

## 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)

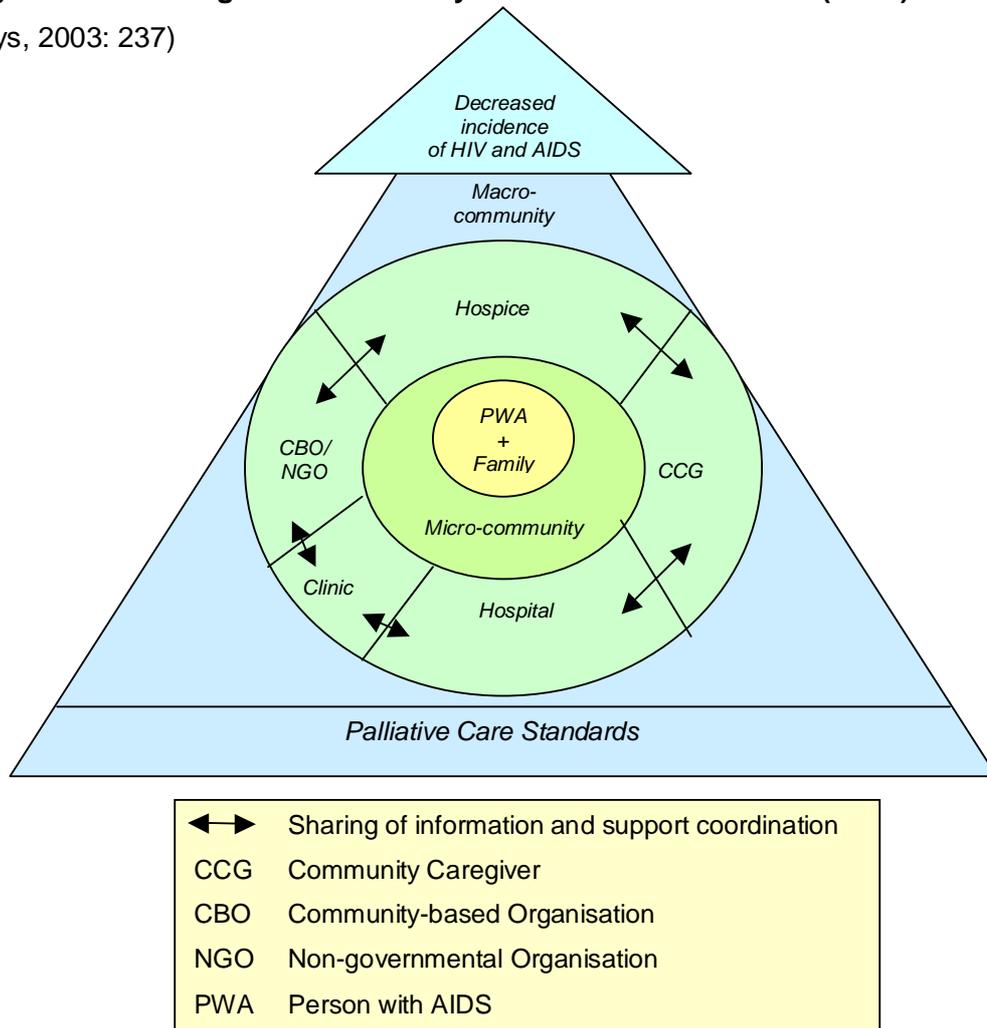


Figure 2.1 demonstrates the Integrated Community-based Home Care Model. This figure illustrates that it is important for all those concerned to realise that home-based care also improves the illness and death experience. Therefore, that the relationship between dying at home and having a 'good' death 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.