

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

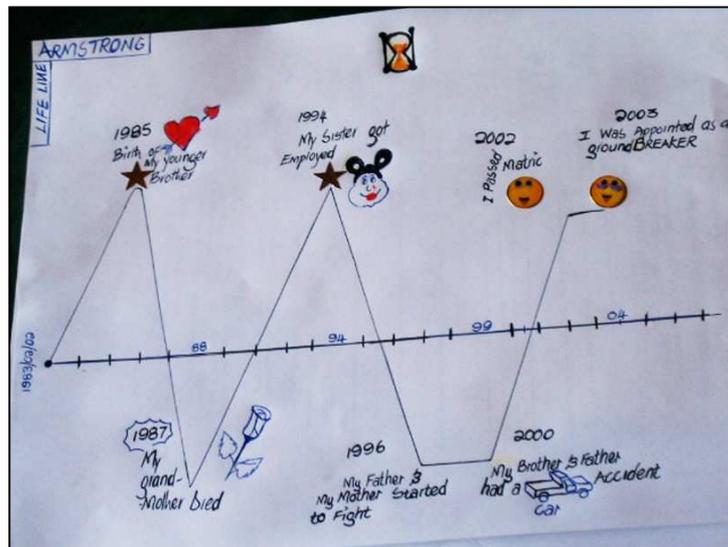


Figure 4.3 is a visual representation of the lifeline of one of the volunteers. The top half of the paper represents all the positive aspects in this volunteer's life, and the bottom half represents the negative aspects in his life.

### 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.

Coovodia (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.