

## 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.