6.2.3 Sub-theme 2.3: 'I must learn from it'**

As part of my research, I chose to incorporate the *lifeline* as part of the Memory Box Making technique, as it could reflect personal value for those involved in the process of making a memory box. It seems natural to include the lifeline as part of the memory box, as the use of a lifeline grants individuals an opportunity to reflect upon their lives, regardless of whether their experiences have been positive or negative. The volunteers who participated in the study referred to their own positive and negative experiences and

reflected that they '*must learn from it*'. The lifeline could thus help in the process of reflecting on the course of one's life, whether positive or negative.

Amundson, in Chen (2001: 535), states that the lifeline exercise can be a very relevant method for exploring an individual's significant story and experiences in personal and sociocultural dimensions. The lifeline therefore gives a sense of permanence as the individual tries to make sense of his or her own experiences. For that reason the volunteers in my study were encouraged to explore their experiences and own personal life stories through making a lifeline for their memory boxes.

During the first visit to Acornhoek, the volunteers reported that including a lifeline as part of their memory boxes had been particularly meaningful to them. As mentioned in Section A, one of the male youth volunteers came to the realisation that the past is still part of him, and that he should not forget it, but rather learn from it. Research suggests that the lifeline is of great value, as this activity requires individuals to demonstrate an appreciation of how experiences are an integral part of peoples' life stories, and to gain an understanding of the complex interplay between personal attributes, contextual factors and serendipity in one's development (Semple, Paris & Howieson, 2002: 28).

The community volunteers who were involved in this research study found great meaning in doing the lifeline as part of their memory boxes. It provided them with an opportunity to reflect upon their lives and share with others their positive and negative experiences. They came to the conclusion that in order to leave behind a truthful legacy for loved ones, it was important to include the negative encounters in a memory box. By using the lifeline as part of Memory Box Making with their clients, they could facilitate personal growth experiences within clients who are struggling with specific aspects of being HIV positive, such as stigma, discrimination and alienation (DeJong, 2003; Lindsey *et al.*, 2003; Siyam'kela Project, 2003). Compiling a lifeline could provide individuals who are affected by HIV and AIDS with an opportunity to reflect on positive life experiences and to recreate a positive and inspirational personal life story.

#### **4.6.3 Theme 3: Barriers in using the memory box**

During the follow-up visit in October 2004, the volunteers reported certain barriers in using the Memory Box Making technique in their work with their communities. Unfortunately the available literature on this topic is insufficient, therefore no comparisons can be made with existing literature in this regard. Here the results obtained through my study again seem to add to the existing literature by filling the gap regarding barriers that have to be overcome when using the Memory Box Making technique. This could be of value to future researchers in this field. A discussion of the barriers experienced by the volunteers themselves follows below.

##### **4.6.3.1 Sub-theme 3.1: 'The children and the parents don't have the IDs'**

A main concern for the volunteers seemed to be the misplacement of important documents. Families are not able to provide volunteers with the documents that are required to, for example, apply for childcare grants or make arrangement for a proper funeral. They expressed the opinion that in the long run memory boxes could provide a place where important documents could be kept in a safe place, should families have these documents in their possession. Research focuses more on the functional value of using the memory box as safe place for keeping important documents and fails to address the issue of misplaced and lost documents. This theme brings to light the fact that families often do not have the documents that research suggests should be placed inside a memory box.

##### **4.6.3.2 Sub-theme 3.2: 'Some of them they don't understand'**

As stated in Section A, the volunteers reported that some of their clients, the elderly in particular, did not understand the purpose of making a memory box, or its possible uses. One of the volunteers mentioned that even though some of her clients did not understand, others could understand the purpose of placing valuable items, such as books and pictures, into the memory box to leave behind for loved ones. One of the male community volunteers stated that he has clients who are embarrassed, and that even though they knew how to make a memory box, they had decided against making one because of their shyness.

Literature (Lindsey *et al.*, 2003; Uys, 2003) states that problems arise when individuals living with HIV and AIDS do not want their families to know their status for fear of being rejected or discriminated against, which might add to the degree of 'shyness' (or embarrassment) mentioned by the volunteers. Lindsey *et al.* (2003: 498) also state that stigma often prevents individuals who are living with HIV and AIDS from accessing support services. Families affected by HIV and AIDS could be supported in their grief, and could be encouraged to talk freely about their past, present and future. When community volunteers gain the necessary skills and strategies, they teach their communities the value encapsulated in the making of a memory box. This offers them an opportunity to offer effective support to their clients who are coping with the consequences of having HIV and AIDS.

#### **4.6.4 Theme 4: Advantages of using a memory box**

This theme implicates that there are various advantages associated with the use of a memory box, as supported by literature (which will be discussed in more detail below). This aspect then adds perspective to current research and provides future researchers with the advantage of knowing for what purposes the memory box could be used most effectively.

During the workshop, and also during the follow-up visit with the volunteers, they mentioned various advantages offered by the use of the Memory Box Making technique in their communities. A discussion of how the advantages of Memory Box Making are portrayed in existing literature follows below.

##### **4.6.4.1 Sub-theme 4.1: 'Put valuable things'**

In the relevant existing literature (Viljoen, 2004; Plusnews, 2004; Denis *et al.*, 2003; Sinomlando Project, 2003; Inger, 2002), considerable focus is placed on the value of the memory box as a place in which to store valuable items and documents. As mentioned in Chapter 2, the memory box is a symbol, a physical object that could be decorated with photos, drawings, or any other items that are precious to an individual or family (Sinomlando Project, 2003). This box therefore contains the story of the deceased or dying person, as well as various objects that relate to the history of the family. These



could include photographs, poems, letters or anything else that adds to the exceptionality of a family's history. When selecting objects to be placed in the memory box, care should be taken that the objects chosen are valuable to the individual and his or her family members and will contribute towards facilitating the grieving process.

According to the volunteers, other essential documents that form an important part of the contents of memory box, include a will, Identity Documents, birth and marriage certificates, medical records, and school reports, to name but a few. As mentioned previously, once a will has been drawn up, it is essential that it be kept in a safe place, especially in communities where lawyers and legal fees are a luxury. By drawing up a will, parents dying of AIDS can ensure the safety of, and a future for the children they leave behind. This aspect of the use of a memory box was particularly emphasised by the volunteers. As mentioned in 4.6.3.1, a possible problem could be that some families might not be in possession of such documents. Where these documents are available, families could benefit from the use of the memory box as a safe place for storing them to ensure that they will be easy to find when needed.

The Sinomlando Project (2003: 20) describes memory as the ability to bring back to consciousness past events. As already mentioned, a memory box is a physical object created by a family for storing letters, photographs, tapes or any objects that relate to the history of the family. The purpose of storing these items in a memory box is to build up resilience in families affected by HIV and AIDS so that they will be better prepared to cope in difficult times, for instance when disease or death strikes. This technique could thus be used by community volunteers to aid families affected by HIV and AIDS in the bereavement process, or by families to craft a personal legacy to be left behind for their loved ones (Inger, 2002; Denis *et al.*, 2003).

#### **4.6.4.2 Sub-theme 4.2: 'Commemorate the past'**

The volunteers also reported on the value of the memory box in helping people to remember a loved one who had passed away. Being left with something physical that evokes memories and helps people to celebrate the past as family adds to the remembering purpose. As mentioned in Chapter 2, memory is the ability to bring back to consciousness past events (Sinomlando Project, 2003: 20), therefore the memory box

can be seen as a physical object created by a family to help them remember the past and generate a sense of hope for the future. Literature (Morgan, 2004; Sinomlando Project, 2003; Smetherham, 2002) also suggests that items such as special books and other objects such as jewellery and pieces of clothing could be placed in the memory box for children to admire and reflect on when their parents have passed away.

The making of the memory box is a process. Sharing the memories of the ill parent or family member, or remembering the deceased and recording and storing these memories in the memory box helps family members to break the silence about disease and death (Inger, 2002). In their book, *Counseling Children*, Thompson and Rudolph (2000: 453) state that parents or caregivers should allow children to express their grief, talk freely, and ask questions about death and dying. These authors refer specifically to *children* who have lost parents or siblings due to chronic illness or sudden death. The strategies these authors use are related mainly to counselling to help children who have experienced loss through death. They place their emphasis on children, since the possibility exists that the needs of children may be overlooked by the grieving adults in the family. The grief-stricken adults may be unable to empathize with the children. Techniques such as the use of the memory box as a form of creative artwork could help children and their families to relieve the pain associated to the grieving process and to facilitate remembering of the past – *together*. This would support the child in developing a feeling of hope for the future.

#### **4.6.4.3 Sub-theme 4.3: 'That thing [the memory box] it can help the orphans to know their future'**

During the October 2004 follow-up visit to Acornhoek the volunteers pointed out that the memory box could help them to provide their clients with the necessary hope for the future. By reminding them that there is still a future for them without the family members who passed away from AIDS, individuals affected by HIV and AIDS could be provided with the necessary hope for the future. The volunteers' focus was mainly on the children in their communities. As mentioned in Chapter 2, Viljoen (2005: 40), who did research on Memory Box Making and vulnerable children, states that even items such as achievement certificates and awards received by either a parent or the child could be placed inside the box to reveal the parent's dreams and wishes for a child, providing the

child with a sense of hope for his or her future. This could remind them that although their parents are gone, life has to continue for them.

The Memory Box Making technique as a process creates an opportunity for family members to talk about illness and death, thus helping them cope with the loss of their loved one. Community volunteers are in a position to encourage the ill parents to recount the history of the family in the presence of their children. In this way they facilitate the bereavement process for the children. Making a memory box can also help children build their identities and strengthen their emotional capacity, to understand the past and be less afraid of the future. According to the Ten Million Memory Project (2005), memory-work often recognizes and strengthens the remarkable capacity of people to survive, even to celebrate life amidst all the challenges that face them.

The findings of the Sinosizo Home-based Care and Oral History Project (2001) suggest that the aim of Memory Box Making is to help families create a memento to keep alive the memories of the family, therefore facilitating the bereavement process. They found that children, in particular, who had participated in the memory box project expressed gratitude about having gained some understanding of their family tree and of their culture. As mentioned previously, children whose parents die of AIDS find it especially difficult to deal with the stigma attached to this disease and the feelings of fear brought about by their parents' death as a result of AIDS, therefore the Memory Box Making technique could help children in easing the bitterness and anger toward the deceased parent. The emphasis on making a memory box is therefore not on death and dying, but on stories of hope and on people's dreams.

#### **4.6.4.4 Sub-theme 4.4: Experience of application**

**Category a) 'We need to help them to make a memory box for their parents and this I think it can bring some relief, some ways to help'**

In their discussions on the application of the Memory Box Making technique (as set out in Section A of Chapter 4), the volunteers mentioned how much it means to them to be able to share with their clients the importance of the healing value of Memory Box Making and pointed out that this opportunity to share also relieved some of the stress they

experience as a result of the nature of their work. Appropriate psychological, spiritual, and practical care for bereaved family and friends is intended to reduce the physical and emotional health risk to which the bereaved are exposed (Field & Behrman, 2002: 171).

Laurie (2004) found that when a household begins to feel the effects of HIV and AIDS, family relationships provide the most immediate source of support. Emotional support by volunteers in terms of affective support, love and concern, sympathy and commitment was also found to be of considerable value to community family members (Owens, 2003: ¶4). Volunteers also provide concrete support to families, which implies physical support, such as providing a place to live, assistance with parental responsibilities and the preparation of meals, doing laundry and providing transportation to clinics, doctor's consulting rooms and social services offices. Volunteers also provide the necessary cognitive support that relates to supplying families who are affected by HIV and AIDS with information they need in order to be able to cope with the disease. All of these aspects demonstrate how important support is in helping infected individuals and their families to cope with the effects of HIV and AIDS on their lives, and that community volunteers are able to provide these individuals and families with the necessary relief.

#### **Category b) 'They feel proud of that [memory box]'**

As discussed in Section A, the volunteers reported that clients who make memory boxes take great pride in their memory-work. Volunteers also reported that they had not previously realised how great the value of a memory box can be in terms of support of those who are grieving, or are devastated by the heartache and sadness associated with HIV and AIDS. Olshansky, in Beverley *et al.* (2001: 160), states that having a chronic illness could cause a state that he calls 'chronic sorrow', indicating that this condition is marked by persistent feelings of sadness that recur with varying intensity throughout one's life. This relates strongly to people with HIV and AIDS, as this is a lifelong condition, affecting family and friends alike. The Memory Box Making technique could provide community volunteers with skills required to support communities with their basic psychosocial needs (Owens, 2003; Sinomlando Project, 2003), such as 'chronic sorrow', to alleviate the emotional burden that HIV and AIDS places upon individuals and families affected by the disease.

An article published in The Mail and Guardian (2004) points out that in KwaZulu-Natal in South Africa HIV and AIDS is referred to as *mashayabhuqe* ('completely destroys'), which provides an indication of how the disease affects every aspect of an individual's life. Sikkema *et al.* (2000: ¶13) states that persons living with HIV infection face the prospect of many personal losses, including loss of relationships, employment, lifestyle, sense of control, intellectual or behavioural functioning and ultimately premature death. Therefore coping with these issues remains a difficult task.

Memory Box Making could serve as a therapeutic technique, where a variety of materials such as crayons, paint, stickers, cardboard, and so forth (see Appendix J for the materials used), and different methods can be used. The educational psychologist Violet Oaklander (1988: 48) mentions that painting has its own very specific therapeutic value, and that as paint flows, often so does emotion. She also states that children especially enjoy painting, but often are given very few opportunities to paint once they have finished nursery school and kindergarten. This could explain the obvious pride that people (both adults and children) take in making their memory boxes. The box is the client's own creation – a flow of emotion, as Violet Oaklander so aptly states. When a client creates a memory box, s/he is provided with another way of coping with the various personal losses associated with the disease. A memory box is therefore a creation of emotion *of which s/he can be proud*.

**Category c) '... I must also start before I can go and talk to the orphans and have ideas'**

The volunteers found that unless they had experienced the effect of making a memory box, they could not teach others about its value. Therefore they found it very useful to have their own memory boxes ready and to share the way they personally experienced making them. Lindsey *et al.* (2003: 498) suggests that one of the most identified needs in terms of home-based care is the need for counselling. However, the health care workers involved felt that they lacked the *skills* required to be able to meet this need. Literature (Lindsey *et al.*, 2003; Uys, 2003) also indicates an identified need for effective interpersonal communication and psychosocial support, particularly to families in need of bereavement counselling and anticipatory guidance. In their study on home-based care offered in Botswana by older women and younger girls, Lindsey *et al.* (2003: 299) found

that members of community home-based care organisations reported that they lacked the means to effectively provide their communities with psychosocial care. This caused volunteers to avoid counselling rather than attempting to meet the families' needs.

Coovadia (2000) states that even though the provision of care, counselling and support for people living with HIV and AIDS is one of South Africa's top 10 national priorities, heavy workloads and a shortage in skills makes this 'an ideal rather than a reality'. As mentioned in Chapter 2, reference is frequently made to pre- and posttest counselling for individuals affected by HIV and AIDS, but little reference is made to emotional care and support for families who suffer the consequences of the disease once a loved one has passed on. Therefore, volunteers need to acquire the skills required to support their communities and to offer support to people during the grieving process. The Memory Box Making technique could serve as one of the many therapeutic bereavement techniques in the field of bereavement counselling.

#### **Category d) 'It is valuable to do a memory box'**

In Chapter 2 it was mentioned that one of the challenges of helping individuals through the grieving process could be to build trust and acceptance in communities so as to make it easier for people affected by HIV and AIDS to talk more freely about their disease (Winkler, 2003: 19). The community volunteers then play a pivotal role, especially in the sphere of emotional support for families affected by HIV and AIDS, as they could be the ones with whom community members could feel safe enough to share their experiences and stories about how HIV and AIDS have affected their lives. Winkler (2003: 19) also points out that people with HIV are often the victims of discrimination and prejudice. During the research process, the volunteers reported that Memory Box Making creates opportunities for families to come together and share in 'the good spirit' of the dying one, discovering together what resources are at their disposal, and determining how these may be accessed in the future.

The *value* of the technique of Memory Box Making is encapsulated in the unique way the memory box provides South African families affected by HIV and AIDS to cope with disease, death and grief, as well as to plan their children's future. This technique also provides HIV-positive parents with the means to leave their children a legacy of

information, memories and a warm feeling of love (UNICEF, 2005; Siyam'kela Project, 2003; Smetherham, 2002). The Memory Box Making technique also provides a dying parent with the opportunity to disclose his or her status to the child, which has been reported by volunteers to be a very difficult decision (UNICEF, 2005; Inger, 2002).

Other valuable facets of the Memory Box Making technique is that everyone can actively participate in the creation of their own memory boxes, and the more each participant contributes to the process memory retrieval, the more they themselves are likely to benefit from it. Making a memory box could also help children who are affected by HIV and AIDS to build their identities and strengthen their emotional capacity. It could enable them to understand their past and become less fearful of their future. The process of Memory Box Making could help other members of the family, as well as friends, to cope with the death of their loved one by creating space for them to break the silence and talk about the disease and about death.

#### **4.7 CONCLUSION**

In this chapter the results obtained through this study, as well as the literature control of those results were discussed. Section B summarizes the results and compares them with the available literature on the advantages offered my Memory Box Making as way to guide the bereaved, and on the role of the role played by community volunteers in supporting their communities struggling to cope with the effects of HIV and AIDS. The final conclusions based on the result of the research will be presented in Chapter 5. An overview of the preceding chapters will also be given and the purpose of the research study and the research questions will be discussed. Possible limitations of the study and recommendations for future research will also be addressed.

## **CHAPTER 5 – CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS**

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### **5.1 INTRODUCTION**

This chapter presents the final conclusions made on the basis off my research. I shall briefly review the preceding chapters and revisit the purpose of my research study and the research questions that I set out to explore and describe, as mentioned in Chapter 1. I will also look at possible limitations of my study and make recommendations for future research.

### **5.2 OVERVIEW OF CHAPTERS**

Let us consider the chapters leading up to this point. Chapter 1 served as an introduction and explained the rationale and purpose of the study. Reference was made to the research question that would be guiding the research study, and the secondary research questions of the study, the research design that was selected for the purpose of this study, as well as the research process related to the various research questions. Data-gathering methods and authenticity and trustworthiness were also dealt with. I furthermore provided reference with regard to the informed conceptual framework and clarified the main concepts that relate to the study.

Chapter 2 comprised of a literature review and some of the most recent and authoritative theorising about the topics relating to my study were explored. This included the role played by community volunteers in supporting their communities struggling to cope with the effects of HIV and AIDS and Memory Box Making and the supportive value of this activity for people dealing with grief and/or loss due to a terminal illness or, as in this study, HIV and AIDS. I found a many resources dealing with the Memory Box Making process, but relatively little information on the role played by community volunteers in offering emotional support. Generally the available literature focuses more specifically on the volunteers' role in terms of physical support.

In Chapter 3, I reflected on the research process as a whole, considering the story behind my experiences (personal and professional), and describing the process and



methods that were utilised during the research project. Ethical considerations were also discussed and the trustworthiness of the research was confirmed.

Chapter 4 describes the context within which the results were obtained, as well as the resulting themes. It also includes a literature control relating to the uncovered themes and details the results of my study in the light of the available literature on the role of community volunteers in offering support to communities struggling to cope with the effects of HIV and AIDS, as well as literature on the value of using the Memory Box Making technique as a form of bereavement guidance.

### 5.3 PURPOSE AND RESEARCH QUESTIONS

Taking into account the research questions introduced in Chapter 1, I will now attempt to establish whether they have been answered through the results of research done. The research question that guided my study is: *How do community volunteers apply the Memory Box Making technique to support coping with HIV and AIDS?* In answering this question, I had to attend to the secondary research questions first. These are:

- 1) *What is the Memory Box Making technique?*
- 2) *What is the existing role of community volunteers?*
- 3) *How can community volunteers be trained in the Memory Box Making technique?*
- 4) *How did the community volunteers apply the Memory Box Making technique?*

By way of a comprehensive literature study I answered the first secondary research question and established what the Memory Box Making technique is. I determined that it is a technique used by community volunteers in supporting their communities to cope with the effects of HIV and AIDS. This technique can therefore be used to aid in the bereavement process, as well as for crafting a personal legacy to be left behind for loved ones after an individual has passed away. (Also refer back to Chapter 2 for a detailed discussion of the Memory Box Making technique.)

Through interviews and focus-group meetings held with the community volunteers in Acornhoek who participated in the study, I was able to establish the nature of the

existing role of community volunteers. The volunteers view their role as one of support and care, with the focus on physical rather than on emotional support and care. They did make reference to the fact that they experience themselves as being the eyes of the communities, i.e. that they represent their communities. (Refer back to Chapter 4, and to the transcriptions in Appendix F.) According to current literature, the most prominent current role retained by volunteers is that of offering communities physical support. (Refer to Chapter 2.)

I developed a programme for training the community volunteers in Memory Box Making and implemented the programme as a two-day workshop. This allowed sufficient time for the volunteers to become familiar with the techniques associated with making a memory box. During a presentation, I shared with the volunteers the theory behind Memory Box Making and explained how it can be used in the community. By providing them with this information and giving them an opportunity to make their own memory boxes, I enabled them to consider how they could implement this technique in their communities.

In following the process from exploring what Memory Box Making is to examining the existing role of community volunteers and how they could be trained in the Memory Box Making technique, I could, by way of a follow-up focus-group meeting, explore how the volunteers applied the Memory Box Making technique in their communities.

#### **5.4 FINDINGS**

In considering the research questions as set out above and addressed by way of the research conducted (refer to previous chapters), I have come to the following conclusions:

**Firstly**, I found that *the volunteers experienced the application (at an occupational level) of the Memory Box Making technique in their communities to be of great value.* Formerly they did not possess the means to offer emotional support their communities, as established during a previous visit to Acornhoek by my supervisors, Liesel Ebersohn and Irma Eloff (refer to Chapter 3). Therefore, the role played by the volunteers was focused on the provision of physical support to communities suffering from the effects of

HIV and AIDS by providing care in the form of medication and food packages. The volunteers then identified the need for more efficient means to support the people in the grieving process and provide some form of counselling. After being introduced to the Memory Box Making technique, the volunteers found that the support they were able to give to their communities became more emotional and spiritual and enabled them to cope better with the grieving related to HIV and AIDS. The outcome was that the volunteers reported that they are also now equipped to provide people in their communities with psychosocial support.

**Secondly**, through my research I found that, in terms of *learning acquisition*, the diverse group of volunteers working in the region of Acornhoek were able to acquire the necessary skills required for the application of the Memory Box Making technique. They succeeded in adapting these skills to suit their own working environment and developed the confidence needed to teach the technique to other volunteers and care workers with whom they come into contact.

**Thirdly**, I found that the Memory Box Making technique also *added value to the volunteers' personal lives*. They reported that, through acquiring and applying the technique, they experienced a sense of emotional and personal identity, as well as a feeling of pride and self-worth. In order to be trained in this skill, the volunteers had to make their own memory boxes to ensure that they would understand and be able to apply the technique in their communities. Because of this personal experience, they could attest to the value of Memory Box Making as a way to alleviate the trauma of grieving for a loved one who passed away, or even to bring families closer together. The volunteers were able to apply their learnt skills with confidence and enthusiasm. This process seemed to have a snowball effect in that the volunteers who had attended the original workshop subsequently trained some of their colleagues in the use and application of the Memory Box Making technique. The fact that they feel a need to pass on their knowledge and skill is a possible indication of the value the volunteers attach to the application of Memory Box Making technique as a means to help people to cope with the heartache and loss caused by HIV and AIDS in susceptible communities.

**Fourthly**, I found that the Memory Box Making technique is *an uncomplicated skill* that the volunteers could acquire and use without having to have the extensive knowledge of

the underlying theory that is required of people working as social workers and/or counsellors. This technique therefore provides the volunteers with a means of supporting people who have to cope with the effects of HIV and AIDS in an effective and *ongoing* manner, without having to overcome the obstacles associated with formal studying, for example the lack of financial resources, study material and time availability. The Memory Box Making technique encapsulates the theory behind death and dying, as well as the stages usually associated with the grieving process. Therefore, as mentioned in Chapter 1, Memory Box Making offers cathartic, restorative or curative support to a range of individuals who are infected with HIV and AIDS, who are already dying of AIDS, or have lost a love one to this dreaded disease.

**Lastly**, certain indications of pitfalls were found. These include some disadvantages, as described in more detail in Chapter 4. A first disadvantage is that the volunteers reported that some of the clients they worked with in their communities *did not have important documents in their possession*. As a result the use of the memory box as a safe place to store such documents could not be demonstrated. Many clients, especially orphaned children, did not have identity documents or copies of birth certificates. The volunteers reported that without such documents it is extremely difficult to obtain childcare grants for their clients. Another problem that was experienced was that some clients, especially the elderly, could not understand the purpose of making and keeping a memory box. Other clients, described by the volunteers as 'shy' or embarrassed understand the purpose of such a box and know how to make it, but show no interest in making one, maybe because they are afraid to disclose their HIV status, or because of a lack of knowledge.

These findings add to theory as the existing literature has thus far not yet focused on the importance of community volunteers working in HIV and AIDS-susceptible communities. The research conducted for the purpose of this study confirms the pivotal role played by community volunteers in supporting communities coping with the effects of HIV and AIDS, especially with regard to their role in guiding the grieving process of affected families. The research findings regarding the use and application of the Memory Box Making technique by volunteers especially adds to the field of educational psychology, and specifically to the systems theory in terms of volunteers impacting on the groups

within the community, sharing and applying their knowledge to support those individuals suffering from the emotional effects of HIV and AIDS.

## **5.5 LIMITATIONS OF THE STUDY**

Under this heading I will be considering aspects that were experienced as barriers in my research study. Viljoen (2005: 113) states that, even though barriers are seen as negative influences in a research study, they could contribute to a better understanding of the research that has already been done. Aspects that influenced the research study are discussed below.

### **5.5.1 Limited scale of participants**

Even though 30 community volunteers participated in the two-day workshop, only a few volunteers returned for the follow-up focus-group meeting. Results are therefore based on the feedback received from only a small group. A larger group could have provided me with richer detail in terms of how volunteers apply the Memory Box Making technique in communities that are susceptible to HIV and AIDS. Possible reasons could be that the volunteers did not want to come, that they experienced transport problems, or that they were busy with their responsibilities as volunteers in the community. The fact that the reason for their absence could not be ascertained can be viewed as a limiting factor since this insight could have enriched the findings of the study.

### **5.5.2 Limited generalizability**

The most commonly heard objection to case study research is its low generalizability, the fact that only one or two cases are studied (Verschuren, 2003: 122; Cohen *et al.*, 2000:184). But, as mentioned in Chapter 3, other researchers disagree. Berg (2001: 232) states that when case studies are properly undertaken, they should not only fit the specific individual, group, or event studied, but should generally provide understanding about similar individuals, groups or events. In undertaking research related to the Memory Box Making technique, I could therefore say that my study is generalizable to *theoretical propositions*, even though the research conducted would not be generalizable to populations or universes. As stated in Chapter 3, I believe that in using an

*instrumental case study* in my research, I had an opportunity to do an in-depth and comprehensive investigation of the Acornhoek community volunteers, and gain insight into how they experienced the use and application of the Memory Box Making technique to help people in their communities to cope with the effects of HIV and AIDS. The fact that the case is not generalizable to groups in other areas of Southern Africa could be regarded as a limitation.

### **5.5.3 Observer/Researcher bias**

Another weakness in the design of my research study is that the study is susceptible to selectivity, biased, personal and subjective, as well as observer biased. Working from and interpretivist paradigm allowed me to acknowledge that my views and opinions as the primary researcher could impact on the themes uncovered through the research process. Throughout the study I found that it was imperative for me as the primary researcher to monitor personal views. In doing so, it was important to question my own predispositions as the research progressed. I did this by keeping a research diary. However, despite the fact that I continuously monitored myself as the researcher, I must admit that there were times when I realised that I was being subjective and had to remind myself to guard against being biased in the interpretation of results. This aspect proved to be a limitation in the study. However, I would also like to add that subjectivity in a study such as this one is still preferable to 'objectivity', as I believe that it is my subjectivity that provided me with the specific insights that were gained through this study.

## **5.6 RECOMMENDATIONS**

This study revealed that community volunteers have found the Memory Box Making technique to be of value for their practice of supporting their communities in coping with the effects of HIV and AIDS. The results therefore suggest that the volunteers have found a technique that they themselves can use and apply in their communities, be it with individuals who are dying from this or other diseases, or families grieving the loss of a loved one.

### **5.6.1 Recommendations for practice**

If we consider the findings, as mentioned above (5.4), one could say that being trained in the Memory Box Making technique and personally undergoing the process could create enthusiasm among volunteers who are experiencing difficulties in efficiently helping their communities to cope with HIV and AIDS. The sense of personal value that develops as a result of making a memory box could possibly provide volunteers with the confidence needed to apply the Memory Box Making technique, to adapt the skills they have acquired to suit specific needs, and to teach them to others in the community. Seeing that the Memory Box Making technique is uncomplicated, volunteers could quite easily apply the technique and could therefore offer ongoing and sustainable support to their communities. The Memory Box Making technique provides an alternative way for community volunteers to offer their communities the essential psychosocial support, whether emotional or spiritual, to guide them through the grieving process associated with HIV and AIDS.

#### **5.6.2 Recommendations for training**

On the basis of the results obtained, I recommend that more people be educated in the use of the Memory Box Making technique in order to satisfy a need identified by the community volunteers in Acomhoek. The volunteers indicated that, in their opinion, it would be more beneficial if the technique were taught in community establishments such as faith-based organisations or schools, and/or in groups. The volunteers also mentioned that the functional aspect related to the memory box is helpful in that the box provides for the safekeeping of important documents. More emphasis could be placed on this essential aspect of the use and application of the memory box. The community volunteers could also, after being trained in the Memory Box Making technique, serve as guides in creating a culture of acceptance of individuals coping with the effects of HIV and AIDS through the use of this technique.

#### **5.6.3 Recommendations for future research**

This study describes the application of the Memory Box Making technique by community volunteers in supporting their communities coping with HIV and AIDS. Other qualitative research with an interpretive stance could include questions such as the following:

- How does the Memory Box Making technique sufficiently support individuals in the grieving process?
- How could using the memory box as an official tool benefit community volunteers in helping communities to cope with HIV and AIDS?
- How could communities benefit from volunteers' involvement in training other institutions in the use and application of the Memory Box Making technique?

It is also recommended that in future quantitative research more participants be chosen. Since only 30 volunteers participated in the original workshop and only about ten attended the follow-up focus-group meeting, future research involving a greater number of participants could enrich the findings of a potential study.

## **5.7 QUALITY CRITERIA**

### **5.7.1 Credibility**

Credibility in my study was ensured through the multiple perspectives I considered (crystallisation), as well as by way of member checking. By way of crystallisation I considered the results obtained from not only one, but many angles of incidence. I thus did not rely only on my own interpretation of the results, but also on various professional inputs, as well as the meaning the participants brought to the research and the results. After the themes had been uncovered, member checking was done by way of contact with the contact person, Mr Sedibe. This process of member checking was done via e-mail and telephone calls as explained earlier in this chapter. Finally, professional peers<sup>1</sup> at the 2004 Research Indaba reviewed my research proposal, which also added to the credibility of this study.

### **5.7.2 Transferability**

In terms of transferability, I provided a detailed description of volunteers, and of the setting and context in which my study was implemented (refer to Chapter 4). By using

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<sup>1</sup> I was awarded the prize for "Best Research Proposal by a Master's Student" at the 2004 Research Indaba, Faculty of Education, University of Pretoria.



interpretivism as a backdrop to my research study, I could obtain different inferences of the data collected and was therefore able to provide rich descriptions of the data (see Appendix F for examples of transcripts).

### **5.7.3 Dependability**

A chain of evidence related to the process of my study is evident, as I included various documents outlined in the Appendix. The reader will therefore be able to accept my work and research as being true. Member checking also adds to the dependability of my study in that the actual participants could clarify that my descriptions and interpretations are accurate, based on the information provided (as mentioned previously in Chapter 3).

### **5.7.4 Confirmability**

Throughout the research process I kept a research diary in which I recorded my thoughts and experiences, as well as detailed accounts of the process. This provides a self-critical account of the methodology used. My aim was therefore to understand and interpret the meanings and intentions that underlie the different actions, recognising the role of my internal frame of reference during the research process (refer to Chapter 3).

## **5.8 CONCLUSION**

The memory box is not only a physical object for safekeeping of important and exclusive artefacts, but holds the spirit of hope and anticipation for the future, especially after the passing of a loved one. In reflecting upon this research study done on Memory Box Making and its supportive value to volunteers in their quest to support their communities in their struggle to cope with HIV and AIDS, one could say that this skill has added to the volunteers' ability to offer emotional support to their communities. Therefore, the volunteers now not only have the means to offer physical support to families and individuals, but are able, through using a supportive technique such as Memory Box Making, to also offer emotional and spiritual support.

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