

# CHAPTER 1

## INTRODUCTION

### 1.1 VOLUNTEERS WITHIN THE HOSPICE CONTEXT

Hospice care began in England in the 1960s with the opening of St Christopher's Hospice in London. Emphasis at St Christopher's was on palliative care and little was done to prolong life. This approach was evident in that there were no intensive care units and no heart-lung machines present. The objective was to keep pain under control and to assist patients in approaching death in a psychologically healthy way (Santrock, 1995). The Hospice movement spread to America in the 1970s where rapid growth took place (Bee, 1996).

In 1982 the hospice concept had become so accepted that the American Congress added it to benefits paid for by Medicare. Today there are over 1,500 hospice programmes in America taking care of the needs of terminally ill patients and their families (Santrock, 1995).

Volunteers, an integral part of the Hospice team, come from a wide range of backgrounds. The majority are female; they are usually older; they have varying vocations; different economic statuses, (Brazil & Thomas, 1995; & Scott & Cladwell, 1996; Chng & Ramsey, 1984) and belong to different ethnic groups (Scott & Cladwell, 1996).

The context of this present study is a hospice situated in Gauteng. The focus, much the same as that of early hospice care, is on symptom control and pain management as opposed to curative treatment that is emphasised within the medical model. The hospice focus is on quality of life even though the patient is going through the dying process. The holistic philosophy of caring for others presents a specific type of care for the terminally ill and their families and necessitates a multi-disciplinary team able to supply the resources that can address the different aspects involved in assisting the patient through the dying process. The team comprises nurses, social workers, doctors and

volunteers who develop an individual plan of care for each person (unpublished hospice notes).

Volunteers are selected for suitability to the demanding nature of work with the dying. They are required to undergo different modes of training that comprise structured exercises, supplemented by self-exploration exercises leading to the promotion of self-awareness. Activities include reading relevant theoretical material, role-plays, and lectures, writing exercises and viewing videos. The volunteer then has to undergo an orientation programme during which they are introduced to the different departments and functions of the hospice. Each volunteer participant is required to pay an enrolment fee and to attend all training sessions spread over a ten-week period. This initiation and training programme is much the same as other hospice volunteer programmes described in literature (Hayslip & Leon, 1992; McArdle, 1985). Hayslip & Leon (1992) claim that this approach heightens the credibility of the volunteer's role and ensures that each person receives competent training. Formalising the programme puts the volunteer's contribution on par with those of the other team members. It gives the hospice credibility and visibility in the eyes of the community in which they are situated. In this particular hospice ongoing training is provided throughout the year including bimonthly supervision sessions.

The volunteers in the hospice in this study provide a number of services such as fund-raising, providing transport, organising and facilitating regular social gatherings for the terminally ill, taking intake calls, assisting in the inpatient unit and providing supportive counselling.

## **1.2 PHILOSOPHY UNDERLYING THE HOSPICE MOVEMENT**

Maruyama (1999) has claimed that hospice has not as yet become a real philosophy of care as it caters only for one type of patient, the cancer patient. This is not the situation in this South African hospice as the organisation does cater for diseases other than cancer. However, a vast majority of the patients in this particular hospice are cancer patients. To use a hospice facility one has to be aware of impending death and this suggests that one would

necessarily be suffering from long-term illness of which cancer is the most common.

There are various types of hospice models, but regardless of differences all hospices share the following beliefs (Hayslip & Leon, 1992):

1. Death is seen to be part of a natural process. It is to be faced and not avoided (Bee, 1996; Hayslip & Leon, 1992).
2. Both the patient and the family should prepare for death by exploring feelings around the situation and in the case of the family, preparations for the future (Bee, 1996; Hayslip & Leon 1992; Owen 1985).
3. The family are encouraged to be involved with the caring of the patient so that each member can come to some formal resolution of his or her own relationship with the dying patient (Hayslip & Leon, 1992).
4. The control of care is given over to the patient and their family (Bee, 1996; Hayslip & Leon, 1992).
5. Care is palliative not curative. Patients are given medication and treatment to assist in symptom management. No invasive life prolonging procedures are undertaken (Bee, 1996; Owen, 1985).

The above principles are not separate entities but interrelate to form the Hospice philosophy as a whole (Hayslip & Leon, 1992). The following expansion of these beliefs emphasises their implications and how they integrate to form the hospice milieu. The emphasis is on holistic care in that it incorporates both the needs of the dying patient and the family. It also focuses on the psychological needs of the patient in preparing for death as well as the physical needs at this time.

Referring to the Hospice philosophy Hayslip & Leon (1992, p.3) states, "Hospice enables the dying person to continue to live until the moment of

death". This is partly achieved by encouraging the dying to stay within the family unit in a home-like environment as much as possible so that contact with both friends and family is feasible. In this way the dying process is incorporated into the home as a natural part of life. This emphasis also ensures that the patients retain their social support system throughout their illness and death. The importance of social support for the dying has been noted in research. Carey (1975) found that individuals with high levels of social support report lower levels of pain and depression in final moments of illness. Spiegel, Bloom, Kraemer & Gottheil (1989) noted that dying persons who participated in a support group maintained longer lasting survival rates as opposed to a control group that received no added support. In a society that tends to ignore death by isolating the dying, people often experience social death before they die physically (Hayslip & Leon, 1992). The Hospice structure provides an alternative to this situation. Hospice staff members visit the dying at their homes providing the necessary support structure for the family to cope with having their terminal member at home. Nurses care for the medical needs of the patients whilst volunteers and social workers take care of the psychological needs of the patient and their families.

To remain a part of the family until death has many benefits not only for the dying but for their loved ones as well. The difficult process of losing a loved one can be addressed within this context. Hospice gives an opportunity for the family to express the feelings associated with loss, and helps survivors to face living and the future without the deceased in their lives. The hospice thereby provides a setting in which the whole family can deal with unfinished business (Hayslip & Leon, 1992).

Within this home context the patient and the patient's family have more control over the dying process, as family are involved with the day to day care and administration of any medication. A central goal of hospice is to give the dying individual an appropriate death. An appropriate death involves dying in a manner that the terminal patient chooses. Handing the control of the dying process to the patient and their families facilitates this (Hayslip & Leon, 1992).

Hayslip & Leon, (1992) argue that there are four components that have to be present in order to accomplish an appropriate death:

1. Awareness and knowledge that the illness is terminal, and how this impacts the way one would like to spend the remainder of one's life, is essential. This awareness is crucial for open communication to exist between the dying patients, the staff and family members.
2. Acceptance of life's end and a willingness to confront the problems encountered during this time.
3. Propriety. This relates to behaving according to society's values and the dying patient's personal values about life-and-death.
4. Timeliness. Although hospice does not practice euthanasia or encourage suicide it does suggest an acceptance of the fact that there comes a time that a longer life would serve no particular purpose. Individuals' private sense of what is a right and proper time to die is respected.

The philosophies discussed are expressed in the dying patient's bill of rights, which is included as Appendix 1.

### **1.2.1 The Hospice Philosophy in Practice**

The following quote provides an example of the culmination of the hospice philosophy and its outworking on a practical level.

“Experience in hospices suggests that it is sometimes possible for a husband and wife to work together towards an acceptance of the approaching death of one of them. If the circumstances are right, they can share some of the anticipatory grief which each needs to feel. The striking thing about such cases is that, despite the sadness which is an inevitable component of anticipatory grieving, couples who choose to face the future in

this way often seemed to win through to a period of contentment and calm which persists to the end. After bereavement has occurred, the surviving spouse is likely to look back on this period with a satisfaction that contrasts with the dissatisfaction expressed by many who have chosen to hide the truth” (Parkes, 1986 p.150-151).

### **1.3 THE CLIENT-CENTRED APPROACH TO THERAPY**

The hospice in this study trains their volunteers according to Rogerian counselling techniques. According to Maddi (1996), Rogers’ theory states that at the core of the personality is the drive to actualise inherent potentialities. These potentialities serve to maintain and enhance human life. Rogers believed that there is nothing in the inherent human nature that, if accurately and straightforwardly expressed, would be destructive either to itself or to others. The drive to fulfil these potentialities is called the actualising tendency. The potentialities are seen as genetically determined for each individual. However, the self-concept is socially determined. Socialisation therefore influences the sense of who one is and this sense may then differ from what the inherent potentialities of the individual are. This potential incongruence between self-concept and potentialities occurs if society fails the individual by giving what Rogers calls conditional positive regard. If unconditional positive regard is provided by society, no conditions of self-worth and no defensiveness will develop. The individual is free to express inherent potentialities which will be congruent with the self-concept (Maddi, 1996).

Barton (1974), expanding on Rogers’ theory, states that he proposed that problems arise in individuals because they have departed from their own values, taking on the values of others. Therefore the counsellor does not impose or wish to impose his own values upon the client. The centre of the therapeutic process resides in the client in that it is not the therapist’s values, feelings or opinions that are important. The client is seen as having powers to shape their own destiny and to think their own thoughts. Given the right context, clients will follow their own potentialities that are inherently positive

and right for themselves. The therapist's aim is to understand the world from the client's perspective (Barton, 1974).

The client is seen as having the ability to make sense of his or her own difficulties. In light of this, there is no need to devise elaborate theories to help understand the client. He is rather assisted, through the therapeutic process, to make sense of his own experience. It is the client's own account, his own description of his own life experience, that will enable him to make sense of his world. Difficulties arise because the values and authority of others have been accepted (Barton, 1974).

Counselling within this framework therefore does not advise, direct, manipulate or theoretically interpret the client. The goal of the therapist is to present an understanding, empathic presence to the client so that the client can explore his own feelings. Different techniques are used to achieve this goal. The counsellor's reflection of the feelings of the client is one technique utilised to explore the client's world. Without the therapist's focus on feeling, the client may focus on thoughts, theories and explanations which may lead to focusing on external sources for problem solving, opposed to finding a solution in keeping with his own values. The goal of therapy is for the client to live out his natural self. Primarily it is a way of the therapist respecting the client while understanding him at the same time (Barton, 1974).

The counsellor is to understand the client's feelings empathically and communicate this understanding to him (Barton, 1974). This approach fits well with the philosophy of hospice to enhance self-determination in the dying process. It respects and accommodates the vast differences and preferences in individual approaches to dying and bereavement. Authenticity and positive regard are emphasised. The aim is to provide an atmosphere conducive to self-exploration and support as the client unfolds his/her real self. The hospital setting provides a certain approach to disease and death that does not account for individual differences, the control of the process is in the hands of the doctors and staff.

#### **1.4 MOTIVATION FOR THE STUDY**

The hospice volunteer is viewed as an integral member of a multidisciplinary team, with various roles directed at enhancing the quality of life for patients and their families (Brazil & Thomas, 1995; Lafer, 1991). They are a free labour source, in terms of wages, and without their efforts many hospice programmes would be unable to operate (Patchner & Finn, 1987). Their role is therefore a critical one. Despite this there is a scarcity of literature about this specific sub-group of hospice workers. While literature contains many references regarding stress and burnout in professional staff, little has been written about hospice volunteers (Glass & Hastings, 1992). Research has also led to an enhanced understanding of the dying and bereaved, but this is not matched by sufficient knowledge concerning the experience of lay persons counselling these populations. Increased knowledge in this area could result in better service to clients and lessened distress for counsellors (Garfield & Jenkins, 1981).

As well as a neglect of the specific category of hospice volunteer, research has also ignored the uniquely human dimensions involved in the helping endeavour. Often, books that have been written about helping others, focus rather on content, research and skills. There is little exploration of the joys, passion and commitment associated with helping others (Kottler, 2000). Reflecting this trend, that which has been written about hospice volunteers also focuses on specific aspects such as motivation, role and stressors. 'It (current research) does not offer us an integrated picture of the whole person or of the impact of the hospice volunteer experience on the individuals' lives' (Uffman, 1993, p.8).

The above findings were confirmed when, on commencing this study, a literary search using Psychlit and Eric databases was conducted. Only one study, carried out in the USA by Uffman (1993), explored the helping experience of the hospice volunteers and how this affects their day to day lives. There is therefore a need to explore the human dimensions of the volunteer role and to examine this within the specific sub-category of the hospice volunteer.

## **1.5 OBJECTIVES**

The objective of this study is to provide an integrated picture of the volunteers, their role, the human dimensions of this experience, and the impact this has on their lives.

## **1.6 APPROACH TO THE STUDY**

An interpretive paradigm has been chosen as an appropriate framework to address the objectives of this study. This paradigm seeks to understand the phenomenon under study from the participants' point of view. It explores the subjective reasons and meanings that lie behind behaviour (Terre Blanche & Durrheim, 1999). The research design utilised is that of ethnographic case studies and thematic analysis for interpretive research as suggested by Terre Blanche and Kelly (1999). Chapter one gives a description of the context of the study; chapter two contains the literature review; chapter three details a description of the methodology; chapter four is an introduction to the three case studies, chapters five, six and seven contain the three case studies; in chapter eight the findings of the case studies are compared and conclusions are given in chapter nine.

## **1.7 CONCLUSION**

Although the participants in this study are recognised as the experts of their own experience, all research is born from various theoretical frameworks, hunches and ideas from past research (Creswell, 1997). The following chapter looks at some of the past research and literature on volunteers in general, as well as hospice volunteers and hospice workers. It will serve as a background to the specific aims of this study as opposed to forming a guiding framework. The theories reviewed will be utilised during the data analysis phase of this research to assist in interpreting and bringing structure to the data (Creswell, 1997).

