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THE CAREGIVING RELATIONSHIP:

PALLIATIVE CAREGIVERS' RELATIONSHIPS WITH PATIENTS AND FAMILIES

VOLUME 1: THE THESIS

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DECLARATION

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ABSTRACT

The purpose of this study was to investigate the relationship- and communication experiences of hospice caregivers with patients and families. Two research questions were addressed: 1. How do caregivers experience these relationships and what is the nature of this relationship?, and 2. what role does communication play in the development and maintenance of these relationships?

The study was designed as a field study using in-depth interviewing as the principal data collection strategy and a phenomenological-psychological approach as an analytical technique. The research inquiry consisted of three separate but linked parts: a pilot study with ten participants at a hospice in Great Britain, a subsequent focus group interview with seven of these ten caregivers at the same site, and a follow-up study with twenty-six participants at four different hospices in Great Britain. A total of thirty-six individual interviews were conducted using a long-interview design.

The analyses of the data in this study suggested that the relationship experiences of hospice caregivers with patients and families are grounded in a particular mode of relating or relationship conduct characterized by a display of feelings, closeness, and solicitude. This conduct is the basis on which the caregiving relationship develops. The development and maintenance of this relationship also depends on caregivers' ability and willingness to involve themselves in the total situation of patients and families, to keep essential boundaries intact, and to find the right balance between distance and closeness.

The themes of communication that were identified in this study (communicating about diagnosis and prognosis, telling and accepting the truth, facing and accepting death) - as well as the subthemes (finishing "unfinished business", resolving unresolved conflicts, "letting go"), and the communication problems that arise in this context - are all part of the meta-theme of preparing the patient/family unit for the occurrence of death.

CHAPTER I

INTRODUCTION

This thesis is a report of a phenomenological study of palliative caregivers' relationships and communication with patients and families in their care. The study was based primarily upon thirty-six in-depth interviews with professional caregivers at four British hospices. In the first chapter of the thesis I present the background of the study, specify the problem or topic of the study, indicate relevant previous work on the topic, describe the study's significance, note the delimination of the study, and provide definitions of some key-terms used. The chapter concludes with an explanation of how the thesis is organized.

BACKGROUND OF STUDY

Starting in the mid-twentieth century a noticeable general shift in attitudes to *dying and death* occured in Western society. This shift was set in motion by the publication of a number of seminal works (for example, Becker, 1973), "widespread complaints" (Callahan, 1993: 37), the results of Elisabeth Kübler-Ross' inquiries, and the findings of numerous ethical - and legal committees (Callahan, 1993) which all criticized the way dying and death was "managed" by the medical profession (see Chapter III). In time these critical reactions gave birth to a number of reform movements in the USA and Europe and to the establishment of hospice programmes, based on the pioneering work of Dame Cicely Saunders, throughout the Western world.

The hospice movement became a spectacular success: by the beginning of the 1990s, 1874 palliative/hospice care centres were operating in the USA (Callahan, 1993: 39) and 487 in the European Community (Griffin, 1993: 12). At the same time that these care centres were established, a philosophy of palliative care evolved that sought to identify and specify the elements involved in providing the *total care* aimed for in these settings. One important aspect of translating this philosophy into the actual practice of caring for the terminally ill was the idea that medical staff and other professionals working in this field needed a special type of education and training which incorporates the evolving philosophy of the movement.

The view that a holistic education and training in working with terminal patients and their relatives is essential to the delivery of high quality palliative care is generally accepted by institutions and professionals in this field. One crucial aspect of these education- and training programmes is communication:

> Communication is of course the key to this (interprofessional education); listening and sharing are important. We also have to be aware of nonverbal communication and how we communicate in that way ourselves. There is undoubtedly a ripple effect, showing how people interact. The ripple effect spreading from patients outward to families, friends and staff and returning back in again from the bank of the pool. Understanding this interaction is crucial in delivering high quality care (Calman, 1993: 48).

That communication continues to be a crucial issue in working with patients and relatives who confront a life-threatening illness is highlighted in a recent article by David Charter in *The Times*:

> **Doctors are too stressed to relate to frightened patients.**
> By David Charter - Health Correspondent
>
> BRITAIN'S most experienced cancer doctors are so bad at communicating that almost 90per cent of their patients do not receive vital information about their condition, researchers said yesterday.
>
> This lack of clarity and detail from doctors led to greater anxiety and depression among patients, longer stays in hospital and more litigation, the Global Cancer Conference in Brighton was told.

> The survey of patients followed research among consultants of up to 30 years' experience, which showed that many still did not know how to relay basic information to patients who were emotional, withdrawn or in denial.
>
> The Cancer Research Campaign, which carried out both studies, said that it was a national disgrace that more resources were not put into teaching communication skills to doctors and nurses.
>
> Lesley Fallowfield, director of the CRC's psycho-social oncology group, said that in a 40-year career a consultant would conduct between 150,000 and 200,000 interviews with patients.
>
> Yet her research with 178 of the country's most senior doctors found that 43 per cent felt it very difficult to communicate with members of the ethnic minorities, 38 per cent thought it hard to relate to people much older or younger than themselves and 29 per cent struggled to talk to emotional patients.
>
> Among senior cancer nurses, 46 per cent found it very difficult to give full information to emotional or withdrawn patients and 39 per cent admitted communication problems with ethnic minorities. An analysis of the doctors' own mental states showed they were as stressed as patients recently found to have cancer.
>
> In another study, which asked senior doctors to grade the psychological needs of 2,000 patients in cancer clinics, almost 800 of the patients were given the wrong classification. Professor Fallowfield, from the school of biological science at Sussex University, said: "In a survey of almost 2,500 patients seen in UK cancer centres by senior cancer doctors, 87 per cent said that they wanted as much information as possible, be it good or bad news, but most doctors were seriously underestimating this.
>
> "Many doctors simply lack the skills to communicate with someone who is withdrawn or depressed or highly anxious. The doctors had similar health questionnaire scores to their patients - they were in a mess as well. You can hardly expect them to get near the emotional and psychological needs of their patients if they are too burnt out with stress themselves."
>
> Better communication was cost-effective, she said, with one American insurer charging 7 per cent less for doctors who had been on a communications skills course. "If communication is good, patients are going to understand and recall more of the information. They are going to have a reduction in anxiety and uncertainty. And they are more likely to adhere to different treatment and advice."
>
> Professor Fallowfield runs intensive training courses for the CRC and a review of its success in improving communication is shortly to be published in *The Lancet*. (*The Times*, June 26, 2001).

It is a guiding premise of this study that for verbal communication to be effective in these particular settings and circumstances it needs to be rooted in a *relationship*, i.e. that the relationship is primary and that the success or failure of communication depends on the quality of the relationship one can establish. In other words, to improve communication in these situations, we need to know more about the particular kinds of relationships that are developed and maintained by these professionals with their patients and clients.

Furthermore, the findings of the pilot project which formed the basis of this study indicate that professionals working in this field consider their relationships with the people in their care of primary importance (see Chapter V). My decision to focus on the relationship aspect of palliative care work was determined by the importance attached to it by professionals working in the field (see Chapter V). My own interest in this topic derived from working as a psychotherapist with clients who confront a life-threatening illness and from my work as counselling supervisor in the Oncology Department of a London Clinic.

PROBLEM STATEMENT

The purpose of this study was to analyse and describe how palliative caregivers experience their relationships with patients and families and what role communication plays in this experience. The more specific questions this study will attempt to answer are: Is there a typical way of relating for caregivers that underlies these experiences which leads to the formation of a particular relationship? How can this way of relating be described and what kind of relationship is formed through it? What role does communication play in the development and maintenance of this relationship?

PREVIOUS WORK ON TOPIC

A full review of the relevant literature is presented in Chapter VII and focused on three keywords: palliative caregivers, communication, and relationship. The main finding of the literature search was that, as yet, there seems to be no phenomenological study examining the caregiving relationship from the perspective of the caregivers, based solely on their experiences.

The literature was classified into three different levels, I - III, with Level I being "background studies" and Level II containing relevant studies addressing some of the keywords and/or issues raised in this thesis. No study could be found for Level III. The field of palliative care is a very wide one and and indication of the expanse of studies found under the three keywords is summarised in Chapter VII.

The phenomenological approach as applied in this study was also the chosen method of analysis for researchers, such as Stiles (1994) and Jones (1997). Stiles (1994) examined the "meaning of the nurse-family spiritual relationship" whereas Jones (1997) analysed the data generated during supervision sessions with five Macmillan nurses. Structured, long, and in-depth interviews were data collection methods preferred by a number of authors. For example, Herman (1997) grouped the "spiritual needs of dying patients" into six themes and Weinandy (1998) added self-reports for his study on nurse/patient quality of interaction and communication. A communication skills programme for palliative nurses was evaluated by Wilkinson et al. (1998); their findings suggested that nurses felt more confident in handling difficult situations after completion of the programme. Difficulties in communicating vs. open communication, i.e. talking about dying and death and telling patients the truth are further aspects addressed by researchers, such as Misbin (1990), Haven and Maguire (1997), Hinton (1998), and McGrath et al. (1999). Arguments have been put forward which suggest that "open communication" should be strived for and can be facilitated by communication skills training, although not telling the truth may be less stressful for patients. The nature of nurse-patient communication was studied, among others, by Jarrett and Payne (2000) who suggested a theme of "optimism" running through the "cheerful nature of nurse-patient interaction".

A stance was put forward by, for example, Coberly (1998) is that communication and relationship are closely linked. Von Friederichs-Fitzwater (1987) focused on "a language variable called immediacy" which refers to caregivers being able to associate with the concerns of and the patients themselves. At the other end of the scale is the aspect of "distancing" in a relationship using communication to do so (e.g. von Friederichs-Fitzwater, 1987; Clair 1987). Sander (1991) examined the issue of a "confidant" selected by patients among the hospice staff with whom they form a closer relationship than with other caregivers. In a similar light, Raudonis (1995) conducted research on empathic relationships between terminally ill hospice patients and their nurses. Quality of interaction between patients and caregivers was the focus for, e.g. Samarel (1989), whereas Raudonis and Kirschling (1996) emphasized the relationship between family caregivers and hospice nurses. The issue of relationships has also been addressed within a philosophical framework (e.g. Rompp, 1987) and von Manz (1994) expanded on "how the notion of the other is essential for the notion of the self", a point linked to the suggestion which will be put forward in Chapter IV, that the death of 'myself' can be transformed by the dying patient into the death of 'another'.

SIGNIFICANCE OF STUDY

It is hoped that this study will make a contribution to the knowledge of interpersonal relationships in general and helping relationships in particular. More specifically, the study aims at increasing knowledge that may be of use to practitioners in the helping professions, especially to those dealing with patients and families confronting a life-threatening illness, to counsellors and psychotherapists, and finally to patients and relatives in palliative care.

DELIMITATIONS OF STUDY

Phenomenological research focuses on what individuals experience and attempts to describe this experience in a language that is as loyal to the lived experience as possible. The phenomenological approach does not intend to prove or test a theory but aims at describing and elucidating the meanings of experience and the structures that underlie consciousness. This study is an initial exploration of palliative caregivers' relationship experiences with patients and families in their care. Initial explorations of comprehensive and complex phenomena, such as relationships, have certain inherent limitations. In this case, the design of interviewing a relatively large sample composed of individuals of various professions and backgrounds, and having different levels of experience working in palliative care, may have lead to a description of the phenomenon-in-general that lacks a certain specificness. The description arrived at in this study is a broad one which needs further research to refine it and make it more specific.

DEFINITIONS OF KEY-TERMS

Palliative Caregivers: The term "palliative caregivers" is used in this study to refer to professional - (doctors, nurses, counsellors, chaplains, administrators, etc.) and volunteer staff (sitters, drivers, etc.) associated with hospices and who are involved in the actual care of patients and families.

Patients and Families: The study focused on the *patient-family unit* rather than on the individual patient or relative.

Acting-as-a-Friend: The term "acting-as-a-friend" was coined by me to refer to a distinct way of relating or relationship conduct of palliative caregivers with patients and families as described in Chapter V of this study.

The Caregiving Relationship: This term refers to a particular kind of relationship between palliative caregivers and patients and families and is described in Chapter X of this study.

STRUCTURE OF THESIS

This thesis is organized in the following way: Chapter II explains the methodology used in this study, states the rationale for selecting this particular methodology, and describes step-by-step the research practices employed in carrying out the study. Additional and more detailed explanations of the process of analysis used are provided in Chapters V and VIII. Chapters III and IV describe the background of the study: Chapter III gives an overview of the contexts of the topic while Chapter IV focuses on the specific situation of patients and families in palliative care. Chapter V presents the data, analysis, and findings of the pilot study and Chapter VI the results of the focus group interview which followed the pilot study. Chapter VII provides a review of the relevant literature on the topic. The review is placed here rather than, as is customary, in Chapter III because it was conducted after the pilot study and focus group interview were completed. Chapters VIII and IX present the data, analysis, and findings of the follow-up study: Chapter VIII focuses on the relationship and Chapter IX on communication. Chapter X provides a structural description of the caregiving relationship and Chapter XI summarizes the study and the outcomes and discusses the implications of these outcomes.

The appendices, in Volume 2, are organized as follows: Appendix 1 contains the list of participants in this study as well as examples of contact letters and other correspondence with them; Appendix 2 provides documentation on how the data of the pilot study was analysed; Appendix 3 includes the pre-questionnaires used for the focus group interview and the transcript of this interview; finally, Appendix 4 contains eight transcripts of the twenty-six interviews of the follow-up study.

CHAPTER II

METHODOLOGY

INTRODUCTION

The research approach adopted for this study was a qualitative one. I designed the investigation as a field study utilizing in-depth interviewing as the principal data collection strategy and a phenomenological-psychological method of analysis as an analytical technique. The aim of the design was to produce a comprehensive qualitative description of the investigated phenomenon.

In this chapter I discuss the reason for choosing a qualitative research approach and provide a brief description of the particular approach chosen. I also show how one of the pioneers of applying this methodology in the field of psychology used it himself in a particular research situation. I provide examples of qualitative studies in the field of health care using this methodology and describe (step by step) the research practices I have employed in carrying out the study.

THE RESEARCH APPROACH

The topic of my investigation was the relationships of palliative caregivers with patients and families in their care. These relationships can be considered an aspect of the broader field, or 'science', of *caring*. The concept of caring is an emergent construct which has many different connotations (Lemon and Taylor, 1997: 227). Attempts have been made to operationalize caring as a set of behaviours that can be quantified in some way (Watson, 1979; Leininger, 1981), but these approaches have been criticized because caring is highly context-dependent. As Dunlop (1994: 37) emphasized: "If we conceptualize caring as a finite set of caring behaviors, then caring can be examined in the traditional scientific way. But, equally, if we operationalize caring in terms of context-free variables, ... we are likely to end up with something different from what we now recognize as caring". Caring, in this perspective, "is thus seen not to reside in a set of practices, but in a thinking-feeling (thoughtful in its fullest sense) mode of being that gives rise to activity" (Dunlop, 1994: 38).

As Lemon and Taylor (1997: 228) pointed out, there are many definitions of caring (within the literature of nursing, for example) but no overall consensus of how it is defined, what the components are, and what the process of caring consists of. The concept of caring is not only an emergent one but also complicated, comprising both behavioural and philosophical elements. In addition, it generally involves an affective component: "The importance of this affective caring component is often emphasized by nurses, in their advocacy of 'holistic' models of nursing care which is either expected or evaluated highly by the general public" (Lemon and Taylor, 1997: 228). Affect, of course, is hard to quantify and so are "accessibility, interpersonal skills of nurses, empathy and attentive personal service, which many people would regard as the hallmark of a caring service" (Lemon and Taylor, 1997: 228).

It is for the reason stated above that more recent research in the field of caring increasingly turned to qualitative, and especially phenomenological, methodologies (Crabtree and Miller, 1992: 25) which emphasize investigating phenomena in natural (rather than artificial) settings, focusing on meanings (rather than behaviour), and seeking to identify cultural patterns (rather than scientific laws). It is for the same reason that I chose a phenomenological approach to my investigation: the relationships investigated here are not only context-dependent but also involve a particular '*mode of being-with*' which contains a strong affective component as well as a distinct philosophical orientation.

I am aware of the fact that there is a continuing - and sometimes heated - debate between qualitative and quantitative research traditions in the field of psychology (Stevenson and Cooper, 1997: 159) caused by a gradual paradigm shift in recent years challenging positivistic methodologies. Because of this shift:

> Qualitative approaches are becoming increasingly accepted as a valuable part of modern psychology. This change is particularly visible at research levels, where an increasing number of conference papers and research projects are incorporating qualitative analyses to augment and enrich quantitative information, and some have eschewed quantitative techniques altogether. A growing concern about problems of artificiality in research data, together with an equally growing interest in 'ecological validity' and research which is relevant to the problems of society, have produced a realization that qualitative techniques may have a great deal to offer (Hayes, 1997: 2).

My own position on this matter is best expressed by Giorgi (1970: 224-225):

> To be scientific, according to criteria that emerge from the way science is practised, psychology must deal with the experiential-behavioral relationships of man in a detailed way, and it must arrive at intersubjectively valid truth among a group of men who are qualified to judge the data and facts arrived at. To be objective, or accurate in our terminology, the psychologist must be able to arrive at intersubjectively valid knowledge; he must be able to assume a specifiable attitude towards his phenomena; and he must be open to himself, others and the world in such a way that he allows what is present to him to be the way it presents itself. To be empirical, psychology must be based upon phenomena that are given in experience. To be human, it must have as its subject matter the human person and he must be approached within a frame of reference that is also human, i.e., one that does not do violence to the phenomenon of man as a person. The last point does not necessarily imply a lack of rigor or discipline.

PHENOMENOLOGICAL RESEARCH

"The guiding theme of phenomenology is to go 'back to the *things themselves*' (Husserl, 1970/1900: 252) and for a phenomenological psychologist one interpretation of the expression means to go to the everyday world where people are living through various phenomena in actual situations" (Giorgi, 1985: 8). Phenomenological research involves "a direct analysis of the psychological meaning of naive descriptions of personal experiences provided by individuals from all walks of life in situations that are easily recognizable as belonging to everyday life" (Giorgi, 1985: 1).

Phenomenological research is concerned with describing the lived experience (*life-world*) of individuals, using as few theoretical or social constructs as possible. It is also concerned with describing and elucidating the meanings of these experiences: "The empirical phenomenological approach involves a return to experience in order to obtain comprehensive descriptions that provide the basis for a reflective structural analysis that portrays the essences of the experience" (Moustakas, 1994: 13). In order to "portray the essences of the experience", the phenomenologist attempts to get beneath how individuals describe their experiences to the structures that underlie consciousness, i.e. to general or universal meanings. "By adopting a strictly descriptive approach, we can let the phenomena speak for themselves, and when we do we discover that whatever appears suggests in its very appearance something more which does not appear, which is concealed" (Giorgi, 1985: 151). Lived experience, the meanings of experience, and the structures or essences underlying experience are the focus of phenomenological research.

The basic methods phenomenological researchers employ to discover the nature, meanings, and essences of human phenomena are *bracketing, psychological reflecting/intuiting,* and *describing.*

Bracketing means that the researcher adopts and maintains a certain psychological stance or attitude when attending to a phenomenon so he or she can "take what is experienced just as it gives itself in any instance (Husserl, 1971/1925: 42)" (as quoted by Giorgi, 1976: 313). If, for instance, I want to understand an experience a participant describes during the interview, I must start by suspending, or bracketing, all presumptive constructs about it and adopt an attitude of "open-ended presence to the phenomenon that is unfolding" (Giorgi, 1976: 313). The procedure of bracketing is employed in all phases of a phenomenological inquiry.

Psychological reflecting/intuiting is used by the researcher in his or her attempt to grasp the essential psychological meanings contained in the testimonies of the participants. This procedure aims "to bring the phenomenon itself to self-showing" (Aanstoos, 1985: 91) and it proceeds, in Giorgi's approach, by the way of 1. identifying *meaning units*, 2. specifying their *central themes*, and 3. articulating their *psychological sense or meaning.*

Describing involves organizing the structural meanings derived from the procedure of reflecting/intuiting into a systematic structural description "in order to grasp the relation of the essential meanings through their coherence" (Aanstoos, 1985: 92). The procedure usually consists of two steps: 1. A description of the situated or individual structure of each of the testimonies *(ideographic analyses)*, and 2. the analysis or interrogation of these individual structures in order to arrive at a description of the structure of the phenomenon-in-general *(nomothetic analysis)*.

The steps of phenomenological analysis are summarized by Giorgi (1979: 83) as follows:

> (1) The researcher reads the entire description of the ... situation straight through to get a sense of the whole. (2) Next, the researcher reads the same description more slowly and delineates each time that a transition in meaning is perceived with respect to the intention of discovering the meaning. (From this, he or she obtains) a series of meaning units or constituents. (3) The researcher then eliminates redundancies and clarifies or elaborates to himself the meaning of the units he just constituted by relating them to each other and to the sense of the whole. (4) The researcher reflects on the given units, still

> expressed essentially in the concrete language of the subject and comes up with the essence of that situation for the subject. Each unit is systematically interrogated for what it reveals. The researcher transforms each unit, when relevant, into the language of psychological science. (5) The researcher synthesizes and integrates the insights achieved into a consistent description of the structure of (the situation).

To demonstrate how Giorgi himself (1985) applied phenomenological analysis to a particular research topic *(verbal learning)*, I now quote excerpts of a specific example which show the process of analysis from the original testimony *(naive description)* through the phase of *qualitative analysis* to the *ideographic description* of the investigated phenomenon:

> **Naive Description**
>
> In a health food store in downtown Pittsburgh a friend and I asked the clerk if she knew how to make yogurt. She said yes and proceeded to give us the recipe. This is what I thought she said: To a half-gallon of milk, add 1/4 cup of plain Dannon yogurt, to serve as the culture. Keep this mixture at a temperature between 90 and 110 degrees for five hours. Then chill the yogurt in order to make it firmer. Because of its simplicity, I did not write down the recipe but assumed that I could remember it. I tried the recipe about 10 days later. I added 1/4 cup of plain Dannon yogurt to a half-gallon of milk. Then I put the mixture in our oven at 110 degrees and made a mental note as to when five hours would be up. I checked the mixture four or five times during the five hour period. I noted some thickening in the beginning but did not get past a soupy consistency even after it had been in the oven for five hours. Unsure as to whether it was progressing properly, but wishing to follow the directions and impatient for the yogurt to be finished, I took the bowl out of the oven and put it into the refrigerator thinking that perhaps it would firm when chilled. I checked it in the refrigerator once after two hours and again after four, and all that had occurred was the chilling of the soupy mixture. Then I decided that something had gone wrong, and I tried to think of what it was. I immediately considered the period when I kept the mixture in the oven because I was uncertain about it when I took it out. Perhaps I hadn't given it enough time ... but the recipe said five hours. Aha! Although I had kept the bowl in the oven for five hours, the recipe called for keeping the mixture at 90 to 110 degrees for five hours and the mixture started out quite cold. I added another 1/4 cup of yogurt in case I had killed the first yogurt culture by the temperature changes it went through in the

first unsuccessful run. I put the bowl in the oven and left it for 10 hours (overnight). When I got up the next morning, I checked it, and the mixture had become yogurt. I took it out of the oven and put it in the refrigerator, where it got thicker ... (Giorgi, 1985: 53).

Qualitative Analysis:

Discriminated meaning units expressed as much as possible in S's language based upon perspective that description was an example of learning.	*Discriminated meaning units expressed more directly in psychological language and with respect to relevancy for the phenomenon of learning.*
1. In a health food store, S and friend get recipe for yogurt.	1. S gets instructions she desires from "expert other".
2. S remembers recipe as "1/2 gallon milk and 1/4 cup yogurt - keep mixture at 90 - 110 degrees for 5 hours - chill to make firmer.	2. Instructions consist of step procedures wherein subsequent phases presuppose correctness of earlier phases. Three essential steps are given.
3. Because of recipe's simplicity, S assumed she could remember recipe - tried it 10 days later.	3. Instructions seem simple to S; therefore she committed them to memory and attempted to execute procedure 10 days later.
4. S adds 1/4 cup to 1/2 gallon milk - puts in oven at 110 degrees - made mental note for end of 5 hours.	4. S begins to follow procedure, executes first step, and proceeds to second step.
5. S checks mixture occasionally, but does not get past soupy mixture even after 5 hours.	5. Second step of process does not meet S's expectations.
6. S impatient and unsure - therefore decided on next step - mixture only chilled but did not thicken.	6. Second step still does not meet S's expectations. S then moves on to the third step hoping that it may come out correctly anyway.
7. S decides something is wrong.	7. Third step of process seems not to help, thus S continues to have doubts about correctness

	of procedure and decides that there is an "error somewhere".
8. S searches for possible errors: distinguishes between 5 hours in oven and 5 hours heating at 90 - 110 degrees plus notes fact that mixture starts cold.	8. Reflection on procedures uncovers "a lived ambiguity" - S now realizes a crucial distinction where previously she assumed a univocal meaning. S specifically aims for more fitting interpretation ... in procedure.
9. S adds another 1/4 cup of yogurt in case old culture died and puts mixture in oven for 10 hours.	9. Because of error S spontaneously modified procedure "to be sure" and follows clarified second step.
10. Mixture becomes yogurt and then thickens in refrigerator.	10. Process is successful (Giorgi, 1985: 54, 55).

Specific Description of Situated Structure of Learning

A learning situation begins when S attempting to follow a procedure involving steps never before carried out by her, discovers that the execution of the steps does not meet her expectations. S decides therefore that an error was made and reflection on her procedure shows that the second step, apparently clear, involved a "lived ambiguity". Her reflection distinguishes two meanings of the lived ambiguity, and proceeding according to what S believed to be a clarified, proper interpretation of the second step enables S to achieve her intention ... (Giorgi, 1985: 56).

General Description of Situated Structure of Learning

Learning is the acquisition of knowledge concerning, and the actual execution of, as well as the belief in one's ability to execute on one's own, on demand, a progressive steplike procedure which initially involved the clarification through the mediation of others, of ambiguously lived-through moments on account of lack of knowledge or wrongly posited assumptions (Giorgi, 1985: 56).

The final step of phenomenological analysis aims at integrating the various descriptions of the situated structure of the experiences (ideographic analyses) to provide a synthesis of the meanings and essences of the experience (nomothetic analysis). The three excerpts of nomothetic analyses that follow show different approaches to this task and demonstrate the range of application of phenomenological research. The first is Yoder's (1990) description of her co-researchers *experience of guilt*, the second is Aanstoos' (1985) depiction of the general structure of *thinking in chess*, and the final one is Rhodes' (1987) account of *women's movement from dependency to autonomy.*

> Feelings of guilt are signs of significant turbulence, flaring up within the person. They come like a storm with lightening and cold winds ... guilt feelings close in. They are an imprisonment in which there is no way out ... The feeling of guilt is sharp and jagged. It is "being on the hook", a "knife", a pain as sharp as a surgical incision. The feeling of guilt is fast ... guilt feelings are "a heavy weight". They are experienced as a "crushing blow". The feeling of guilt pushes, removes, evokes withdrawal, a sinking enormously heavy feeling. It comes in waves ... (Yoder, 1990: 111 - 114, quoted in Moustakas, 1994: 144).

> Thinking as it is exemplified during chess playing is a process of discovering and making explicit certain implicit possibilities that are taken by the thinker to be present in the position. These possibilities are experienced as dynamic currents of force, avenues of virtual action that hold the ambiguous promise of transforming the position. This effort of making such possible transformations explicit is therefore essentially telic in the sense that the aim is to achieve a favorable transformation of the position within the overall aim of winning the game. Thinking concerns itself with these possibilities in three ways: by taking them as questions, by characterizing them as possibilities in their own specificity, and by determining their pragmatic appropriateness to the context of the game. In doing so, thinking thematizes the relation of these possibilities to the position as a whole. In other words, thinking grasps this relational unity through the way that it is implied by the possibilities. This relational unity is itself a network of implications, with both temporal and spatial references to further possibilities. Temporally, it implies relations between past, present and future moves. Spatially, it implies relations between pieces on the board. Thinking grasps this relational unity from the particular perspective of the player, illuminating only those aspects of it that appear as relevant from that point of view. The specific means by which thinking determines the implicitory significance of its possibles is by grasping their if - then relations within the larger referential unity of the position. (Aanstoos, 1985: 94).

> The movement of women in an intimate relationship from dependency to autonomy is characterized by distinctive qualities in each of these major transition periods. Of particular importance in the dependency phase is the woman's sense of her self. To the degree that it is determined by her mate's priorities (experiences as an inferior part of a larger whole, which would include the culture and the marital system), the woman's identity becomes subservient to that of her husband. The women in this study started marriage believing that they were expected to take care of the home, the children and their husbands. In turn, they would be financially supported and emotionally and sexually rewarded by their mates. Self-esteem would be experienced vicariously through the successes of the husband. The submerging of the self into that of the male and the family was the common adaptation, however varied were the particulars ... (Rhodes, 1987: 119-128, quoted in Moustakas, 1994:146).

A rich source showing the range of applications - as well as the development of theory - of phenomenological research are the four volumes of the *Duquesne Studies in Phenomenological Psychology* (Volumes 1: Giorgi, Fisher, and von Eckartsberg, 1971; 2: Giorgi, Fisher, and Murray, 1975; 3: Giorgi et al., 1979; 4: Giorgi, Barton, and Maes, 1983). Recent doctoral dissertations using phenomenological analysis in the field of health care include: Brykczynski (1985), Haberman-Little (1993), MacLeod (1990), Madjar (1991), Schilder (1986), Stuhlmiller (1991), and Wnos (1993).

STUDY DESIGN AND RESEARCH PROCEDURE

The analytic techniques I used in this study were based primarily on Giorgi's (1979) outline of his phenomenological-psychological method of analysis (as cited above) and elaborated by Aanstoos, Fisher, Giorgi, and Wertz (Giorgi, ed., 1985). My application of these techniques was influenced by van Kaam (1959, 1966) and Moustakas (1994) who developed similar methods of analysis and by Benner, et al. (Benner, ed., 1994) who applied phenomenological analyses in studies in the field of health care.

My research inquiry consisted of three separate but linked parts or phases: a *pilot study* at Hospice A from 12th to 15th of September 1995, a *focus group interview* at the same site on 1st October 1997, and the *follow-up study* at four different hospices in Britain (hospices A, B, C, and D) from 4th to 27th November 1997 (see Appendix 1).

The Pilot Study

The purpose of the pilot study was to explore the domain of palliative care work in order to identify one or more significant elements of this domain for further study (Weller and Romney, 1988: 9). My assumption was that a general exploration of the experiences of caregivers currently working in the field would uncover a number of significant issues or themes, one of which then could become the topic of the follow-up study. The primary aim thus of this phase of the investigation was *identification*:

> The aim of identification is one of the most neglected aspects of scientific inquiry. All too often, investigators create concepts based on some "gut" feeling, their own reasoning, or the literature. Then they produce measurement instruments that reify the concept, giving the appearance it really exists "out there". The result may be research that is powerful (minimal type 2 error) and minimizes false positives (type 1 error) but also may be solving the wrong problems (type 3 error) or solving a problem not worth solving (type 4 error). Qualitative field research, the documentary-historical style, and philosophical inquiry are ideally suited for the essential task of identification. (Crabtree and Miller, 1992: 6).

The choice of the most appropriate research strategy in a particular study is generally determined by the *focus* of the study: philosophical inquiry focuses primarily on ideas or concepts, documentary-historical research on artefacts, and qualitative field research on the "human field" (Crabtree and Miller, 1992: 4). The "human field" of palliative care thus is best investigated using the qualitative field research approach.

The two basic data collection techniques used in qualitative field research are *observation* (unstructured, structured, or participant) and *in-depth interviewing*. The first technique is generally employed when behaviours and the meanings attached to them are the focus of the research, while in-depth interviewing usually seeks to "uncover the participant's meaning perspective" (Marshall and Rossman, 1989: 82) on a selected topic. The decision whether to use observation or in-depth interviewing as the principal data collection strategy in the pilot study was guided by the discussion of the strengths and weaknesses of data collection techniques by Marshall and Rossman (1989: 101-110), and by Crabtree and Miller's (1992: 17) observation that "many nurses and family physicians eagerly share information in the form of explanatory talk. Whenever two or more gather, they usually seize the opportunity to share experiences, puzzlements, insights, and frustrations. Interviewing works well with family doctors and nurses."

Populations and Sample

The population for the pilot study comprised ten caregivers at one hospice in Britain. The selection of the participants was *purposive*: the selection process aimed at *maximum variation within one setting* in order to obtain the broadest range of perspectives:

> The naturalist is likely to eschew random or representative sampling in favour of purposive or theoretical sampling because he or she thereby increases the scope of the range of data exposed (random or representative sampling is likely to suppress more deviant cases) as well as the likelihood that a full array of multiple realities will be uncovered (Lincoln and Guba, 1985: 40).

The participants came from different disciplines and backgrounds (hospice nurse, Macmillan home care nurses, hospice doctor, chaplain, social worker, volunteer, secretary, manager) and they ranged in age from the mid-thirties to the mid-seventies. All had extensive (i.e. years) experience in palliative/hospice care work.

Sample Characteristics

Seven of the participants were female and three were male. Their age, as mentioned, ranged from the mid-thirties to the mid-seventies but most were in the middle-age group. None of them knew me, and none was paid for her or his participation in the study. All volunteered to participate during non-working hours (i.e. in their free time).

Procedure

Access to the site was gained through a co-ordinator who after several discussions with me selected and recruited the participants. I contacted each of them by mail, introducing myself, briefly describing the pilot study (see Appendix 1), and enclosing two copies of a *Standard Ethics Protocol* (see Appendix 1) that stated the rights of the participants and assured them of confidentiality. Times and dates of our meetings were arranged by the co-ordinator.

Each participant was interviewed individually and face-to-face. The interviews lasted for approximately one hour each. All interviews took place at a seminar room at the hospice with only the participant and I present.

In keeping with the primary aim of this phase of the investigation, I used *unstructured interviews*: "Unstructured interviews are so labelled because the interviewer does not enter the interview setting with a planned sequence of questions that he will be asking the respondent. The objective of the unstructured interview is to surface some preliminary issues so that the researcher can formulate a good idea of what variables need further in-depth investigation (Sekaran, 1992: 190). I followed suggestions by Johnson (1990), McCracken (1988), Kuzel (1992), Gilchrist (1992), and Kvale (1996) in preparing for and conducting the interviews. The overall objective was to elicit testimony "in as an unobtrusive, nondirective manner as possible (McCracken, 1988: 21). I had no conscious expectations or preconceived ideas on the nature of the data generated in the interviews. No hypotheses were presented or tested, no instructions were given by me, and no attempt was made to direct or focus the inquiry on any particular issue or theme.

All interviews were recorded on tape and a verbatim transcript of each was made. A research assistant transcribed the recordings and I then compared these typed protocols with the testimonies on tape in order to check for any errors or discrepancies and corrected them where necessary.

Data Analysis

The decision on the type of data analysis strategy most appropriate for the purpose of this phase of the study was made by me shortly after the interviews were completed and while the tapes were being transcribed. In general, the choice on what strategy to use in data analysis is influenced by the kind of research question, by the aim of the research, by what is already known about the topic, and by the data collection techniques employed (Crabtree and Miller, 1992: 20). The most important factor in this list, is the aim of the research. My aim in the pilot study was firstly to identify some core issues or themes of palliative care work and secondly to explore one or two of them to arrive at an initial subjective understanding: "When the goal is subjective understanding, exploration, and/or generation of new insights/hypotheses and when scant knowledge already exists, the more interpretative styles (of analysis) are preferable" (Crabtree and Miller, 1992: 20).

There are basically two "more interpretative" data analysis styles: The *editing analysis style* and the *immersion/crystallization style* (Crabtree and Miller, 1992: 18). The latter technique (exemplified, for instance, by Moustakas' (1990) *heuristic research* approach) requires that the researcher deeply immerses him- or herself into the text and the experience of the text in order to achieve an intuitive crystallization of it. Heuristic research involves a great deal of self-reflection and intensive inner searching by the researcher and it entails that "the researcher ..., in addition to narrative descriptions, seeks to obtain self-dialogues, stories, poems, artwork, journals, and diaries, and other personal documents that *depict* the experience" (Moustakas, 1994: 18).

Since I considered this approach too subjective, intuitive, particular, and interpretative in regard to the aims of my inquiry, I chose the editing analysis style as a strategy. Giorgi's method of analysis (cited above) exemplifies this approach. I shall describe in detail how I applied this strategy in Chapter V (see also Appendix 2 for documentation).

The data analysis of the pilot study consisted of two parts or phases: 1. an analysis of the ten testimonies aimed at uncovering core issues or themes in palliative/hospice care work, and 2. an initial exploration of two of these core themes. The two core themes that were uncovered in the first phase of the analysis were: *the issue of dying and death of patients and the effect this has on the caregivers,* and secondly, *caregivers' relationships with patients and families in their care*. The initial explorations of phase two of the analysis then focused on these two aspects of palliative/hospice care work. I summarized the outcomes of these explorations in a paper (86 pages) which consisted of four parts: Part I focused on *the Relationship*

Experiences with Patients and Families, Part II on the consequences of these experiences for the caregivers (*Costs and Rewards)*, Part III on the experiences of patients and families confronting a life-threatening illness (*The Structure of the Situation)*, and Part IV on the attempt to integrate Part I to Part III (*The Structure of the Experience*). I also wrote a *Summary Report* (22 pages) of the pilot study and the outcomes.

The Focus Group Interview

After writing these papers, I sent each participant of the pilot study a copy of the summary report and asked her or him to participate in a focus group interview (see Appendix 1) as well as to complete a pre-questionnaire (see Appendix 3). Seven of the original ten members of the pilot study agreed to participate and completed the questionnaire. The co-ordinator of the pilot study acted as moderator for this interview which took place on October 1, 1997 in the seminar room at hospice A, and lasted for two hours.

The purpose of the focus group interview was to clarify, amplify, and explore the findings of the pilot study on the specific topic of *caregivers' relationships and communication with patients and families* which I chose for further investigation. I used the pre-questionnaire to direct and focus the discussion on the research topic (Morgan, 1997: 57) and asked the co-ordinator to adopt a low-moderator-involvement approach to the group meeting which is the preferred operational mode when the purpose of the research is exploratory (Morgan, 1997: 54). I was present during the interview as an observer and took notes but did not participate as a moderator or in the group discussion.

The focus group interview was audio-taped and transcribed (that is, the parts of the interview addressing the research topic. Unfortunately, the emphasis shifted at one point during the interview and the participants discussed the late Diana, Princess of Wales, for a considerable time. I provide the analysis and the outcomes of the interview in Chapter VI.

The Follow-Up Study

The focus group interview served as a preparation for the follow-up study. The analysis of the data generated in the questionnaires and interview allowed me to roughly "map the terrain" of the research topic and to identify some important themes and subthemes of the topic.

Population and Sample

The population of the follow-up study comprised caregivers at four hospices in Britain (see Appendix 1). As in the case of the pilot study, I chose purposive sampling to increase the scope of the range of data generated and to uncover multiple perspectives and experiences on the topic. A new group of participants was recruited at hospice A who did not participate in the pilot study and the focus group interview. The selection process in this study, as in the pilot study, aimed at maximum variation to obtain the broadest possible range of perspectives and experiences on the topic. I recruited a co-ordinator at each of the other sites (hospices B, C, D) who were informed in detail about the purpose of the study, the findings of the pilot study as well as the earlier selection process for participants. Each one of them, in turn, selected what they considered the most promising participants for the study.

Sample Characteristics

Twenty-six participants at four hospices in Britain participated in the follow-up study: Twenty-two of them were female and four were male. Their age ranged from the early twenties to the mid-sixties, most of them, however, were in their mid-thirties. The length of time they worked in palliative/hospice care also differed considerably (from eight months to twenty years) but the *average* time of work experience in this field was slightly above eight years (8.33 years). The participants came from a variety of disciplines and backgrounds: eight hospice staff nurses participated in the study, five home-care nurses, four physicians, three volunteers, three counsellors, and one of each of the following: matron, lecturer in palliative care, and hospice administrator. As in the case of the pilot study, none of the participants knew me, and none was paid for her or his participation. All volunteered to be interviewed during non-working hours.

Procedure

Access to the additional three sites was arranged with the help of the co-ordinator at hospice A, who provided me with the names of three physicians at different hospices who she thought might be interested in participating in the study. I contacted each of them by letter, stating the purpose of the study and enclosing a copy of the summary report of the pilot study. I also asked for an initial meeting to discuss the study and the arrangements for the interviews. All three responded positively and I met with them in October 1997 at the hospices where they worked.

Following our discussions, the four co-ordinators selected and recruited the participants of the follow-up study and arranged the dates and times for the interviews. I wrote to each participant, introduced myself briefly, explained the purpose of the study and their participation in it (see Appendix 1), and enclosed two copies of the *participant's release agreement* (see Appendix 1).

The results of the pilot study had convinced me that in-depth interviewing works well with the population under study and that it produces data of high quality ("rich descriptions"). Both considerations together made it an appropriate choice of data collection for the follow-up study. A total number of twenty-six interviews were conducted by me with each interview lasting approximately one hour. All interviews took place at seminar- or conference rooms at each site with only the participant and I present.

I decided not to structure the interviews by using an interview guide but to allow the participants to relate their experiences to me in a free-flowing, unstructured manner. The only structuring I used was the instruction (contained in the contact letter as well as expressed again by me at the start of each interview) to keep the focus during the interview on the research topic and on concrete, experiential data. As with the pilot study, no hypotheses were presented or tested, no other instructions were given by me, and no attempt was made to direct or focus the inquiry on any particular issue or theme of the research topic.

All interviews were audiotaped and a verbatim transcript of each was made. Transcribing procedures were the same as the ones used in the pilot study.

Data Analysis

The analysis of the twenty-six protocols followed the same steps as applied to the pilot data and described in detail in Chapter V (pilot study) and again in Chapter VIII (follow-up study). The findings of the follow-up study are presented in Chapters VIII and IX. In Chapter X, I present the nomothetic description of the investigated phenomenon which incorporates - in addition to the findings of Chapters VIII and IX - those of the pilot study and the focus group interview.

SUMMARY

This exploratory study of palliative caregivers' relationships with patients and families was designed as a field study using in-depth interviewing as the principal data collection method and - as an analytical technique - a phenomenological-psychological style of analysis. The research inquiry consisted of three separate but linked parts: a pilot study conducted at a hospice in Britain involving ten caregivers, a focus-group interview at the same site with seven of the original ten caregivers interviewed for the pilot study, and a follow-up study at four hospices in Britain involving twenty-six caregivers. The pilot study aimed at identifying one or more significant issues or themes of palliative carework to be further explored in the focus group interview and the follow-up study. The overall aim of this investigation was to produce a comprehensive qualitative description of the phenomenon under study. Before presenting the data and findings of this inquiry and the description based on them, I shall describe in the next two chapters the broader context in which the investigated phenomenon is embedded.

CHAPTER III

THE CONTEXTS

INTRODUCTION

Some of the recently published work on interpersonal relationships contain a note of warning about thinking simplistically about relationships (e.g. Wood, 1995; Mamali, 1996; Duck, 1993, 1998). It is simplistic, these authors argue, to think about relationships as being solely "private preserves" (Wood) or "personal constructions" (Duck) that involve only individual choices and emotions. All relationships are influenced by the values and norms, the constraints and opportunities of the specific contexts within which they develop (Mamali, 1996: 217). Contexts structure relationships through processes and circumstances beyond the control of those directly involved in the relationship (Duck, 1993: 4). To ignore the influence of contexts, to investigate relationships as if they were simply private affairs, these authors warn, is common but it reduces the validity of these investigations: "Attention to the ways in which contexts influence relationships is the exception to the trend to investigate relationships as if they were private preserves immune to the overall social order" (Wood, 1995: 114). This lack of attention and "attempts to focus explanations for relationship processes only on the inside of the relationships or the individual partners' choices and emotions" (Duck, 1998: 6) produce investigations which are "incomplete and limiting" (Duck, 1998: 6). Duck (1998: 4) summarized his argument as follows: "Sociological content, structural factors and social forces are ever-present houseguests in the ways in which we decide what is 'appropriate' in human relationships ... It is clear that simply *having* emotions (or simply *expressing* them naked and raw) is not all we need to understand about relationships: we need to think more about contexts."

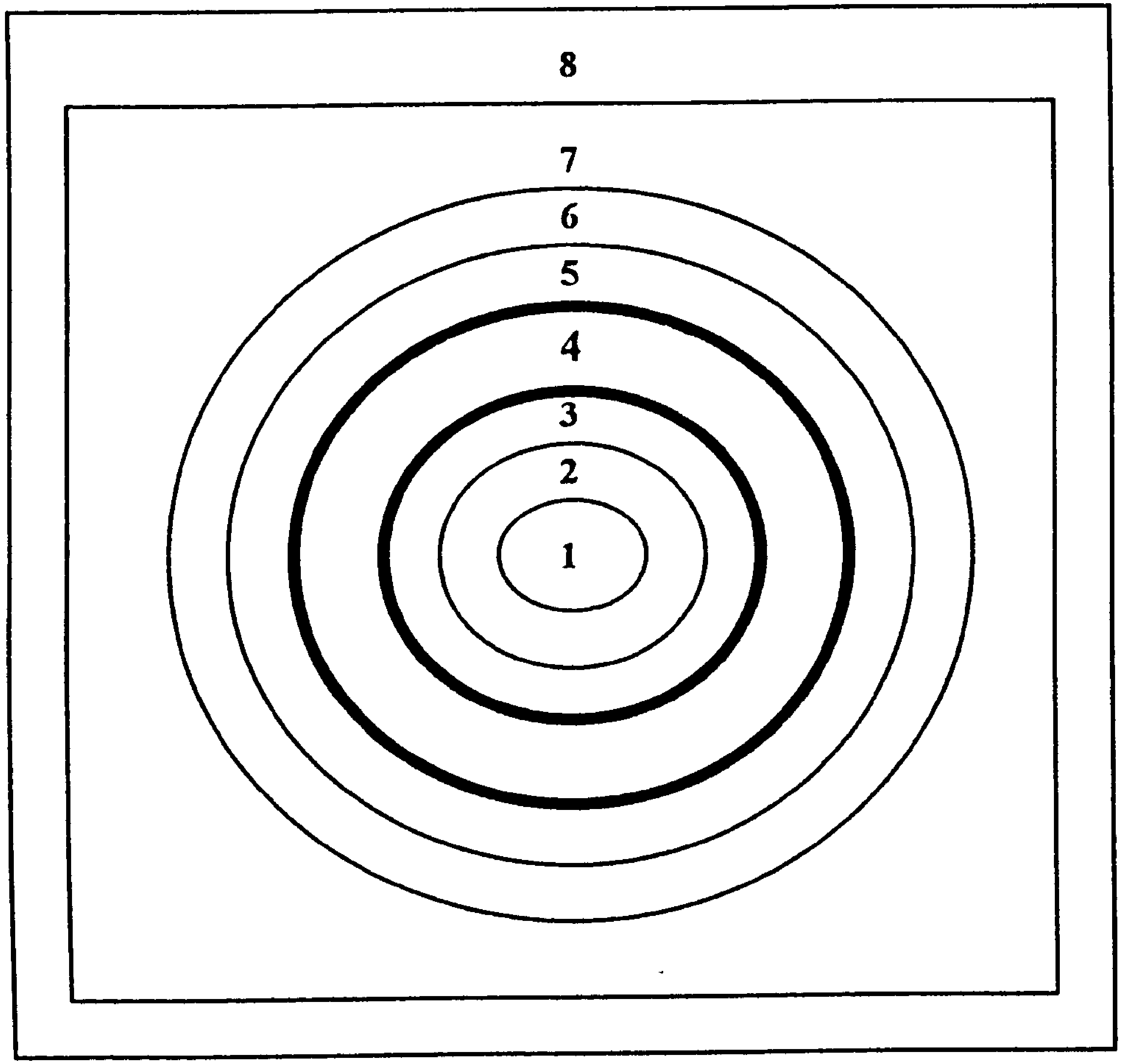
I think this is a valid and important point, especially in regard to the relationships investigated here. As noted in Chapter II, the domain of *caring*, in which these relationships develop, is considered highly context-dependent (Dunlop, 1994: 37). Since *caring* is conceptualized here not as a set of practices that can be operationalized in terms of context-free variables but as a "thinking-feeling mode of being" (Dunlop, 1994: 38), it stands to reason that the relationships developed in this domain are also context-dependent, and that the possible influences of these contexts should therefore not be ignored.

In this chapter I point out some likely influences of four major contexts on the way caregivers relate and communicate with patients and families in their care. I briefly describe each context, focusing on aspects most relevant to the topic of this investigation, and then discuss what impact these aspects may have on caregivers' communication with patients and families. Firstly, however, I introduce a conceptual framework for 'thinking about contexts'.

THE FRAMEWORK

What are contexts? *The Concise Oxford Dictionary of Current English (1996: 288)* provides a simple definition: Contexts are "... the circumstances relevant to something under consideration". The key word in this definition is "relevant": a *background* of something under consideration may or may not be relevant to the foreground or figure, but contexts are assumed to have definite relevance. In the case of interpersonal relationships, relevance may be defined as *being able to influence* or *having the power to influence*, that is, structure or shape relationships in particular ways; and contexts may be defined as particular sets of interrelated circumstances that have this ability or power. What are then some of the circumstances that may have a bearing on and influence interpersonal relationships? One could compile quite a list. Duck, for example, discussed the influence of social, sociological, and cultural circumstances on the development of relationships, and he suggested that "personal meaning systems", the media, "audiences for behaviour", nonverbal communication, language, and the physical environment are all factors that have an impact on human relating (Duck, 1998: 1-34). One can easily add to the list: individual psychological and physiological processes of each partner in a relationship, the behaviours and the interactions they engage in with each other, and the group their relationship is a part of may all have an influence on the relationship. Is there a way one can categorize these diverse factors? Is there a framework that could help one to think more systematically about the influences of these different circumstances on human relating and how they may be connected with each other?

One way to proceed is to return to Duck's (1998: 6) basic distinction between "the inside of a relationship" and what is not "inside", i.e. the outside or the contexts of a relationship. The inside of a relationship consists of the physiological, psychological, behavioural, and interactional factors of each partner in a relationship, of the "personal meaning systems" and verbal- and non-verbal communication. The outside of a relationship, the contexts, are the social, sociological, and cultural circumstances, the group or groups of which a particular relationship forms a part, and the physical environment or setting. Hinde (1996) conceptualized the interrelations between these groups of factors or sets of circumstances as "dialectical relations among levels of social complexity" (see Figure 1). Each level (or process) in this schema stands in dialectical relations with those on either side. This means, for example, that *interactions* have dialectical relations with both *relationships* and *individual behaviour*; or a *group* has dialectical relations with the *relationships* within it and with the *society* of which it is a part. Dialectical relations in this framework means "being influenced by" *and* "influencing", it is a two-way, dynamic relation and, according to Hinde (1996: 10-11), each of these levels has:



1. Intraindividual Systems
2. Individual Behaviour
3. Interactions
4. Relationships
5. Groups
6. Society
7. Socio-cultural Structure
8. Physical Environment

Figure 1
Dialectical Relations Among Levels of Social Complexity
(Adapted from Hinde, 1996, p.10)

> ... properties not relevant to the preceding level: for instance, the relationships within a group may be arranged hierarchically, centripetally, and so on, but these properties are irrelevant to a relationship. And each level has dialectical relations with those on either side. Thus the nature of the group both influences and is influenced by the relationships within it, and influences and is influenced by the society of which it forms part ... All the levels are to be thought of not as entities but as involving processes continually influenced by the dialectical relations between levels ... It is essential to remember the dynamic nature of the phenomena and the two-way relations between them.

The *physical environment* and the *sociocultural structure* are "special" levels in the sense that they influence and are influenced by *each* of the levels of social complexity (I have indicated this in Figure 1 by giving them a square shape) and not just by the ones bordering them. As Hinde (1996: 11) explains:

> ... we must also consider two further levels, though here "level" is being used in a somewhat different sense. One is the *physical environment*, which both influences and is influenced by each of the levels of social complexity so far mentioned. For instance, the interaction between a car driver and her companion may be affected by obstacles on the road, and the skill with which she manipulates the controls may be affected by her anxieties or hopes about their relationship. The other is the *sociocultural structure* ... it may both affect and be affected by each interaction, each relationship, and indeed all the levels of social complexity. For instance, the behaviour of a couple to each other will be influenced in part by local cultural conventions and values concerning how couples ought to behave; and how couples actually behave affects cultural conventions about how they should behave.

To summarize, a particular relationship directly affects and is affected by the interactions between the partners of the relationship as it is also directly affected by and affects the kind of group of which it is a part. In addition, this relationship is influenced by and influences the physical environment in which it is situated and by the sociocultural structure "... in the heads of the individuals concerned" (Hinde, 1996: 11). There are then four major contexts to consider which together make up the "outside" of a relationship: the group of which a particular relationship is a part, society which influences both the group and the sociocultural structure of the individual partners making up the relationship, the sociocultural structure itself, and the physical environment in which the relationship is situated. In regard to the relationships investigated here, I have limited my discussion of these contexts to certain but principal aspects: the particular *physical environment of hospices*, the current *philosophy of palliative care*, *society's* changing attitudes to dying and death, and the nature of *multidisciplinary workgroups* in which caregivers in this field work.

THE CONTEXTS

The Physical Environment

The idea that the physical environment of hospices should resemble as much as possible the home environment of patients has a long history. One Sister Lily, who visited St. Luke's Hospice several times between 1884 and 1923, described the physical environment she encountered as follows:

> Walls with wallpaper, pictures not confined to texts ... wards mostly of three beds, the largest with four, comfortable beds made up in pure linen and white counterpanes ... A bedside table covered with linen, with a vase of flowers, a dish of fruit or sweets, generally a treasured photograph and a few books, patients in flannel prettily made, their colour harmonizing with that of the room, basket chairs; piano, window boxes outside, plants and flowers inside (Coldin, quoted by Manning, 1984: 44).

A comfortable *home away from home* and, I imagine, for many patients at that time not just an alternative but a more pleasing alternative to home. The contrast between this description and the description of a contemporary hospital: "cold, naked, clean, half-workhouse and half-jail" (Coldin, quoted by Manning, 1984: 42) is striking. Others described the physical environment of St. Luke's as a "converted house", with "low, red-tiled passages and corridors", "broad-beamed roof" and "pleasantly coloured wards and rooms" (Manning, 1984: 44).

This vision of a hospice as a home away from home stayed very much alive. Here is how Manning (1984: 120), an American journalist, described St. Joseph's in Hackney: "The gates to St. Joseph's hospice open into a busy East London road. The roar of traffic thundered around me as I walked toward the main entrance. The stillness was breathtaking and I stood gazing at the very deliberate serenity of the blue shutters, the sparkling picture windows revealing hanging plants. Flower boxes, brilliantly full of colour, tipped over the balconies. The place was full of life and I almost forgot, as I walked through the doorway, that this was a hospice ...". And next is the description of her impression of Helen House in Oxford (Manning 1984: 132-133), a hospice designed exclusively for children:

> As I walked through the wide blue gates into the beautiful grounds of All Saints Convent, where Helen House is situated, the sound of laughter greeted me ... The buildings and grounds looked pampered and well cared for. Inside, a sense of purpose and direction was reflected in the deliberate colour scheme. Sparkling white walls highlighted by red door handles and trimmings, a rainbow of bright primary colours made me feel somehow *defined* - comfortable and relaxed. The padded red sofas in the reception area were smaller than average, in fact almost child-size. The scale of furniture, even here, was designed more for small people; every effort was being made to make them feel at home. After all, it was *their* place. Wonderfully coloured patchwork cushions were scattered randomly on the chairs and a quite stunning wall hanging caught the light as it slid up the staircase. The sense of well-being and happiness in the air was almost tangible and for a moment I quite forgot where I was. I felt as though I was in a home, not a hospice.

The physical environments of the hospices I visited during this study can be described in a very similar way: some are converted large houses, others are, or seem to be, specially built and both types are usually situated in quiet residential areas well back from busy roads. Grounds, lawns, and gardens appear to be carefully landscaped and are well cared for; the interiors of the buildings are comfortably furnished and pleasing to the eye, with pleasant colour schemes and plenty of open spaces. It is indeed easy to "almost forget" when first entering these environments that one is in "the house of death", as some of the residents in the communities where the research was conducted, call the hospice. Many visitors and many volunteers, trainees, and new staff who have never been to or worked in a hospice are surprised, often astonished, by these settings. And so are, I imagine, many patients and their relatives. The physical environments of hospices still differ considerably from the physical environments of most hospitals, and they are purposely designed that way:

> The fourth priority is that a hospice is built on a human and residential scale, as much like home as possible. The multi-storey impersonal concrete hospital structure which makes a person feel like the 'gall bladder in 906' or the 'ovarian cyst in 623' is not the ideal environment for relaxation and meditation. Privacy is too easily defined in a hospital setting as isolation, but this is never the goal in a hospice setting where everything is kept in the open, rooms are spacious and bright, energy positive and constructive. The hospice aims to make a *person* feel larger than the walls that enclose him and, like the early medieval hospices, his spirit is encouraged to expand and fill the space. Rather than feeling like a stranger and outsider, the patient is encouraged to feel at home - welcome and comfortable (Manning, 1984: 47 - 48).

There is evidence from research in the field of environmental psychology that supports the notion that people respond positively to environments they perceive as comfortable, pleasing, and tranquil (see, for instance, Bell, Fisher and Loomis, 1978). In the case of interpersonal relating, environments thus perceived tend to enhance people's inclination and willingness to communicate with others, and they also appear to have an effect on the quality and outcome of these communications:

> ... The spaces *within* the larger structures begin to direct the action patterns of humans; they begin to dictate mode and frequency of

> communication - on all its levels ... There is an abundance of evidence to support the contention that *where* one confronts a communicative venture is as telling to the final outcome as on *what subject* and *from whom* ... Are not people inclined to communicate more freely and at greater length when time and place seem more appropriate? ... Very often, too often, the communicator contradicts or compromises the act of sharing by offering it in an atmosphere which carries an impression of carelessness, friction, insincerity and indifference, which the listener reads as a *true* representation of the speaker's thoughts and feelings (LaRusso, 1977: 127, 128).

Communication, of course, is an integral part of interpersonal relating and so whatever facilitates the free flow of communication, facilitates the development of relationships.

To summarize, the physical environments of hospices affect the relationships investigated here by creating a particular atmosphere that is generally perceived by those making up these relationships as tranquil, open, harmonious, and welcoming. Environments thus perceived tend to enhance a person's inclination and willingness to communicate, they affect the mode and frequency of communicating, and they facilitate "the act of sharing" (LaRusso, 1977: 128).

The Sociocultural Structure

Patients who enter a hospice or who are in regular contact with home care teams encounter a particular sociocultural structure that is as distinct as the physical environment of hospices. Hinde (1996: 11) defined sociocultural structure as a "system of beliefs, values, myths, conventions, institutions with their constituent roles, and so on" which "resides in the heads of the individuals concerned". Some of these beliefs, values, conventions, etc. are shared by all members of a particular society, some by certain groups within this society, and some just by particular dyads. The components of the sociocultural structure merge with the beliefs, values, and myths idiosyncratic to individuals and "it is because the various elements of such a system may influence each other that we refer to the sociocultural *structure*" (Hinde, 1996: 11).

One aspect of the sociocultural structure shared by palliative caregivers is the *philosophy of palliative care* and how this philosophy should be translated into the actual day-to-day practice of caring for the terminally ill. It has been said, in fact, that "*hospice is primarily a philosophy, not a facility*. It is an approach to the giving of care, rather than a place in which services are offered" (Corr and Corr, 1983: xi). Maison Michel Sarrazin (1982) outlined this philosophy in a brief and concise way:

> 1. A person is an energetic entity which expresses its vitality in various ways; physically, emotionally, mentally and spiritually.
> 2. Death is a stage in the process of personal growth, just like birth, childhood, adolescence, adulthood and old age.
> 3. The dying person is a man (or woman) living through the last stage of his human condition. During this stage LIFE offers him a last chance to grow and integrate every dimension of his existence, to become more human.
> 4. The work of a multidisciplinary team, composed of professional and volunteer members, is required to help express and implement all the various needs of these cancer patients and their families.
> 5. The spirit which gives vigour and meaning to the work of the team is based on the principle that one is responsible for one's life, and that one needs other people in order to grow and fulfil one's destiny.
> 6. When the survival of the patient has become impossible, all personnel have only one objective in mind: to improve the quality of the life left in the patient, by relieving the 'total pain' and by a better preparation for death (quoted by Manning, 1984: 49 - 50).

Sarrazin also outlined three basic *principles of caring* based on this philosophy: 1. Respecting the dignity of the person: "It gives him the possibility of living out his own death. This dignity in death gives the possibility of alleviating pain, being cared for in a human atmosphere and environment and choosing, to a certain degree, the conditions of life during this terminal stage" (Sarrazin, 1982, quoted in

Manning, 1984: 50); 2. Telling the truth: "By being told the truth, he gets all the information about his own state. By telling the whole truth while caring for the dying person, he gets an answer to all his questions and can truly live out his own reality. This will allow him to live his own life to the full, up to the final conclusion" (Sarrazin, 1982, quoted by Manning, 1984: 50); 3. Having respect for the whole person: "This will urge people to consider the patient living through this dramatic moment as a complete person, and consequently to respect his choices, his means of expression, his reactions, and his physical and moral integrity. By respecting the dying patient, one respects and considers him as a fully fledged human being" (Sarrazin, 1982, quoted by Manning, 1984: 50).

One of the ways in which this philosophy of caring is passed on to individual caregivers in the field is through a holistic education in working with terminal patients. Education is considered an essential component of good hospice care and many educational- and training programmes are on offer to caregivers. Most hospices in Britain have study centres and libraries, and many run their own staff training programmes. A number of teaching hospitals also offer courses on death and dying as part of their student curriculum. The courses and training programmes on offer range from a brief introduction to the subject of dying and death to in-depth lectures on symptom- and pain control; from intensive explorations of students' feelings about cancer, altered body image, pain, loss, and dying patients to training sessions aimed at increasing students' awareness of the particular needs of terminally ill patients and their families. At a European Conference on Palliative Care (12 and 13 November 1992) organized by the *Cancer Relief Macmillan Fund* on behalf of the *Department of Health* the following recommendations for education and training were put forward:

> 1. Palliative care should be part of the formal teaching programme for health officials. Additionally many other groups in society would also benefit from learning about palliative care, for example, the police, porters and domestics.

> 2. Ideally there should be a multi-disciplinary approach to training in this area, that is doctor and nurses in the same training group, although it was recognized that initially there might be some resistance.
> 3. Palliative care should be a substantial component in a health professional's training, not a half-day in a five-year-course!
> 4. In order for this approach to care to be put into practice, there has to be more than bottom-up education. Those in positions of power must also be educated.
> 5. There should be a balance between practice and theory in any training programme. Opportunities for supervised practice should be incorporated into the training (Griffin, 1993: 59).

One can see from these recommendations that education and training is considered essential to the delivery of high quality palliative care. One crucial aspect of these education- and training programmes is communication. As quoted earlier: "Communication is of course the key to this (interprofessional education); listening and sharing are important. We also have to be aware of nonverbal communication and how we communicate in that way ourselves. There is undoubtedly a ripple effect, showing how people interact. The ripple effect spreading from patients outward to families, friends and staff and returning back in again from the bank of the pool. Understanding this interaction is crucial in delivering high quality care" (Calman, 1993: 48). This view is accepted by most institutions and professionals in this field.

To summarize, one aspect of the current sociocultural structure that affects caregivers' relationships with patients and families is the evolving philosophy of palliative care which focuses on the potential (and responsibility) of individuals to develop and "become more human" (Sarrazin, 1982, quoted above) until the very end of their lives. One guiding principle of this philosophy is that "one needs other people in order to grow and fulfil one's destiny" (Sarrazin, 1982, quoted above). If other people are indispensable to personal growth and integration, communicating and relating with them become crucial tasks for those involved. For patients and families, the multidisciplinary team and its members are "the other people" with whom they are in regular and close contact during this last phase of someone's life. It is reasonable to assume that the caregivers involved, having been educated in and having to some extent internalized this philosophy, may feel like 'agents' of these principles and take on the required role. In order to act as agents and to fulfil the role, they *need* to establish relationships with those in their care.

Society

The evolution of a distinct philosophy of palliative care and its application to the practice of caring for the terminally ill is intimately linked with and reflects a recent shift in attitudes to dying and death in Western society. This shift was set in motion by a number of critical reactions to the circumstances in which many people died and how death was 'managed'. In the mid-twentieth century when these criticisms started, the 'management of death' was firmly in the hands of doctors and medical institutions who collectively developed and propagated a notion of death which was very different from the shared and accepted ideas of previous times. Callahan (1993: 30, 31) traced this development as follows:

> By the eighteenth century, life expectancies had begun their shift toward modern standards. They were accelerating still more rapidly by the end of the nineteenth century. The great cultural changes that took place during these centuries showed a move away from the idea of death as a fixed, collective destiny, to one that focused on the death of the isolated self, and from there to the death of the other, the loved one taken away amid grief and with a sense of enduring loss. Death soon ceased to be simple and familiar. The emergence of nineteenth-century rituals of dramatic mourning, of death pictured as the brutal snatching of the loved one from the unwilling grasp of family and friends, in one way carried on the tradition of death as a communal evil, destroying the fabric of human relationships. But in another way it also signalled a gradual shift to death as a more segregated personal and psychological event, first from the community at large to the family, and then, by the late twentieth century, taken out of the hands of families and put into those of doctors and medical institutions.

The transformation of the traditional ideas of death by modern medicine was based on the belief that technology had the power and ability to fundamentally alter man and nature,

> ... that medicine can, in its conquest of disease, remove the unpleasant, distressing *causes* of death, thus transmuting it from a condition to be feared to one that can be managed and tolerated. If death can be socially hidden, and medicine can remove its sting, then it can cease to be of consequence in the lives of individuals or society ... Death remodeled, domesticated, and camouflaged by medical technology. That way has been tried now for at least three or four decades. It is not working. Death has not been pleasingly remodeled or successfully domesticated. That is not the way death has turned out, not at all. Nor is there any good evidence that we will soon see such a nicely polished death (Callahan, 1993: 32).

It was this failure to domesticate death that lead to the critical reactions mentioned above. Three early landmarks of this development were Geoffrey Gorer's article "The Pornography of Death" in 1955, Ernest Becker's Pulitzer prize-winning book "The Denial of Death" in 1973, and Philippe Ariè's book "The Hour of Death", published in 1981.

The core of the medical notion of death, "technological brinkmanship", as Callahan (1993: 40) called it, was increasingly questioned and came under attack by "widespread complaints" (Callahan, 1993: 37), the work of Elisabeth Kubler-Ross, and the findings of numerous ethical- and legal committees. In the USA, this reaction in time gave birth to the *death-with-dignity* movement which attempted to reform existing conditions. Similar reform movements started in Europe. One aspect of this reform was to articulate patients' rights to reject life-extending medical care (if they so wished) by means of advanced directives ('living wills'). In addition to giving patients greater power of self-determination, these movements became instrumental in establishing hospice programmes (based on the pioneering work of Dame Cicely

Saunders in Britain) throughout the Western world. The hospice idea caught on, and by the beginning of the 1990's, 487 palliative/hospice care centres were operating in the European Community (Griffin, 1993: 12) and 1,874 in the USA (Callahan, 1993: 39). A recent aspect of the reform effort was the idea that medical staff and other professionals working with the terminally ill needed a special type of education and training which incorporated the evolving philosophy of the movement.

The death-with-dignity and similar movements, however, have not been as successful as had been anticipated; the effects of these reform efforts are "much, much less than anyone had hoped ... their effect on medical practice has been, at best, modest, and surely so in comparison with the early high expectations. They have made, and can increasingly make, important contributions to many individuals, but they are unlikely to more generally transform the way most of us will die" (Callahan, 1993: 38, 39). So the debate and "the search for a peaceful death" (the title of Callahan's book) continues. One of the outcomes of this continuing debate is a considerable increase in publications and other media output dealing with various aspects of the issue. While the high level of media involvement in this debate reflects a growing public interest in the issue, it simultaneously raises awareness of and stimulates debate in the community which all in turn affect the evolving philosophy of palliative care and its application to the practice of caring for the terminally ill.

To summarize, society affects relationships through both the influence it has on the sociocultural structure and on the groups which make up society. In case of the relationships discussed here, the reform movements have had and have a considerable influence on the philosophy of palliative care and its translation into practice. The spread of the hospice movement with its emphasis on special education and training was, as we have seen, one outcome of these reform efforts. The movements' aim to increase patients' power of self-determination has undoubtedly been beneficial. Patients today are generally better informed, know more about their rights, and are less hesitant to ask for or demand them as they used to. As a hospice nurse mentioned in the interview: *"Where we used to fight for them, they now fight for themselves"* (P 8). The less-than-hoped-for success of these movements and the continuing debate about dying and death in the community and in the media also have an impact on both caregivers and patients and thus on their relationships.

The Group

> The objectives of hospice care are: To relieve distressing symptoms, such as pain, nausea, etc., by effective medication. To establish relaxed and easy communication with the patient in order to dispel loneliness and to give opportunities for discussing the implications of the patient's condition. To provide social, emotional, psychological and spiritual support in accordance with the patient's needs. Total care includes the support of the family during the illness and continuing into the subsequent bereavement (Dr J. F. Hanratty, Medical Director, St. Joseph's Hospice, quoted in Manning, 1984: 7).

The means by which the objectives outlined by Dr Hanratty are aimed to be achieved and by which the philosophy of palliative care is aimed to be translated into practice are through the work of *multidisciplinary teams*. The concept of multidisciplinary team work may be called the essence of palliative care. Total care, it is reasoned, can be provided only if a mixture of professionals with a variety of skills and resources pool efforts and work together. A multidisciplinary team can consist of doctors, nurses, social workers, counsellors, chaplains, physiotherapists, occupational therapists, as well as volunteers. A patient thus may be visited by, and to some extent become involved with, up to "thirty professionals" (M) in the course of the illness. In actual practice the composition of palliative/hospice teams varies considerably:

> In the palliative care centres responding to the questionnaire the following team composition applied for both intramural and extramural teams. However, it was found that home care teams usually had fewer members drawn from a smaller number of professions.

> The minimum team was found to be comprised of doctors and nurses. Of the responding units 19 per cent were found to operate solely with doctors and nurses. It should be noted that these teams can work with very few staff, the survey found that 23 per cent of teams had three or less members.
>
> In addition to doctors and nurses, the profession most commonly represented in the teams are social workers, who featured in 118 teams (57 per cent) of the 208 surveyed. Followed by physiotherapists, who are involved in 108 teams (52 per cent). Sixty-six of the centres (32 per cent) had psychologists. Religious representatives were team members in 98 centres (47 per cent) (Griffin, 1993: 14).

While intramural teamwork in hospices developed rapidly in the 1970s, *home care- and hospital support teams* evolved during the 1980s. The initial focus on in-patient hospice care was broadened in order to provide hospice-quality care in other settings already involved in patient care: "In 1980 the Wilkes Report (Wilkes et al., 1980) recommended that further development should give priority to home care services ... in an effort to disseminate more widely the expertise which had been established in hospices. To a great extent recent developments in terminal care services have followed the Wilkes recommendation, with a rapid increase in domiciliary nursing services and hospital based support teams" (Lunt and Yardley, 1988: 1). Home care- and hospital support teams have since evolved and diversified and become a major part of palliative care.

In-patient- as well as home care teams meet regularly (usually once a week) to discuss and examine (or re-examine) patients' care programmes. During these meetings, members of the team are encouraged to express their feelings and explore the problems they encounter with particular patients. These meetings also serve to arrange reciprocal support among team members which is needed because working with terminally ill patients and their families is generally experienced as highly stressful

(Vachon, 1995; Dunne and Jenkins, 1992; Lunt and Yardley, 1988) and team support is one of the most commonly used coping strategies for caregivers in this field:

> Social support was identified early as being crucial in palliative care ... High levels of mental ill health in hospice nurses were ... found to be predicted by a lack of social support ... A professional caregiver's support system may change over time. While initially, family members and friends may be useful in helping the neophyte practitioner to debrief, over time, caregivers turn more to colleagues, who are more able to understand the specific stressors to which they are exposed (Vachon, 1995: 98).

Communication thus is a central aspect of team meetings (formal and informal ones) since it serves a number of different purposes: making decisions about patients' care programmes, expressing emotions, exploring problems, and giving and receiving social support. The importance of effective communication is underlined by research which indicates that team *communication problems* rate high as work environment stressors as reported by palliative caregivers:

> Team communication problems involve such factors as dealing with a lack of team stability, intergroup conflict, and intragroup conflict. Colleagues have been found to be both a major source of stress as well as a major stress reducer. Organizational factors, such as personality issues and team conflict, were more commonly reported stressors than were problems in dealing with patients and families and issues related to death and dying" (Vachon, 1995: 99,100).

In addition, two of the main objectives of hospice care, namely "to establish relaxed and easy communication with the patient in order to dispel loneliness and to give opportunities for discussing the implications of the patient's condition", and secondly "to provide social, emotional, psychological and spiritual support in accordance with the patient's needs" (Hanratty, quoted above) are sometimes difficult to achieve because of "communication problems". These were reported "when patients and family members came from a different social and cultural group from that of the caregiver, or when the value system of patients and families were different" (Vachon, 1995: 102) and they also occured when patients and families responded to the illness "in a way that differed from the norm" (Vachon, 1995: 102).

To summarize, the influence of multidisciplinary teams on individual caregivers' relationships with patients and families is significant: the need to work together effectively and to get along with each other in providing care requires that each team member internalizes to some extent the "spirit of the group". This is especially important because the work with terminally ill patients and their family members is generally experienced as highly stressful and the group is relied on to provide social support. Thus the overall aim of the group, to achieve the objectives of palliative care (*total care*), needs to become, to some extent at least, the aim of each group member. In order to achieve the objective of total care, constructive working relationships with patients and families will have to be developed as their co-operation is needed. It is reasonable to assume that each team member will work towards accomplishing this goal, or at least do her or his part in trying to accomplish it, and that the resulting relationships are affected by this effort.

SUMMARY

Wood (1995), Mamali (1996), and Duck (1993, 1998) have argued that interpersonal relationships should not be investigated as if they exist outside of the overall social and physical order because research that focuses only on the personal choices and emotions of those directly involved in relationships and ignore the larger contexts in which these relationships are embedded, is "incomplete" and "limiting" (Duck, 1998: 6). I think this holds true in the case of the relationships investigated here. For example, ignoring the way society influences (through the death-with-dignity movement, as an instance) the current notion of what kind of relationship is 'appropriate' in this context would considerably distort the description of these relationships. The same distortion may happen if the role which the philosophy of palliative care plays in the development of these relationships is not taken into consideration, or the influence of multidisciplinary work-groups on individual members. All these contexts have at least some impact on caregivers' ideas and ideal of what these relationships should be like and on how caregivers should conduct themselves in developing and maintaining these relationships.

Contexts are broadly defined here as those circumstances outside of the relationship but which may have a bearing on the relationship, that is, may have the ability and power to structure or shape it in some way that is outside of the control of those directly involved in the relationship. Hinde (1996) identified four sets of interrelated circumstances that can have an impact on interpersonal relationships: the physical environment in which a relationship is situated, the sociocultural structure particular to those involved in the relationship, society as a whole, and the group or groups of which a particular relationship is a part. Because of space, I have limited the discussion of these contexts to certain, but I think principal, aspects: palliative caregivers, like most of us, belong to more than one group at a time, society affects them in many ways that may have an influence on the way they relate with others, the sociocultural structure they adhere to consists of more than just a philosophy of caring, and the physical environment of hospices is only one of their environments. I have focused on these specific aspects of the four contexts because they are *most likely* to affect the way caregivers relate with the people in their care.

I return to the issues of communication raised in this chapter again in Chapter IX. Before presenting the results of this study, however, I shall describe one final 'set of circumstances' that probably has the greatest impact on the way caregivers relate and communicate with patients and families: the special *situation* of these patients and families in palliative care.

CHAPTER IV

THE SITUATION

INTRODUCTION

Whilst certain aspects of the physical environment, the sociocultural structure, society, and the multidisciplinary group undoubtedly influence the relationships discussed here, this influence may be subtle and indirect and may vary considerably amongst individual caregivers. The specific *situation* of patients and relatives in palliative care, however, has a direct and powerful affect on these relationships because a particular illness (cancer, for example) and the psychological reactions to this illness which determine the situation are at the core of these relationships. As a participant who is a lecturer in palliative care pointed out:

> What brings people together is going to be different in a terminal illness. There is that illness, which I think will be the focus of that relationship; at the back of your mind you are always forming a relationship knowing that the central point is the illness. In the cases that I can recall, the illness has always been the focus, the central point, anything else would come from that, with relatives, with the patient, it does, it's always that (W 3).

The situation patients and families find themselves in (sometimes find themselves *thrown in* without little prior warning) can, from a psychological viewpoint, be characterized as a *period of suffering and distress*: "... suffering is a common experience" during this time (Hinton, 1980: 229). Individually, the severity of suffering or degree of distress may vary considerably, as do the causes attributed to the suffering. The causes or attributions are not always only the "unpleasant physical symptoms" (Hinton, 1980: 232) most, but not all, patients experience during this time. The suffering of patients and their relatives may come from many sources or combinations of sources: the feeling of helplessness, the loss of control over one's life, a reduced social position due to the illness, apprehension over the quality of the remaining life, the anxious concern for the others involved in the situation, and the awareness that the illness may be fatal, that a life is about to end (Hinton, 1980: 227-243). But regardless from what sources the suffering may come, the experience of a life-threatening illness usually is a joint experience that involves other people in addition to the patient, and the suffering the situation brings with it is also jointly experienced. This is why the situation is called *the situation of patients* and *families:* "In many respects patients and relatives are the obverse and reverse of the same coin ... The dying person is the key individual, but the family is an integral part of the situation, particularily first-degree relatives" (Hinton, 1980: 234, 227).

In this chapter, I describe the situation of patients and families in palliative care from the viewpoint of a particular conceptual framework which focuses exclusively on the progressive inner changes often experienced by those involved in the situation. There are other viewpoints stressing other aspects of the experience, but for the topic under investigation here the psychological perspective chosen seems to be the most relevant. I also briefly discuss how these changes may affect the relationships with caregivers developed during this time. I begin by presenting some of the data from four interviews of the pilot study which show how caregivers in this field perceive this situation and what - for them - appear to be the most salient aspects of the experience of a life-threatening illness. The excerpts are from the interviews with a *social worker* (P 1), a *doctor* (P 5), a *nurse* (P 8), and a *chaplain* (P 10). The additional data presented in the section discussing the *relationships with caregivers* are also from the pilot study. The excerpts are - in addition to those from the *nurse (P8)* and the *chaplain (P10)* - from the interviews with a *bereavement service manager (P3), a senior nurse and executive manager (P7), a Macmillan nurse (P9), and a home care nurse (P6).*

THE EXPERIENCE OF A LIFE-THREATENING ILLNESS

Palliative caregivers are uniquely placed to provide an intimate description of the situation discussed here: they are in regular and close contact with many patients and families in this situation, they are witnesses to the changes and developments that typically occur during this time, and they are, to a large extent, an integral part of the unfolding situation while still remaining outside of it. How do they perceive the situation? Do they find commonalities in these experiences, common psychological responses in those involved?

The Social Worker

> The worst that can possibly happen to them is happening to them, they have a disease that is not only going to kill them but is very painful; people who are diagnosed as having cancer feel devastated and frightened; one cannot sort out the problems because death is what is going to happen and there is nothing that can be done about it; one cannot help the patients with what they are really frightened of or dreading: working with terminal patients becomes a question of containing the situation, of just being there to help people through, in this situation you are alone, nobody can come with you when you die, it is something you have to do on your own, it is very frightening (P 1).

The Doctor

> Many people live without any thought of dying and they are not prepared when suddenly something happens, and although they do have the ability to see and they deeply know that they are never secure, they do not think hard enough about what it means to them personally: it is difficult when people exercise their absolute right to enter upon the process of dying without any conviction of what they need to do and of what is going to await them, people should have the opportunity to prepare themselves, one wants them to find a sense of fulfilment which some of them are clearly lacking (P5).

The Nurse

> Very rarely do healthy people think about dying and death and the issues involved, most patients do not experience their illness as terminal, even if they cannot be cured, they can be made to feel as if they have no illness at all, and so normality re-enters their lives, patients who are resigned to dying when they come to the hospice are rare, most come in a fighting spirit [but] the prospect of death affects different people in different ways (P 8).

The Chaplain

> All sorts of things impinge [on patients and families], like the search for meaning: Why? is the big question that gets asked: why should this happen? Why should it come this way? Why should it happen at this time? Why should it happen to him or her?; [the peace of patients] may be disturbed by the whole question of "What is going to happen to me?" Which may be a question of the Here and Now or it could be: "What is going to happen to me when eventually I come to die?" Many of the patients that come here turn to religious thoughts and it is surprising how many do turn to talk about these things when they have not bothered about them for years and years; in a situation like this, one is asked all kinds of questions and one has to be prepared to answer questions about suffering, death, dying, life after death (P 10).

That "the prospect of death affects different people in different ways" (P 8) may well be true. It may well be that the subjective experience of one's own impending death is unique to each person. And, as P 8 also pointed out, one does not *have* to experience one's terminal illness as terminal, it is possible (perhaps even common in some situations) to circumvent the whole event (which is not necessarily the same as denying it). It is possible, for example, for me to psychologically transform my own death, *the death of myself*, into the *death of another* (for a discussion of this "strategy" see: Koestenbaum, 1971, *The Vitality of Death*). The *death of another*, that is, the death of a stranger with whom I have no personal connection, elicits a totally different set of responses in me than the *death of myself*. I may be shocked, outraged, or saddened by another person's death, or, more commonly, I may feel nothing at all. I can adopt a practical, distanced, even callous attitude to it. *The death of another* is simply one of the occurrences in the world for me to which I may respond to or not. Conversely, it is also possible for me to experience the *death of another* as my own death: a mother, for example, may experience the death of a loved child as the "death of herself" and her own subsequent death may simply become the *death of another*. Either way, however, means that I can *disown* my own death and consequently become largely indifferent to it, which is another way, in addition to the much written-and talked about *denial* strategy, "not to experience [my] illness as terminal even if [I] cannot be cured" (P 8) and certainly will soon be dead.

The other three statements quoted above (P 1, P 5, P 10), however, portray the situation as one where the prospect of imminent death is more or less *faced* not denied or disowned. Given the fact that at least some patients and families are able to do this at least some of the time, what then is the experience like for them? Are there common psychological responses that are typical if death is confronted? The statements suggest that the following responses are both shared and typical:

> The situation is perceived as extreme and potentially overwhelming (P 1);
>
> There is a lack of psychological preparation and no general strategy to deal with it (P 5);
>
> Intense feelings and emotions are associated with the experience (P 1);
>
> The experience may trigger a "search for meaning" (P 10).

Extreme and potentially overwhelming situations, for which people are unprepared and without strategies to deal with, which elicit intense feelings and emotions and often trigger a search for meaning are called *traumatic life-events* in the field of psychology (DSMIII, 1984: 248-251). Research suggests that the experiences of traumatic life-events, which in addition to life-threatening illnesses (e.g. cancer) include criminal victimisation (e.g. rape), natural disasters (e.g. earth quakes), serious accidents (e.g. air plane crashes), human-induced disasters (e.g. military combat), torture, and concentration camps engender similar responses in its victims (DSM III, 1984: 248-251). To see how in the case of facing a life-threatening illness these responses may develop, how they may interact, and how they may be integrated into a coherent conceptual framework, let me assume three specific situations:

1. The diagnosis of severe and acute somatic damage which requires full medical care;

2. Additional tests reveal the somatic damage as life-threatening;

3. During or after initial treatments a temporary stable condition is experienced without rapid improvement or further deterioration.

THE FRAMEWORK

In Figures 2, 3, and 4 the essential features of the framework are summarized. The framework is based on the work of Stone (1973) and Janoff-Bulman (1992).

Figure 2 depicts some major responses in the case where *severe and acute somatic damage has been diagnosed.* The diagnosis may trigger a *crisis.* A typical crisis experience has both a developmental and a psychological aspect. The development of a crisis usually progresses in four phases: 1. The occurrence of a precipitating event (in this case, the diagnosis), 2. the appraisal of the event as a serious threat, 3. an activation of coping strategies and personal resources brought into

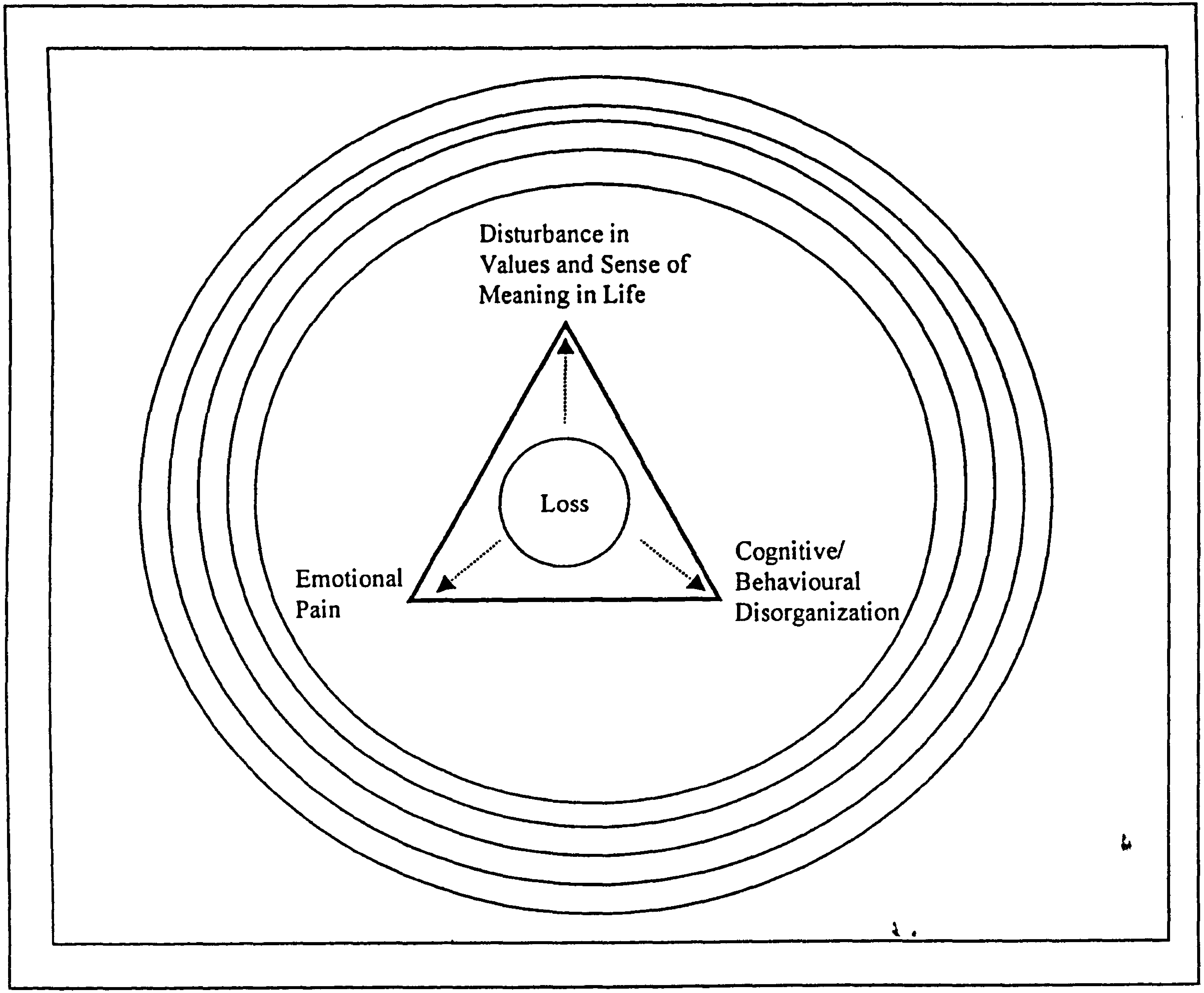


Figure 2
Structure of Crisis Experiences
(based on Stone, 1973, Crisis Counselling)

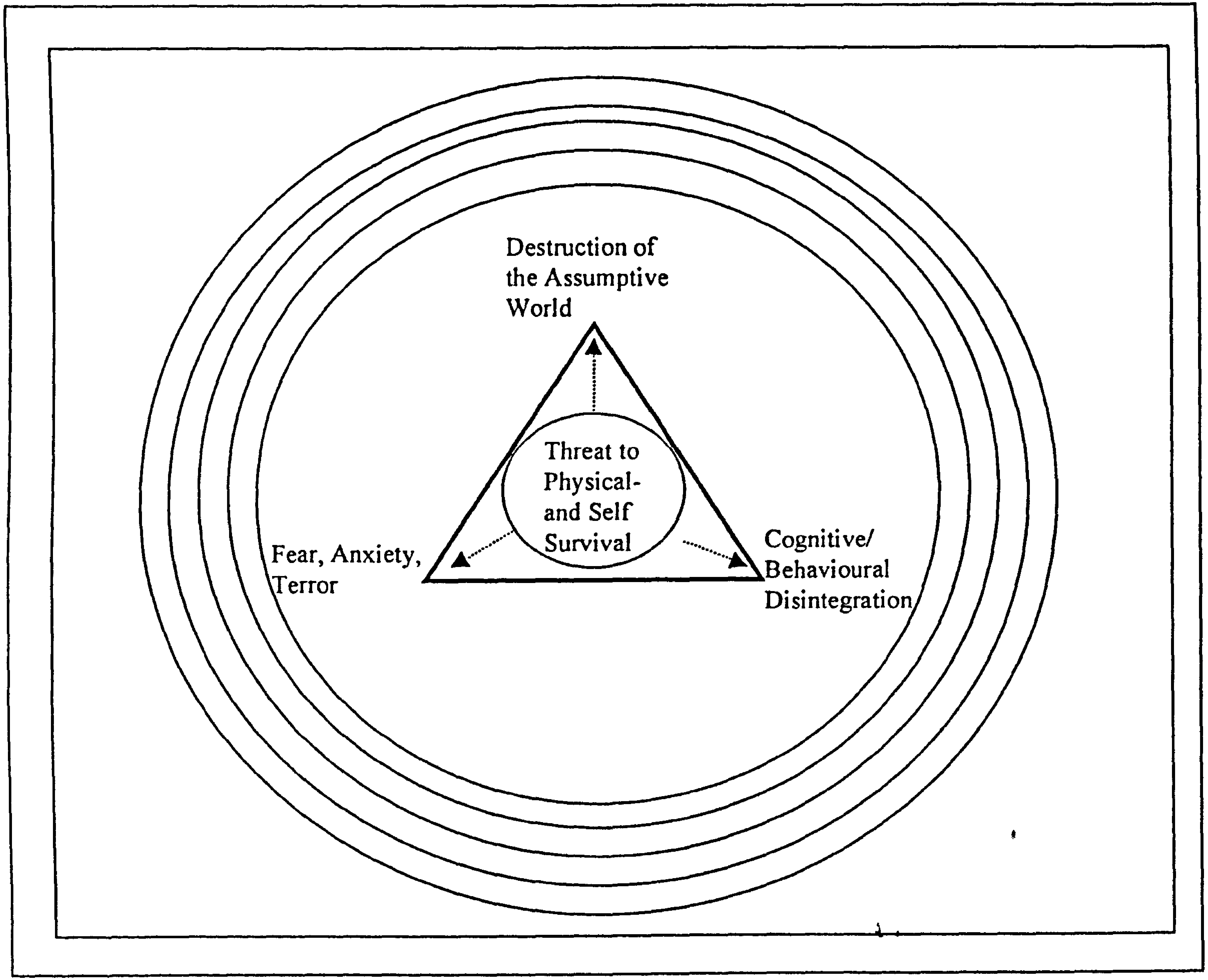


Figure 3
Structure of Traumatic Experiences
(Initial Phase)
(based on Janoff-Bulman, 1992, Shattered Assumptions: Towards a New Psychology of Trauma)

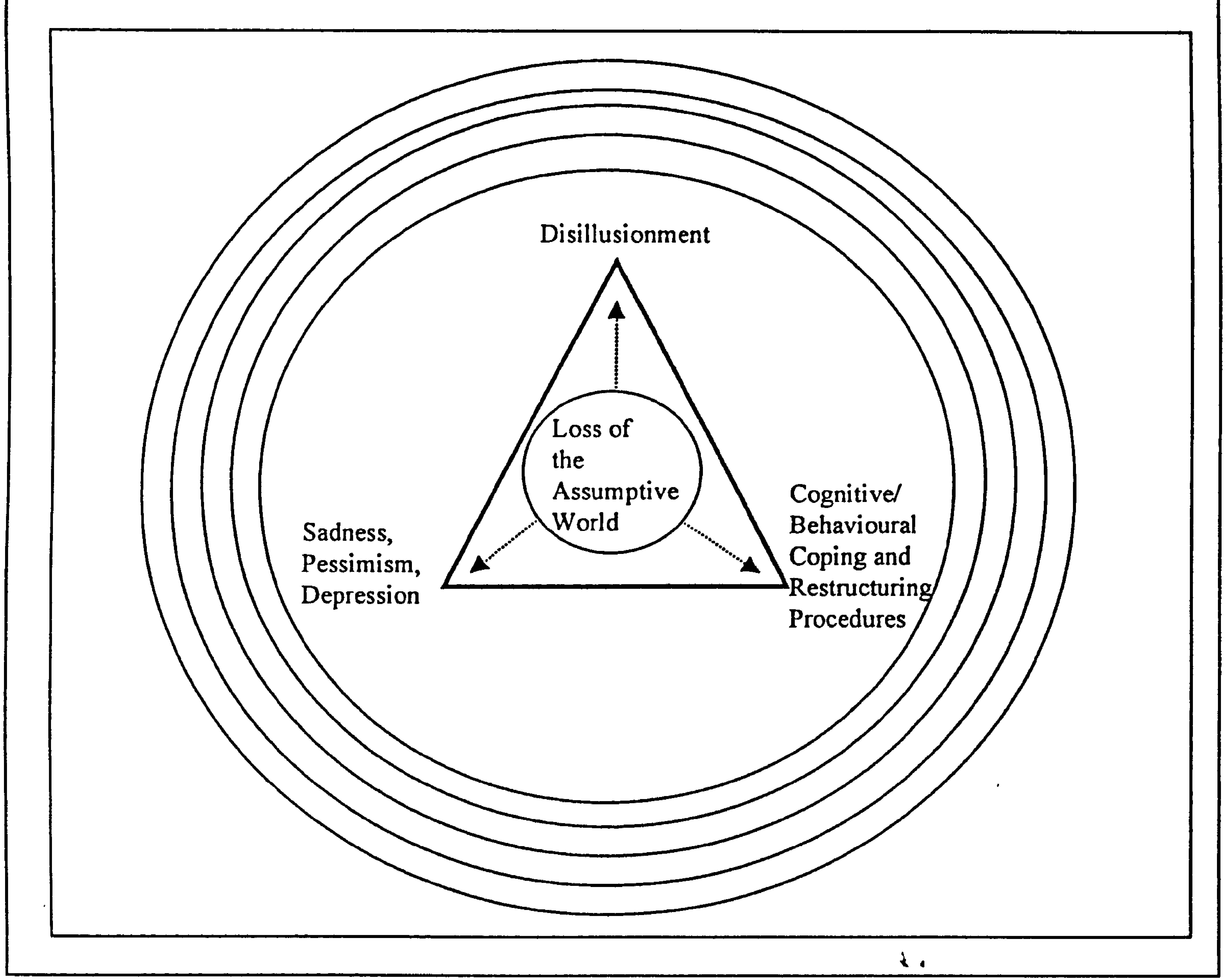


Figure 4
Structure of Traumatic Experiences
(Secondary Phase)
(based on Janoff-Bulman, 1992, Shattered Assumptions: Towards a New Psychology of Trauma).

play to reduce or eliminate the threat, and 4. the failure of this manoeuvre to resolve the threat. In phase 4, the person enters an *acute crisis* (Stone, 1973: 12-14). Figure 2 outlines the psychological aspects of an acute crisis: at the core of this experience is the occurrence of an event which is perceived as entailing a serious *loss* or *threat of loss* (in this case, the loss of health). The initial psychological reaction to the experience of loss is *shock*: the loss is experienced as a threat to existing self-structures that elicits intense feelings and emotions (*emotional pain*) and *cognitive/behavioural disorganization*. In an acute crisis, reality is perceived as overwhelming and a *disturbance in values and the sense of meaning in life* is experienced (Stone, 1973: p.14).

If additional tests reveal *the somatic damage as life-threatening*, the crisis may escalate and become a *traumatic life-event*. The psychological structure of this experience is delineated in Figure 3: At the core of the traumatic experience is the occurrence of an event which is perceived as entailing a *direct threat to physical- and self-survival* (the loss of life and self). The emotional responses and cognitive/ behavioural reactions induced by this threat are similar to but generally more intense than those of acute crises experiences. The "disturbance in values and the sense of meaning in life" experienced during an acute crisis may be intensified and result in the *destruction of the assumptive world* of the individual (Janoff-Bulman, 1992: 6).

The *assumptive world* of individuals consists of a number of abstract beliefs they hold about themselves, the external world, and the relationship between the two. These fundamental beliefs are the nucleus of a person's inner world. Janoff-Bulman (1992: 6) proposed that there are three such universal beliefs which together make up the core of our assumptive worlds: "The world is benevolent, the world is meaningful, and the self is worthy". The belief in a benevolent and meaningful world and in a worthy self, she argued, produces a general feeling of *confidence, trust,* and *invulnerability*. These core assumptions are rarely considered or examined during the normal course of events in people's lives. They seem to serve them well, providing them with the means of making sense of the world and for tackling new experiences with relative confidence. 'Normal' change is expected and accepted, but since it involves only gradual and incremental accommodation it is perceived as neither particularily threatening nor as particularily challenging. One feels generally secure, safe, and protected.

All this changes with the sudden onslaught of a traumatic life-event. The new data of the experience do not resemble the data known from the experiences of normal change: the experience is unique and powerfully threatening. Traumatic events are a massive assault on victims' core assumptions and they inflict injury to the inner world. All traumatic life-events entail a sudden and directly experienced threat to survival and self-preservation which forces victims into a dramatic confrontation with their own fragility (Janoff-Bulman, 1992: 53). The experience breaks through the barrier of cognitive conservatism and the complacency of the unquestioned assumptive world and induces a profound psychological crisis. The immediate reaction to the event is shock, disbelief, and confusion. The internal and external world is suddenly unfamiliar and threatening as the basic trust in these worlds is ruptured. The external world becomes a frightening place, made all the more frightening by a total lack of psychological preparation. The inner world is pervaded by thoughts and images representing *malevolence*, *meaninglessness*, and *self-abasement* (Janoff-Bulman, 1992: 53). The dominant emotions are intense fear and anxiety. "To experience a traumatic victimization is to powerfully, experientially confront mortality, danger, and our 'creatureliness'. The result is terror" (Janoff-Bulman, 1992: 61).

In a *temporary stable condition*, the early responses to the traumatic event may in time be joined by a new set of psychological responses which typically co-exist with them but often outlast them. Figure 4 shows the basic structure of this third phase: at the core of this experience is *the loss of the assumptive world*. The loss of old, deeply held beliefs about the world and the self engenders a *profound disillusionment* accompanied by feelings of *sadness, pessimism, and depression.* A wide range of *coping- and restructuring procedures* are then set in motion to reconstruct fundamental schemas and to re-establish a coherent set of basic assumptions:

> The coping task for survivors of traumatic life-events is that of reconstructing fundamental schemas in the face of psychological breakdown and cognitive emotional disintegration. The search for equilibrium involves efforts to re-establish a coherent set of basic assumptions following the shattering of the victim's old assumptive world (Janoff-Bulman, 1992: 90).

For some individuals this takes weeks, for others months or even years. In time, *if there is time*, the reconstructing processes will fundamentally change individuals: "In the end, their inner world is different from that of individuals who have not experienced an extremely negative life-event" (Janoff-Bulman, 1992: 90).

DISCUSSION

Three of the four palliative caregivers quoted at the beginning of this section described the situation of a life-threatening illness in terms which are identified in the psychological literature as that of a traumatic life-event. Research on traumatic life-events suggests that the experience has a common psychological structure, that is, it tends to engender similar responses in those involved. The framework outlined above attempts to integrate these responses and to show the progressive inner changes that may be experienced by those going through the event. Looking at Figures 2, 3, and 4, one can recognise the connection between each set of responses and the next and the overall progression which characterizes this experience. It is not simply that "things are getting worse", or that emotions are becoming more intense when an individual moves (or better, is moved) from a crisis into a traumatic life experience, but his or her whole inner life changes. This change may be more or less dramatic, more or less profound, but it is nevertheless a fundamental change resulting "in a different inner world" (Janoff-Bulman, 1992: 90).

Figures 2, 3, and 4 show the process through which this change may come about: cognitive/behavioural disorganization can turn into *disintegration* as the crisis becomes more severe, the initial experience of a disturbance in values and the sense of meaning in life can escalate and result in the *destruction of the assumptive world* of the individual, and emotions can intensify, moving from emotional pain to outright *terror*. The sense of loss that lies at the core of this psychological progression can be experienced as more and more *catastrophic* (P 5). Eventually, however, if there is time, these early reactions may successively be replaced by a new set of responses: the loss of the core beliefs and assumptions which have sustained the individual throughout his or her previous life's crises may be mourned (*sadness, pessimism, depression)* and a profound disillusionment may be experienced. But at the same time reconstructing efforts may be set in motion which aim at recreating the inner world and providing the individual with new guidelines for being-in-the-world.

One could view the scenario outlined here as the description of a *spiritual journey*: the death and rebirth of an individual ego or self. It is mostly a painful journey and resistance, retreat, and other defensive manoeuvres are commonly employed and are understandable. It is not inevitable that an individual transverses the whole terrain and completes the journey. There are choices here, and there may be a strong tendency to abscond or to disown the whole experience. One can deny what is happening, one can be terminally ill without experiencing the illness as terminal; one can distance oneself from what is happening, one can turn one's own death into the *death of another* and become largely indifferent to it. Adding to the difficulty of the journey is that it is essentially a *lonely* one, one has to do it on one's own: "In this situation, you are alone, nobody can come with you when you die, it is something you have to do on your own" (P 1) - yet, at the same time, perhaps paradoxically, one tends to be more open, more accessible, and less defensive in regard to others and much more grateful to [for] them: "I am often touched by the immense gratitude that [these] people seem to express for such small, such trifling little things" (P 10). Other people continue to *matter*, perhaps more so than ever before, and this has a direct bearing on the relationships formed with those who care for them.

RELATIONSHIP WITH CAREGIVERS

Stone (1976: 20) referred to the greater openness and accessibility of individuals going through an acute crisis as *heightened psychological accessibility* and he considered it to be the result of a "regression" to "primitive coping methods": "The more seriously threatening an individual's appraisal of an event, the more primitive or regressive his or her coping resources will be ... The result of this regression to primitive coping methods is increased suggestibility and diminished mistrust, leading to what is referred to as 'heightened psychological accessibility' " (Stone, 1976: 20). "Regression", in my view, may or may not result in a state of heightened psychological accessibility, and there may be other reasons which bring about this change, but regardless of what engenders it, it is a common experience for many practitioners that individuals experiencing a traumatic life-event are often less defensive, more open to outside help and assistance, and more vulnerable to interventions than they were previously. One can assume that this change will have an impact on how caregivers can and do relate with these individuals and on what kind of relationship they can develop with them. How do the participants of the pilot study experience their dealings with patients and families and how do they usually respond to them and the situation they are facing?

The Bereavement Service Manager

(formerly a home care sister)

> As a home care sister the job was very stressful, but the satisfaction that I had as a home-care sister was very different from any other job that I had ever encountered before. The satisfaction was working with families, was being open with people, drawing out feelings, sitting and listening, I find that very satisfying, but you absorb a lot of feelings, and afterwards you realize how stressful it is. But at the time, you find it very satisfying working with people (P 3).

The Senior Nurse / Executive Manager

> We are obviously dealing with patients and patients' families at a time when they are extremely vulnerable. And we are dealing with relatives at a time when they are being faced with the loss of somebody close to them. It is very few people, I think, who don't want to feel that they can be of help to others, I mean, very few people who totally isolate themselves. And I think if you do feel that you do want to help people, people at this time in their lives are very, very grateful for the help they get, and they are very appreciative of the help they get. It's a very personal time for them. And because we go in to them in the role we are in, they in many ways let us share part of this very difficult experience. And I think that to be allowed to, to be let into these situations, it's really very, very gratifying, because people shut out a lot of others, they don't talk to their friends, they don't talk to colleagues, they keep at bay. Whereas with us, it works in the opposite, they are quite willing to actually let us in and, as I said, let us share the situation with them (P 7).

The Macmillan Nurse

> [People] think you can't get any satisfaction because the end result is going to be death, people die anyway. They don't think of the process of going in, having the pleasure to give along the way. They don't see, you know, the period that you get. What we find is when we are put into a situation where we go in in the last couple of days, now that doesn't give you any satisfaction at all. You go in, the patient is in the terminal phase, and dies the next day. You don't get to know the situation, you don't get to know the family, and that I think is very stressful (P 9).

The Home Care Nurse

> I think I probably get far more out of this work then I put into it. Perhaps seeing people work through from the despair of diagnosis to an acceptance of what's happening to them, perhaps helping a couple who've been close all their lives and all of a sudden have a barrier between them in as much that they both know the diagnosis but aren't able to share it, and to get them back together and to hear the partner who is left, say that the last few weeks have been so precious, I mean that's where the joy comes, and perhaps seeing people rebuilding their lives after the death of a loved one, helping people achieve goals that they want, I think that's the positive side of it, and yes, I find it very rewarding. And it far outweighs the stressful side of it (P 6).

The Hospice Nurse

> I think sometimes we get more from [patients] than they get from us because they look to us for getting symptoms controlled but they teach us so much about life and death ... But people's perceptions, the general public's perception of this unit, is ... that it is very quiet, how can I explain, its dark but not in a lot of ways, you know, actually subdued, but you know, to walk around this unit [you] see patients laughing ... they actually live their lives, whereas you see so many healthy people not living their lives. What you find is that patients appear much more authentic, they will speak to you about their fears, about their feelings (P 8).

The Hospice Chaplain

> It has been a good thing to come here, you realize the more important things, I am often touched by the immense gratitude that people seem to express for such small, such trifling, little things; you know, this place locally gets the name of being a death house, and when the nurses come in, very often they are amazed, utterly amazed, they can't believe it, they can start laughing and the patients too, one teasing the other, and very quickly the sort of anxiety with which they first approached the place simply withers away (P 10).

These statements seem to confirm that a state of heightened psychological accessibility is not uncommon in this situation and that the greater openness and accessibility of both patients and some of the relatives 'allow' these caregivers to enter and to become part of the situation. To be allowed into the situation and share the situation are satisfying and rewarding experiences for them, just as it is stressful for them not to know the situation and the people involved. There was a consensus of opinion amongst the participants of the pilot study that, generally speaking, their work, although highly stressful at times, was rewarding, and that the rewards experienced outweigh the costs incurred. They also generally agreed that these rewards came *from the relationships themselves,* that is, it is the relationships with patients and families that make their work rewarding.

SUMMARY

From the psychological viewpoint adopted in this chapter, the situation of patients and families in palliative care can be characterized as a period of suffering brought about by the occurrence of a life-threatening illness and by the psychological reactions to the illness of those intimately involved in the situation. At the core of this suffering, it seems, lies the awareness that the illness may be fatal, that one's own life (or the life of someone one is close to) is about to end. The presence of this awareness implies that death is, to a greater or lesser extent, *faced,* not categorically denied or disowned by those involved in the situation. Facing imminent death can turn into a traumatic life event that sets in motion a psychological process which profoundly alters the individual's psychological make-up and strongly affects his or her interpersonal relationships.

Psychological research suggests that the process victims of traumatic life events go through engenders similar responses in them. The conceptual framework introduced in this chapter identifies what these responses are, how they develop, and how they are rooted in an everyday experience known to all of us: the experience of a crisis. What links a crisis experience to the experience of a traumatic life-event is the sense or feeling of *loss*: all loss or anticipated loss threatens an individual's existing self-structure by calling into question his or her core beliefs or assumptions. In living through a traumatic life event, where loss of life and self is confronted, the assumptive worlds of individuals may be annihilated and they may find themselves in a psychological and spiritual 'no-man's land' without any certainties at all. At this point in the process or journey, the individual reaches a cross-road where he or she may proceed in different directions: one may despair, one may think of or actually commit suicide, one may "allow oneself to die" (Baudrillard, 1990, about Barthes in *Cool Memories*), or one may, in one way or another, more or less consciously, go to work and reconstruct one's inner life by developing a new set of basic beliefs or assumptions. These new assumptions at the core of the inner world may be more realistic (in regard to life and the world) and more authentic (in regard to the self) than previous ones, but whether or not they are, the individual cannot but have changed.

According to Stone (1973), individuals going through this process tend to experience, at least at times, a state of heightened psychological accessibility. This state of greater vulnerability, openness, and accessibility to others has a facilitating affect on interpersonal relating. For those who provide the care and accompany these individuals, being a witness to and becoming involved to some extent in this process is a profound and deeply moving experience. Caregivers are *touched* by these experiences and they tend to respond to the situation and the people involved in a certain way that has an influence on how they relate with them. In the next chapter, which provides the analysis and results of the pilot study, I shall focus on this way of relating or being-in-the-relationship.

CHAPTER V

THE PILOT STUDY

INTRODUCTION

In this chapter I present the analysis and results of the pilot study which focused on exploring relationship experiences of palliative caregivers with patients and families in their care. The aim of this exploration was to identify and describe the essential elements or *invariant constituents* - on the caregivers' side - involved in these relationship experiences and how these elements interact to produce a particular psychological structure or *gestalt*. First, however, I describe how the data was analysed and provide the rationale for choosing *relating with patients and families* as the topic of this study.

DATA ANALYSIS

As explained in Chapter II, the purpose of the pilot study was 1. *to identify* (from the perspectives of caregivers currently working in the field) a core theme of palliative/hospice care work, and 2. *to explore* this theme in order to lay the groundwork for the follow-up study. The process of analysis broadly followed Giorgi's (1979: 83) procedural steps of "phenomenological analysis" and Moustakas' (1994: 118-122) "procedure of phenomenological analysis" (see Chapter II).

Phase I of the Analysis

The objective of the first phase of the analysis was the *identification of themes*. The transcribed interviews (*protocols*) were analysed in the following way:

1. Each of the ten protocols was read a number of times and the corresponding tape was listened to in order to become familiar with the experiences described in them; (for an example of such a protocol, see Document 1, Appendix 2);

2. next, each protocol was read more slowly and every time a shift or transition in the data was noted, the shift was demarcated directly in the protocol;

3. each block of data thus demarcated was scrutinized repeatedly in order to identify and name the particular theme involved;

4. the identified themes were written down on a separate list.

Phase II of the Analysis

The objective of the second phase of the analysis was the *identification of core themes*. Core themes are here defined as themes which tend to recur in each protocol and across protocols, which involve a number of significant issues for caregivers, and which have a noticeable impact on caregivers' life-worlds. Four protocols were randomly selected from the ten for this further analysis. The protocols thus selected were those of a *social worker (P1)*, a *hospice physician (P5)*, a *hospice staff nurse (P8)*, and a *hospice chaplain (P10)*. The analysis of these protocols was continued in the following way:

5. the *meaning units* (for examples of "meaning units" see Document 2, Appendix 2) corresponding to each identified theme were "extracted" from each protocol and placed in the left-hand column of a new document (see Document 2, Appendix 2). The meaning unit was expressed as closely as possible in the participant's language;

6. in the right-hand column of this document I attempted to make the meaning unit more explicit by expressing the content more directly and in more general terms (see Document 2, Appendix 2);

7. the meaning units identified in each of these protocols were then grouped according to their related content into three categories: 1. *themes*, 2. *issues* derived from the themes, and 3. the themes' *impact* on the participant's life-world (see Document 3, Appendix 2);

8. the *themes-issues-impact* lists were scrutinized repeatedly and compared with the list of themes written down in phase I of the analysis in order to determine what themes could be designated as *core* themes and what kind of interrelationship between core themes could be detected.

Results of Phase I and Phase II of the Analysis

Two of the themes identified in the ten protocols were designated as core themes: the theme of *dying and death* of patients and its impact on the participants and, secondly, the *relationships* the participants developed with patients and families in their care. Both themes recurred several times in each protocol and across all ten protocols: of the 140 meaning units discriminated in the ten protocols (the number of units varied from 11 to 18 per protocol), 55 referred to aspects of dying and death and 50 to relationship experiences with patients and families. In most instances the two themes overlapped and became a composite theme containing elements of both. The themes-issues-impact lists indicate that a number of significant issues were connected with each core theme and that both themes had a considerable impact on the life-worlds of the participants (see Appendix 2). I chose, therefore, the topic of *relationships with patients and families* as the topic of this study and continued the analysis as follows:

Phase III of the Analysis

The objective of the third phase of the analysis was to *explore* the core theme *relationships with patients and families.* The analysis was continued in the following way:

9. each meaning unit corresponding to the core theme was cut out and pasted onto an index card;

10. redundant, repetitive, and vague statements were eliminated;

11. the remaining meaning units were scrutinized and sorted repeatedly in order to determine: 1. the *basic elements* of the core theme, 2. *interrelations* between these elements, and 3. the *structure or gestalt* emerging from these interrelationships.

In the following sections of this chapter I provide the findings of these initial explorations which are based on the data of the four protocols analysed in phase III. I will attempt to identify and describe the basic elements involved (invariant constituents) and the structure or *gestalt* emerging from the interplay of these elements.

THE FINDINGS

Exploring the data involved posing a number of specific questions that served to guide and focus the inquiry: What does the data disclose about how these caregivers *actually* relate with patients and families? Are there commonalities in these accounts that point to a typical way of relating, and if yes, what kind of relating is this? In what circumstances and with whom do these caregivers relate in this way? Can it be broken down into its essential elements and what are they? And finally, how do these elements interact and what kind of structure is produced by the interaction?

Quoted below are four short narratives, one from each of the protocols, in which a particular relationship experience is recounted. I suggest that these accounts are representative of a particular way caregivers relate with patients and families and that they, taken together, highlight the essential elements involved in this way of relating.

The Social Worker

> We had one case the other day where, I don't know, everything just went in the right way. He was a young chap of, he was only thirty-one, and very good-looking, pleasant, intelligent young man, who went totally bananas when he was told that he had a brain tumour, that they couldn't do anything else for him; and we all worked together as a team with him and his mum because he couldn't cope on his own. We were all with him from the very beginning, through the fear, the anger ... He was with me and his mum, and he was running around like a scorched cat, and this was awful to see, but everything was done calmly and quietly, and in its own time, and he died about three weeks ago, you know. Looking back over that period and the way that we all helped, it was a good thing to be part of. It doesn't always happen like that, but if you only get one out of ten, then you actually feel you're doing something. And we obviously need to feel that we are making a mark somewhere, that what we do does have an effect, a positive effect, that's all you can hope for, basically. But what you're left with is the emptiness when the person dies, I spoke to him shortly before he died, it was dreadful, I am thinking about my own half with it, I was absolutely shattered after that, going to my car, I drove over the court and just crashed, I was totally spaced out (P 1).

The Doctor

> I think the greatest stress comes when you haven't adequately come to grips with what you are actually

> able to do, so, for example, having actually the patient who died just now on my mind, I was called in early this morning to try to sort out the situation where the lady deteriorated more rapidly than I thought she was going to, so my expectations what we were going to be able to do were higher than what we actually could do, whereas, conversely, there is also a ninety-year-old lady who died today whose death has caused me no stress at all because it was entirely expected, and we did all the right things, whereas the lady of fifty-five, she died of respiratory failure which is disturbing, and we had not perceived that she was going to die as quickly as she did, hence our reaction was not to make her comfortable and let her die, trying to do something for her, and now obviously what we had in mind to do for her probably made her death less comfortable than it should have been, because we didn't sufficiently sedate her, we were trying practically to treat her, in other words, our perception where the disease had gone was behind where it actually had gone, so when things came to a close, I wasn't actually prepared, and that is a great cause of stress, with a young patient, obviously (P 5).

The Nurse

> There are patients who affect you more than others, we had a patient who died yesterday morning and he was somebody you couldn't get close to, he wouldn't let you help him, and because he wouldn't let me help him I found it very difficult to actually nurse him, and when he died ... I felt useless and that was very frustrating ... [usually] men, male patients, like to be looked after by women, especially the older ones, even if they have been single in their life, because there is so much physical contact, much more in this type of area than in the general ward area, you often hold patients, cuddling them, and they would cuddle you back, holding the hand, its more natural, you know, a women to a man, people can't accept men to women in that situation mainly because it is a physical environment, you know, relatives would come and hold you after the patient has died, they look for that comfort (P 8).

> I had a patient here who's been dying here for some time, and, she was even out for some days, and then came back, and, in a sense, she was a very likeable person, she was so compassionate with understanding, as a patient in the day centre she contributed an enormous lot to the other patients and the staff, and she came here, and she died. And it was a bad day, I've never before or since seen the staff so deflated, yet they all knew it would happen ... We had a very interesting case on [another] occasion, she had a sister with whom she had quarrelled and she wanted to make up, well, we weren't quite sure whether she wanted to make up, but I think the sister wanted to, is it all right if she came? "Oh yes, we let her in". So in came her sister, put her arms around her and kissed her, and the patient lay back on the pillow and said: "Do you know, that is the first time anybody ever kissed me since before I was married". And I couldn't believe it, she was the one that couldn't be touched ... I was always reaching for a hand, you know, she wouldn't allow me to hold her hand, she never, ever she never, ever [allowed me to] (P 10).

Clearly, what these narratives describe are true *relationship* experiences. They are not cool and detached observations of the plight of other people but accounts that indicate emotional involvement, personal attachment, and caring for others. Death is the main issue in these narratives, but it is not death *per se* but *the death of a person with whom one is in a relationship* that is described. The imminence of death, it seems, produces an atmosphere of urgency; time, one feels reading these accounts, is of the essence: not just for the tasks involved or the objectives aimed for, but for the relationship itself.

The same narratives also provide an indication of how these caregivers respond to this urgency, of how they adapt their relationship conduct to the demands of the *situation* (see Chapter IV). This response involves a number of psychological factors that are apparent in all four narratives, although one factor seems to dominate in each case. I suggest that these interacting factors engender a particular way of relating or relationship conduct that is essential to the development of what I shall refer to from now on as *the caregiving relationship*.

The relationship conduct by which the caregiving relationship is developed is characterized by the presence and activation of three factors that are clearly revealed in the four narratives quoted above: *feelings* (narrative 1, P 1), *solicitude* (narrative 2, P 5), and *closeness* (narrative 3, P 8 and narrative 4, P10). These factors can briefly be described as follows:

> 1. Caregivers in this mode of relating tend to *feel with people*, they respond emotionally and become emotionally involved in the situation;
>
> 2. they tend to be *solicitous*, are interested in and concerned about patients and families, participate actively in their lives, and feel responsible for them;
>
> 3. they tend to *get close* to them, experience feelings of attachment and intimacy.

I now present additional data (*meaning units)* from the four protocols to make this brief description more concrete and to show how these factors may 'operate' in individual cases and what form they may take.

THE DATA

Feeling With People

> I mean we obviously made choices coming to work in a place like this and we always think we get some work

satisfaction out of it, but I think at the same time it does take a lot out of you ... because of the anguish people feel when they are dying ... The feelings of the family ... The feelings that you can't put things right (P 1);

We are busy all the time and we don't look at our own feelings and what needs to be done with them because we are concentrating too much on helping the patient (P 1);

The power of prayer, I think, if you are seeing someone [and] there is nothing else you can do for them, and they are in pain, and they are suffering, what else do you do with your feelings? You've got to do something for this, if it is only prayer (P 1);

I think because everybody's individual feelings, you are soaking this up, and everybody is feeling the same way, the intensity of feelings all the time - which is normal. I mean in normal life you have one or two bereavements and this is a horrible thing to go through, and you do and go on; but here it is happening every day; so you've got all this feeling, all this anguish, and as caring people that must affect, mustn't it? So we tend to be quite difficult with each other (P 1);

In this field [you have] a sense of feelings with people, these are not patients, they are people; somebody once wrote: when someone is told they have a malignant disease, it is, as the words were, loss, catastrophic loss, and we have to deal with these people like that ... well, you can say, that's just their situation, of course, that's an attitude, really, but I think most of us though are quite sensitive, we say: Well, I could be in that person's position (P 5);

It's hard when they die, I think a lot of nurses can't deal with those experiences [especially] when young people are dying, it's such a shock to the system, you are absolutely devastated because you feel part of you is gone (P 8);

It has been a good thing to come here because you realize the more important things, and it's an opportunity to try to show love, feel love, which is

> amazing in itself. And I am often deeply touched by the immense gratitude that people seem to express for such small, such trifling little things (P 10).

Getting Close

> So I had a lot to do with people who were terminally ill before I came here; what I found was that a lot of people couldn't relate to somebody who is dying because of the very fact that they were dying; it seemed to put a barrier between them and that seemed to be most on their minds; so, somehow you got to feel easy and comfortable about being with someone who is dying and being with the family (P 1);

> When people are dying and you don't see them as they want the world to see them, you see them as they are, because there is no need for any pretence anymore; so it's easier to relate to somebody when the barriers are down, and the relationship that you can build up with somebody tends to be very strong (P 1);

> From the point of view of care work, the main issue which we all cope with working in a sort of high stress environment, one where we become attached to patients, which is inevitable, some of our patients we see for quite a prolonged time, some [are] young, [is] what are the mechanisms of adjustment, the way we try to come to grips with, to terms with this (P 5);

> I am sure it's possible to distance oneself, cold, clinical attitude as a consequence, [but] I don't think we can afford to do that, I think we have to, especially since we are dealing with people as people, whole people, with the physical, mental and spiritual aspects of it ... if we allow ourselves to be detached, our care is going to suffer ... We ourselves have to be soft and warm, otherwise we are not fulfilling the needs of the patients ... This is essential, not necessary primarily for the patients' benefit, but our own, possibly survival, in this field (P 5);

> It's easy to distance yourself [but] when you get close to them, you let them come into your space, and it's not the role you were taught, they taught me to keep a distance, we were never to sit on beds and talk to patients, and, you know, patients always called you either "nurse" or "nurse" and our surname, patients [here]call us by our christian names (P 8);

> So, you've got to be non-judgemental, and you've got to be prepared to accept [them], you've got to be prepared to fight for [their] futures, and to let yourself get close ... which through your training you are told not to ... We often cry with the relatives when a patient has died ... You can't help getting attached to a lot of patients (P 8);

> You know, I get much more out of nursing patients with a terminal disease because you are not their nurse, you are friends, you become very close to the families, and it is much more relaxed, it's not a rigid atmosphere, you are allowed to get attached to the patients (P 8).

Being Solicitous

> It's such demanding work, basically, [and] over long periods of time, but you get hooked on it; [my husband] says: Go away for six months and just forget about it. I won't forget about it, you know, if you're worried about people here, [you are worried] about what they won't be getting, the sort of services I can provide, I am not saying I am brilliant or better than anybody else but I care about what I do, and I do the best I can (P 1);

> I mean you get married, so you got a deep relationship with someone ... You have the same thing [here] and [when] things happen, you tend to stick by whoever it is, and work through the problem, and I think with our patients ... [they] got people they are going to stick by [them] for a whole lot of time, that doesn't happen anywhere else ... you know, you got through all the stages in your life, people come and go, but on this one,

when you are referred here, then we are with you until you die (P 1);

You can't just go horsing in, [do] anything and just do it, because people soon know, they know if you don't care, it's the feeling about them [as] a caring person, because you are talking to [them], you're learning about [them], [they know] I'm not bullshitting about what I am saying, and if you are going to do that, you're in a lot of trouble yourself (P 1);

I think this job is a calling, I don't think medicine always is these days ... But as far as I am concerned, I am talking about, say, a patient who has a wife at home, and three small children, and has constant problems with vomiting, so I am focusing on that ... and I utilize my knowledge to be able to help in this situation, it's not a detached thing, while general medicine can be very detached (P 5);

So, I came back [here] and meant to stay for two years ... And five years later I am still here ... but I have been happy [here], at least I know I don't have to leave a patient to take somebody else to the theatre ... So to me this is nursing ... I want to have contacts with patients as I do here (P 8);

I was a local parish priest and this place was going to be built, and in due course my Bishop, who is my boss, came to see me and said he wanted me to do the chaplain duties, and then, I was a bit reluctant because I was busy, but he gave me a curate, you know, that's an assistant, so I could get on with it, and I have been coming here nearly every weekday since the beginning, I say nearly because there are occasions when I miss, and I don't come on a Sunday, just sometimes, ... I get anxious about my wife, because she puts up with the being out, [but] she still encourages me to come here day by day, and she is very good, she comes herself as a volunteer once a week ... Five years ago I retired from the parish ministry, in our church we have to when we are seventy ... And I continue this because I was asked to ... And I was very glad to do so because otherwise it meant to be cut off from everything ... Perhaps this is selfish but here I am and spend all the time I can (P 10).

INVARIANT CONSTITUENTS

The brief description of the factors at the beginning of this section can now be extended by using the above data. The data discloses additional invariant constituents of each factor and the most significant ones can be summarized as follows:

Feeling with People

1. This mode of relating *invariably* involves an element of feeling, an emotional component;

2. these feelings arise as a response to the *situation* and to the emotions experienced and expressed by patients and relatives;

3. the deaths of patients elicit the most intense feelings, multiple deaths increase the overall intensity of these feelings;

4. in addition to the feelings generated by the situation of patients and families and their emotional reactions to the situation, the feelings of co-workers and team members also have an impact on caregivers;

5. feelings are often *absorbed*, team support is the primary strategy of dealing with them;

6. as a result of constantly being exposed to and experiencing strong emotions, the work is sometimes experienced by caregivers as stressful, relations with co-workers at times as difficult, and the workplace as a high-stress environment.

Getting Close

1. Caregivers in this mode of relating *as a rule* do not distance themselves from the situation of patients and families;

2. they tend to become attached to the people in their care, attempt to get close to them, try to become 'friends', and allow them into their own personal space;

3. they generally feel at ease and comfortable in their presence;

4. they attempt to be non-judgemental, to accept patients and families as they are.

Being Solicitous

1. In this mode of relating, caregivers *worry* about the people in their care, they are concerned about the general welfare of patients and families and about the care they themselves are providing;

2. they attempt to provide whatever help is needed, participate actively in the lives of patients and families, often beyond the specific tasks of their professions;

3. they 'stick' to those who are in their care, are *committed* to help them to cope with and work through whatever problems are present or arise.

The interaction of these constituents, I suggest, engenders a distinct way of relating or relationship conduct (referred to from now on in this paper as *acting-as-a-friend)* the immediate objective of which is to *connect* with another person on a fundamental human level.

DISCUSSION

Acting-as-a-friend is a particular way of relating - a *being-with* - that involves feeling with the other, closeness to the other, and a sense of solicitude for the other. As noted in Chapter II, *caring* has been conceptualized as a thinking-feeling mode of being (rather than a set of particular practices that can be operationalized in terms of context-free variables) which give rise to activity (Dunlop, 1994: 38). Caring can also be conceptualized as a *mode of being-with* since it inevitably involves, in addition to thinking and feeling, *relating*. To relate in this mode as a caregiver, I suggest, is an attempt to establish a relationship with someone who is in care, or to become *connected*, since connectedness on a fundamental human level is the hallmark of any true relationship.

Although every contact with others provides us with an inherent opportunity to connect with them, we generally do not do this easily (or with ease) or often, and if, on certain occasions, we do attempt to connect, we attempt to connect selectively and with a purpose. What facilitates becoming connected with others? Certain responses in us, I think, need to occur in order for this to happen (a feeling of being 'touched' or 'moved' by them, for example) that open us up, make us more attentive to others, more fully present, and more oriented towards them. If the other person is vulnerable and in need as well as open and accessible, we tend to respond by *wanting to help*.

Wanting to help has a purpose. By wanting to help we want to *change* something, a certain condition or situation, by providing relief, support, or at least hope. I have called the mode of relating most conducive to helping, *acting*-as-a-friend (rather than, say, being-a-friend) to draw attention to the goal-directedness of this conduct. To act-as-a-friend means to act, or at least to try to act, in order to affect change and the most likely way to achieve this is in the state of connectedness. Being connected increases our power to affect change, just as it increases the other's power to affect change in us, it is a two-way road. The objective of acting-as-a-friend, I suggest, is to become connected in order to be able to help someone who is vulnerable and in need and who has neither the resources nor the strength to do it on his or her own. Acting-as-a-friend is acting *for* the other.

SUMMARY

The analysis of the data of the pilot study indicates that the relationship experiences that stood out as especially memorable for the participants are of a certain and distinct kind. The common psychological structure of these experiences is referred to here as *the structure of connecting*: one tends to remember the people with whom one was truly connected at one time, regardless of how long this connection may have lasted. The pilot data further indicate that the state of connectedness in the context of the particular situation described in Chapter IV, is experienced as highly positive and rewarding by caregivers, despite the many negative feelings and emotions that usually arise (see Chapter VI). The prerequisite of becoming connected, it seems, is on the side of patients and families a certain degree of openness, accessibility, and willingness (heightened psychological accessibility) and on the side of the caregivers a certain way of relating or relationship conduct.

Relating in this way does not require that a caregiver restricts her- or himself to stereotyped behaviours, role playing, or a limited repertoire of interactions and communication. She or he is free to adopt a number of different behaviours and play a variety of roles. To relate in the way of acting-as-a-friend is to relate with the *whole person*, which, as was shown in Chapter III, is a principal objective of the philosophy of palliative care. The analysis of the pilot data suggests that acting-as-a-friend is characterized by the presence and activation of three components: *feeling with people*, *getting close* to them, and *being solicitous*. The interplay of these three components I consider the essence of this way of relating.

There is another way for caregivers to relate with patients and families: they can stay strictly within their professional roles, 'stick by the rules', and limit the scope and variety of their interactions and communications; they can curtail any emotional involvement, attachment, and the sense or feeling of solicitude. The data of the Pilot Study indicate that the participants of the study are very well aware of and use both modes of relating, as they are aware of the costs involved as well as the possible rewards. There was a consensus of opinion that this second mode of relating is easier to adopt but far less satisfying and rewarding than acting-as-a-friend, which, in turn, is considered more difficult, costly, and stressful for caregivers. The loss of a relationship that involves feelings, closeness, and solicitude can be experienced as devastating, and multiple losses of such relationships can become intolerable. The data indicate that the participants acknowledge that they cannot indiscriminately relate in such a way without endangering their psychological health.

Further aspects of the caregiving relationship will be described in Chapters VIII and X. First, however, I present the findings of the *focus group interview* which was based on and followed the pilot study.

CHAPTER VI

THE FOCUS GROUP INTERVIEW

INTRODUCTION

In this chapter I present the analyses and results of the pre-questionnaires and of the two-hour focus group interview which followed the pilot study. The participants of this part of the study were seven of the original ten interviewed for the pilot project: a senior nurse/executive manager (F1), a hospice chaplain (F2), a Macmillan home care nurse (F3), a hospice nurse (F4), a male volunteer (F5), a secretary (F6), and a social worker (F7). The moderator of the interview was a senior hospice physician (M). In the first part of this chapter, I describe the questionnaire (see Appendix 1), present the data from the completed questionnaires (see Appendix 3) and discuss the findings. The second part of the chapter deals with the interview itself and follows the same general outline as the first part.

PART I: THE PRE-QUESTIONNAIRE

As explained in Chapter II, the purpose of administering the questionnaires was twofold: 1. to get from the respondents a response to the topic of this study as derived at by the analysis of the pilot study, and 2. to direct and focus the subsequent group interview on this topic. All seven co-researchers who participated in the interview (as well as the moderator of her own accord) filled out the questionnaire; they all responded to the first two questions, but only two of them answered the third one. I will suggest some possible reasons for omission of the latter in the discussion of this section. The questionnaires had been posted to the respondents several weeks before the focus group interview and the completed questionnaires were collected at the start of the interview to avoid any possible subsequent alterations and/or additions.

The questionnaire consisted of three open-ended questions that focused on relating and communicating with patients and families. Two of these questions asked for a subjective response in the light of the experiences of the participants, while the third question attempted to elicit a response to the findings of the pilot study. The questions were formulated as follows:

> 1. When you think about your experiences of relating/communicating with patients and families, what comes to mind?
>
> 2. What kind of things have made relating/ communicating with patients and families either easier for you or harder for you?
>
> 3. The analysis of the interviews of the pilot study in which you participated suggested that there are three aspects which appear to be typical of caregivers' experiences of relating with patients and families: commitment, intimacy, and emotionality (see page 3 for a general description of these terms). Do you have any comments on these aspects? Does your experience suggest any other?

I grouped all answers by the eight respondents to these three questions into four categories:

1. Experiencing emotions
2. Building a relationship
3. Being committed
4. Telling and accepting the truth

I now present the data in each category and discuss the findings before turning to the group interview. Words, phrases, and sentences quoted verbatim from the questionnaires and the interview are set in *italics*.

THE DATA

Experiencing Emotions

> Emotionality [is] inevitable but can at the same time be distressing for carers (F 1).
>
> Emotionality arises largely unbidden. It is important it should be expressed, people appreciate a degree of shared emotions. But too many emotions rob people of the strength of support they look for from us. We can be afraid of emotionality in such a way as to make us run away from the situation which produces it (F 2).

Emotions came 'to mind' most readily when the respondents were asked to think about their relationships and communication with patients and families: five out of eight responded to the first question by including at least one, but more often several, emotions (see Appendix 3). Three of these five respondents answered the first question by focusing almost exclusively on emotions. The number of 'distressing' emotions reported exceeded 'rewarding' or positively experienced feelings by almost two to one. The most commonly noted were fear or anxiety (*frightening especially initially, fear, worry, uncertainty of future, a feeling of uncertainty)* followed by helplessness (*helplessness* [by two participants] and *inadequacy*). Other emotions reported were *anger, guilt,* and *egotism*. The most commonly stated positively experienced emotion was *empathy* (by three of the participants) followed by *hope, humility, sympathy, gratitude* [for care] *and a sense of warmth, pleasure, and trust when the relationship is going well (M).* One participant noted that *compassion* made it easier to relate and communicate with patients and families.

Building a Relationship

> Intimacy in small subgroups of patients-carers quickly develops (F 1).
>
> We tend to avoid too deep an intimacy for fear of hurting people [or ourselves] when relationships have to end after a death. We cannot go on and on piling up more and more intimate relationships. Nevertheless intimacy is important as an expression of self-giving. It can arise unbidden and needs to be balanced with a degree of detachment (F 2).

Three of the eight respondents answered the first question by focusing almost exclusively on the issue of intimacy or closeness. Several respondents noted that an important point in establishing close relationships with patients and families is *time making: (be sure there is ample time, not being in a hurry,* [take] *plenty of time).* Other behaviours or attitudes mentioned were: *open-mindedness, non-judgemental attitude, acceptance, listening - caring - sharing, privacy, honesty, confidence, open friendliness, touch, basic smiling happiness (fun), being there, openness, warmth and understanding, shared vulnerability, being unafraid of silences.* It was noted that carers should *adjust* [their] *attitudes and communication to the* [specific] *patient / family situation* and that there is an *immense closeness and intimacy when patients shared their feelings and fears (M).* It is harder to relate and communicate when there is *a lack of patience* and *personal grief or problems* and, on the patient/family side, *heavy leaning, personal inadequacies* [e.g. *shyness*], and *physical issues* [e.g. *loss of hearing* or *speed*].

Being Committed

> Commitment at all levels and undivided (F 1).
>
> It is hard to balance one's commitments with another. [There is] a need for priorities. [Commitment is] costly in time, effort, attention, emotionality, even intellectually, [it] can be very tiring (F 2).

The smallest proportion of participants commented on this issue. Typical answers were: *a sense of responsibility, a desire to help, a need to help people, 'going the extra mile'.* Mentioned also were *knowledge of the patient in full* and *awareness of family dynamics.*

Telling and Accepting the Truth

The respondents noted that it is easier for them to relate and communicate with patients and families when there is *an open family situation* [where the] *illness and its implications are discussed openly*, when *the patient is accepting and open even when the outlook is very poor,* when the diagnosis and prognosis can be discussed *with patients* [who are] *fully aware of their disease and the family unit* [is] *close and supportive*. Relating and communicating are more difficult for the participants when families [are] *unwilling for patients to know the truth*, when *different relatives are in different stages in accepting* [the] *illness* [which] *causes resentment between them,* when *patients deny the truth* [collusion with family], have *impossible expectations, are not being told the truth,* and when *sudden, unexpected questions about dying* [are asked] *especially when the family has asked that the patient* [should not know].

DISCUSSION

The data of the questionnaires indicate that relating and communicating with patients and families tends to elicit strong emotions and feelings in the participants. This finding supports the notion put forward in the last chapter that *feelings* are a major factor in these relationships. Feelings typically arise *unbidden*, as *F2* puts it, which means that caregivers cannot prepare for or anticipate them, they are often *intense*, and they can be feared *in such a way as to make* [one] *run away from the situation which produces them (F2)*. They can also be and often are, according to the data, very distressing for the respondents. I suggested in Chapter V that some of these feelings may arise because caregivers tend to identify to some extent with the situation of patients and families. If this is the case, it becomes understandable why the greater part of the emotions experienced by caregivers are distressing ones. *Fear, anxiety, helplessness, inadequacy, anger*, and *guilt* are also typical emotional reactions of both patients and families to the situation, as are, on the positive side, *empathy, hope, humility*, and *sympathy*.

Building a relationship with patients and families, the questionnaire data suggest, is for the respondents primarily a matter of getting close to or establishing intimacy with the people in their care. This finding supports the idea brought forward in the previous chapter that *getting close to people* is the second major factor in the formation of these relationships. Most of the attitudes and behaviours written down in response to the first two questions are important elements in the formation of *any* close relationship (see Appendix 3). The fact that they wrote them down here, it can be argued, expresses a desire or an aim to establish this kind of relationship with the people in their care. As mentioned in Chapter V, the participants are well aware of the two ways they can relate with patients and families, and they consider the second mode of relating (*professional role*) as easier but closeness (*friend*) as more satisfying. Perhaps one of the reasons that makes *acting-as-a-friend*, even at the risk of experiencing distressing emotions, more rewarding to them than staying within the professional role is *the sense of warmth, pleasure, and trust, when the relationship is going well (M)*. However, as *F2* pointed out, there is at the same time a tendency *to avoid too deep an intimacy for the fear of hurting other people* [or ourselves] *when relationships have to end after a death.* Multiple deaths, as pointed out in Chapter V, increase the overall intensity of the emotions experienced by caregivers and they cannot therefore *go on and on piling up more and more intimate relationships (F2)* that all end in death.

Less data were generated on the issue of *being committed* compared to those of *emotions* and *closeness.* Although more than half of the questionnaires contain references to this aspect of caregiving, not much was really said about it. There was a call for *undivided commitment at all levels* by one participant (F1), but also the sober reflection by another that commitment is *costly in time, effort, attention; emotionally, even intellectually,* [that it] *can be very tiring* and needs to be balanced and prioritised (F2). In Chapter V, the notion of *solicitude* was posited as the third major factor of these relationships and commitment can be considered as one aspect of the more general factor of *being solicitous.* At the core of this component seems to be the *desire* [or] *need to help,* as mentioned by two of the participants, and, as we shall see in the second part of this chapter, there is a general consensus on this point.

Whilst the data in the first three categories (emotions, closeness, commitment) are on relationship issues, the data in the final category *(telling and accepting the truth)* refer back to the situation of patients and families, the primary context in which caregiving relationships are developed (see Chapter IV). The data suggest that one, possibly crucial, aspect of this situation in regard to forming relationships is the extent to which the patient/family unit is willing and able to be told and to accept the truth about the patient's condition. How this issue is handled by both patients and family members seems to have a strong effect on how caregivers tend to relate and communicate with them and on how they experience these relationships. The data in the second part of this chapter show that this issue is one of great concern to the participants and I return to this point after the data has been presented.

As stated in the beginning of this section, only two of the eight respondents answered the third question in the questionnaire. The moderator suggested to me that the main reason for this reluctance may have been that the question was formulated too abstractly, "academically", she said. This may have been the case. A further reason may have been that simply providing 'key terms', even with a definition but without further explanations or descriptions, may have had an adverse effect on the respondents' willingness to comment on these aspects. Nevertheless, all eight respondents themselves commented on the issues raised in the third question when answering the first two questions; however, no one made a suggestion regarding "any additional aspects".

To summarize, the data of the pre-questionnaires generally support the findings of the pilot study by indicating that the factors 'feeling with people', 'getting close' to them, and 'being solicitous' are major constituents of the respondents' relationships with patients and families. The data add some new elements to the initial description of these factors provided in Chapter V by showing what kind of emotions and feelings are experienced, how closeness is aimed to be achieved, and what may hinder or facilitate this way of relating.

PART II: THE INTERVIEW

The purpose of the focus group interview was to further explore the issues raised and commented on in the pre-questionnaires. Before the meeting, I had suggested to the moderator that she could use the first two questions of the questionnaire to broadly structure the interview. In addition, I had asked her to limit her own involvement in the discussion to mainly asking clarifying questions and to keeping the discussion focused on the topic (low involvement moderation); and only once did the focus shift away from the topic. I was present during the two-hour meeting but did not participate or intervene in the discussion. The interview was audiotaped and a verbatim transcript was made (see Appendix 3).

I grouped the main themes that emerged during the interview into seven categories: 1. perceptions, 2. relating and communicating, 3. communicating about diagnosis and prognosis, 4. breaking bad news, 5. facing death, 6. patients who accept, and 7. dealing with emotions. I now present the data in each category and briefly summarize what I consider to be the most salient aspects of each theme.

THE DATA

Perceptions

How the professionals in this field are perceived by patients and families, whatever *prejudices* they may seem to have in regard to individual professional roles, has an influence on how fast trust can be established and a caregiving relationship can be formed:

> But I think people come along with a lot of prejudices as well, don't they? Because, you know, they see nurses as being helpful people. You don't always see social workers as being helpful. And they don't always see ministers as being helpful, so sometimes you've got to get over that ... before you do anything to help them. Hopefully you are accepted by them (F7).

> It's part of trust, isn't it? And it doesn't always come straight away. I shouldn't think so anyway (F1).

> No I mean, sometimes you face a lot of aggression and unhappiness ... (F7).

> It's interesting, because I find in my professional role I have to do my best ... to be a bit unprofessional ... to try to show a bit of friendliness ... to get anywhere near them. And that's just the difference of people's conceptions of a role (F2).

> ... a nurse on the unit wears a uniform, so although you are (F4) the nurse, you are also a person outside nursing, whereas you (F3) go in to someone dressed as you are. So, they don't instantly think you are a nurse, do they? So, the situation is quite different there (F6).

It may help to *be a bit unprofessional* to hasten the process along, or, if that fails, to hand over the task to someone else: *Nobody, you know, is sufficient for everybody, and there is going to be a patient here and I wanted do something with but I haven't got the rapport with that patient that you have. So I got to get out of the way and let you do it and you're only going to do what I wanted to do. But I must be happy to let you do it (F2).* In addition to the perception of particular professional roles, the place itself, the hospice, tends to be perceived in a particular light, with a particular fear:

> The whole prejudices come up because the name of the unit [hospice] ... Tuesday night when I was trying to persuade a lady to [accept] help ... and she said: "Where are the nurses coming from?" and I said: "[name of hospice]", she said: "Oh, no, no, no." she said. So I said, where would you accept them from? And she was quite willing to accept them from [a hospital] but she did not want them from [the hospice] (F7).

> Because - did she - could you expand on that (M)?

> Because, it's ... about the place and when they come into that place, then there is no hope (F7).

> I think that maybe that happens more ... with the family than it does even with the patients, because I think it's the patient that has got major problems ... nobody else is managing, doing anything about. I think that patients get to the point that they don't care where it comes from but as long as you can do something. But I think, you know, relatives have got this view, and I think it's probably due to the fact that up to this time [they managed] [but now] they have to accept that [the hospice] needs to be involved. They can perhaps say to themselves, maybe it's not as bad, maybe the diagnosis isn't right, maybe my relative is going to get over it. But I think once they have to take on board [the hospice], I think they've also got to start taking on board the fact that, you know, this relative is ill, and this relative in the end is going to, you know, die (F1).

Most hospices have some patients *on the books for years (P5)*, they go in, and out again and again. So, *coming into that place*, is not necessarily hopeless, but it does confront, especially the relatives, with a confirmation of the seriousness of the illness and the possibility of death, both of which they may have done their best not to confront. Not that *actually* entering a hospice makes this *taking on board* any easier for the relatives:

> We get people coming in here who are terrified of looking around and I find that they gradually relax as they find people laughing and [families] together ... I do think it's important, you know, sort of normal happy surroundings, bright and colourful, and a lot of laughter, not too much, but plenty of it around. I think that that is really what helps (F2).
>
> Yeah, I think that helps the patient but I don't think it helps the relatives. You know, they've got somebody that they love dearly who is dying and they do hear a lot of laughter and ... (F7)
>
> That depends ... (F2).

> is really quite upsetting (F7).

> I also think that the relatives are far more aware of what's going on in other parts of the unit, you know, they see the other patients equally ... as their own loved ones. It comes across quite a lot when you are actually with a patient and the relatives are there, if the patient wants answers they want them now (F4).

> But they, you know, I often feel that the patients when they come in because they are so desperately ill have been putting on brave faces for their relatives [and] the visitors ... and when they come in they can relax and the true illness comes through and it threatens the relatives, because the reaction we get: "He was all right at home until he came in here, and look at him now" (F1).

Patients and their relatives tend to perceive and experience the hospice differently: patients want relief from symptoms and *they don't care where it comes from* as long as it works, they are usually susceptible to the pleasant atmosphere of hospices (as described by F2), and they often, after they come in, *can relax* to some extent. Relatives, on the other hand, may observe other patients and *become far more aware of what's going on,* the atmosphere may grind on them (especially *laughter*), and the extent of the illness may become more apparent. Above all, the *thought of mortality* becomes more difficult to circumvent:

> You know, the interesting, an interesting thing to me about that conversation that you had, an eighty-four-year old woman, right, eighty-four, had been into hospital before, but it was too painful to think of coming to a place like this, at eighty-four, when you think that the thought of mortality would have beaten around her head a long time, you know, a long time before that, and she would've worked out some way of coping with the fact that she was going to die some day (F2).

> I don't think it's actually possible, I mean, ... I think if people have been well, I don't think they see themselves as being as they are, whether it's seventy, eighty, or ninety ... (F7).

> Or maybe that something [this hospice] does (F2).

> It's always something in the future, isn't it (F7)?

> I think, I like to come back to this fear of [the hospice]. I don't, I mean I think in order for people to accept [the hospice], you'd have to change people's view about death and, you know, dying. You would have to have people who were, you know, were accepting: "Yes, that I am ill", you know death is going to be the end of all of us (M).

Regardless of how old we may be, as long as we are *well,* the thought of our mortality does not usually *beat around in our heads*, because *it's always something in our future. People's views about dying and death,* their attitudes, have not much changed and cannot much change unless we learn to *accept* that illness, dying, and death *is going to be the end of all of us.*

Relating and Communicating

> From being on the ward, [one] not always got the privacy to actually discuss what the patient wants to discuss ... quite often the patient will ask, not always at appropriate times, ... when we give out lunches, and the patient [is] with other patients, relatives of the patient, [or] other members of staff actually in the room (F4).

> From feeling the experience, how is that for you (M)?

> It makes you feel a bit uncomfortable because you want to be honest with patients and their relatives, you don't want to back away, but you are aware that the other

> people are hearing what you are saying, trying *not to* listen, but hearing what you say, and [you are] quite torn between opening up to the patient and actually backing off a little bit at the same time (F4).

> It is especially difficult if someone is a bit deaf, and you get deafness, of course ... (F2).

> Patients are probably aware of the situation and what you [can do]. Because, I think, when you actually are a patient, I think, if somebody does draw your curtains around you, it does what we say it does, it really gives the illusion of a bit of privacy ... the feelings [of patients and families] [are] probably totally different to actually what the staff's are (F1).

> It's very difficult, I mean, ... you cannot move them out of the situation they are in when they are asking, because you could easily lose them ... you sort of have to make the best of it with the situation because they have asked in an open forum (F4).

> What actually happened in your situation (M)?

> ... just have to cry ... I just have to turn off the conversation ... actually I crash ... we were there, you know, were there for her. I think, she wanted to make a statement and leave it at that but wanted somebody to be with her, not walk away (F4).

Communicating about dying and death in this situation requires some *privacy.* The lack of privacy on wards was also complained about in the pilot interviews, not just by nurses but also by other caregivers including doctors. It must be frustrating and emotionally upsetting for caregivers not to be able to talk seriously with patients, not to answer their questions *honestly,* because they are asked *in an open forum* and/or at inappropriate times. In this situation, caregivers are *torn between opening up to the patient and actually backing off* with the result of *easily losing them.* Creating *the* *illusion of a bit of privacy* by drawing curtains around the patient is obviously no solution, conversations can still be overheard by others in the room.

> I think that you change the way that you deal with people [when you] actually go into particular people's homes, and the type of home you go into, and what you were doing, ... the words that you use in one home probably would be totally different ... because you probably make a judgement of, I mean, what patient and family would understand ... (F3).
>
> So you have to assess the situation on its merit or whatever, you have to make some sort of assessment (M).
>
> And it isn't just the words that you use either, the whole attitude ... can change according to the whole situation (F3).

There seems to be less of a problem with privacy for caregivers who work in a homecare team. The main issue of communicating in this situation appears to be to successfully adapt one's behaviour to the particular home environment encountered. This requires, on the one hand, *some sort of assessment* of the home itself, and, on the other hand, a decision on how to communicate *(what words to use*) and what approach to take (*the whole attitude*).

> I think it's much easier sometimes to be in the professional role rather than be taken in as a member of the family, which happens ... (F3).
>
> So there are some difficulties you sense if you become a friend rather than a professional person in forming the relationship you want (M)?
>
> I think, it's probably more difficult to be objective ... (F3).

Which one gives you more satisfaction, which type of situation (M)?

I think, probably the ones where you are treated very much as the professional ... (F3).

Several participants all talk together

Gives you more satisfaction (M)?

Several participants: Oh no! Oh no!

It's easier (F3).

Several participants: Yeah, yeah

In what way easier then (M)?

What you deal with, whatever problem it is they present you with, and then, fairly often you feel as though it's actually the cut-off-point. You then [do] what they want of you, and you leave (F3).

Do you think also, the more emotionally involved you get, the more hurt you are if something bad happens, so you try to protect yourself from that as well (M)?

Several participants: Oh yes, oh yes.

And each time it happens, you get back [to the ward] and do it again (F4).

If the patient wants answers they want them now. Not when you've finished seeing the bloke who is in the corner. And I think they find it quite distressing to actually, you know, realize that you can't drop, just drop everything and go there. But they want, they just want you to be one-to-one, and they get frustrated because you've got all the others (F4).

> You have patients who have two weeks [to live] and the person who they want to speak to primarily is the home cancer staff. Not the whole staff. But they specifically ask for, you know, the main home care sister because they feel at home it's one-to-one (F3).

Patients often select a particular member or members of staff to form a *one-to-one* relationship with and they become *distressed* and *frustrated because you've got all the others* (i.e. other patients and families).

Communicating about Diagnosis and Prognosis

> Do you think coming to [this hospice] makes them face up to having cancer? You can fool yourself when you are outside of [this hospice], but as soon as they come in, that's the reality sets in: "I've got this awful cancer and I am going to die". And I think [this hospice] makes them face up to their diagnosis perhaps a bit more than they would do if they were outside. I don't know. And I do wonder what is their state of mind when they come in (F6).
>
> I wonder whether the process of getting the truth across to people hearing the name [of the hospice] is in itself a great help for us at least in getting people to face the truth. What [this hospice] is about, and as *soon* as it's mentioned to them, they may say: "Oh". But why do they? Why? Because they suddenly realize the truth (F2).
>
> It's sort of facing up to their diagnosis, you know (M).
>
> [But] it surprises me the number of people who come in who don't seem to realize ... (F2).
>
> It's quite a proportion ... (M).
>
> They don't even know where they are (F4).

To *face the truth*, to *face up to the diagnosis* seems to be a difficult and distressing process for most patients as well as their families. There appears to be a consensus of opinion here, however, that they should do this and that very few, actually, are able to.

> But how do you face the relatives when they come in? [They say] they are not to be told what's wrong with them (F1).

> Well, my answer to those relatives would be that I'd be honest with patients, because unless I am honest with them they will not trust me, not even to look after them ... So, I won't hide behind, you know, a story, just so the relatives feel better. If a patient asks me in a way that you can see they know what's going on ... and I'd say 99 percent of the time when you actually sit down and talk to the patient, they know exactly what's wrong with them, you know, there is no further treatment, and they just wanted somebody to be honest with them and say: "Well, yes, this is the situation" and because nobody else has actually done that (F4).

> I mean, it's incredible ... that relatives who, when the relative is actually within [the hospice], are saying they don't want somebody to be told ... I mean, it's really a lack of communication between relative and patient (F7).

> [Patients should] be given an opportunity to talk about how they feel and I, you know, I think this has helped a lot, because if they've been denied that chance to talk about how they're feeling and what they actually going through, it's coming to a place where people are going to be honest with them and actually giving them an opportunity to unload on somebody else (F4).

> The greatest difficulty I, as an individual trying to go into a home as a volunteer to transport a patient, either for treatment or bring into day-care and take home again, the biggest difficulty has always been dealing with the relatives, because they're the ones who are usually in my experience showing overtly the greatest

> concern about [the] uncertainty about the future. And they frequently come up with totally inappropriate questions to me, because I am just there from [the hospice] to take the patients [but] asking about the future and this and that ... I find is the most difficult thing to deal with (F5).
>
> I find that the really difficult people are the relatives ... (F2).

Facing up to the diagnosis is different for patients than it is for relatives: *I'd say 99 percent of the time when you actually sit down and talk to the patient, they know exactly what's wrong with them, there is no further treatment, and they just want somebody to be honest with them and say: "Well, yes, this is the situation" and because nobody else has actually done that.* Relatives, however, often want that patients *are not to be told what's wrong with them*; there seems to be *a lack of communication between relatives and patients.* This lack of communication makes it difficult for the caregivers who want to be *honest with patients* and give them a chance *to talk about how they are feeling and what they are actually going through.*

Breaking Bad News

> I think, it's really the difficulty the doctors have in explaining to patients how ill they are, at whatever point they diagnosed ... (F7).
>
> So that breaking bad news ... (M)
>
> Yes. Basically, you know, everybody puts it onto somebody else. In the case of this woman, because she is a good example, she is in Ward 2 in single and instead of the sister on my ward or one of the oncologists or one of the nurses saying: "We are going to refer you to [this hospice]", because, I mean, this case is terminal, she was told: "Oh, a nurse will call you and see you when you get home" and left it like that.

But what did happen was that one of the registrars on the ward was responsible to inform the GP, and then it was left to the GP to go out and say: "Well, you know, we think perhaps [the hospice] is a good [place] in this case we refer to them". So, it's just been pushed down the line all the time and this woman isn't really to know about it because the GP in this case isn't interested (F7).

It affected your relationship, didn't it (M)?

Of course, it affected a lot of things ... (F7).

Are you suggesting ... (M)

If somebody had the courage to sit down in the first place and treat them responsibly and intelligently, because, you know, this sort of illness can happen to anybody at any time, you can't run away from it, it's got to be accepted ... (F7).

So a lack of communication down the line makes your work more difficult and your relationship with patients, if they had the honest truth before ... (M)

I think so, but it's the way they are told, because, I mean, we get people with the screaming horrors, don't we, when the doctors gone in, in an open ward, and said: "Oh, we've had your results back, it's cancer", and then walks out. And just leaves them sitting there thinking, 'Well, have I a day or a fortnight?'... and, you know, what do you do with that? You can't discuss it, because the doctor finds it too difficult, is gone, the family are very angry because they weren't there, because the doctor would have found it twice as difficult if he had somebody watching him saying that (F7).

But quite often, I think, it's left to the doctor to tell the patient [who has only] met the patient once or twice, so there is no relationship, [that is] why is this patient reacting in this way? People quite often find, you know, that they say: "they didn't even look me in the eye when they told me" (F4).

And very often it's a junior doctor (F7).

Yeah, and, you know, they have so little to do with these, you know, the poor patient in there ... (F4).

But if they haven't got that sort of intelligence from, you know, from their own background and their own experience of life, surely, it should be part of the training earlier for doctors ... you know, why do they come into medicine? Do they come in because they just see, you know, a lot of symptoms over there that they want to sort of get rid off to make that person whole, or do they see that person as a person, who is not just a lot of symptoms but somebody who has got feelings, thoughts, intelligence, and (F7).

So how do you get around that (M)?

I think, the sad thing of it is that most hospices have now been going quite a long time and, I mean, an awful lot have been spoken about, in breaking news and, you know, [some] sort of education has been aimed at but, I mean, my guess is that probably, I mean people on the ordinary sort of wards are only marginally better at it than they actually were, I don't know, twenty, twenty-five years ago, I mean ... (F1).

You know, you don't have to tell the patient, you can get the patient to tell you. It's the way you sit down and talk to them and see what they're thinking and what they're frightened about ... They are intelligent, [being on] a cancer ward that hasn't responded to any of the treatments likely to be something very nasty, isn't it? You know, you can get things out of people by talking to them in a certain way and get them to tell you. So you, as a doctor, they tell you what's wrong with them by the way you question them (F7).

I don't think [enough] time is actually spent with the patient, it's the way, you know, things are on the ward. I mean, I don't think they are creating the sort of working situation where it encourages people to be able, you know, to sit and actually listen to the patients, because everybody is so busy hurrying around from A

> to B to C and, of course, it's the patients in the end that suffer (F4).
>
> And it's getting worse (F7)
>
> Worse, yeah, it's not getting any better (F4).

It seems that nobody really wants to *break bad news* to patients or their relatives. Doctors are especially criticized in this context, not only for not wanting to confront patients and give them bad news but also for the way they conduct themselves in this situation. There is *a lack of communication down the line*, apparently no or little *earlier training* for doctors how to manage this task, and *no relationships* with the patients. *And it's getting worse.*

Facing Death

> The other thing that I find interesting is that sometimes I will go to a patient and particularily when they just been visited and somebody is gone out to get a meal and they are coming back later and I don't know why, because I am a bit foolish, but I do, I ask them sometimes: "Do you feel lonely?" And it is amazing how many people will tell you, their immediate reaction is: "That's right, dreadfully lonely." And they just had their nearest and dearest there, how, I don't know what the answer to that is (F2).
>
> Have you asked them why they feel lonely (M)?
>
> Well, yes, you do ask them why, but very often they don't know (F2).
>
> The loneliness ... and actually listen to them. Does this tie in somewhere (M)?

> Oh, I think it does. If the person guesses the truth for themselves but nobody tells them, then they feel very isolated, I think without a doubt, 'at sea', as one would say (F2).
>
> I think the apathy, or the actual knowledge that, you know, nobody else can go through the illness for you and nobody else can die for you, you know, it's very much 'you' and, I mean, however much everybody else has got empathy, I mean, in the end it's between you and you alone (F7).
>
> And nobody knows how I am feeling (F2).
>
> No, no, no (M).
>
> I mean nobody can really (F2).
>
> You go on your own (F7).
>
> Yeah (F2).
>
> Do you feel sometimes they exclude you from this as well, even though you come very close to these patients, but if, that they exclude you from the biggest experience that they're going through (M)?
>
> A lot of patients shut themselves off as well towards the end (F4).

Facing death is a *lonely* experience that cannot be wholly shared with or communicated to others, even if they are the *nearest and dearest.* The particular loneliness experienced by the dying cannot be easily explained to others (*very often they don't know*) because dying is essentially *between you and you alone*.

Patients Who Accept

The most difficult patients, I think, ... she, on Ward 5, she was a young women, and she literally accepted everything ... and just lay there, and caused no end of problems for the staff, for her own family, but she was happy, she was contend ... (F4).

How did she make you feel (M)?

Terrible (F4) (Laughs)

I think, [it's] totally contradictory ... It's much much more difficult to deal with people who are totally accepting (F3).

Than it is with people who are kicking and screaming every inch of the way (F7).

... on the day that she decided she ought to say good-bye to everybody ... I came up to fetch you as she wanted to see you as well, and [we were] the only ones that she was allowing in there, you know, even when I was trying to back off to give the family time, one of them would by coming out saying: "Mum", you know, "Mum want's you." ... And the other one, [he] actually died on the Monday but I didn't even have the courage at the end of my shift to go [in], because I just, I couldn't, I was so numb, and I, he was so: "Yes, I know I am going to die, I know I am going to die; it's going to be very soon", and I just felt if I went in to say goodbye to him, I just start crying, and I will be totally useless to him (F4).

Why should this threaten us, because this is what it is, isn't it? If somebody comes to total acceptance (F2).

I think it's a feeling of failure, and (F4)

Why (F2)?

I don't know, it's probably the wrong words but you want patients to fight for life. But with total acceptance that seems to go. And it's as if you don't push them over the edge, but it's you are taking life away from them because they totally accept what is happening to them ... (F4).

I think, if it is you who is ill, your decisions would be totally different. Now I mean, I think, we probably find it hard, because, well, to have somebody who is going to die, to say: "Yes, I am going to die, I expect it", that doesn't seem, you know, natural, doesn't seem right, we feel they should be hanging on, you know, fighting in there (F1).

The other thing is, research shows that people who don't accept, the people who are angry, people who fight, live longer (F3).

I wonder if it's something like that we can't fulfil our role or we feel we're not needed anymore if they accept. That's what we are setting out for, isn't it (F2)?

It's interesting how you could be aiming for something and yet, when you got there or at least not when you got there but when the actual patient has got there ... you cannot cope with the fact that they got there (M).

I think also because it doesn't happen that often, it's (F1).

I suppose that should be the question: "Why we're here? Why we're doing these things? Why you nurses, why am I here?" Is it because we ourselves are being fed? We are in a sense being fed, aren't we, by our patients and their relatives but what are we being fed with? And are we being fed with something which we find very difficult to be without? In the sense that we need to be needed (F2).

Patients who are *totally accepting are much more difficult to deal with* than patients *who are kicking and screaming every inch of the way.* Acceptance for some reason seems to be *threatening* to caregivers, it induces *a feeling of failure*, it does not seem *natural, it's something like that we can't fulfil our role or we feel we're not needed anymore if they accept.* But, acceptance is also something *aimed for* and *yes, when you got there or at least not when you got there but when the actual patient got there ... you cannot cope with the fact that they got there.*

Dealing With Emotions

> If we think about crying in front of the relatives, that sort of thing, I am not very good at crying (F2).
>
> But I should imagine if you cry with the relatives that is rather nice for them in some ways because they know you got feelings with them (F4).
>
> A lot of relatives say to me after death, they say: "Do you know, everybody loved him, even the staff were crying when he died." And they do appreciate that (F2).
>
> [But] it can go so far that they are comforting you (F3).
>
> Do you (then) cease to be of any use to people (F2)?
>
> You can't (F3).
>
> I mean, yes, I think there is a difference between the showing that you are upset, and you're with them, and still being able to cope with the situation, [but] [playing the saint], I mean, you're absolutely of no, no use at all and they having to sort somebody else out (F7).
>
> Can I ask a question (F2)?
>
> Please do (F4).

In your training, do they frown on crying (F2)?

It seems such a long time ago ... certainly, in our day, yes, you do not show any emotions at all (F4).

I ask because I find that members of staff seem to be a little ashamed when they cry. I think most of the crying is done privately, so to speak, in the loo or in the office, or just when the Chaplain happens to walk in (F2).

You know, at the end you can be desperately upset if somebody dies, hopefully not in front of the relatives, ... but after they are gone, yes, [you] may need other staff (F4).

Yes (F2).

You know, to express your fears (F4).

And how do you deal with that (M)?

... I tend to just go off on my own because I've got to go back and be there for [other relatives] and also patients, that are not going to want to see me with red at the eyes, ... So, it's at the end of the shift when you get home, that I start thinking about what's happened during the day, but it tends to bottle up anyway (F4).

I think sometimes ... what we do to ourselves, going from patient to patient on the unit, each patient has got different views, is at a different stage, and perhaps you're with somebody who's really accepted ... and you go to the next patient and you have to put aside all those feelings and be perhaps bright and talkative for the next patient. I do wonder what we do to ourselves when we try and change our emotions (F7).

I wonder whether we really know what this emotional strain does to us because I always remember when your husband [a psychiatrist] came in ... to deal with staff stress and I remember him saying to me on one occasion: "I can tell as soon as I come in if the staff is

> under stress, because there is a lot of giggling going on." And I thought, that's the last thing I expected somehow (F2).
>
> That's true, because on Monday mornings when I come to the unit I'd know exactly what happened the weekend because if you were all standing ... really silly ... I'd know that it had been a very, very stressful weekend (F1).
>
> But you wouldn't have expected that, would you (F2)?
>
> You know, what (F4) was saying earlier, where you literally got to go from a very stressing situation dealing with somebody dying, bereaved relatives, and then go back and smile at the patients who are there, you know, give them food, give them tea, you know, carry on that way and perhaps then go back to those relatives who are sitting with somebody who is dying. And just go back and forth and your emotions get so mixed up that whether you are laughing or crying by the end of it (F7).

Dealing with the inevitable emotional responses to the situation can at times become a problem for caregivers: *when* to show emotions, *how much* emotions to show, whether with the relatives or alone or with other staff. There needs to be a balance in order to *still being able to cope with the situation* and *be of use to people*. In addition, there is the problem of going *back and forth* between different situations with different patients and relatives: *going from patient to patient on the unit ... and perhaps you're with somebody who's really accepted ... and you go to the next patient and you have to put aside all those feelings and be perhaps bright and talkative for the next patient.*

DISCUSSION

One of the distinguishing characteristics of the caregiving relationship, I suggested in Chapter V, is that the two persons making up the dyad can *connect* on a very fundamental human level. Patients' and families' perceptions of the professional role of caregivers, and implicitly of the type of person typically in that role, may have a considerable bearing on their willingness and ability to connect in such a way and on the ease and speed with which this connection can be achieved. The perception of the nature of some professional roles (like nurses, for instance) seems to facilitate the formation of this link, while the perception of others (doctors, chaplains, social workers) may initially become a barrier. Some caregivers in these latter roles consciously and purposefully make efforts to *take off the professional overcoat* at times to make it easier to connect (by being *a bit unprofessional*, as F2 puts it) and even nurses have to make the effort at particular times with particular patients and families. It is not rare that patients and relatives, but especially patients, connect with a cleaner or porter rather than with the immediate carers, i.e. the nurses, doctors, or chaplains.

The common perception of patients and relatives that a hospice is a "place of death" is not unfounded: many patients do die during their relatively short stay in hospices. As a hospice doctor (in the follow-up study) explained: *Our average length of stay is fourteen to sixteen days. Forty percent of our patients go out of here alive, the other sixty die* (C 3). And many of the ones "going out alive", sooner or later return to become part of the "sixty percent". In addition, as the same doctor pointed out, there is often the question of "What next?":

> The questions is: What next? Do they go home, or? You know, some of them will be very definite they want to go home [but] there is quite a percentage, I would say fifty to sixty percent, with whom it's not certain that they go home, or where they go. Families can't cope with

> them, or they live on their own and they can't cope any longer, and nursing home is the only option, really. They can't stay here 'cause our beds are such a premium that once their symptoms [are] controlled, they really have to move on. We've had patients who have gone out of here crying, to a nursing home, it's dreadful, and there is no solution to it, because we don't have enough beds (C 3).

In some respects, hospices *are* "bad news" for patients and families. Entering a hospice is often a sign that a last and difficult phase of life has begun, that a threshold has been crossed, from which there is no likely return to "normal life".

The everyday practical aspects of *relating and communicating* with patients and relatives discussed by the participants revolve about creating the right conditions to *connect*. There are many obstacles for hospice caregivers that have to be overcome in order to achieve this: a lack of privacy, constant interruptions, the scarcity of time, other patients and relatives, even colleagues and other staff members, all tend at times to frustrate this endeavour. As a hospice counsellor (in the follow-up study) described:

> It was desperate, really, nowhere to see anybody, I mean, that was the other thing, you know, you had to do your counselling at the bedside with the curtains round you, if you were lucky. Nurses spring through, interrupt you, you'd think: I've just got a really important point here, how am I going to manage this? I was used to sitting in a quiet room listening to somebody, making my interpretation, or not, as the case may be, not dealing with some stupid nurses: "Oh, hi, cup of tea?", you know (A 4).

It is difficult, and often impossible, to move patients and relatives *out of the situation* and thus create more favourable conditions for connecting. Furthermore, it is not possible to foresee *when* patients and relatives are willing and ready to do this, and with *whom*. Caregivers usually have to wait for their move, they themselves rarely take the initiative.

Breaking bad news and *communicating about diagnosis and prognosis* are two sides of the same coin, so to speak. The basic issue here seems to be a reluctance to talk about death and what it means to those involved. Doctors and relatives appear to be more reluctant to face this issue than nurses and patients, although some patients, especially young ones, find it very difficult or impossible. As the counsellor quoted above pointed out:

> One young woman I was working with, really couldn't talk about dying; she could talk about the possibility of it in the future, she couldn't talk about it like right now, and right now was pretty much on the agenda. And with young people that tends to be more so ... It's rare to talk straight about death, it's much easier to talk about it in a metaphorical way (A 4).

A reluctance to *talk* about dying and death does not necessarily mean that it is not thought about by the people involved, or that it is denied. It may simply be, as in the case of the more general issue of relating and communicating in this situation, a question of creating or finding the right conditions, the right environment and time, for this kind of communication as well as the right person. The apparent reluctance to *break bad news* on the side of the medical staff as well as the reluctance to discuss "the bad news" by patients and relatives may also reflect the influence of the broader *sociocultural* and *society* contexts that, as was shown in Chapter III, have, in the past, fostered a particular notion of dying and death as sharply separated from living and life.

Facing death, in most cases, is a gradual process that typically starts with certain diagnoses ("secondaries in liver and bones", for example) which reveal the life-threatening nature or progression of the illness, or with the transition from treatment to palliation ("we can't do anything more for you"). The process of facing death is for most individuals a lonely and distressing one that, as portrayed in Chapter IV, may engender profound inner and spiritual disturbances and changes which, in some extreme cases, can transform the individual almost beyond recognition. As a homecare specialist nurse (in the follow-up study) described it:

> There was a family recently that I went into, the husband, he was the patient, was reluctant perhaps to have any help, was denying really what was going on with him, family probably wanted as much help as they could. It was almost frightening for me, really, because he was getting very angry during the interactions, physically. And he was raising his voice, and he was using very strong language. And it was all out of character apparently for him. He was rejecting his family, he actually asked his wife to leave the house, and she had to. Psychiatric team was called in at some point, he was threatening to commit suicide (W 6).

The *exclusion* of others, the *shutting off*, the turning away are not uncommon in this situation; they may be stations along the way of letting go of life which, of course, does not necessarily mean the acceptance of death.

Acceptance, as the participants in the focus-group interview mentioned several times, is rare and it is, they implied, an achievement of a kind that *does not seem natural*. Accepting death appears to be a positive state with a high degree of self-containment that considerably reduces the need for others (including the caregivers), although the individual remains firmly rooted in the social and physical worlds. Perhaps it is like this:

> And she said: "I want you to take me outside", this was the day before she died, "I want you to take me outside". So I took her outside in her wheelchair, and I knew, she had something sort of planned for me. And she had liver secondaries, so her sight was going, and she said to me: "I want you to go over there, I want you to pick up a piece of each [herb] in the herb garden". So I picked one of each of these herbs, gave it to her, and she held [it], she smelled each one, and she said: "This is so-and-so", and she gave it back to me, and it was like this symbolic "Hello and Good-bye" to the world. It was one of those things, really, one of those memories that I shall never forget, and very beautiful. And

> I took her off and back up to her bedroom, and the next day she became unconscious and she died (A 4).

CHAPTER SUMMARY

The respondents' answers to the questions of the pre-questionnaire indicate that the issues of *experiencing emotions, building a relationship,* and *being committed* are primary aspects of the way they deal with patients and families in their care. The data thus support the claim advanced in Chapter V that these factors are essential elements in the development of the caregiving relationship. The data also allows the extension of the description provided in Chapter V by clarifying *what kind* of emotions are generally experienced, *how* a close relationship is attempted to be built, and what may *facilitate* or *hinder* achieving this. The fourth issue raised by the participants, *telling and accepting the truth,* appears to be a central issue since it recurred often and became the focus of discussion for long periods of time during the interview.

The focus-group interview itself added another important issue to the list, namely how patients and families tend to *perceive* both individual caregivers and their professional roles and the institutions in which they work or are associated with. The nature of these perceptions apparently affects patients' and families' willingness and ability to enter into a relationship with caregivers. The data of the interview also disclosed some of the experiential and pragmatic aspects of *relating and communicating* with patients and families and of *dealing with the emotions* inevitably experienced by caregivers.

The central issue raised in the interview, however, was the issue of *telling and accepting the truth* which already featured prominently in the written responses to the questionnaire. This issue, broken up in this chapter into its components *communication about diagnosis and prognosis, breaking bad news, facing death,* and *patients who accept*, will be taken up again and further discussed in Chapter X in connection with the follow-up study.

CHAPTER VII

REVIEW OF THE RELEVANT LITERATURE

INTRODUCTION

The literature search was based on the analyses of the pilot study, the pre-questionnaires to the focus group interview and the focus group interview itself. The literature search was deliberately delayed up to this point in order not to influence the data collection either intentionally or unintentionally by applying pre-conceived ideas or concepts as reported in the existing literature in the field.

The wider field of dying and death has seen a great number of publications ranging from, for example, books written as self-reports by terminally ill patients to articles in newspapers and magazines, to Internet sites, and specialist studies conducted by students, academics and professionals working in the field.

SEARCHES AND SELECTION PROCEDURES

Hand- and Computer Searches

The literature search was initiated by handsearches conducted at the *Swiss Cottage Library,* in the Psychology Section at the *British Psychological Society's Library* at Senate House, at *City University Library,* at *Regent's College Tate Library, London* and at the *Medizinische Universitätsbibliothek, Köln* (Cologne, Germany). These searches revealed a number of books and journals addressing the wider issue of dying and death and the processes, people, experiences and practicalities surrounding it.

A combination of handsearch and computer search of the available specialist literature on aspects of care for the dying, as well as on dying and death, was done at *St. Christopher's Hospice Library, London.* Finally, an exhaustive computer search was conducted at the *British Psychological Society's Library* at Senate House, Malet Street, London, searching the following databases:

PsychLIT journal articles database
PsychLIT chapters and books
Philosopher's Index
Index to Theses
Dissertation Abstracts On-line
Periodicals Contents Index Web (http://pci.chadwyck.co.uk):
1979 - 1999

I did a final check of the literature in mid-June 2001 and decided at that point not to check the main databases, i.e. PsychLIT journal articles database and those listing dissertation abstracts although I am aware of the possibility of a study or thesis having been published since, which may have a bearing on this research study.

This study focuses on the interactional field between caregivers and the patient/family unit, encompassing the caregiving relationship and communication between the participants. The context and situation which influence the area under investigation are addressed in Chapter III and IV; this set the framework in which the study is placed.

Therefore, *not* addressed here are a number of topics, such as: stress experienced by caregivers, societal or health care aspects, for example, societal ideas on "a bad death", the notions of "a good death" and "an appropriate death", or cultural influences on dying and death. The influence on caregiving by the hospice administration, the hospice structure, the role of the medical director, the influence of the 'group' on caregivers, issues of funding or the state of the NHS have been examined by other researchers. Additional topics not addressed here are the attitudes to dying and death of those working in hospice settings, or the reasons for caregivers to enter palliative medicine, their education and training, their personal life and its effect on their work, or their 'years of experience'. From the patient and family perspective: bereaved families' experiences and feelings or their expectations of caregivers, anticipatory mourning and bereavement, their anxieties, or their experiences of dying and death are not covered here, as are many other aspects of the wider field, which were investigated elsewhere.

Selection Procedures and Keywords

The keywords initially used for the literature search were: *relationship, caregiver,* and *communication.* As the initial search revealed only a few relevant studies, the search was extended by using the thesaurus provided for the PsychLIT database and a much wider variety of keywords was checked, first on their own and then in combination with each other in order to narrow the search down. Although, as stated above, my selection criteria were the three terms *relationship, caregiver* and *communication,* I decided to check as many related terms as feasible in order to ensure that the three issues covered by the keywords selected by me were not addressed in the literature under any other terms and might, therefore, be missed in the literature search.

In the first sorting of the selected literature, the keywords and their context were highlighted; the subsequent search separated the material into three levels according to their relevance to this study. This revealed that number or appearance of these keywords in a study does not equal relevance.

Level I: studies in the hospice or dying and death context containing the relevant keywords but in a wider, background context;

Level II: studies in the hospice or dying and death context which may have also used slightly different keywords but which addressed some of the aspects of caregiver relationship and communication discussed in this paper;

Level III: any remaining studies which addressed the chosen topic for this thesis.

Examples of the literature grouped together into Level 1 will be summarized as 'background' to the study and studies in Levels 2 and 3 will be presented in more detail.

Search Lists

The keywords and results (hits) for each keyword or combination of words is presented in the following lists, headed by the respective database where the search was conducted or the source made available by. (Combinations of keywords are listed here *without* 'and' or '&' as used in the searches). As studies are usually cross-referenced with several terms, the same studies are likely to appear under more than one of the keywords used in these searches, so that the number of 'hits' per entry may not be exclusive. The search lists of only three of the databases checked here are presented as they provided the majority of studies examined.

PsychLIT database journal articles and chapters/books (up to 05/2001):

hospice caregiver relationship patient: 0 hit
dying: 6,275 hits)
patient: 43,654 hits)
carer: 136 hits) combined key word search:
dying patient carer: 0 hit
caregivers communication: 0 hit
caregiver patient communication: 1 hit; selected: 0
hospice carer patient communication: 0 hit

helping: 12,390 hits)
helping relationship: 238 hits) narrowed down to:
helping relationship dying: 0 hit
helping relationship death: 0 hit
helping relationship hospice: 0 hit
relationship hospice: 0 hit
helping hospice: 2 hits; selected: 2
palliative care patient communication: 0 hit
palliative care communication: 0 hit
caregiver: 565 hits
hospice care relationship patient: 0 hit
carer patient interaction: 0 hit
caregiver: 565 hits
caregiver patient relationship: 6 hits; selected: 2
relationship: 91,726 hits)
patient: 43,654 hits)
carer: 136 hits) combined key word search:
carer patient relationship: 4 hits; selected: 0
hospice nurse patient relationship: 0 hit
terminally ill patient: 91 hits; selected for further reading: 2
terminally ill patient carer: 0 hit
terminally ill care hospice: 3 hits: selected: 3
terminal: 3949 hits)
care: 66653 hits) combined key word search:
empathy: 5132 hits)
terminal care empathy: 0 hit
terminal empathy: 0 hit
care empathy: 3 hits: selected: 0 (related to child/adolescence/nurturing/development)
palliative: 910 hits)
hospice: 725 hits) combined key word search:
empathy: 5132 hits)
palliative: 31 hits (chapters/books): checked: 31, selected:
palliative caregivers: 0 hit (chapters/books)
palliative caregivers: 1 hit (journals); selected: 0
palliative care: 141 hits; all checked; selected: 0
palliative care hospice: 114 hits; selected: 3
palliative care communication: 1 hit; selected: 0
palliative care relationship patient: 15 hits; selected: 2
hospice: 590 hits (chapters/books; search narrowed down to: hospice caregivers)
caregivers: 903 hits (chapters/books; search narrowed down to: hospice caregivers)
hospice caregivers: 7 hits (chapters & books): selected: 7
hospice caregivers: 4 hits (journals); selected: 4
hospice caregivers relationship patient: 0 hit
hospice care relationship patient: 0 hit
hospice caregiver patient interaction: 0 hit
hospice staff patient interaction: 0 hit
hospice staff patient relationship: 1 hit; selected: 1
hospice quality of care: 34 hits; selected: 4
hospice patient: 1 hit; selected: 0

PsychLIT database, continued:

hospice communication: 0 hit
carer: 5 hits: checked: 5; selected:
carer patient interaction: 0 hit
carer patient relationship: 0 hit
care patient relationship: 1 hit; selected: 0
care relationship: 4 hits; selected: 0 (refer to care in the medical field)
communication: 48,861 hits
intimacy: 4110 hits
care intimacy: 2 hits; selected: 0 (refer to E. Erikson and marital intimacy)
terminal care intimacy: 0 hit
solicitude: 52 hits; all checked; selected: 0 (refer to parent/child relationship)
care solicitude: 0 hit
terminal care solicitude: 0 hit
relationship: 121,888 hits
terminal relationship: 1 hit; selected: 0 (1972 study on IQ scores)
care relationship: 26 hits; selected 26
terminal care relationship: 0 hit
communication: 63,403 hits
terminal care communication: 0 hit
terminal communication: 2 hits; selected: 0 (refers to young children and language)
care communication: 26 hits; selected 26

The Philosopher's Index was checked initially for relevant literature on the phenomenological approach used in the design of this study as well as for the existential background to the study. The term 'dying' was used for a further search as the emphasis was placed on the direct context (the situation) of this study. As with the literature search of the PsychLIT database, the range of search terms used here was also extended considerably.

Philosopher's Index (1960 - 1999; as available at time of search)
(Combinations of keywords are listed here *without* 'and' or '&' as used in the searches)

hospice existentialism: 0 hit
hospice phenomenology: 0 hit
dying: 135 hits; all checked; selected: 9
hospice care: 6 hits; selected: 1
terminal care: 6 hits; selected: 1
terminally ill: 64 hits; all checked; selected: 0 (none was relevant for this study)
relationships: 1,398 hits)

Philosopher's Index continued:

relationship: 4,690 hits) combined key word search:
interpersonal: 428 hits)
interpersonal relationship: 7 hits; selected: 2
communication: 2,585 hits
interpersonal communication: 6 hits; selected: 2
close: 1,211 hits
close relationship: 46 hits; selected: 2
close interpersonal: 1 hit; selected: 0
personal: 3,646 hits) combined key word search:
personal relationship: 19 hits; selected: 5
care: 2,540 hits
care relationship: 2 hits; selected: 0
patient: 1,181 hits
patient care: 48 hits; selected: 5
communication: 2,585 hits) combined key word search:
patient communication: 4 hits; selected: 1
nurse: 48 hits
patient nurse: 5 hits; selected: 3
nurse communication: 0 hit
staff: 4,245 hits
care staff communication: 0 hit
hospice: 32 hits)
communication: 2,585 hits) combined key word search:
hospice communication: 0 hit
human: 17,319 hits)
caring: 274 hits) combined key word search:
human caring: 1 hit; selected: 0
hospice relationship: 0 hit
terminal: 103 hits)
ill: 463 hits)
terminal ill relationship: 0 hit
terminal care: 6 hits; selected: 1
hospice care: 6 hits; selected: 0
palliative: 19 hits)
medicine: 3,074 hits) combined key word search:
palliative medicine: 1 hit; selected: 0
nursing: 155 hits
palliative nursing: 0 hit
palliative care: 15 hits; selected: 0
interpersonal relationship: 7 hits; selected: 2
close interpersonal relationship: 1 hit; selected: 0
close relationship: 46 hits; selected: 2
care relationship: 2 hits; selected: 0
personal relationship: 19 hits; selected: 5
terminally ill relationship: 0 hit
patient care: 48 hits; selected: 8
patient communication: 4 hits; selected: 1

Philosopher's Index continued:

interpersonal communication: 6 hits; selected: 2
nurse communication: 0 hit
care staff communication: 0 hit
hospice communication: 0 hit
hospice nurse: 0 hit
hospice nursing: 0 hit
doctor: 392 hits
hospice doctor: 0 hit
physician: 772 hits
hospice physician: 0 hit
counsellor: 4 hits
hospice counsellor: 0 hit
nurse patient: 5 hits; selected: 4
human caring: 1 hit; selected: 1
palliative medicine: 1 hit; selected: 1
palliative nursing: 0 hit
palliative care: 15 hits; selected: 0
palliation: 4 hits; selected: 1
patients families: 44 hits; selected: 9
patient relative: 3 hits; selected: 0
patient family communication: 0 hit
patient relative communication: 0 hit
patient family relationship: 1 hit; selected: 0

ProQuest Dissertation Abstracts (International) 1989 - 1999
(as available at time of search)

caregiver patient relationship hospice: 12 hits; selected: 12
hospice carer patient interaction communication relationship: 0 hit
hospice carer patient: 2 hits; selected: 2
hospice carer patient relationship: 0 hit
hospice carer patient communication: 0 hit
palliation: 13 hits; all checked; selected: 0
hospice care: 50; all checked; selected: 5
terminally ill patient: 62 hits; all checked; selected: 4
interpersonal relationship caregiver hospice: 0 hit
relationship hospice care: 11 hits; all checked; selected: 0
relationship palliative care: 14 hits; all checked; selected: 0

SEARCH RESULTS

Methodology

As explained in Chapter II, the design chosen for this study was a qualitative one using a phenomenological approach for data analysis. Only few other studies in the field were found which also used this approach: Leichtentritt et. al. (2000) used phenomenological methods to analyse the "essences of the good death phenomenon", and Stiles (1994) examined the spiritual relationship between nurses and bereaved families. She offered the term "the shining stranger" for both, nurses and bereaved families; each taking on the role of the shining stranger for the other. Jones (1997) combined "psychoanalytical ways of thinking" with an existential phenomenological approach to understand the data generated during supervision sessions by the author with five Macmillan nurses. Jones (1997) offers suggestions on interview techniques and for clinical supervision and, in addition, emphasizes the importance of a "structured environment" to help Macmillan homecare nurses in their work. Both studies, though similar in their research design to the present one, emphasize very different aspects of the caregiving relationship compared to those in this study.

Hermann (1997) used structured interviews to group "spiritual needs of dying patients" into six themes, and Exley (1999) conducted "focused interviews" to explore the "experience of living with cancer" from a patient's point of view. A combination of participant observation and in-depth interviews was adopted by Ward (1998) in his study on boundaries between hospice caregivers and patients; a data collection method also used by Raudonis (1991) in her study on empathy. Self-reports and interviews with hospital nurses and terminally ill patients were used by Weinandy (1998) in his study on nurse/patient quality of interaction and communication. A very expansive interview and participant observation study was conducted by Munns (1991) on the quality of life from the dying patient's viewpoint, whereas Beach (1995) focused on the family caregivers' point of view. She investigated their communication experiences with the terminal patients in their care and reported that there were communication difficulties between the family caregiver and the patient, as well as between the family caregiver and other family members.

Background Studies

The patient-family-caregiver relationship and their communication were addressed in a number of studies, emphasizing very different topics and aspects to the wider area of care for the dying and death, thereby highlighting the expanse of the field. As it would breach the scope of this literature review, only a brief summary of research examples in the wider field is given here.

"The phenomenon of how [hospice] nurses thrive in this difficult caring role" was explored by Lamendola (1998) who studied nurses caring for AIDS patients, whereas Pruyser (1985) examined the "existential impact" on professionals working with life-threatening or terminal illness. Larsen (1993), in his book "The Helpers Journey" had the goal "to provide an opportunity for you to compare your inner life as a helper with those of fellow helpers". The disintegration of a dying patient's self was examined by Lawton (1998) in three different contexts: institutional, NHS and a contemporary English societal understanding of dying. The 'quality of life' of dying patients (e.g. Munns, 1991; Cella, 1992) is another aspect studied, as are the expectations dying patients and their families have of a specialist palliative care team (Jarrett et. al., 1999). The processes involved in dying at home as well as the distress of both, patient and carer when managing pain at home, were addressed by Vachon (1998) in her article on "psychosocial needs of patients and families". Raudonis (1991) conducted research on empathy in a hospice environment and Lynn (1993) published a book on empathy based on her experiences working in nursing homes and hospices. "Spirituality" was the subject of other researchers, such as Stiles (1994), Hermann

(1997), Burkhardt and Nagai-Jacobson (1997), or Johnston (1997). Patient care in hospices is based on "a philosophy of care for the terminally ill" and its application has been the focus of studies by, for example, Mesler (1994-1995).

Dying and death not only take place in hospices but more often than not in hospitals which have been the setting for several studies in the field, for example, on communication between physicians and patients, incorporating the notion of 'telling the truth' or not. Coberly (1998), for example, examined communication and caregivers' education, suggesting that "the Tybetan Buddhist psychology of death and dying" would help to fill the need for a "more expansive and transpersonal view" in hospice care and education. On the other hand, Heitman (1988) linked communication and ethical hospital care to the needs of non-English speaking patients. A hospital was also the setting for Weinandy's (1998) research into nurse/patient communication which was evaluated by the participants as "confusing and ineffective". Wilson (1975) described "the traditional practice of 'telling the family but not the patient' " as a "howler in communication" and argued that courage in being truthful towards patients is "not a virtue but a necessity". This argument was in part taken up again later by, for example, Misbin (1990): "Telling the truth" is seen as the duty of a physician, but only if the cancer patient wishes so. He posed the question: "Should [a] physician write a Do Not Resuscitate Order without prior approval by the patient?" In a similar light, Justin (1987) emphasized the importance of "clear communication" from a patient: "Competent patients need to record directives about their care [when they die] in advance of a crisis situation." Von Guten et. al. (2000) emphasized that "structuring" communication should ensure "competency in end-of-life care" by physicians and may lead to "satisfactory relationships of care".

The carer-patient relationship has been the topic of studies as diverse in focus as, for example, "elder abuse" (Compton et. al., 1997), an analysis between lay- and professional caring relationships (Kitson, 1987), the "inherently flawed biomedical model of relationship between physicians and patients (Rosenberg and Towers, 1986), or the ethical aspects of the nurse-patient relationship (e.g. Murphy and Hunter, 1983; Fry 1989; Wilson 1994). The role of a close relationship in physician-assisted death was the focus of a study by Jecker (1991). The relationship between patients, their families and physicians was examined by Warr (1999) in the light of "society's denial of death" and the need for all involved to "redirect their thinking [when] treatment fails ... and hope fades". Miller (1996) investigated yet another relationship aspect, namely the efforts of caregivers in paediatric medicine "to be neither judgemental nor nondirective in their relations with patients". On the other hand, Seulin et. al. (1989) discussed the development and validation of a measurement scale of patient involvement in the carer-patient relationship, whereas Moore et. al. (1992) argued that the relationship between physician and terminally ill patient is a key factor in the successful outcome of home care.

"Spirituality" was a concept examined from a variety of viewpoints. For example, Stiles (1994) concentrated on the "meaning of the nurse-family spiritual relationship", whereas Hermann (1997) developed the Spiritual Needs Inventory (SNI) with dying patients in hospice care. "Dying is more than a medical occurrence; it is a psychospiritual process ..." was the stance taken by Burkhardt and Nagai-Jacobson (1997). They suggested that psychospiritual care can be enhanced if caregivers are willing to share patients' and families' psychospiritual concerns. However, Johnston (1997) differentiated between psychological and spiritual care and found that caregivers considered spiritual care to be more difficult than psychological care of dying patients.

The issue of 'facing dying and death' is addressed, among others, by Benn (1993) in his article discussing the difference between "conceiving of" one's own death vs. "conceiving of what it is like [to die]". Choron (1964) published a book about "the problem of 'how to cope with the acute awareness of mortality' ", whereas Slote

(1975) offered a "unified and detailed explanation" of aspects related to the fear of dying as discussed earlier by Pascal, Kierkegaard, Heidegger, and Sartre.

Level II Studies

Communication

Communication by hospice caregivers, e.g. palliative nurses was the focus of studies such as the one by Wilkinson et. al. (1998). They evaluated a communication skills training programme and reported that after completing the programme, palliative nurses felt more confident in their handling of difficult situations. Communication and interpersonal skills "which can be easily learned" were 'advertised' by Gordon and Edwards (1995), to create "collaborative and mutually satisfying relationships with patients".

The need for a "prioritization of communication skills in nursing education" was put forward by McGrath et. al. (1999) who reported several difficulties in communication when palliative nurses try to talk with patients and families openly about dying. The authors conducted a descriptive and thematic analysis of 167 "incidents" related to nurse-patient-family communication about dying. They suggested that, for example, denial, resistance, anger, and interference are "blocks to open communication". Open communication is also the main focus in a longitudinal prospective study by Hinton (1998). He conducted an extensive number of interviews with dying patients and the relatives who were the main caregivers. Hinton examined the role of open communication in relation to acceptance of dying and death by patients. However, in contrast to the stance put forward by other researchers in the field, he suggested that greater openness, especially when talking about feelings "seems to be linked to greater anxiety or depression" in patients. Hinton thereby questions the assumption that open communication is the kind of communication that should be practised for the benefit of dying patients. In a similar light, Misbin (1990) argued that although the physician has the duty to tell the patient the truth, this should only be done if the patient wishes to hear the truth. But, it could be argued, as does Franks (1997), that the reluctance to break bad news is based on a perhaps wrongly "long-held belief that patients may be psychologically damaged by being told the truth", a view which is based to some extent on the Hippocratic oath:

> It is interesting to note that classical statements or codes of medical ethics, such as the Hippocratic oath, mandate no requirement of telling the truth in the patient-physician relationship. While the traditional medical codes did not explicitly call for deception, they certainly made no appeal for full revelation, and it was widely believed that the withholding of much information might well be justified (Brody, 1988).

An important study on patient-nurse communication, based on an assessment skills training programme, was conducted by Haven and Maguire (1997) into a) the ability of 42 female nurses - caring for hospice patients - to correctly "register" the concerns of patients when doing an assessment on them, and b) the selectivity by patients in what concerns they disclosed. Their results indicated that patients showed "a strong bias toward disclosing physical symptoms", withholding between 60% and 80% of other issues, such as concerns about their future, their appearance (e.g. hair loss) and "loss of independence". However, of those concerns that were disclosed, "nurses registered only 40% ..., and less than 20% of patients' concerns were identified appropriately". It seemed that nurses were more receptive to some concerns, like pain and family worries, than to others, such as emotional worries.

Jarrett and Payne (2000) thematically analysed recordings of nurse-patient communication and focused on the theme of "optimism" as displayed in the "cheerful nature of nurse-patient interaction". They suggested that both, nurses and cancer patients create and maintain this cheerful interaction and that, contrary to other suggestions in the literature, the "chatty nature" is *not* due to a lack of nurses' communication skills.

The stance that communication is closely linked to relationship was taken up by von Friederichs-Fitzwater (1987) who based her study on the assertion that "health care is essentially a social relationship" and that the "interaction between provider and patient ... is the crux of the health care system". She set out to examine the communication between different levels of caregivers (doctors, nurses, hospice staff / volunteers) and terminally ill patients in both, a hospice and a non-hospice setting. The focus of her study was on the "language variable called immediacy", defined as "the degree to which a person associates himself/herself with the topic of a message or with the other person in the interaction" (Bradac et al., 1979; quoted by von Friederichs-Fitzwater, 1987). At the other end of the scale in von Friederichs-Fitzwater's study is the concept of "distancing", i.e. caregivers avoid either the "topic of a message" or the other person, i.e. the terminally ill patient. The main finding in her study was that "there are significant levels of nonimmediacy in the communication of providers and of dying patients".

The aspect of "distancing" was also reported in a study by Clair (1987), albeit not in a hospice setting but in an oncology unit. He concluded that at the point when physicians perceive that nothing more could be done for the cancer patient, they distanced themselves either gradually or abruptly. At the same time, dying patients are expected "to limit their claim on others for attention, imposing as little burden as possible, are encouraged not to verbalize certain complaints, ... and rely on themselves to the extent possible", with the family being expected to take care of their needs. Clair's (1987) findings on distancing of physicians was contradicted by Brolan (1993) who found the exact opposite result with his study, i.e. medical oncologists "clearly communicate with patients and families when the 'nothing more to do stage' has been reached". He suggested that physicians "actually join and bond with both patients and families" and "marshall their own internal resources as well as those of the ... hospice toward comprehensive, palliative care for the patient with active support for the family."

Level II studies

Relationships

The relationship between caregiver and patient-family unit has also been examined within a philosophical framework. Rompp (1987), for example, highlights "the mutual dependencies of individuality and ethical self-understanding which ground man's original relation with his fellow man". However, von Manz (1994) addressed "how the notion of the other is essential for the notion of the self", a point related to the suggestion in Chapter IV that the death of 'myself' can be transformed by the dying patient into the death of 'another'.

A link between communication and relationship is postulated by Coberly (1998) in a study which was based on the premise that "caregivers are increasingly required to interact with dying patients for longer periods, in more intimate ways, and in more meaningful ways." Despite the initial appearance of relevance to this thesis, the focus of her study, however, was placed on the development of models of communication, suggesting that "Tibetan Buddhism is particularly relevant to the transpersonal study of death and dying in the West ...". A small-scale case study with four hospice patients was conducted by Sander (1991) asking "how these patients developed close relationships with hospice staff who served as their confidantes". She reported that although these relationships "had the emotional intensity of family bonds", patients, however, confided in selected staff those thoughts, experiences, and feelings which they felt they could not share with their families. This study also highlights the importance that open communication plays in the relationship between caregivers and patients.

Relationships, especially between the patient-family unit and caregivers in a hospice setting, have been addressed, for example, by Raudonis (1995). She conducted in-depth interviews with 10 terminally-ill hospice patients about their relationships with hospice nurses. All patients had formed empathic relationships with at least one nurse. Raudonis (1995) suggested that an empathic relationship consists of three phases and "occurs most often over time", stressing that the possibility for forming such a relationship is enhanced if patients and nurses have rather more than less time to do so. An empathic relationship also includes "reciprocal sharing" (communicating) as one of its constituent elements. In a longitudinal study in a hospital-based hospice unit, Samarel (1989) used participant observation and informal interviews to analyse how "10 nurses interacted with 147 terminally ill patients ..." in the hospice unit. The quality of these interactions was found to be determined not by an "acute" or "terminal" status of a patient but by the responsiveness patients showed towards the nurses.

An interview study with nine bereaved family caregivers by Raudonis and Kirschling (1996) initially addressed the same areas as in this study: "The key component of hospice nursing is the interaction between the nurse, the terminally ill person, and the family". The authors set out "to describe the relationships between the hospice patient, the nurse, and the family caregivers". Their final focus, however, was placed on the question: do "family caregivers ... develop empathic relationships with ... hospice nurses". Raudonis' and Kirschling's (1996) main conclusion of their study is that hospice nurses were perceived by family caregivers as being part of the bereaved family. Therefore, despite the initially very similar sounding topic, the focus of the study is quite different than the one presented here.

SUMMARY

The main findings of this literature search are first, that there is a wide range of background studies and literature addressing either one, two or all three of the initial keywords identified for this search. However, these studies are classed here as 'background' because they refer to either the context in which this thesis was conducted or because they address issues also raised here but with a different focus, for example, Raudonis (1991), Lynn (1993), Mesler (1994-1995), Wilson (1975), or Coberly (1998), Weinandy (1998) and Warr (1999). A phenomenological approach as used in this study was also the chosen method of analysis for some researchers, such as Stiles (1994) and Jones (1997).

The second major finding of this literature search is that there are a number of studies identified here as 'Level II' addressing the issues of communication and relationship albeit with a different focus: caregivers' "immediacy" and "distancing" when communicating with patients and families were addressed by, for example, Friederichs-Fitzwater (1987), Clair (1987) and Brolan (1993). The concept of "immediacy" could be linked to the concept of *connecting* as put forward in this thesis, whereas the concept of "distancing" could be linked on one hand to caregiver communication problems as reported by some of the participants in this study, who spoke, for example, of feeling uncertain about what to say, a point made also by Lefevre (1992). On the other hand, "distancing" could be linked to communication problems originating in the patients, who may not communicate at all or only partially with the caregiver.

It is important to note that communication does not take place in a vacuum and it is suggested here that communication and -skills alone do *not* ensure a caregiving relationship between caregiver and the patient/family unit. There exists an interdependence between communicating and relating, both having the 'ability' to influence and form each other. As Doyle (1984) and McCann and Pearlman (1990) argued:

> Not infrequently, it is within the context of a relationship of trust that the patient will begin to explore the nature of his illness. He may want to know ... what the probable outcome of his illness will be, although these issues may be raised obliquely rather than in a direct manner. (Doyle, 1984).

> ... most people who are traumatized want and need to experience a relationship with a real, warm, concerned human being who is actively involved with them in an empathic, responsive way. (McCann and Pearlman, 1990; quoted in Janoff-Bulman, 1992).

Other Level II studies, for example, Sander (1991), Raudonis (1995) and Coberly (1998), addressed the relationship between caregivers and the patient/family unit, however, again emphasizing a different focus and perspective to the one postulated in this study: patients and family caregivers (e.g. Raudonis and Kirschling, 1996) form close relationships with hospice based caregivers, especially nurses. The main, third finding of this literature search is, that as yet there seems to be no phenomenological study examining the caregiving relationship from the perspective of the caregivers, using only their experiences as data.

One aspect not addressed in this thesis is pain, especially intractable pain and its influence on all concerned. However, I would like to mention it here because of its importance to communication and relationship. In their article on "intractable pain in the terminally ill", Laval et al. (1997) argued that intractable pain effects the "balance of relationships within the family" as well as the "quality of relationships within [caregiver] teams". The first point about the balance of relationships within the family was explained by Dame Cicely Saunders, who described intractable pain as "a total pain that gradually overwhelms the patients' consciousness, cutting them off from other people" (as quoted by Laval et al., 1997).

CHAPTER VIII

THE STUDY: PART I

THEMATIC ANALYSIS: THE RELATIONSHIP

INTRODUCTION

In the next three chapters I present the analysis and findings of the follow-up study which aimed to further elucidate the topic identified in Chapter V and explored in Chapters V (pilot study) and VI (focus group interview), that is, how do palliative caregivers relate and communicate with patients and families in their care.

This chapter focuses on *relating*, Chapter IX on *communicating*, and Chapter X provides a general description of the *caregiving relationship* incorporating the findings of both previous chapters as well as those of Chapters V and VI.

The aim of this chapter is to identify and describe the major *themes of relating* as revealed by the analysis of the data of the follow-up study. These themes are presented here in a sequence that shows how they may interact with each other and what role they may play in the development of the caregiving relationship. The four major themes identified and described here are: *involvement*, *balance*, *relating*, and *connecting*. Before introducing each theme, however, I briefly explain how the data of the follow-up study (referred to from this point on simply as "the study") was analysed.

THE ANALYSIS

As explained in more detail in Chapter II, twenty-six palliative caregivers at four hospices in Britain were interviewed for the study: eight hospice staff nurses, five home care nurses, four physicians, three volunteers, three counsellors, one matron, one lecturer in palliative care, and one hospice administrator. All interviews were transcribed verbatim for subsequent analysis (see Appendix 4 for examples of these protocols).

The analysis of the twenty-six protocols as well as of the focus group interview (Chapter VI) initially followed the same procedural steps as applied in the analysis of the pilot data (see Chapter V). *Meaning units* were identified, extracted, and collated to reveal the underlying dominant themes. These themes were then analyzed.

The subsequent thematic analysis followed Wertz's (1985: 174, 175) outline of a method of *psychological reflection* which he described as follows:

1. Empathic immersement in the world of description;
2. slowing down and dwelling;
3. magnification and amplification of the situation;
4. suspension of belief and employment of intense interest;
5. the turn from objects to their meanings (Wertz, 1985: 175).

As Wertz pointed out (1985: 173), *reflecting* in order to arrive at what he called "psychological sense" (1985: 173) is both an ambiguous and complex endeavour that relies heavily on spontaneous insight and intuition and is difficult to specify or describe in detail because "... the researcher both *finds* and *makes* sense at the same time. Psychological insight is both a discovery and a creation" (1985: 173).

THE THEMES

I suggested in Chapter V that the way of relating called *acting-as-a-friend* in this study may be initiated, and facilitated in the early stages of contact by the activation of two psychological states: a period of *heightened psychological accessibility* in patients and/or family members, and the *'feeling of being touched or moved'* by them in caregivers. If caregivers are able to emotionally respond in such a way, their inclination and willingness to become involved may be enhanced. *Involvement* in this context means going beyond the fulfilment of one's professional role, responding as a person as well as a professional, and participating in the whole situation. Such an involvement, I suggest, is a precondition for *truly* acting-as-a-friend; without this kind of involvement this way of relating can easily turn into just an act. Thus, the first major theme in the development of the caregiving relationship is the *theme of involvement.*

BECOMING INVOLVED

The data in Chapter IV suggest that becoming involved with the whole person and participating in the whole situation is generally experienced by caregivers as positive and rewarding. To be allowed into the situation and share it, to become part of the psychological and spiritual process the situation engenders in patients and families, is a moving and often profound experience for many caregivers, while, conversely, not to be allowed into the situation, not to be able to become part of the process, is experienced as frustrating and stressful (see Chapter IV). To become or not to become involved in such a way, therefore, is an important issue for caregivers. The analyses of the protocols of the study indicate that three aspects of the theme of involvement are seen as particularily relevant by the participants: 1. The feelings and consequences associated with *not* becoming involved, 2. the keeping of *boundaries*, and 3. the feelings and consequences associated with becoming *too* involved.

Not Becoming Involved

There are basically two reasons why caregivers do not become involved in a given situation: 1. the patient and/or family does not want this kind of involvement, and 2. the particular caregiver cannot become or declines to become involved in such a way. The three episodes that follow are representative of the first case:

> And there was another man up there too who was referred to us again for support of his wife - and I knocked [on the door] and a very frightened lady opened, obviously this patient's wife, and she took me to this very meticulous room and this very pale [man] sitting on this single bed, looking down and I remember saying to him: "I am Carla, and how are you feeling?" And he sort of said: "How the bloody hell do you think I am feeling, I've got cancer of the stomach, don't ask that question again." And his wife sat down but she was obviously frightened of him, I suppose this had gone on for ages. And again I recall the 'I don't know what to do' going on in me and sitting there thinking, sitting in silence for ages, and eventually got round to [talk about] his pain, he was very slow in responding and giving an answer to any question. I just sort of sat. And the feeling I can recall was: 'I have to stick here but I don't know what to do'. And fortunately for me at that time his doctor arrived and I sort of said to the doctor: "I don't think [name] wants me to be here at all but I would advise" and I was giving the doctor advice on his pain control (W 5).

> There was a family recently that I went into, the husband, he was the patient, was reluctant to have any help, was denying really what was going on with him. [The] family wanted probably as much help as they could have, and this particular one is an extreme one because it was almost frightening for me, really, because he was getting very angry during the interactions, physically, thumping with the side, on the arm of the chair, he was raising his voice, and he was using very strong language and it was all out of character apparently for him. But it was difficult to find a way in to reach him. He was just being very angry about everything and denying what was happening ... I started off letting him actually get all this out and on future visits I was turning round what he was saying to me back to him, but he was still not getting too far, really. ... He was very choosy of who he let in to talk with him, he let me in. I don't know why he let me in as opposed to

> anybody else, but it was very difficult to know how to help this man (W 6).

> The most recent death that has touched me quite significantly, a lady who was in her late thirties, and all the way through her admission here, was extremely calm. It's not that I expect patients to be angry, [but] sometimes I am amazed that patients aren't more angry, it's incredible that realistically thinking about the end of their lives and they are not cross, and I think: "Would I ever be in their position without being cross at dying at that age? Could I ever achieve that?" And this lady was extremely calm throughout her whole stay with us and very very realistic from the word "go", had many things to sort out, very categorically she wanted to work through all the things that she needed to do. I was in awe of her, I think, a little bit, and I often wondered if we would see an angry spell before she died. But she was like that to the end. And I wondered how that was for her family? Was it hard on them that she was so calm? And in some ways coping with somebody's anger is easier than not seeing their anger. It's almost unbelievable to see somebody that peaceful and somehow harder, perhaps because you wonder what you could offer that person, maybe you're feeling that you're not being of much use, or in some way helping this person as much as you would like to on their journey, and it makes you realize again how individual it is, that they don't all need you to help them on that journey, maybe the time out from their own environment is all that they do need and to recognize [that] is even more important and not doing something that you don't need to do. And all we gave her was the ability to do that and we actually didn't need to help her. And that was a huge, a big thing for me, a very special thing, because I was in awe of the woman, absolutely in awe of her (C 1).

There may be a number of reasons why patients and/or family members do not want to or will not allow caregivers to become involved. In the three episodes recounted here, it was the patient who did not want the involvement. In the first situation the patient refused to talk about his feelings, or, for that matter, about anything at all ("sitting in silence for ages"). Faced with a non-communicative patient and a relative who apparently was too afraid to communicate, the caregiver felt helpless and useless ("I don't know what to do"). The feeling of not being wanted to be there and of not being allowed to help led the caregiver to psychologically withdraw from the situation. In the second situation, the patient's denial, anger, and reluctance to be helped made it difficult for the caregiver to become involved with him ("to find a way in to reach him"). However, she persisted in her effort and used different strategies to overcome the patient's resistance, but in the end felt that she had not really succeeded ("it was very difficult to know how to help this man"). This particular caregiver did not withdraw but did not really feel involved either and was dissatisfied with the outcome of her interventions ("he was still not getting too far").

The third experience quoted above is very different from the other two. Here the patient had attained a psychological state that did not require the caregiver's involvement ("extremely calm, very realistic, peaceful"). It was an unusual situation for her to deal with ("a very special thing") that left her bewildered and in awe ("you wonder what you could offer that person"). Realizing that her involvement was not asked for or needed ("we actually didn't need to help her"), she acknowledged the *individuality of the journey* and the importance of not intervening when intervention becomes unnecessary ("not doing something that you don't need to do").

That the first two situations are not an uncommon experience for caregivers is supported by similar accounts by other participants in the study. The assessment of caregivers that a particular patient-family unit is not coping well and needs help while at the same time being psychologically inaccessible, which makes it difficult or impossible for caregivers to become involved, typically engenders feelings of dissatisfaction, frustration, and "helplessness" and the apprehension of not providing the care required. Caregivers, of course, cannot and usually do not force themselves on those in their care or intrude into their situation; all they can do is to reach out and communicate their willingness to help.

There may be as many reasons why caregivers choose not to or cannot become involved in certain situations or with certain patients and families as there are for the patients and families who will not allow this involvement. Palliative caregivers often carry heavy workloads, the work itself is emotionally demanding and often draining, and as a result they often feel tired, "strung up", and exhausted (Parkes, Relf, and Couldrick: 1996). Their willingness and capacity to involve themselves may be affected by this. The participants in the study talked very little about this aspect and there is not sufficient data in the protocols to draw any conclusions about or even describe this aspect in more detail. The episode that follows, however, reveals what can happen if the caregiver's involvement is not an involvement with the whole person:

> He was also here [in the hospice], and this is going back quite a long time for me now, he's somebody that stayed with me and I probably couldn't have talked about him until about a year or two ago, he was a chap who was only thirty-two, and he'd got AIDS, he was referred to me really as a last ditch in terms of pain control because he'd been getting a lot of abdominal pain. I met him when he was about to go home after the operation, and he was pain-controlled when he went home [but] having lost so much weight and the change in his appearance, he couldn't work, and he focused a lot on work, and so once he couldn't work he also lost a lot of motivation and got very lonely, in fact, he didn't want to live, but on the other hand, he was very afraid of dying. After he'd been home for a couple of weeks, his condition really deteriorated a lot, so the GP rang up and said, could I go and start a syringe-drive which is what we do when people are dying, so I went out and did that and we put some drugs in. [Later] his [partner] phoned up and [said] that [the patient] was in pain and he was really uncomfortable and could we come and do something. So I had to ring the GP to come out again and we gave him some more drugs, we gave him, we had to give him about [four times] the doses, so four lots of injections to get him comfortable, and that was just very tense, very worrying, again you felt quite helpless because is he going to die with uncontrolled pain? And about two hours [later] his partner paged me and said that [the patient] had died, and that he did die peacefully. I remember feeling I was just so relieved that the whole thing was over and that it had ended up all right but I also felt a bit guilty because I felt we killed him by giving him so much drugs. Now, looking back, I don't think it did contribute, because usually people are going to die their own death, but that's not what I thought at the time. I think because he was so vocal, he cried and screamed in pain, I think that made us all panic, I think we all were out of control and distressed, and I think we have a vicious circle where he was distressed and that distressed us and that distressed him more, so, I think that might have been happening. I think as well because he was screaming and he couldn't talk to us, we couldn't really assess him properly, so, we couldn't do much to help, and, the other big issue, I think now, is that

> because he expressed his pain physically, that we all felt the need to do something. And I think the drug probably didn't help because, first of all, it might not have been the right drug, secondly, [the patient] expected a certain amount of pain, but I think we missed the bigger picture as well with him. I think we missed that he [remembered] his sister's death, that he was very much afraid of dying, that he was concerned about his parents, concerned about his partner and what was going to happen to him, and I think we missed all of that. We didn't see the need of being with him, we did all the doing to him but we didn't do the being with him (W 7).

Her perceived failure to involve herself with the whole person, with *all* the issues confronting this patient, had a profound and long-lasting impact on this particular caregiver ("this is going back quite a long time for me now, he's somebody that stayed with me and I probably couldn't have talked about him until about a year or two ago").

To summarize, the data suggest that an involvement with the whole person and the whole situation is something desired and aimed for by caregivers and that a failure to achieve this is experienced as frustrating and distressing. *Not becoming involved* is seen as detrimental to providing the total care aspired to in palliative care work.

Keeping Boundaries

Although the involvement aimed for in palliative care is an involvement with the whole person and the whole situation, boundaries between the parties must still be kept intact. A loss of boundaries may not only interfere with performing the professional duties involved in caregiving (W3), whether to a greater or lesser extent (A6), it may also be experienced by individual caregivers as a personal "disaster" (W2) or as "becoming emotionally overwhelmed" (W1). A loss of boundaries may start innocently enough by simply leaving one's private telephone number in a situation that is not fully assessed:

> When I first came to the hospice, I went to visit this gentleman who said: "Yes, well, I know what's happening, I sort of got this cancer", but it was very sort of, something to do with his leg, I think, I can't remember the details now, but suddenly [there] was this spread into the lungs and he became very ill and went into the general hospital and died. I think I only visited him three times and during that time I said, as we do: "How is your wife?" "Well, she is not really coping terribly well, but she doesn't really want to see you, not from the hospice." I said: "That's OK, well, here is my number, that's fine." They were a family with lots and lots of hang-ups, and so I was really just making in-roads with this gentleman when he suddenly died, and I was due to visit on the day that he died, so I actually went up to the hospital which isn't far, and I think I only met his wife once before, so it was only the second time of meeting, I met her in the hospital and he was just dying when I got there, so she sort of flung herself on me, and in my desire to be of help I thought: "Oh, gosh, here is somebody that needs me", and it was a Friday, I wasn't working weekends, and I knew it was my own guilt that I felt "gosh", you know, "What do these people do at the weekend?", that was one of my anxieties, so I said: "Look, here is my telephone number, if you want anything at the weekend, just please phone." Big mistake! Big mistake! I mean, to cut a very long story short, she became very attached to me. I got to the point where at the weekends it was very difficult for me to answer the phone in case it was her, and that was my own need, seeing my own needs, really, [it was] a disaster. Anyway, eventually it resolved itself as things do, but with my empathy and my willingness to help, [at that time] I'd suddenly become [her] 'Mum', and by the time I saw it, it was very difficult, so, that's a warning, a stern warning of how not to do it in a way. And I think you only need one of those. And I hear people now sometimes say: "I think I leave my phone number", and this warning bell goes in my head and I think: "No, don't do it." (W 2)

The caregiver recounting this experience belatedly realized that "her need to be needed", in addition to her empathy and willingness to help, created a situation that facilitated the development of an inappropriate attachment ("I'd suddenly become her 'Mum' ").

Boundaries can be lost if a caregiver identifies with a particular patient or relative:

> You see the lady in the bed with her younger son, and you think 'Oh, that's like me with my son', and it does it, it recalls things, it makes you

> very emotional at times, very hard to cope with, very hard sometimes, and I think sometimes we have to put on a slightly abrupt behaviour, you put, what I call, your professional coat back on, it's done up tight this professional coat, sometimes the coat is undone, and it is slightly off your shoulders, sometimes it is completely off, and you just break down and lose it, other times you are in-between (A 6).

It may be easy, natural, and an 'automatic' reaction for caregivers to identify with someone in their care if this person happens to be of the same gender, similar age, and comparable personal circumstances ("you see the lady in the bed with her younger son and ... think: 'Oh, that's just like me with my son' "). But identifying with someone in this situation not only engenders emotions which, at times, are very hard to cope with, but also conflict:

> A lot of feelings are generated within the carers themselves, I think for me there was this aspect where you actually get a little [too] attached to the patient and sometimes to the family, you become part of their life, and I said earlier, his age and his gender, that there was some kind of identity there where you could identify with him as a brother, as a fellow, you know, male and things like that. And that tends to sort of, I don't know whether it's clouding the caregiving, but it gets in the way to some extent, and I don't think there is any professional likely to say: "Don't feel attached" as long as the attachment doesn't interfere with the professional judgement and duty you are there to perform. But it always creates a lot of conflict within the people giving the care, and at times it also affects them at the end, when they have died here, there is a loss that people feel (W 3).

Caregivers, it appears, have to be on their guard against becoming too attached by identifying with certain patients or relatives and use certain strategies to counteract this tendency: the caregiver quoted above (A 6) put "her professional overcoat back" on and employed "slightly abrupt behaviour" while the caregiver in the following quote relied on skills learned in a counselling course:

> I can remember that during my counselling course I had to have several clients and one of them was a bereaved person, and this man had so much grief, it was just horrendous for him, his partner had been a patient of ours, but only for a couple of weeks. They had moved from a London area to be here, and, in a nutshell, he left his wife to come away with this lady, and virtually as soon as [they] arrived in this area, she became ill. It was a very virulent cancer and within a very short space of time [she] had died. So, his losses were the Church of which they were both members, had refused to have anything to do with them in the area where they lived, he'd lost his family, his wife and his three sons had nothing to do with him, he then came to this area with this lady who he was very much in love with, and then she died, so he was left with nothing. Many losses and a lot of guilt, and it was horrendous for him [and] very horrendous for me, I must say, because I felt for this man so much, but still trying to keep back. And in one of the sessions, he knew that he was bereaved, he knew he was lost, just didn't know where he was, and he was a very stoical individual, he found it very difficult to express, and in one of the sessions, he started, it was just a great outpouring, I have never experienced anything like it in my life. It was an explosion, it was just as if there was this barrage coming towards me, all this grief, and I actually felt it, it was incredible, so strong, it was just as if this was coming towards me but it was deflected, and it was almost as if I had this suit of armour on, so I tend to think, rightly or wrongly, that these counselling skills are like this suit of armour, so it doesn't quite get to me. Having said that, it sometimes seeps through, but, I mean, I don't think I could have done this job had I not done the course (W 2).

To summarize, a loss of boundaries, as these accounts demonstrate, may turn relating with patients and families into a threatening experience for caregivers against which they have to guard themselves in some way. Similar accounts by other participants in the study support this argument. Boundaries are necessary to protect caregivers from being emotionally overwhelmed or from being coaxed into undesired and/or inappropriate roles. Intact boundaries create and maintain a certain and necessary *distance* between the parties which appears to be essential in caregiving relationships.

Becoming Too Involved

The collapse of boundaries, the loss of this distance, can lead to some very intense experiences for caregivers as the following two accounts illustrate:

> When I first came into palliative care I went to work in a big oncology unit, and I don't know if it was my personal preference, or just because there were so many people there, I ended up picking up a lot of young people [to work with]. And I worked in two or three instances, I worked intensively, and maybe that was a reflection of my need at that junction, to do good, if you like, to do a good job, and I think that's something people go through with when they first go into palliative care. They need to have this very intense relationship with patients. It's something as a supervisor now I watch out for. It's interesting, for oneself there is a gift in it, but for the patient, I don't know. And so I developed, I had a quasi-counselling relationship with this [young man] and probably a quasi-friendship, and quasi-all sort of things. At that time I was trying to integrate meeting someone of my own age in a hideous situation, facing up to their own death, facing up to my own death, facing up to their unconscious anger towards me, facing up to my anxiety, the fact I may die if I got something like this. This chap was a poet which is probably why I got friendly with him, sort of intellectual, really, and I found it more difficult to give him any counselling, [so] I talked to him as a human being and usually lost my safety, my sort of 'professional overcoat', if you like. Probably was a gift for me, it was a very painful learning curve. I think I needed to loose this sort of pseudo-professional counselling stance. Anyway, this guy seemed to be getting better and we used to have a lot of conversations, and every now and then he'd pop in and have a coffee. We didn't have a relationship, and it was never in the cards, it was never spoken of, really, but I think it was probably somewhere in the background. You know, I felt quite comfortable with this relationship. Anyway, this guy eventually came back and I remember one of the doctors saying to me, something about him not lasting 'till Christmas. And I just couldn't believe my ears, I was absolutely flabbergasted. I didn't know, should I tell this guy, nobody else seemed to be telling him, and within the next week he was admitted and he was dying. It was quite clear he was dying, and he was in an awful lot of pain, nobody really knew how to deal with him, they left him to me, really. And I came in on Christmas Day, very unusual [for me], going up to the ward, and all his family at the bedside. You know, one of the things I teach now, about joining the family at the bedside, "Don't do it". [I felt] like a pseudo-daughter-in-law, that sort of way. And I remember him saying: "You have to go [now]", and that was probably the only time I knew he knew. And about two days later he just became

> unconscious, and these poor Welsh folk [his family] kept saying: "Why can't [he go home], we are in London". And what I had in my head was that he was now really unconscious and his mother did not want him to die there. So I begged and pleaded with everybody concerned with me getting an ambulance and sending him home. And they were absolutely horrified, this idea, you know, he die in the ambulance, what's he going to be like, blah, blah, blah. [But] I just got into my head we had to make this right. So this is what we did. And [they'd] got a thousand pounds for a private ambulance from the bank. And he was sent down [to Wales]. And he died a week later (A 4).

> A patient in the hospice who came in, he came from a certain part in Ireland, which is where my father came from, and people from [this area] in Ireland have a very unusual accent. And my father had died about five years earlier. I met this patient and he had exactly the same accent and I found it very difficult to talk to him in a work environment because I kept treating him as I would my dad, and whenever he used my christian name, he was the only other person to ever pronounce it like my dad did and it was very very hard when he said my name and I used to be almost drawn to going in to see him, but for the wrong reasons. I wanted to talk to him because for that minute I had my dad back and I wanted him to say my name because that was a very comforting thing for me and I was acutely aware that I could not be around when he died and did everything I could to avoid being there when I knew he was deteriorating, to the extent that I took a day's holiday as a safeguard, just in case it would happen, because I didn't feel I could share any of those feelings with the rest of the nursing staff. To me it was very private, and also I didn't want people then to watch what I was doing. It was a very very odd situation, it was a situation that I found I had virtually no control over, and I'm very pleased that I knew him, and I'm pleased that I had the opportunity to hear that accent again and to hear him talk again, but it was a very selfish thing for me, it gave me a lot of pleasure, and he had a good death, and I am very pleased that he had a good death and that we did look after him well. And I hope at some stage, he died about a year ago, so it's still fairly new, that I will be able to share that with other people. Perhaps in an environment where somebody else is struggling with a similar thing, I am sure it must be happening to staff all the time, it just had never happened to me, and when it did, it was an amazing feeling. Whenever I go into the bay where he was, I can every now and again, deliberately, will conjure up his voice (C 4).

An intense involvement with patients and/or family members may be experienced as a "gift" (A4) by caregivers or as something that gives "a lot of pleasure" (C4) but what effect it may have on the other party or parties involved is not easily assessed (A4). It may interfere with performing one's professional duties or enacting one's professional role (C4), it may lead to a withdrawal from the situation (C4), or it may result in "inappropriate" professional conduct ("so I begged and pleaded with everybody concerned") (A4).

To summarize, *becoming too involved* and the point at which boundaries are overstepped are not clear-cut issues. The consequences of becoming too involved, as well as the feelings associated with it, may be positive or negative, they may be different for the different parties involved, and different at different times. For A4, the whole concept of involvement is "nonsense":

> I was very aware that I was involved. I don't really have that concept anymore. I think what I understand from that experience is that if you are going to go on the journey with people, you're going to have to jump in, jump on the bus and stay there ... I learned from that ... that the concept of being uninvolved, involved, and over-involved is nonsense and that what we need to be is to be there, and being aware of how you are being there, in that individual circumstance, and that you can actually love people (A 4).

If one "can actually love people" (A4), the whole question of involvement becomes redundant since love implies total involvement. I think, however, that in the context of palliative care work this stance is somewhat extreme and that it may not be shared by the majority of caregivers working in this field and none of the other participants of this study expressed such a radical view.

FINDING THE RIGHT BALANCE

For most palliative caregivers, the data suggest, there needs to be some sort of balance between becoming involved and keeping a distance in dealing and relating with those in their care:

> I think you're different with each family. I mean you could go into one family and you feel really at home straight away. You're going to another one and it takes you a long, long time to be comfortable in the situation, not for any particular reason, because they will be quite open, it's just that feeling. I think you go in and you have to be a friend to a certain extent [but] it is very difficult because you get so involved in their life by going into their own homes and very privileged in the fact that they share so much with you. But it is quite hard to make that distinction between a friend and a professional because sometimes [when] you go in for a length of time they forget your professional part. I mean you have different feelings with each family [but] I think it is harder on you emotionally if you become too close to them, it is hard (S 3).

Finding the right balance becomes a task for caregivers, and it is not a simple task because each patient/family unit is different and responds differently to each caregiver, as the caregiver responds differently to each patient/family unit. It becomes a "balancing act" (S1) between remaining objective and reacting subjectively:

> Yes, that's quite difficult, really, because if you've known somebody over a long period of time, you do become more of a friend, but you still have to have a certain amount of distance to be professional and to look at things more objectively, 'cause I think once you get a bit too close, you are not very objective. It's very much a balancing act 'cause I feel if you are too distant you are not giving sufficient of yourself to empathise with the family. It's a sort of a fine line to be drawn, really, because people often say to me: "Oh, well, you must get used to it", and my feeling is, that if you do get used to it, you aren't doing the job anymore. I think, you do lose that knack that you have with people if it just becomes, you know, a family where somebody dies of cancer. I think that's why the role can be quite demanding. Your own life is totally separate, and you'll be going in to certain patients, and then you're out again. And that family will have to carry on without you, so they can't become [too] reliant on you. It's about a tailing-off process, if you like (S 1).

To achieve the right balance between becoming involved and keeping a distance, between reacting subjectively and remaining objective requires that caregivers constantly adjust to changing conditions and are aware of their own agenda, as the following three episodes illustrate:

Well, the first one is a girl who is forty-two years old, she got cancer of the kidneys, it's her primary, she's got quite a lot of disease, spread in her lungs and her stomach, which makes it sound as though she is extremely ill, and she is now, but to about two, three weeks ago, she was working nearly all the time. She's got a young teenage family, a son who is nineteen and a daughter who is sixteen, and she hadn't told them about what was the matter with her at all, although they did know that she'd had the cancer of the kidney in the past, had surgery, and as far as they were aware she was all right from that. Her husband did know what was the matter with her and he didn't want to tell the children. Then she suddenly got very ill with her lung disease and that was when I started visiting her at home and I was quite anxious before I went in, because of the situation and knowing that she hadn't told the children and knowing her husband wasn't an easy person and I did find him quite hard to relate to. Mainly because he didn't really talk. All the way along she's [the patient] been frightened about dying, well, not so much frightened really, but she just doesn't want to die. She wants to see the children grow up, all those kind of things and that can be quite sad and you can feel quite helpless because when she says: "I don't want to die", what can you say? I was feeling helpless, the district nurses were feeling helpless, and the GP is feeling helpless. We sort of at this stage hadn't really managed to get her talking much about dying except to say that she didn't want to die. And the way she carried [on] with this was by talking about practical things and we focused on [those]. Sometimes I think she is feeling guilty for having cancer and I think that's partly about the suffering she is causing her family. [We're] trying to find a way to make her feel better but some of the distress you can't take away. Her symptoms have improved quite a lot with the different things we've been doing, also her husband, but we still have the issue about the children. [But] we did manage to get them to talk [to them] and I found it quite hard to draw the boundaries of how far you should go in trying to get a person to do something, to talk about issues. And you know that you should be impartial but it's quite difficult when you know that the children are likely to have a need to know. I find it quite hard not to impose my own agenda. And a bit of me thought, because then they talked to the children about when she was going to die, how it was likely to be, where she wanted to be, and what the children wanted in that, and there's a bit of me that wishes that she could die shortly after that because that would be the perfect ending. But she hasn't died, she still doesn't want to die, she still wants to have some treatment, and I think we have to respect that, really, she just does want to live on as long as she can. [And] it's quite difficult now, a lot of times when we go round she's in tears and I don't think that she'll ever accept the fact that she is dying. But she has come a long way and she is doing things to prepare for her own death now, she talked about where she wants to be, she knows what it's likely to be like, she is thinking about things that she can do for the children. She's come a long way really (W 7).

Another man here, he was diagnosed with cancer in the stomach. When I first met him he was very positive [and] again I remembered thinking: 'Hmmh, I don't think you will be able to do this'. And at that early stage [I had] sort of mixed feelings myself, thinking: 'Do I want to dampen his spirits?' But he was just getting weaker. He was still working, then he was off sick, he was at retirement age, and then he came here [the hospice]. There was an artist here at the time as therapist, and he discovered, the patient, you know, that he was a really good artist and loved it. And he had worked on night duty in some sort of foundry where he said there was sort of black and white, or red and white, fire. And he began to appreciate the colours of the flowers and the trees and everything. And he taught me a lot, really, because he was showing the world as he saw it and one of the things he said was: "Oh, I wish I could show people the world as I now see it", because he just had a different experience from his life-long experience of going to work. And his whole experience was enhanced by having cancer. And he subsequently died but before he did he sort of must have known he was going to die fairly soon and he was saying goodbye to everybody and bought some seeds for the garden and planted them, etcetera. So, I think what I learned from him [is] that you can go on growing, you know, learning and changing your view of life, right up to the end. So he sticks in my mind (W 5).

I suppose my other experience that I carried with me is right at the beginning when I took up [the] post here. We had a twenty-one-year-old patient [who] had curative treatment over many years and it suddenly became apparent that his disease was escalating and curative treatment was suddenly stopped and he was acutely ill. His family was desperate that he wouldn't spend any more time in hospital but they couldn't take him home because his nursing needs were so great and he didn't want to go home. He classed home as going when he was well and he didn't want to take his illness to his house. So he came here. He was a delightful young man, very very intelligent, very articulate, with a very articulate, loving family and he had hoped that he would have months, and he had a project that he wanted to finish, he was an architect, starting architecture. And our doctor went in to see him and he asked her very straight questions, and I sat in on the interview, and I found it very painful to watch him being so sadly disillusioned about what's left of his life. And it was like watching building blocks being taken away from a child. I viewed, as I watched him, that he made a pyramid of brightly coloured boxes, beautiful pyramid, beautifully structured, because he was a very organized structured young man, and as the doctor spoke, blocks were taken away. But they weren't taken away from the top, they were taken away at odd places, so you were aware all the time that you were weakening this structure, that if you took the wrong block away, the whole thing would collapse. The

> easy way would have been to start at the top. But he didn't want to do that. We started with him where he wanted to start which was a very fundamental question which removed one of the main blocks, and we ended up with a shell of blocks where he still had some structure, so he could still go on, but he was very very weakened by it. He was very sad, there were lots of tears, I felt, part of me, that if it had been me doing that, I would have ignored this first question and gone to the easy option and the easy blocks, because I didn't feel I could pick up the pieces if he crumpled. But I had great admiration for the person controlling the interview, in the fact that she did have the skills, which is I am sure why she did it. He expressed his sadness at not achieving this long-term goal and after his parents came in he wanted his parents to hear exactly the same thing that he'd heard, with him present. And which again was very painful because they were distraught of losing their son and were surprised by the short time he had left. So it was discussed that his father would carry on this project in memoriam for him and his funeral was organized and what he would like, so it was all very final, and very very painful. But in hindsight, he died three days later, and he died a peaceful death, he was grateful for what he'd been told and expressed that very well and his parents in turn, coming back, expressed it very well (C 4).

As these accounts illustrate, finding the right balance is a demanding task for caregivers. Not only do they have to adjust to constantly changing conditions and needs of patients and families, they also have to be able to freely move between the poles of acting-as-a-professional and being-a-friend to meet these needs. In order to do this, caregivers need to be aware of and monitor the situation as it develops, as well as their own reactions and responses to the situation.

RELATING

A balanced involvement in this context will typically engender a way of relating that although it allows all aspects of the situation to enter the relationship (relating with the *whole person*), it still keeps the essential boundaries intact: caregivers will respond to the changing situation in flexible and creative ways, moving, whenever necessary and appropriate, either closer or further away, reacting either more or less objectively or subjectively, as the situation at the time demands.

The three episodes quoted in the last section of this chapter illustrate, in three very different situations, both how boundaries are kept throughout changing circumstances and how caregivers can respond creatively to the needs of patients and families. These episodes also provide an insight into the *nature* of these relationships. In the two quotes that follow now, the relationship becomes the focus. The first is an excerpt from the interview with a lecturer in palliative care (C3); "I" stands for *Interviewer*, i.e. the author of this study:

> I: If you compare relationships with patients and with relatives that you experience in your work, say, with relationships with people outside of your work, people who are not ill, who are not a relative, who are not bereaved, what is the essential difference between these sorts of relationships? Do they differ in some fundamental respect or are they the same, except the context is different?
>
> W3: I think the main difference is the context. The relationships with patients within the terminal units, [the illness] is the focus, that's the pivot of that relationship. Whereas with other types of relationships the focus may be different. What brings people together is going to be different in terms of [a] terminal illness. Here it is that illness which I think will be the focus of bringing that relationship, therefore, at the back of your mind you're always forming a relationship knowing that the central point is the illness.
>
> I: With both patients and families, the focus is the illness?
>
> W3: It is the illness.
>
> I: Or is it that behind the illness is the possibility of death?
>
> W3: Yes, as well as, but I think initially you are starting with the illness and then explore further on, like meanings of this illness ... Outside work, it may depend if we meet in a social setting, then the social setting may be the focus initially, and then it may move to other areas.
>
> I: But this movement is not there in relationships where the illness is the focus? The illness sort of stays at the centre of the relationship, so to speak?

> W3: Yes, yes, most of the time. In the cases that I can recall it's been the illness [that] has always been the focus, the central point, yes, then anything else would come from that, but [it] always comes back to the illness, the central focus. With relatives, with the patient, it's always that. And, interestingly, if you meet for instance the relatives outside of the setting of the care environment, the illness still tends to be the central focus, you know, because that was like the initial prompt to you to meet, so it still tends to dominate that, and I suppose even when you talk about bereavement, that is also a follow-on from the illness because that's the thing that leads on to bereavement, so it has, I think, a very powerful impact on what happens afterwards to the individual and his relations.

In the next excerpt, from the interview with a senior hospice physician (A1), this *lack of breadth* of the relationship is acknowledged but, as he points out, not breadth but *depth* is the primary characteristic of this relationship:

> A1: But I think the difficulty is when you're making [medical] decisions or when you try to work through decisions with people who you have a relationship with, [when] you're aware of the fact that there is a relationship there.
>
> I: There is not always a relationship there?
>
> A1: No.
>
> I: But sometimes
>
> A1: Sometimes there is.
>
> I: What makes it a relationship? Is it the people, the personality, or the match between you and the person, or what?
>
> A1: I think it's both of those [and] sometimes situations too. I mean, most of us find that it's more likely that we will build a relationship with somebody who is young, when I say young I mean our sort of age, rather than seventy or eighty, and has dependants, particularly children, because we could feel, you do feel [with] people who are in situations you could identify with, whereas one's capacity to be able to

feel, I mean it's not that one doesn't want to, it's just that to some extent the ability to be able to empathise with somebody depends to having been there or being close enough to actually be able to feel what they feel. We just lost a forty-one-year-old with a husband of my age and no children. Now that you can feel very deeply. That precipitates a relationship. And I suppose because you understand and also maybe, if one is honest, because you perhaps make a little bit more effort. You can't make a relationship with every patient but when you look back there are particular ones. To illustrate the point, a lady of fifty-four, ... was her name, she is the sort of person who when she was dying asked me how I was! And that does something, it makes you feel more involved with the patient when they actually reach out to you, which is actually a key area, if patients reach out to you then a relationship is much more likely to develop. Very often times come when you sort of seem to touch patients very closely or you are given permission to touch a patient, I don't mean in a physical sense, I mean in this deeper, what one may term spiritual way, and that happened with this lady. I must confess I do miss her. I remember her well although she died about five months ago. I forget most people who die here but I shan't forget ..., there was that touching somehow.

I: They stick because you go beneath the surface?

A1: Yes. It is almost as if you can touch somebody at a deeper level because you are talking about life and death issues and you don't actually have to follow-up building a relationship with the normal things that we build relationships with, you know, it's almost redundant. So the relationship can be quite deep with only a short amount of contact.

I: If a relationship is build with a patient, does it happen quicker than with another person that is not a patient?

A1: Yes, yes.

I: Because of time?

A1: Hmmh, hmmh.

I: I wonder if the limited time available has some kind of impact on the relationship formation, and also on being able to go deeper?

> A1: Yes, I think so, although in some ways it doesn't depend upon sort of breadth. I mean it isn't the breadth of the relationship, it isn't even the breadth at a certain depth, it's the fact [that] at a certain point the opportunity opens up for you to actually reach deeply into that person's life [but] you haven't got the breadth there. I mean if that person suddenly gets well and goes out, the chances are that it wouldn't actually develop into a relationship ... I can actually take on the concept of friendship with a patient here in a much more full way because I know that the relationship is not going to be something that endures because the patient is, at the end of the day, terminally ill. I think the point at which we contact most patients is empathy or at least strong sympathy and ability to identify with where they are and sudden demonstrations of need, of vulnerability, I think that's another keyword, vulnerability. When a patient demonstrates vulnerability then something inside most of us wants to be able to help, to sort of meet that vulnerability and that's normally the point at which the depth of touching a patient seems to be.
>
> I: Regardless of how long or short such a relationship may be because of death, is there a sort of movement, a development, a process that changes?
>
> A1: I think it's just the point of touching somebody at a vulnerable point, then probably it goes deep to that depth straight away and doesn't deepen further. I suspect. I am not sure that there is the facility to deepen that point of contact, you know, unless there is something else, something else in common occurs.
>
> I: This moment of perceived vulnerability, to what does this link in the carer, what is the other pole?
>
> A1: Vulnerability perhaps, maybe it does.

Caregiving relationships, the data suggest, have a number of distinguishing characteristics. On the caregivers' side, these relationships are grounded in their ability to "empathise" with those in their care, a response that is facilitated if they can "identify" to some extent with the situation. On the patient/family side, the development of this relationship seems to be facilitated if they 'demonstrate' "need and vulnerability" and a "reaching out" to caregivers. The caregiving relationship usually has a rather narrow focus, it does not require "breadth" but the "touching" of another person "at a very deep level". It also does not require a building-up over time but can become "quite deep with only a short amount of contact". The essence of this relationship seems to lie in the touching of, or *being in touch with*, another person at an essential level, something that is referred to in this study as *connecting*.

CONNECTING

That connecting is a very real experience and not just an abstract concept is made clear in the following excerpt from the interview with a hospice physician (C3):

> We have a patient in the ward at the moment, who really will not [talk] with anyone, he is very angry and just wants to be left alone. But I think in general, people want to communicate, maybe connect is the better word, because it's about being acknowledged as a person, not necessarily communicating a message, but communicating care, or whatever and that's an interesting question, really, 'cause maybe I am [in] a bit of a split there right now, from the point of view of my medical training, my medical model, and all that, you know. If they are distressed, sometimes you reach below that and meet them, and that's non-verbal, really, it's a connection, you connect, and I know when it happens and I know when it doesn't happen, and quite often when it doesn't happen, it doesn't happen because I am too distracted myself. It's not something that I can describe, it's sort of being in my middle, I suppose, in my inner self, sort of being in touch with that within me, and sort of find the same level. But nonetheless, there is the medical side of things, which is about, you know, empathising with people and so on, and I think I tune into people's feelings quite fairly well, sometimes I don't. But in general I focus more on the feelings than I do on what people are actually saying. But then in the medical model, you know, if you are assessing somebody for pain, you have to ask the questions and you have to make a contract with them about time as well, because you can't spend hours with one patient. And that sort of level of communication, is, I think, the split for me, the model and how I want to communicate. I think the medical model bit can get in the way, if you know what I mean? ... I think for me it is enriching, because it is about being connected to people, you meet people when they are very vulnerable, [when] they are moving from one crisis to another, so you meet people at a deep level very quickly, and I think I am that sort of a person that needs [this]. I couldn't work in a, well, I

> could work in a shop or supermarket, but I probably start talking to everybody about how they were, what happened to them, going on, talking to them. To me that's why it is enriching, because it's really communication at a deep level. It's just the privilege of meeting people, and that they are so open and ready to just talk to you, and you get, I can't say how, how it is, I get so much back from the people I meet. There is an equality in a funny sort of way about it, I think, it's not just me doing something for somebody, it's an interaction on an equal level rather than: "Oh, you're the doctor, you'll know what to do", or whatever.
>
> I: But from an objective point of view it isn't equal?
>
> C3: No, no.
>
> I: Yet you feel so, you experience it.
>
> C3: Yes. And maybe it's because of communication, there is an equal footing somehow, even though, I guess, they're, the patients don't know all my troubles, and I know more about their troubles, and so on, but there is something, yes, it's equal, but again, it's maybe equal and unequal, this bit in the middle, that you somehow find, the dynamic in the middle
>
> I: Or it takes place at a level where we're all equal.
>
> C3: That we are going to die, I mean, that's the bit where we are all facing our own death.

The ability to "meet people at a deep level quickly" is also one of the prerequisites of effective counselling in palliative care, as this counsellor (A4) found out:

> This work (counselling) needs to happen quickly, this folk don't want to be messing about. I am quite pro-active in teaching and in my own practice, because with people who are dying, there is an agenda and the agenda is about working out where are they spiritually, where are they sexually, where are they emotionally, what do they want to know from you, do they need to know anything, you know, what's going on? You've got to get the picture and you got to get it pretty quickly. So

> you need to ask in a very skilful way. The symbolic stuff is the most important to me, but I am always very conscious that this might be the last interview, so the symbolism within each interview needs to be a piece of work in itself, 'cause you might not do any more. And also that that person will be doing that sort of deep work in different levels at different times with different people, and so I just may happen to be one of them. They might do it with a nurse, they might do it with the cleaner, you know, does it matter? (A4)

Another counsellor interviewed (W4) pointed out the "healing" engendered by connecting: "The focus of my work lies in the meeting, that's me with the other, that moment's meeting, and what can come from that is the healing, the therapeutic moment, the possibility lies in the connection of one human being with another." Connecting, at its core, may turn out to be a spiritual matter:

> At the core of it, I say, and I have reflected quite a bit on it, it's getting into a spiritual realm when we are in this sort of relationship with people. It's not physical, I don't think it's emotional either, although there are emotions expressed. I think that it's more in the spiritual realm where we all affect each other and we connect in some different dimension, because people are more real. You know, in the face of death, I found people are more real, more themselves. To connect at a deeper level, which is a great privilege in my work, is what life is all about (W5).

These accounts show that the experience of connecting is immediately recognized by the caregiver ("I know when it happens, and I know when it doesn't happen") (C3) but difficult to describe ("It's not something I can describe") (C3). The data of the study suggest that connecting is not an uncommon experience for palliative caregivers and that it is usually felt to be highly rewarding ("To connect at a deeper level, which is the great privilege of my work, is what life is all about") (W5).

SUMMARY

I have suggested at the beginning of this chapter that palliative caregivers' relating with patients and families in the mode of *acting-as-a-friend* may be facilitated by the state of *heightened psychological accessibility* in patients and/or family members and by *the feeling of being touched or moved* by them in caregivers. The data provided in this chapter supports this argument. In periods of heightened psychological accessibility, individuals in an acute crisis often display *vulnerability and need* and a *reaching out* to others. A positive emotional response to this reaching out often enhances these others' willingness to *involve themselves* in the situation.

The nature of palliative caregivers' relationships with those in their care (*the caregiving relationship*), the data indicate, is characterized by caregivers' involvement in the situation. Involvement is defined here as going beyond the fulfilment of one's professional role, responding as a person as well as a professional, and participating in the whole situation. The data also suggest that for the majority of caregivers interviewed for this study a *balanced involvement* is aimed for and considered appropriate. Non-involvement, under-involvement ("doing all the doing but not the being with") (W7), and over-involvement are generally experienced negatively. A balanced involvement means keeping the essential boundaries intact and finding a right balance between *distance* and *closeness*. This ongoing task requires of caregivers that they are able to adjust in a flexible way to changing circumstances by being aware of and monitoring the situation as it develops and that they are aware of themselves in the situation.

The data finally suggest that the caregiving relationship is generally characterized by a *lack of breadth* and by a *limited amount of contact*. As one hospice nurse (A2) pointed out:

> I used to work in Oncology for quite a long time and I found that the relationships that we had with the Oncology patients were far different to the ones I have with patients here, probably because of the length of time that we actually spend with them. I suppose the emphasis here is symptom control and they've passed all the treatment stages and we know they will be dying at some stage within the next ... I don't know. But in Oncology it was more of an ongoing thing. It was more intense a relationship you had with people. I think because they were starting their travel, they've been diagnosed and had the pain of the diagnosis, the treatment, the fight for life and then, quite often, death. So I think relationships were more intense. [Here] they ended the treatment stage, they are at the end of their road. You don't have much time and it's a different sort of time. I suppose in Oncology people sort of rely on you in a different way. I think there is a lot of hope there, where I sit, there is not hope, there might be some time but there is no hope of a cure or long life where, I suppose, in Oncology there is and it's all very raw and very new to people, and [if] it's not raw and new, then they've got the fight for life, so your relationship is, and the trust they have in you, is very different. Here you might get people for a few weeks and that's not really long enough to get anything deep and meaningful. You might have a good relationship while they're here but the relationship, once they died, it goes very quickly. And I think when they die [they] are very different from somewhere else in their life. We are meeting at an unusual time (A 2).

"Not having much time" may be one of the reasons for this lack of breadth in the relationship. The primary characteristic, however, of the caregiving relationship is *depth,* not breadth, and moments of "reaching deeply into a person's life" (A1) can happen at any time, with anyone, and with very limited amount of contact. "Meeting people at a deep level" (C3) is referred to in this paper as *connecting* and, the data suggest, it is not an uncommon experience for caregivers.

CHAPTER IX

THE STUDY: PART II

THEMATIC ANALYSIS: COMMUNICATION

INTRODUCTION

In this chapter I explore three areas of *communication problems* identified in the analysis of the study, which, the data suggest, are commonly experienced by palliative caregivers in their communication with patients and families. I also provide quotes and interview excerpts in an attempt to clarify *the nature of communication* between caregivers and the patient/family unit, and indicate subthemes to the dominant *themes of communication* which were identified, analysed, and discussed in Chapter VI.

COMMUNICATION PROBLEMS

In Chapter III, I pointed out the importance assigned to communication in the field of palliative care and discussed how different contexts may affect the quality of this communication. I also drew attention to the central role communication plays in the formal and informal meetings of the members of multidisciplinary work teams as well as to research which suggests that communication problems rate high as work environment stressors as also reported by the palliative caregivers who took part in this study. The following quotes give examples of the difficulties caregivers experience when communicating with patients and relatives.

There are patients who you can meet time after time and never get any further than: "I'm all right, doctor, don't worry." They don't want to talk about it, and maybe they are all right. But we all feel terrible if this patient keeps coming back to us and saying: "I'm fine, I'm not frightened of dying, everything is under control." Should we disturb that equilibrium that he has achieved somehow? He says he is all right. Maybe we think he is not all right, maybe he is giving us other signals that he is not all right, but he is saying he's all right. And we get patients that we never ever get to [go] deeper than that. They are telling us they don't want to talk: "I'm all right, doctor." (S 4)

I think you have to respect the individual, although you know, there are instances when deep down, and the consensus of the whole team is that a particular patient or relative needs to talk, needs to discuss the way they feel, even to the extent that they are in control and they decide, but you still feel that there is that brick wall. And yes, we would try on occasions, given the opportunity, but I think we would respect that's the way they want to be. ... But it can be frustrating when you feel there are some aspects that you can help with, sort of help them if that's their wish ... [communication] is dependant on so much, isn't it? You only know what they tell you and their experiences in life in general. (S 8)

And I can think of a lady where the mask never came off, and I am not saying that people should, I mean, I wouldn't dream of having as a goal to take away people's defences, but I'm now thinking of this lady, a mum, back a couple of years ago, who was dying, and she had two, three small children. And she died on the hospital ward. The day that she died on [was] her daughter's birthday, [and] without ever mentioning to her husband or her children that she is dying, despite all our efforts to help her. And the hospital organized the child's birthday party on the ward, and I can remember lifting this woman, no, I said to her: "How do you want to respond when the children arrive for this party?". There she was in bed and she said: "I want you to lift me up so I can watch them coming down the ward." So we did that, we lifted her up and she watched these children come around the ward and she went: "Hi!" as though nothing is wrong, and she died an hour later. And never said goodbye to them or anything, never acknowledged with her husband that she was [dying], well, that's keeping a mask screwed on till the end, I mean, she literally [went] "Hi!" and she did it through the party, I mean, tears come to my eyes talking about that, 'cause I think that was awful, and awful for the children, and the father remained very very buttoned up, I don't think feelings have been

> expressed in that family since, it's very sad! And I also think that this horrible experience is most common in mothers with small children, I can think of several, in fact, the young mothers with small children are the ones most likely not to be able to talk about what's happening. And I suppose as a mother myself I can understand that. (W 4)

> Like this gentleman recently, we must have weeks and weeks of hours and hours of chats and conversations about his life, and how he felt, and he always cried, and we found we were actually getting, well, I looked at all these notes and I realized we were getting nowhere. People would sit down and be there literally five, six hours, and it's very hard-going. But it was repetitive, and I realized the people he needed to speak to, his wife and his children, he wasn't. So when we tried to sort of set that situation up, whether he wanted a nurse or a doctor to be there, and to start the conversation to see just how things went, he wasn't very interested in that. And I realized, and he actually admitted it, that [all] this was a way of getting the attention he wanted. He didn't want anybody to sort out his problems, actually he was quite annoyed, he enjoyed, enjoy is probably not the right word, he was grateful that he had these problems, he didn't want to be ill, but if he was ill he was quite grateful that he could cry and get quite upset because it brought people to him, and people would sit down and give him the time. He welcomed all this attention. ... So, I used to keep my visits quite short, be to the point, give them what they needed, and leave. I couldn't, I couldn't really feel I could sit to have a talk. (A 7)

> Some of the patients I was very fond of, one case in particular, she had multi-neurone disease, and this was about two years ago, I nursed this particular lady, and that was quite difficult for me. She didn't want to go to hospital, she wanted to stay at home. So during her last three weeks of her life, I found myself in the [most] stressful situation in twenty-five years [because] she didn't communicate. Originally when I started going there she could write things down and communicate them, in the last three weeks I was there on an almost daily basis and I just felt I had nothing to offer her and I found it very very stressful to look after her. The family wasn't coping very well. She was obviously frightened, and I visited daily, twice daily in the last week or two, and I found that very very difficult, her staring at me. And I can remember thinking: "You want me to say things", but thinking: "Well, if I do that I would be assuming that I know what she is feeling, and I don't, I shouldn't do that". Perhaps she is not so frightened or anxious. (S 9)

These accounts suggest that caregivers in this field generally expect patients (and relatives) to talk openly and truthfully about their situation and the feelings it engenders. Although the right of patients *not* to communicate is acknowledged and accepted, not to do so seems to be perceived as a hindrance to establishing a relationship and a barrier in providing the total care aimed for.

Communication With Relatives

Additional problems may arise for caregivers because communicating with family members and relatives may require a completely different approach than communicating with patients. This applies especially when the patient and relatives disagree on what should openly be talked about or where communication between family members is only now resumed. A further communication problem for caregivers are unresolved intra-family issues which - up to now - have either not been addressed at all or not been resolved, but which are brought up at this stage in the patient's life.

> I am visiting a family at the moment, two families, actually, where the patient's telling me one different story, if you like or one different sort of objectives and the family is totally opposite and I, it's hard to know how to bring them together. And you're almost talking to them separately and it's very difficult. The way I manage [conflict] is to get both of the points of view and then put it to both of them separately that there is a need to come together because of the stresses and maybe lack of time, these things need to be ironed out and that has worked in the past. We're aware of the time factor, that people we visit generally haven't got as much time for small talk, if you like, you have to fairly quickly get to the nitty gritty, otherwise time is lost. (W6)

> [A situation] comes to mind which I found quite hard to communicate, with a relative who was a son who had been parted from his mother for some time. He was a man in his forties and there had been some family discord and he had some treatment in one of the mental hospitals for a breakdown. He attributed this to something that had happened in his childhood. He was abused by his stepfather and he blamed a lot of this on his mother and so they parted company and had no contact for some time. And when he knew she was terminally ill, became involved again and wanted to do as much as [he] could for her. But he didn't want to lose her now that he'd just found her again, and so he found the prospect of losing her again quite hard. I found communication quite difficult with him, I think there was an awful lot of bad feeling. I

think this is one incident where I think your communication sometimes is quite difficult because what has gone on in the past. We often go into families where we are quite unaware of what has gone on in the past and it makes communication difficult. (S3)

I suppose the thing to say is that the easier conversations are with the patient, usually. I mean easier because they want to know exactly what's what, because they feel what's happening to them, they know what's happening, they're the easier conversations, and [it is] easier to be very honest, because they ask you questions, they want to know, and pretty much you get to know them and how to relay the answers. I suppose the harder conversations are with the relatives because they're not feeling what the patient is feeling, they can only see through their eyes, quite often they don't see what's in front of them. I suppose quite often a conversation that you have with them is a lot harder, 'cause you really have to start from the bottom and work your way up, and the patient has their body. Relatives are usually the people that don't want to tell the person that dies, that they are dying, or they don't want them to know, and that's always very hard because you have to get around two people there, and [one] relative of the person that is dying may well be desperate to talk about dying but, of course, the [other] relative can't even think about it, bear to think about it, they don't get together and talk and miss out on some good time, maybe. We try and be open and honest but we also try to look at all of them and meet their requirements, if you like. ... I don't mind looking after somebody while they're dying, talking to the relatives, it's not a problem, my uneasiness is in the day-after-death meeting after the person has died. I personally find that quite hard, but I always feel it's really stupid because on the one hand we know everybody is dying but on the other hand it's almost a let-down. (A2)

I find it easier to talk to relatives because I can think from their viewpoints [but] I find it quite difficult to deal with relatives who don't care about their family, that's always very difficult, especially people that try to pretend they do, because it's so obvious. And I suppose I migrate to those patients more, and try to give them a little bit more, because they don't have so much support. And also situations where fathers hadn't, or mothers hadn't seen their children for twenty, thirty years, and then they want to get in touch, because it doesn't go so well. I find those people quite hard to deal with. (A7)

There is a lady I do remember, when she came into the hospice it's clear that she was dying, [now] she was ready to talk about things, the family just won't. Husband became very protective towards her and so did the son. There was a daughter as well and she was very up with things and could understand what was going on and didn't have the same level of anxiety. The son and the husband really just wouldn't talk about it but the daughter would. It then caused conflict between the husband and son and the daughter, they were in two camps. She [the patient] had actually asked questions about dying and we were talking to her. The son and the husband didn't want us to talk to her at all. The daughter to talk all up front. (A2)

And they got problems! Sometimes it's the cancer itself, sometimes it can be how people have accepted an illness or not, sometimes the problem is with the family, if it isn't with the patient, and sometimes some of the problems are of a long standing, and so they expect you to be able to help sort that out, and, really, it's the fact that they've got cancer is why you're actually there. You very often get the vibes of what it is that they are expecting from you, I suppose it's up to you then to try and deliver the goods, [but] sometimes I don't think it's feasible. Sometimes it's not possible, they have unrealistic goals, or the fact that you can't sort out the long-standing problems. I have a notion that for some people there is suddenly this shortage of time, and then: "Gosh, we haven't resolved this", whether they want it resolved before people die or whether it's that maybe they never expressed any of this before, that you are there in this counselling role, and maybe it's the fist time that they've ever spoken about it. Certainly for some people, they feel very vulnerable when they had the diagnosis and then it's like they are more open or want to express things, have more of a need, more of an urgency, and maybe it's the same for the families too in a way: "Better get this cleaned up", because they're going to die, and this might be our last opportunity." It never fails to amaze me, the things that people will, even sometimes on a first visit, that they will share with you, and sometimes even more [so] in bereavement. I mean, occasionally, no not occasionally [but] very often, what they want to tell you is a story, what happened from diagnosis, almost. It may be that's only just happened, you know, maybe that's such a shock and they're still reeling from it, [but' even if they're further on than that, people will go back to that. It seems to be where the story starts, and there is a great need to actually tell you that. Relatives if they are in the room at the same time will say: "No, no, no, don't start there, I'm sure the nurse hasn't got time for that", and occasionally will get very irritated, but the patients themselves have a need to go back, a great majority of them, and I think it very much depends on how they've been told, whether [the doctor] appeared to be concerned about the fact of what he was saying, it's very very important, very important. I think there is a great gap between what the doctors, nurses, everybody, what we all think we are communicating with people and what they hear. (W2)

Caregivers' Communication Problems

The third area of communication problems originates in the caregivers themselves. The two quotes which follow highlight a 'lack of confidence' when talking about dying and death as well as an 'uneasiness' or 'fear' of being unable to deal with the issues the patient/family unit may raise.

> I discovered over the years that if you have the confidence to bring it up [the issue of dying and death] with the patients at the right time and in a gentle way, they want to talk about it. But if you're not confident in asking the question or directing it then it's an opportunity missed. And I realized over the years that initially when I first started working I was very nervous about asking anything about death and dying because I wasn't confident in actually bringing it up. I mean, I don't know, still now I mean it's not easy but it's easier. It's like everything, if you do it once or twice and the feedback and the results are OK [but] you have to be so sensitive as to what their wishes and needs are and you can get it wrong and become horribly unstuck and you can't always assume that what they are talking about is what you are thinking they are talking about. (S5)

> So you find yourself avoiding issues because you don't know how to deal with them if they come back to you, if you open a box up and something jumps out that you don't know how to deal with, that automatically puts you at a disadvantage, and no professional likes to feel that they can't deal with a problem. So in a way we protect ourselves that way and I'm constantly aware, should I be intruding in patients' lives and families? We get offered very intimate secrets of people's lives if you are in a very close bedside discussion with somebody who is clearly dying and they want to unburden themselves, whether it's therapeutic or whether it's just unburdening or passing on something that happened to them in their life [but] they want to talk, yes. I think sometimes they are not asking for judgement, they are not asking, but they observe that it hasn't shocked the person and I think then that solved it. They've spoken and they said their thoughts and sometimes it doesn't need [to go] any further. (S4)

To summarize, the data of the study suggest three areas of communication problems encountered by palliative caregivers: 1. with patients who do not wish to communicate or who communicate only in partial, indirect, or restricted ways, 2. problems that arise from the perceived necessity by caregivers to communicate in a different way with relatives who may have a different opinion of what should openly be talked about; unresolved intra-family issues also fall into this area, and 3. communication problems by caregivers who are unsure about their ability to deal with the various issues raised by the patient/family unit in this situation.

Having explored communication problems arising from the 'participants' in the situation, the following part of this chapter addresses the nature of communication in the caregiving relationship.

THE NATURE OF COMMUNICATION

> One of the earliest experiences, and it might well have been my first one, was perhaps one of the hardest, because the patient was not a cancer patient, the patient had motor neurone disease. I was a bit apprehensive when I went, by the time I was involved, his mobility was getting much less, he was able to get to bed but it was stumbling and halting, his speech was becoming rather blurred and not easy to understand, and so there was this apprehension on my part, and I expect there was on his part as well. He'd been married two years at this stage and so I met his wife as well, who was working, and I used to go and sit in the work-time, couple of afternoons a week, just to relieve the monotony, as it were. Always tried to find something to get him start talking, just to get going on something or other. He'd been apparently quite an able horseman in his time, quite a good show-jumper, very active in that field, so from his point of view, his illness although he never complained about it did restrict him very much, and also the point that he was not really able to get around his farm and help. So I went to sit with him. I also brought him to the day-hospice. Then sadly his condition got to a point when he could no longer stay at home and he went into a hospital. I went over there a couple of times to see him and then his condition was such that he went back to his parents, and at that stage, I didn't exactly lose touch totally with him [but] it's out of my area altogether. And the next time I really had anything to do with him was actually at his funeral which I found, you know, quite sad really, because he was so young. (W1)

How much communication takes place and what is talked about as well as the quality of this communication can differ considerably: there may be more or less talking, in-depth explorations or primarily small-talk; or more often than not, conversations about practical matters in patients' lives. All this is very dependent on patients' and families' ability and willingness to share their thoughts and feelings with a particular caregiver. Caregivers have to adjust the way they respond to the different and changing communicative 'accessibility' of those in their care and wait for an opening on a verbal or non-verbal level.

Verbal Aspects

> The majority of patients and families use us as sounding boards and to off-load. They want to talk over and mull over things that might happen, know options that are there. Honestly and openly most of the time. If it's a couple: worries about each other, how things are going to progress, what support is available, things that haven't been resolved in the past, if there's been traumatic or non-traumatic deaths in the past, particularly if the person died of cancer. They almost relive that and compare what happened then to what's happening to them now. It is different things to different people, sometimes the burning thing that they are really concerned with is finances. I sometimes go to families and feel I am getting no further than finances and that's all they particularly want from me but I feel I'm hanging in there in case anything else crops up, so it is sometimes a means to an end. I think that it's probably the beginning of working through, it's kind of putting thoughts into perspective from perhaps being muddled thoughts and concerns and frightening thoughts that if they can talk about them, just say them out loud, that they fall into place, they are not so frightening. And they can see their way through a muddle. And perhaps on the second visit or third you got sort of to know one another, you can bring things up, I can bring things up more easily with them, to see, you know, if there is fears or anxieties about. [But] I tell students if you are going to bring something up [like this] you've got to be feeling strong enough in yourself to cope with whatever is going to come at you as a reply. With some people you can see the work being done [during the visit] with others a visit can perhaps spark things off and the work is being done between that visit and the next, and other people, especially when there is conflict within the family, you feel you're bashing your head against a brick wall. (W6)

What do I say? It all depends, really. I've no set pattern at all, and I suppose the most usual thing to say is: "Are you OK?" or "Are you all right?" to start with and see what response you get, the look in the eye, the eye contact, and see what you get then. And sometimes they just don't speak, can't speak, and so you know it really has affected them quite badly. Sometimes they say: "I'm OK" and then you [go] on anyway: "has that made you feel really upset?", you know, and you spend as much time with them as they need before you feel that they've said what they want to say. (A3)

In terms of me as a volunteer, very little discussion is ever what we would call in-depth. Quite often, the talking between patient and volunteers deals with, not trivial, but lighter things, like: "What did you do when you were working? What did you do there? Where have you been?", you know, your experience generally of life but not in relation to the illness that they are now suffering. I think those discussions are confined predominately to be with a nurse. Similarly, when sitting with people in their homes, they may mention their illness but no information is given. When I go to sit with someone, no one actually tells me what the illness is. And so, as I said, the in-depth discussions are probably with the nurses. I have a fairly cheerful view of life, I think, [but] if people want to be serious, then I will be serious with them, but I try to lighten, if that's the thing, try to lighten the discussion or what I'm talking about. Perhaps try throw in a joke or two or something humorous, because I think when they come here, there is the opportunity to talk to the nurse, and I think they try to forget their situation, and, of course, patients help each other a great deal, they build up friendships. (W1)

Communication is so hugely important and it only really took somebody to come up, one of the girls, and put their hand onto my shoulder or say: "How are you doing and how is your Grandpa?" to actually realize how reassuring that can be. It took very small acts in communication. It didn't really need somebody to come and have in-depth communication at the time. It just took somebody to actually be aware that you were sitting there feeling lonely or feeling scared or feeling worried about what would happen, to be aware of you as a person now, that was very important for me. (C1)

I find that I have a lot more opportunity to communicate with the patients in day-centre because they are that much physically fitter. The patients on the unit are quite physically ill and I think the psychological dependence is more with the families than with the patients. Since working in day-centre I found that they require a lot more psychological support which I feel I'm quite inadequate to give sometimes but, having said that, a lot of them just want somebody to

> listen to, so I find that I'm doing a lot more listening and a lot more problems come to light and it actually surprises me how much people will open up and talk. I think it takes time to build up trust and to develop a relationship enough for them to talk about the things that really matter to them. And the other thing I find a lot is, although the home care sisters are visiting in the home, quite often the patients are trying to protect their relatives from their illness. They won't talk about their cancer in front of their spouse or their children because it's too painful, or because the others won't let them talk. So when they come to the day-centre, we have an open atmosphere, the other patients will talk openly about their cancer and discuss it freely, so somebody who is nervous coming in about it, after a couple of weeks they'll be talking as freely as everybody else. And they'll just say: "Can I have a word?" And then they talk and they have told me things they have never told anyone else because they never had the opportunity because they can't talk at home in front of the relatives, they can't talk to the home care sisters because the relatives are always there, they don't always want to tell the doctor. (S5)

The previous accounts highlight some of the diversity of verbal interactions that can occur in this situation. They are diverse in intensity, content, duration and choice of communication 'partner' and range from "working through" and "small acts of communication" to a refusal to communicate. The accounts also point to the importance of non-verbal communication in these interactions as the following quotes show.

Non-verbal Aspects

> There is a lot of that [non-verbal communication], particularly for me there is a lot of 'hands on' if there is no words that could possibly be said and the silences. But I think sometimes you need to say and open the door for further talk if there is something really hurting someone or concerning someone. But I think it goes alongside, really, rather than instead of. I think there is a lot of non-verbal communication, perhaps we are more aware of that and perhaps it's part of me. (S5)

> I use in my work a lot of therapy, contact, the laying on of hands is very important, just to be with somebody very quietly in a room, just perhaps holding them, touching them, stroking parts of their bodies, their hands, their face, their arms, their feet, that very quiet time is also

very important, very relaxing for them. Sometimes questions come up if you are doing a full massage, they may be chattering as it starts, and they're talking about things that may be worrying them, then suddenly that turns very quiet, very tranquil, and that time is very special for me as well ... You know, it doesn't take [more than] two minutes just to reassure somebody, but not only reassuring them verbally but to place the hand on, it's the touch: "I care, I know how you're feeling", perhaps it's just that little bit more. I think the aromatherapy thing, the way that we use the oils for certain types of things that the patient is experiencing, not only works but the touch as well, that very special time is important. (A6)

And how people change ... I've got a man whom I'm working with whose face is disintegrating, and he smells, and how we communicate around that is difficult, [and] I've communicated with a blind man here, oh I'm sure other people have told you this, through rubbing his feet, I mean, for goodness' sake; I'm not an aromatherapist or anything, but that's the way I established contact with him, I just took his shoes off. That was intuitive as well, so, yeah, I do that very often. (W4)

I was having lunch in the dining room [one day] and the nurse who was doing the drug round came to talk to the doctor who was sitting at the same table. [The patient] was very very agitated and very fearful, as I understood it, everything that could be given her was given to her, but she was still very traumatized, and the doctor said: "I don't know what else I can give her." And I said: "Would healing help? Would she have healing?" And she said: "Well, I don't think so." But the sister was also in the room and she said: "Well, I go and ask her." It has to be on the request of the person seeking [the healing], I can't go and say: "Well, I'm going to give you healing and that's it." It would be a complete waste of time, 'cause it would be of no benefit. This lady [the patient] did say 'Yes, she would try anything', and I understood later on that the only other medication they could have given her would have had the effect of making her comatose, which would have been very sad, because her relatives were coming from quite a distance and were expected in the next twenty-four hours. I went down and she was very fearful, she was sitting in a chair, she couldn't breathe at all, she was very agitated, her eyes were full of fear and dread and panic, and so on. And the minute I opened up, it's really the way to put it, like a wave went over her, and she was immediately calmer, I mean, she took a deep breath. That was really tremendous, because it was so evident, and with breathing difficulties that is really evident. She apparently after that, she died, I think, the next day or two days later, but she was conscious when her relatives came, she refused any further medication, and did not have any further panic attacks. And so the quality of her life, such as it was left, was affected, even if it was a day before [her] death. (C5)

With some patients, it may be easier to establish contact and to communicate in this situation by using non-verbal rather than verbal communication; but, as S5 pointed out, it is not necessarily an either/or communication but a combination of both that may be the most effective. An additional aspect of communication that is not really covered by the term 'non-verbal' is presented in the following excerpt of the interview with a Locum Consultant (S6). Here, the non-verbal mode is not an application of 'skills' but the conscious attempt to put oneself into the patient situation and to communicate from one "human being to another" and not on a "doctor-patient" level. ("I" stands for interviewer, i.e. the author of this study.)

> S6: I guess I really do resent the times that I have been in a patient situation, where I have been a patient, and when I see my own colleagues, I mean, it just looks so ridiculous to me when I am looking at it from the other side, they just look and many are a sad sight, they really think they're getting through to me and they're not because I felt ill at ease and therefore I don't give anything. And I think it's that acute awareness that makes me try so hard. When I am in a communication situation with a patient I tend to take off the cloth of being a doctor because to me it's about one human being to another. So that to me the first stance is to try to put myself in the person's place and say: "How would I feel if it were me?" And that to me makes communication very very easy because once you open up and show yourself as a human being to another person they [respond] because communication is a two-way thing and I always think that if I distance the patient then the patient would distance herself or himself from me, because that is my own experience. So for me I find it a very relaxing experience when I am with patients because I really feel that it's possible for me even with all that's going on around, to really see myself in the moment. Once you put the human factor into it and stop hiding behind the cloak of professionalism and doctor-patient whatever, it becomes easy for me.
>
> *I.: And they respond to you as a person, they don't get stuck on the doctor part?*
>
> S6: Yes
>
> *I.: They go through directly to the person?*

> S6: Yes. Yes. And I think that has nothing to do with being a touchy touchy sort of person but when you are very human and natural with someone, it's about communicating and being on the same wavelength, these are the things that matter. I cannot divorce myself, even as a doctor, as a person from the people [the patients]. I never believed that since I started medicine that you had to distance yourself and put on this professional thing, I don't believe that at all. And the whole issue of breaking bad news is badly done, all the time, every day. Again, they make such heavy weather how difficult it is to break bad news when in fact it's all about putting yourself in another person's place and say: "Would you want to be given a whole lot of bad news sitting by yourself without your family around or with a whole ward full of people or with a whole string of doctors standing over you?" Let's face it: It's all about humanness, just compassionate humanity. I mean, just be human! The doctor-patient interactions need not to be as complex as it happens, but it's made complex.
>
> *I.: So, communication is more that just words?*
>
> S6: Oh, gosh! Oh, definitely, as I said, it's about the using of yourself. I mean, I always give something of myself to patients, like, if it's around the time I am ready to go on holiday or just been back, you relate these things to patients, and ask them if they have had any experience in travelling to my part of the world or things. It's not about taking from people, it's about giving, and giving you receive, because if you can really get to the bottom of this, you can make someone feel; from one human being to another, then you get so much more from them, and then you can get more effective.

Spiritual and Existential Issues

The caregivers in this study spoke also about patients' spiritual issues and a search for meaning and how these are explored and - where possible - resolved within the caregiver/patient communication. The following quote and two interview excerpts highlight some of the issues and concerns raised. ("I" stands for *interviewer*, i.e. the author of this study).

> A lot of our conversations were about spirituality, they were for her about forgiveness, really. She'd had an abortion, she had two abortions,

> actually, because she'd been having treatment for a long time. She had a lot of problems about her abortions, and she knew she was dying, and she could not speak to the minister about these things, and this was quite a big problem for me because I do talk a lot to people about spirituality but I really felt what she actually wanted was absolution. You know, "what do we do about this?" sort of thing. And we talked about the gifts she had given the world and herself, you know, a lot of symbolic stuff, [but] she kept coming back to this issue of abortions, and we talked about it, what did she feel about it, and I did all the counselling stuff, and I just didn't feel right ... And I came back two days later and in the interim I had gone and talked to the Chaplain and said to him: "This lady really needs absolution, that's what she is looking for, she means she is being condemned, and she finds it quite hard to talk about it in absolution terms, but she feels that when she gets to where she is going, that people who do such things ..." And it was all quite a big turning point for me, 'cause this guy is a very astute fellow and he said: "You can give her absolution, she won't see me, you can do it". And I said: "I can't do it. I'm not ..." And he said: "You're working on that level with her, what's your problem? Get back in there and sort it out". Oh, God! So I had to sort of listen to him carefully and I went away and thought about it and thought: "Well, give it a go, really". ... And I went back [to see her] and we talked about this issue of abortions, and I just came up with a simple metaphor, this sort of metaphor of [caring]. And that just found her, and that was a very short, quite simple conversation, and yet to me that was like, you know, a big day sort of thing. (A4)

Excerpt from the interview with A6:

> A6: You holistically look at the patients when they come in and you can go through all the little bits of the holistic assessment until you come to the spiritual side of things, and it may be that their religion was very very strong to them, say, ten, twenty years ago in their life, and that has lapsed through different things, or they were very religious, had a very strong belief, when they became ill, they lost their faith completely. And it's the inner type of pain, anger, the inner feelings that they've got inside of the anger: "Why have I got this? Why have I this disease? Why has it been given to me?" And try to work through these questions. We can sometimes answer those questions to some depth [but] sometimes those questions go too deep and we can't answer them, a minister can probably answer, and once they got those sorted out, sometimes that pain goes. It's the unknown, they don't know what they are going to face, you know, if there is an afterlife, there are loads and loads of questions. I find that in patients that have spiritual pain that I try and answer as much as I can, find out about what their beliefs are, what they feel what will happen, then find out

what the inner questions are, what those worries are, those deep concerns, very deep questions.

I.: Is it mostly "why?" questions?

A6: Yes, yes, "Why?", you know: "Why does it happen to me? Why this? Why that?" What's coming back to them is the "Why?", big "Why?" questions. Sometimes there is an answer, and sometimes we can't answer it. Sometimes we can only give them information, talk to them, and, give them our opinion as well as the colleagues' opinions from the team. It's very hard sometimes. And I think even though people say that religion isn't strong or isn't important to them or they're an atheist, I think there must be some underlying issue as to "Why?": "Why has it happened to me? Why have I got this horrible disease inside my body? Why? Why did you chose me?" I think spiritual pain is something we don't look at as strong as we should do sometimes and I think we bypass it, and I think as for myself I need a lot more to be taught to recognize these things, you know, the difference between depression, the difference between sadness and the words, what they really, really mean, what those words mean to that patient. Quite hard at times.

Excerpt from the Interview with S2:

S2: ... these people [the bereaved] are not psychotic, they are not trying to have an experience, these things happen quite often out of the blue and, speaking as a counsellor, they very often turn a corner in their process after these experiences, quite dramatically change. ...

I.: These issues they touch on in these sessions, is there also the issue of "What does it all mean?"

S2: Definitely ... "What, what the hell is it all about?" and they spend a lot of time when it hits them. For the bereaved people there is often a meaning in this kind of crisis, they spend weeks when all we talk about is: "What's happening, what am I here for, what does it matter, what does anything mean?" And it's a real experience for them.

I.: Yes, I imagine this is a point in life where one would ask, maybe for the first time.

S2: Or we think we got meaning, don't we? We do believe we've got it, and then somebody dies and all this stuff happens, and all of a sudden all comes crushing down and everything we thought had meaning seems meaningless or unimportant. And as a counsellor I find that phase in somebody's grief extremely difficult to counsel because I often get the feeling that they want me to give them an answer and I can't. It isn't a depression, it is a phase of questioning the whole meaning of their existence.

I.: Do you feel that when you talk to the bereaved, that they, how should I put it, find meaning?

S2: It's like, it kind of sneaks through the backdoor, it went out with a bang but it cannot come [back] in. If nothing kind of comes in to change it, there is a bitterness, and it isn't just bitterness about the loss, it's bitterness about why do we have to lose in the first place.

I.: Life, really.

S2: Yeah, exactly. So if there is no meaning, there is this enormous bitterness. Human contact can change this, in some way another human comes into their life, who brings in something, and then the meaninglessness seem to kind of [go].

I.: Do you think the meaning that comes slowly through the backdoor, is this a new meaning, or is it similar to the one before, the meaning that was destroyed by death?

S2: I don't think it is ever quite the same. ... You can't quite get back to the old position. I have seen people who have been empowered eventually after a bereavement and I've seen people who conversely are more frightened and fearful. But I never had anybody say to me: "I'm exactly the same". I never heard that.

I.: So the tendency is either to be empowered or to become more fragile?

S2: I don't know that it is so polarised, I'm sure there are shades of grey right the way through but I never, definitely never heard anybody say: "I'm exactly the same". People say to me: "I will never be the same again." And the other phrase I hear a lot is: "I think I must be going mad, tell me, am I going mad?"

I.: What is this, going mad?

> S2: I think the going mad is about the suffering and the pain. I think we have so many blocks [against it] and it's like grief just gets right through all your coping strategies, all your ways, ways of dealing with the world, that sort of gets wiped away from so many people, they cry in public, and they think they see somebody, they want to whine, they make funny noises when they cry, they want to hide away.
>
> *I.: There is no schooling in suffering, is there?*
>
> S2: No.

Religious, spiritual, and existential issues and concerns, for example trying to find meaning in the suffering or answers to the questions beginning with "Why?", may surface unexpectedly in these encounters. Caregivers may be called upon to communicate with patients (and relatives) about aspects brought about by the experiences of a terminal illness, for which they are not always prepared or have no answers to. The accounts quoted above also show that communication can engender changes in patients if their feelings, concerns and questions are talked about openly and - where possible - answers are found:

> And it's the inner type of pain, anger, the inner feelings that they've got inside of the anger: "Why have I got this? Why have I this disease? Why has it been given to me?" And try to work through these questions. We can sometimes answer those questions to some depth [but] sometimes those questions go too deep and we can't answer them, a minister can probably answer, and once they got those sorted out, sometimes that pain goes. (A6)

THE THEMES OF COMMUNICATION

The dominant themes of communication between palliative caregivers and patients and families were identified, analysed, and discussed in Chapter VI. The identified themes are: *communicating about diagnosis and prognosis*, *telling and accepting the truth*, *breaking bad news*, *facing death*, and *communication with* *patients who accept*. The analysis of the data of the study did reveal some additional sub-themes as identified in this chapter, as, for example, *trying to find meaning, trying to resolve un-resolved issues,* and *searching for answers.*

SUMMARY

People going through a traumatic life event often 'freeze' and stop communicating or, if they do communicate, may do so only in partial, restricted, and indirect ways. Feelings and vital concerns often are expressed indirectly or only at certain moments. Communication in this situation is highly "helpee dependent" (Arnold, 1980: 49), that is, highly dependent on the person(s) being willing to communicate. Caregivers who work in this context generally have to 'wait for an opening' for communication "at a deeper level" to occur. They cannot force or rush *the act of sharing* that lies, I believe, at the heart of true communication.

As described in Chapter IV, going through a traumatic life event is a process or a journey that has a beginning, middle, and an end. Caregivers' communication in this context is affected by the particular phase of the process an individual is going through at a particular time. If this process involves more than one person, each person may be in a different phase and communicating with him or her is affected by this in that the caregiver has to adjust quickly from the communication 'demands' in one patient's phase to those in another phase.

Verbal interactions between palliative caregivers and patients and families are diverse and take on a variety of forms; there is no 'typical communication'. Verbal communication may range from repeated periods of small-talk to intense in-depth explorations about spiritual and existential concerns. Non-verbal communication is ever-present and may become more important than verbal interaction in the later stages of the process when physical and mental factors may make verbal interaction more difficult or impossible.

Inter-family communication problems also affect, to a greater or lesser degree, caregivers' communication with the patient/family unit and it is important to note here that patients' communication with caregivers is only one aspect - and perhaps not necessarily the most important one - of the total communication taking place. As a hospice nurse (S5) observed:

> And the other thing I find very interesting with the day patients [is that] there is a lot of communication that goes on between the patients, self-supporting, quite often I am wallpaper. We sit there, the staff, and they're oblivious to us because they're so used to us being there and they talk among themselves and they give each other so much support. I mean it worried me how they would cope with multiple deaths and bereavement [of day patients] but they actually coped well. I actually think that in some ways it does help to prepare them for their own death. And the other patients communicating their feelings to them and the camaraderie of bereavement actually helps them when their time comes, to know that other people have done it before them. And I think in some way they actually have some sort of communication with all the people that have gone before. They've got that special relationship with each other because only they know what it's like to be told that they're going to die. I think why the ones that actually do come to the day-centre and enjoy coming, are getting something out of it, that they are actually getting something back to put into their lives. I think, they're actually sometimes putting, I never thought of this before but I'm thinking of it now, they're putting relationships into their life, because they actually make relationships on a much deeper level and much quicker in a day-centre than they do in a normal, ordinary outside social group. They actually communicate on a deeper level much quicker, and therefore have a bond between each other, so it's putting something, it's putting friends, if you like, into their lives whom they subsequently gonna lose again, but then, there's others keep coming in all the time, so it's a continuing thing. (S5)

In the next chapter, I will link the topics of communication, communication problems and relationship and indicate how they may interact in this situation.

CHAPTER X

THE STUDY: PART III

STRUCTURAL DESCRIPTION: THE CAREGIVING RELATIONSHIP

INTRODUCTION

Palliative care work, as all care work, consists of two major constituents, namely, *working* and *caring*. These constituents are not independent of each other but interact with and influence each other in a number of ways. For instance, they may - in different cases and at different times - interfere with or reinforce each other. The work aspect and its influence on caring have not been investigated in this study. Neither has the caring aspect's influence on working. This study, and the structural description presented in this chapter, focused only on caring.

Phenomenological structural descriptions of experiences also consist of two constituents: a description of the particular *situation* in which an experience originated and the *reactions* of those 'having' the experience elicited by the situation. These reactions may be feelings, thoughts or behaviours, or any combination of them. The psychological *structure* of the experience emerges when the situation is linked with these reactions in a way that reveals the underlying dynamics or psychological significance of the experience.

The structural description of caring in the context of palliative care presented in this chapter will attempt to elucidate how the experience of a caregiving relationship emerges and what its essential components are.

THE CAREGIVING RELATIONSHIP

The diagnosis of a life-threatening illness typically ushers in a period of great upheaval, distress, and suffering for the patient/family unit. The course the illness may take is often uncertain and unpredictable. Medical intervention may or may not be successful; deterioration may accelerate, slow down, or stop. Reversals may occur. Living with uncertainty is one of the hallmarks of going through a life-threatening illness.

In addition to uncertainty, the feeling of helplessness, the loss of control over one's life, the concern for close others, the apprehension over the quality of the remaining life, and the awareness that the illness may be fatal - all add to the distress and suffering. Facing the possible and imminent loss of life and self can engender a profound psychological crisis or traumatic life-event.

Experiences of traumatic life-events have a common psychological structure: the situation encountered is considered extreme and potentially overwhelming, one is neither prepared nor has any strategy at hand on how to deal with it, intense feelings and emotions are elicited by it, and a search for meaning is set in motion. Traumatic life-events tend to powerfully challenge existing self-structures and the inner worlds of individuals. In certain circumstances, the onslaught of a traumatic life-event can annihilate the inner world of a person and catapult him or her into a psychological and spiritual no-man's land where there is no certainty left at all.

At this juncture of facing a life-threatening illness, the person is at a crossroad where he or she can proceed in different directions: give up, despair, think about and actually commit suicide, or - in one way or another, more or less consciously - set to work on reconstructing his or her inner world.

The reconstruction of the inner world and the subsequent development of new self-structures - struggling to regain some kind of equilibrium in the upheaval - tends to require the intervention or the help of others. Enlisting this help is facilitated by the occurrence of the state of heightened psychological accessibility which tends to make a person more open, more accessible, and more willing to ask for and accept help. The feelings of vulnerability and need so commonly experienced by persons facing a life-threatening illness are apt to be more openly expressed in this state.

For caregivers to respond authentically to this expressed vulnerability and need requires that they are able to *empathise* and *identify* to some extent with the other, are able to put themselves mentally and emotionally in the 'other's shoes'. It also requires a positive emotional reaction to the other, like 'being moved' or 'touched' by him or her in some way.

Openness, accessibility, and a willingness to engage on one hand, and empathy, the ability to identify with, and a positive emotional response to 'the other' on the other hand, facilitate the emergence of a way of relating for caregivers referred to here as *acting-as-a-friend*.

In acting-as-a-friend, caregivers worry about the patients and families in their care, they are concerned about their welfare, as they are concerned about the quality of care they themselves are providing. They attempt to give whatever help is needed and participate actively in the lives of those in their care, often beyond the specific tasks and responsibilities of their profession. They are committed to help them cope with and work through whatever problems are present or arise. They do not distance themselves from the situation but tend to become attached to patients and families, attempt to get close to them, try to become 'friends', and allow them into their own personal space. Caregivers generally feel at ease and comfortable in their presence, attempt to be non-judgmental, and to accept patients and families as they are.

This display of *solicitude* and *closeness* tends to engender a range of emotions and feelings in caregivers. Relating in this mode invariably involves the experience of various emotions which arise as a response to the situation and to the feelings of those primarily involved in it. In addition, the feelings and emotions expressed by co-workers and team members have an impact on individual caregivers. As a result of constantly being exposed to and experiencing strong emotions, work in palliative care is often stressful for caregivers and the work environment is experienced as one of high intensity.

Many of the emotions and feelings elicited in this situation are distressing: anxiety, fear, worry, uncertainty, helplessness, and inadequacy are commonly experienced. Dealing with these emotions can at times become a problem for caregivers: *when* to show emotions and when not, *how* much emotion to show and with whom and under what circumstances. Caregivers generally feel that there needs to be a balance in expressing emotions in order to cope with the situation and be of use to patients and families. Furthermore, having to deal with several patient/family units at the same time who all may be expressing different emotions and going back and forth between them adds to the problem. Positively experienced emotions reported by caregivers include empathy, hope, humility, sympathy, gratitude, and a sense of warmth, pleasure, and trust when relationships are working well.

Working in a highly intense and emotional environment and coping with strong emotions is a characteristic of palliative care work that may become a barrier for caregivers to *become involved* with patients and families. Involvement here means going beyond the fulfilment of one's professional role, responding as a person as well as a professional, and participating in the whole situation. Such an involvement is a pre-condition for *truly* acting-as-a-friend for without this kind of involvement relating in this mode can easily turn into being just an act. Conversely, becoming involved without feelings, closeness, and solicitude may be perceived as interfering and can be detrimental to patients and families.

Most caregivers consider a *balanced* involvement appropriate in palliative care work. Non-involvement, under-involvement, and over-involvement are generally experienced as negative or problematic. A balanced involvement means keeping the essential boundaries intact and finding the right balance between *distance* and *closeness*, between acting-as-a-professional and being-a-friend. This is an ongoing task that requires that caregivers constantly adjust to changing conditions in flexible ways by being aware of and monitoring the situation as it develops.

Acting-as-a-friend and a balanced involvement are the basis of the caregiving relationship. Acting-as-a-friend authentically and consistently produces *trust*, a balanced involvement most appropriately meets the needs of patients and families. The caregiving relationship is a relation of solicitude. Authentic solicitude means being open and receptive to the other's unique individuality by *respecting* the other. This respect is based on the acknowledgement that one can never fully know and understand the other, that there is always something 'more' to him or her.

From an existential (Heideggerian) viewpoint, authentic existence can only be achieved through solicitous relationships with others, never by 'being lost' in the "they" (Heidegger, 1977). Being human (*Dasein*) is essentially a being-with which is an existential constituent of being-in-the-world. Our ontological awareness that our Dasein is not independent of other Daseins, that there is a commonality and community of all Daseins, shows us that we are in essence solicitous beings. By sharing our freedom, independence, and individuality in solicitous relationships, our existence becomes authentic and our life becomes enlarged by being able to enter into the experience of others without the need to actually ever having had this particular experience ourselves before.

In the relation of authentic solicitude, we do not relate with the other in a way that can be described by objective characteristics which can be identified and analysed as something specific to this relation. Authentic solicitude involves something more than an accumulation of interactions of individuals, there is always something 'more' to this relationship (Heidegger, 1977).

The one identifiable characteristic of the caregiving relationship is the opportunity to *connect*. Unwittingly and for no specific reason, caregivers may encounter a *moment in time* when the distance separating one person from another is bridged and she or he, existentially speaking, is plunged into an ontological relation. These moments are precious and rare; they are remembered but the experience is difficult to translate into words. It seems that at the core of it is the *summons or call* for one person from the other that needs to be answered. This call cannot be reduced to a specific request or demand linked to an instant of time; there is a mysterious (mystical, some caregivers would say) and timeless dimension to this encounter that transcends 'normal' relating. Caregivers describe these moments of connecting as "rewarding" and "enriching", as experiences that enlarge their lives.

Connecting may occur during "silent communication" (Heidegger, 1977), in the absence of words, or it may involve verbal interactions; it may happen during a 'therapeutic encounter' or at the bedside of a patient who is unconscious. The kind of communication (verbal, non-verbal, or silent) caregivers can employ is largely determined by the particular stage the illness has reached (in communicating with patients) and by the psychological phase of each individual involved at that time (in communicating with both, patient and family). In the case of patients, if the process or journey begins with the diagnosis and ends with death, verbal communication may be more important in the earlier stages and non-verbal and silent communication in the later ones when physical and mental deterioration may make verbal interaction difficult or impossible.

Whatever the mode of communication predominately used by caregivers at a particular time, there is no question that communication itself is a crucial aspect of the caregiving relationship. The importance of this aspect is underlined by research findings that suggest that communication problems (in communicating with the patient/family unit) are rated high as work-related stressors by caregivers. Dealing with un-communicative patients and family members that employ only partial, restricted, or indirect communication where feelings and vital concerns are not expressed, often results in negative feelings in caregivers, such as feelings of "helplessness" or "uselessness". Ideally, the caregiving relationship is a forum for discussing and attempting to work through the issues of the major themes identified and described in this study - communicating about diagnosis and prognosis; accepting the truth, facing death, and the acceptance of death - as well as their subthemes.

Working-through individual issues arising from each theme for each person involved is an exemplary way of preparing the patient/family unit for the occurrence of death. Finishing "unfinished business", resolving unresolved conflicts, and "letting go" of the notion of an unbounded future, all help preparing the way of attaining a more "peaceful" death and an authentic 'acceptance' in bereavement which are the intentions and aspirations that lie at the core of the caregiving relationship.

SUMMARY

Caring was defined in this study as a thinking-feeling mode of being-with that gives rise to activity - when activity is called for. The quality of caring will affect the quality of this activity since interactions between persons that are in relationship differ considerably from interactions between 'unrelated' persons. The nature of this difference is informative about the quality of the relationship that has been developed.

The caregiving relationship develops through an enduring association of caring between palliative caregivers and the patient/family unit in care. This relationship is in essence a relation of solicitude where activity takes on the form of *acting-for* the other by "leaping-in" for the other and "leaping-ahead" of the other (Heidegger, 1977). Authentic solicitude is not a passive being-with but an active engagement in which the other is never taken for granted but *matters*.

Although the caregiving relationship endures over whatever time is available there are definite and often quite limited boundaries. The caregiving relationship begins when two persons meet in an encounter of openness and accessibility and it ends with death or "acceptance". Authentic acceptance of death, as well as death, terminates the 'acting-for', the interventions of solicitous engagement of the caregiver.

The role of communication in the context of the caregiving relationship is to mediate the passage from the turmoil of the initial phases of this journey to the calmness of acceptance sometimes reached in the later ones by exploring, clarifying, and working-through crucial issues that remain unresolved. Communication also serves as a way to lessen the loneliness experienced, or make it more bearable, by evoking feelings of commonality and community of all *Daseins*.

CHAPTER XI

SUMMARY, OUTCOMES, AND IMPLICATIONS

SUMMARY

Chapter I highlighted the background of this study: the general shift of attitudes to dying and death in Western Society, the development of the hospice movement with its distinct philosophy of palliative care, and the importance assigned to communication in translating this philosophy into the actual practice of caring for the terminally ill. I provided evidence that this communication continues to be a crucial issue in current practice and advanced the proposition that for verbal communication to be effective in these settings and circumstances it needs to be rooted in a relationship. I briefly stated how I became interested in studying the relationship aspect in palliative care and how the results of my pilot study convinced me of its wider significance.

Chapter II provided an examination of the research approach I employed in this study, specifying the research design, the principal data collection strategy, and the method of analysis used. I discussed the reason why I adopted a qualitative (rather than quantitative) approach, described the approach chosen and its application by one of the pioneers (Giorgi) in applying phenomenological research in the field of psychology in a particular research situation, and detailed in a chronological account the research practices I myself employed in carrying out this study.

Chapter III focused on the contexts of the phenomenon under investigation in this study. I identified four major contexts that may have an influence on relating and communicating in this setting (the physical environment, the sociocultural structure, society, and the group) and described in more detail certain aspects of each context (the physical environment of hospices, the philosophy of palliative care, societies changing attitudes to dying and death, and the multidisciplinary group) and their possible influences on caregivers' communication and relationships with those in their care.

Chapter IV described the situation of the patient/family unit in palliative care. I based this description on a psychological perspective that focuses on the progressive inner (psychic) changes commonly experienced in this situation. A conceptual framework was used to integrate these changes into a chronological account that highlighted the nature of the progression and indicated its effects on the development of the caregiving relationship.

Chapter V presented the analysis and findings of the first phase of this study (pilot study) which identified the topic of my research and laid the foundation for the next two phases of the study. The initial exploration of caregivers' relating with patients and families disclosed a particular mode of relating or relationship conduct that is essential to the formation of the caregiving relationship.

Chapter VI provided the analysis and results of the second phase of the study (focus group interview). The results supported the findings of the pilot study in regard to the relationship conduct identified in the pilot study (pre-questionnaire) and revealed some of the major themes of caregivers' communication with patients and families.

In Chapter VII I carefully reviewed the relevant literature on the topic of this study - I concentrated on research studies encompassing the three key terms or variables palliative caregivers - communication - relationship and, finding a scarcity of these kinds of investigation, expanded the search to those which include at least two of these keywords (Level II studies) and then one (background studies). I did not find any study that focused exclusively on the interactional field (relationship / communication) in the way this study does.

Chapters VIII and IX presented the analysis and results of the third phase of this study (follow-up study) which focused on the two key terms: Chapter VIII on relationship and Chapter IX on communication. The findings of Chapter VIII elucidated the nature of the caregiving relationship and its development over time by uncovering the essential themes involved: involvement, balance, and connecting. Chapter IX focused on clarifying the nature of communication in the setting and context of this study and its role in developing and maintaining the caregiving relationship.

Chapter X provided the structural description of the caregiving relationship in terms of the situation and the reactions of those involved in the situation. The caregiving relationship was defined here as a relation of solicitude where caregivers *act for* the patient / family unit in Heidegger's (1977) sense of "jumping in for" and "jumping ahead of". The development of this relationship was found to occur through the interplay between the situation and the psychological reactions of caregivers and the patient/family unit in which communication takes on a mediating role.

In this final chapter, I summarized the study and will discuss next its outcomes and implications.

OUTCOMES AND IMPLICATIONS

The understandings and insights that emerge from this study are of potential value in their application on a professional and societal level. The study points to the following outcomes and implications:

Communication in the context of the helping professions in general and hospice care work in particular should be considered and investigated in conjunction with the relationships formed between caregivers and patients and families. Communication is crucial, but in order to be effective, it needs to be rooted in a relationship. Problems in communication that may arise in the situation when facing dying and death may originate in all the participants, i.e. caregivers may feel unsure about how to talk to patients and families, patients may not wish to communicate at all or only partially, and families may suddenly raise issues not resolved before this situation arose. Communication problems may also arise because caregivers have conscious and/or hidden intentions and aspirations for patients and families, for example, about how they should 'face dying and death'. These intentions and aspirations should be further explored and their influence on the caregiving relationship as well as on caregivers' work should be clarified.

Equal weight should be assigned to all modes of communication, that is verbal, nonverbal, and "silent" communication. Skills training in verbal communication alone will not necessarily improve the effectiveness of the total communication between caregivers and those in their care.

Caring is a mode of being that involves thinking and feeling as well as relating. Greater emphasis in thinking about caring should be placed on the last aspect, on the interactional field shared by caregivers and patients/families. A way of relating that entails *feeling with* patients and families, *getting close* to them, and *being solicitous* is generally experienced by caregivers as rewarding and enriching, despite the negative feelings this way of relating may also engender in caregivers.

Another outcome of this study is that caregivers need to find a balance between *distance* and *closeness* in their relationships with patients and families. The ability of caregivers to freely move on the 'continuum' between these two poles, depending on the individual situation they find themselves in with different patients and families, is beneficial to all concerned. It is recommended that a shift away from 'communication skills programmes' to enhancing this ability to move between distance and closeness may be more beneficial.

From an existential perspective, the notion that *relations of solicitude* are the "royal road" to the attainment of an authentic existence and to an enlargement of our lives should be further examined and implications should be drawn for the community as a whole.

Further recommendations for research are that the issue of the *context* as referred to in Chapter III should be linked to caregivers' experiences of the caregiving relationship; an aspect which was not fully explored in this study. Using a phenomenological approach, I focused on the experiences of individual caregivers, however, the phenomenon is embedded in the context as described in Chapter III, and the accounts of these experiences may not necessarily be exhaustive. Additional investigations into caregivers' experiences may reveal further aspects and increase the understanding of the phenomenon of the caregiving relationship, as would research focusing on the patients' and families' experiences of this relationship.

POSTSCRIPT

My analysis of the relationship experiences of palliative caregivers working in hospice settings showed that effective communication and the ability to listen are in fact basic and essential skills in this kind of care work. However, I have also argued that relying solely on learned skills is at best of limited value unless caregivers pay close attention not only to the verbal and nonverbal communication of patients and their families but also to the kind of relationship they form with them. Reflecting on my own experience during the Viva, where this was modelled and embodied by the examiners, some omissions and inconsistencies regarding this message in the thesis, and initially in the Viva, were highlighted.

In the Introduction of the thesis I presented a brief historical background of the hospice movement. It is important to note that this movement goes back further in time than this presentation led readers to believe. There were hospices dedicated to the needs of the very ill in existence in the 19th century. It is probably true to say that the modern hospice movement built on these foundations and publicised widely an already existing philosophy of hospice care rather than starting it anew.

The thesis would have been strengthened had I used the opportunity my research provided to demonstrate that the way people (including caregivers) communicate and relate is also a reflection or behavioural expression of themselves and their own particular way of being-in-the-world. I would like an opportunity to address this as it has implications for my own continuing professional development as well as future research and practice.

My thesis also may have been strengthened if I had included a brief disclosure of my personal interest and motivation in the research topic. It was only through the process of the Viva that I consciously acknowledged what this was and that I realized the importance of the influence of my personal biography on myself as a researcher as well as the importance of the influence of my interviewees' biographies on themselves as practitioners.

My experiences of death and dying began when I was a small child. My mother, who worked as a district nurse in a rural part of Northern Germany, often took me with her when she visited her patients. Some of these repeated visits, I realized retrospectively, were with patients who were clearly dying. I did not know this, however, nor did I have any notion of dying or death. One day these visits were abruptly terminated and I was simply told by my mother that the patient had died and we would not be visiting him or her anymore. There was no further communication about this matter between my mother and I and any questions that I raised (and I did raise questions) were ignored.

On reflection, it might be assumed that the reason why the interpersonal communication between the caregivers and their clients is not fully addressed in the thesis, is because it "mirrors", or entails "parallel processes" of my own experiences as a child: there was hardly any interpersonal communication between myself and my mother about either of our experiences at the deathbeds of my mother's patients.

In turn, the personal biographies of the caregivers interviewed in this study were perhaps an important factor for me to consider when evaluating their responses to my questions. Additional questions I might have asked could have prompted them to reflect on their own interest and motivation for working in this field, on how death and dying were handled in their families of origin and in their current lives, on who they would turn to and what kind of communication and caregiving relationship they would find helpful or unhelpful for themselves, and on how their own experiences might influence their attitudes and behaviour towards their patients and relatives. Reflective practice, which includes reflecting on one's own personal experiences, is considered a crucial element of effective communication - and counselling skills training for professionals in the helping professions. Without this practice, relying mainly on skills training can lead to encounters where all the right things are said and done but where no trust is established and the people involved are left feeling unsupported.

Re-examining the narratives of the interviewees suggests that some of these caregivers can be assumed to have felt very uncomfortable with any interpersonal communication that went beyond a superficial level. It seems as if getting to know a patient or relative more intimately is somehow "unprofessional". Some interviewees explained their behaviour when genuine contact was made with patients or relatives as if they had somehow crossed the line from a professional to an unprofessional way of behaving and became the patient's or relative' "friend". In fact, the concept of "friendship", which includes the need for reciprocity as well as moments of total one-sidedness on both sides, does not really explain what is happening here.

An effective method of training in communication - and counselling skills might then be one that includes a focus on the life experiences of the caregiver, on how these have shaped their attitudes and behaviour, and on the interpersonal communications between helper and helpee.

Although the origins of how we relate and communicate with others (and thus - in the context of this thesis - ask for, give, and receive help) are rooted in early relationships and experiences, a phenomenological perspective would point out that we are also imperfect and unpredictable and that we can elect to do something different in order to alter our thinking and behaviour (Spinelli, 1994). Electing to do this may result in a more authentic and helpful relationship between caregivers and the patients and relatives in their care, rather than one which is perceived as "feeding" the caregiver by patients or relatives who behave in a way that makes the caregiver feel useful and "needed". This approach may also help to make it a little easier for patients and relatives to ask for and receive help when they are vulnerable - they might elect to choose to change too. A more reflective approach to training and supporting health professionals in communication- and counselling skills is already established in such areas as stroke rehabilitation, assisting physically disabled people, working with elderly and brain injured adults (Burnard, 1989; Hobbs, 1992). Through further research and practice it could be developed for use in the hospice environment.

REFERENCES AND BIBLIOGRAPHY

AANSTOOS, C.M. (1985). The structure of thinking in chess. In: Phenomenology and Psychological Research, ed. by R. Giorgy. (Pittsburgh, PA: Duquesne University Press).

AMERICAN PSYCHIATRIC ASSOCIATION. (1984). Diagnostisches und Statistisches Manual Psychischer Stoerungen: DSM III. (Weinheim und Basel: Beltz).

AMÉRY, J. (1976). Hand an sich legen. (To lay hands onto oneself - suicide). (Stuttgart, Germany: Klett Verlag).

ARGYLE, M., FURNHAM, A., and GRAHAM, J.A. (1981). Social situations. (London: Cambridge University Press).

ARIÈS, P. (1974). Western attitudes toward death; from the Middle Ages to the Present. (London: The John Hopkins University Press).

ARNOLD, W.E. (1980). Crisis communication. (Dubuque, Iowa: Gorsuch Scarisbrick).

BAUDRILLARD, J. (1990). Cool memories. (London: Verso).

BEACH, D.L. (1995). Caregiver discourse: Perceptions of illness-related dialogue. Hospice Journal, Vol 10 (3): 13-25.

BECKER, E. (1973). The denial of death. (New York: The Free Press; Macmillan Publishing Co.).

BELL, P.A., FISHER, J.D., and LOOMIS, R.J. (1978). Environmental Psychology. (Philadelphia, PA: W.B. Saunders).

BENN, P. (1993). My own death. Monist, 76 (2): 235-251.

BERNARD, H.R. (1988). Research methods in Cultural Anthropology. (Newbury Park, CA: Sage Publications).

BRAM, P.J., and KATZ, L.F. (1989). Study of burnout in nurses working in hospice and hospital oncology settings. Oncol. Nurs. Forum (16) 555-560.

BREWIN, T. (1996). Relating to the relatives. Breaking bad news, communication and support. (Oxford: Radcliff Medical Press Ltd.).

BRIDGES, W. (1980). Transitions. (New York: Addison-Wesley Publishing Co.).

BRODY, B. (1988). Life and death decisions making. (New York: Oxford University Press, Inc.).

BROLAN, D.J. (1993). Physician-Patient-Family communication over the course of chronic illness, with a focus on cancer care. PhD thesis: Syracuse University, USA.

BRYKCZYNSKI, K. (1985). Exploring the clinical practice of nurse practitioners. PhD thesis: University of California, San Francisco, CA.

BURKHARDT, M. and NAGAI-JACOBSON, M.G. (1997). Psychospiritual care: A shared journey embracing life and wholeness. Bioethics-Forum; 13 (4): 34-41.

BURNARD, P. (1989). Teaching Interpersonal Skills: A handbook of experiential learning for health professionals. (London: Chapman & Hall).

CALLAHAN, D. (1993). The troubled dream of life: In search of a peaceful death. (New York: Simon and Schuster).

CALMAN, K. (1993). A strategy for palliative care. In: Palliative Care for All: Directions for a Decade, ed. by J. Griffin. (London: Cancer Relief Macmillan Fund).

CARUSO, J.A. (1983). Die Trennung der Liebenden. (Separation of those who love each other). (Bern, Switzerland: Hans Huber Verlag).

CELLA, D. F. (1992). Quality of life: The concept. Journal of Palliative Care 8 (3): 8-13.

CHARTER, D. (2001). "Doctors are too stressed to related to frightened patients." *The Times*. 26 June 2001.

CHELUNE, G.J., ROBINSON, J.T., and KOMMOR, M.J. (1984). Cognitive interactional model of intimate relationships. In: Communication, intimacy, and close relationships, ed. by V.J. Derlega. (London: Academic Press, Inc.).

CLAIR, J. F. (1987). The management of dying: tasks and social relationships in patient care. PhD thesis: The Louisiana State University and Agricultural and Mechanical College, USA.

COBERLY, M. (1998). Transpersonal dimensions in hospice care and education: Applications of tibetan buddhist psychology (Buddhism). PhD thesis: University of Hawaii.

COLAIZZI, P.R. (1973). Reflection and research in Psychology. (Dubuque, IA: Kendall/Hunt).

________. (1978). Psychological research as the phenomenologist views it. In: R.F. Valle and M. King (eds). Existential-Phenomenological alternatives for psychology. (Oxford: Oxford University Press).

COMPTON, S.A., FLANAGAN, P., and GREGG. W. (1997). Elder abuse in people with dementia in Northern Ireland: Prevalence and predictors in cases referred to a psychiatry of old age service. International Journal of Geriatric Psychiatry; Vol 12 (6): 632-635.

CORR, C.A. and CORR, D.M. (Eds). (1983). Hospice care: Principles and practice. (New York: Springer.)

COULOMBE, L. (1995). Talking with patients: Is it different when they are dying? Canadian Family Physician; Vol 41, March: 423-437.

CRABTREE, B.F., and MILLER, W.L. (Eds.). (1992). Doing qualitative research: Research methods for primary care, (Vol. 3). (Newbury Park, CA: Sage).

DEBLEGA, V. J. (Ed.). (1984). Communication, intimacy, and close relationships. (Orlando, FL.: Academic Press).

DeHENNEZEL, M. (1997). Intimate death. (Boston: Little, Brown and Company).

DIETZE, G. (ed.). (1983). Todeszeichen. (Signs of death). (Darmstadt, Germany: Luchterhand Verlag).

DOYLE, D. (ed.). (1984). Palliative care: Management of far advanced illness. (London: Croom Helm Ltd.).

________. (1992). Care of the dying. In: Textbook of geriatric medicine and gerontology (4th ed.), ed. by J.C. Brocklehurst, R.C. Tallis, and H.M. Filish. (London: Churchill Livingstone).

DROLET, J.-L. (1990). Transcending death during early adulthood: Symbolic immortality, death anxiety, and purpose in life. Journal of Clinical Psychology Vol 46: 148-160.

DUCK, S. (Ed). (1993). Social context and relationships. (Newbury Park, CA: Sage Publications).

________. (1998). Human relationships. (3rd edition). (London: Sage Publications).

DUNLOP, M. J. (1994). Is a science of caring possible? In: Interpretive Phenomenology: Embodiment, caring, and ethics in health and illness, ed. by P. Benner. (Thousend Oaks, CA: Sage).

DUNNE, J. J. and JENKINS, L. (1992). Stress and coping in Macmillan nurses. (London: Cancer Relief Macmillan Fund).

EXLEY, C. E. (1999). Living with cancer, living with dying: The individual's experience (hospice). Phd thesis: Coventry University, UK.

FELDMAN, E.J. (1981). A practical guide to the conduct of field research in the social sciences. (Boulder, Colorado, USA: Westview Press).

FRANKL, V. (1962). Man's search for meaning. (Boston: Beacon Press).

FRANKL, V. (1985). Psychotherapy and existentialism: Selected papers on logotherapy. (New York: Washington Square Press).

FRANKS, A. (1997). Breaking bad news and the challenge of communication. European Journal of Palliative care; Vol 4 (2): 6-7.

FRAZIER, M.E. (1985). Teaching relationship enhancement skills to hospice professionals. PhD thesis: The Pennsylvania State University.

FRITZ, P.A., RUSSELL, C.G., WILCOX, E.M., and SHIRK, F.I. (1984). Interpersonal communication in nursing. An Interactionist approach. (Norwich, Connecticut, USA: Appleton-Century-Crofts).

FRY, S.-T. (1989). The role of caring in a theory of nursing ethics. Hypatia; 4; 88-103.

GILCHRIST, V.J. (1992). Key informant interviews. In: Doing qualitative research: Research methods for primary care, (Vol. 3), ed. by B. F. Crabtree and W. L. Miller. (Newbury Park, CA: Sage).

GILLIS, L. (1980). Human behaviour in illness. Psychology and interpersonal relationships. (3rd ed.). (London: Faber and Faber).

GIORGI, A. (1970). Psychology as a human science. (New York: Harper and Row).

________. (1975). An Application of phenomenological method in psychology. In: Duquesne Studies in Phenomenological Psychology (Vol. 2), ed. by A. Giorgi, C. Fisher, and E. Murray. (Pittsburgh, PA: Duquesne University Press).

________. (1976). Phenomenology and the foundations of psychology. In: Nebraska Symposium on Motivation (Vol. 23), ed. by W. Arnold. (Lincoln, NE: University of Nebraska Press).

________. (1979). The Relationships among level, type, and structure and their importance for sociel science theorizing: A dialogue with Shutz. In: Duquesne Studies in Phenomenological Psychology (Vol. 3, pp81-92), ed. by A. Giorgi, R. Knowles, and D.L. Smith. (Pittsburgh, PA: Duquesne University Press).

________. (Ed.). (1985). Phenomenology and psychological research. (Pittsburgh, PA: Duquesne University Press).

GIORGI, A., FISHER, C., and VON ECKARTSBERG, R. (Eds.). (1971). Duquesne Studies in Phenomenological Psychology (Vol 1). (Pittsburgh, PA: Duquesne University Press).

GIORGI, A., FISHER, C., and MURRAY, E. (1975). Duquesne Studies in Phenomenological Psychology (Vol. 2). (Pittsburgh, PA: Duquesne University Press).

________. (1976). Phenomenology and the foundations of psychology. In: Nebraska Symposium on Motivation (Vol. 23), ed. by W. Arnold. (Lincoln, NE: USA: University of Nebraska Press).

GIROGI, A., KNOWLES, R., and SMITH, D.L. (Eds.). (1979). Duquesne Studies in Phenomenological Psychology (Vol. 3). (Pittsburgh, PA: Duquesne University Press).

GIORGI, A., BARTON, A., and MAES, C. (Eds.). (1983). Duquesne Studies in Phenomenological Psychology (Vol. 4). (Pittsburgh, PA: Duquesne University Press).

GLOVER, J. (1977). Causing death and saving lives. (Middlesex: Penguine Books).

GORDON, T. and STERLING, E. (1995). Making the patient your partner: Communication skills for doctors and other caregivers. (Westport, CT, USA: Auburn House/Greenwood Publishing Group, Inc.)

GRIFFIN, J. (ed). (1993). Palliative care for All: Directions for the decade. (London: Cancer Relief Macmillan Fund).

HABERMAN-LITTLE, B. (1993). The experience of Parkinson's Disease in middle life: An interpretive account. PhD thesis: University of California, San Francisco, CA.

HARGIE, O. (ed). (1986). A handbook of communication skills. (London: Routledge).

HATFIELD, E., and TRAUPMANN, J. (1981). Intimate relationships: A perspective from equity theory. In: Personal relationships, ed. by S. Duck and R. Gilmore. (New York: Adacemic Press, Inc.).

HAYES, N. (1997). Introduction: Qualitative research and research in psychology. In: Doing qualitative research in psychology, ed. by N. Hayes. (Hove, East Sussex: Psychology Press).

HEAVEN, C.M., and MAGUIRE, P. (1997). Disclosure of concerns by hospice patients and their identification by nurses. Palliative Medicine, Vol. 11 (4): 283-290.

HEIDEGGER, M. (1977). Sein und Zeit. (Being and Time). 14th ed. (Tübingen: Max Neimeyer Verlag, Germany).

HEITMAN, E. (1988). Caring for the silent stranger: Ethical hospital care for non-English speaking patients. PhD thesis: Rice University, USA.

HERMANN, C. P. (1997). Spiritual needs of dying patients: A methodological study. PhD thesis: University of Kentucky, USA.

HINDE, R. A. (1996). Describing Relationships. In: The diversity of human relationships, ed. by A. E. Auhagen and M. S. Salisch. (Cambridge: Cambridge University Press).

HINTON, J. (1980). Coping with terminal illness. In: The experience of illness, ed. by R. Fitzpatrick et. al. (London: Tavistock).

________. (1998). An assessment of open communication between people with terminal cancer, caring relatives, and others during home care. Journal of Palliative Care; Vol 14 (3): 15-23.

HOBBS, T. (Ed.). (1992). Experiential Training. Practical Guidelines. (London: Tavistock/Routledge).

HUNT, R.G. (1970). Strategic selection: A purposive sampling design for small numbers research: Program evaluation, and management. (Buffalo: State University of New York, Survey Research Centre).

HUSSERL, E. (1977). Phenomenological Psychology. (Translated by J. Scanlon). (Originally published in 1925). (The Hague: Nijhoff).

IHDE, D. (1986). Experimental Phenomenology. (New York: Suny).

________. (1986). Consequences of Phenomenology. (New York: Suny).

JANOFF-BULMAN, R. (1992). Shattered assumptions: Towards a New Psychology of Trauma. (New York: Free Press).

JARRETT, N.-J., and PAYNE, S. A. (1999). "Someone to talk to" and "pain control": What people expect from a specialist palliative care team. Palliative Medicine; Vol 13 (2): 139-144.

________. (2000). Creating and maintaining "optimism" in cancer care communication. International Journal of Nursing Studies 37 (1): 81-90.

JASPERS, K. (1970). Philosophy: Volume 2. (Translated by E.B. Ashton). Originally Published in 1932. (Chicago: University of Chicago Press).

JECKER, N.-S. (1991). Knowing when to stop: The limits of medicine. Hastings-Centre Report: 5-8.

JOHNSON, J.E. (1990). Selecting ethnographic informants. (Newbury Park, CA., Sage Publications).

JOHNSTON, G. (1997). Assessing psychosocial and spiritual well-being in palliative cancer care. Phd thesis: University of Dundee.

JONES, J.C. (1997). 'The blessed experience': Macmillan nurses' lived experience of palliative care as reported in the clinical supervision seminar: a hermeneutic enquiry. PhD thesis: University of Manchester.

JUSTIN, R. G. (1987). The value of history: A necessary family document. Theor. Med.; 8: 275-282.

KAST, E.C. (1972). On being old and on dying. Journal of the American Geriatrics Society; Vol 20 (11): 524-530.

KASTENBAUM, R. (1981). Death, society, and human experience. (2nd ed.). (London: The C.V. Mosby Company).

KASTENBAUM, R., and AISENBERG, R. (1972). The psychology of death. (New York: Springer Publishing Co.).

KAUFMAN, W. (1965). Existentialism and death. In: The meaning of death, ed. by H. Feifel. (London: McGraw-Hill).

KELLEY, H.H. (1979). Personal relationships: Their structure and processes. (Hillsdale, NJ, USA: Lawrence Erlbaum Associates, Inc.).

KIRK, J. and MILLER, M.L. (1986). Reliability and validity in qualitative research. (Newbury Park, CA: Sage).

KOESTENBAUM, P. (1971). The vitality of death: Essays in Existential Psychology and Philosophy. (Westport, CO: Greenwood).

KUBLER-ROSS, E. (1969). On death and dying. (London: Tavistock Publications).

KUZEL, J. (1992). Sampling in qualitative inquiry. In: Doing qualitative research: Research methods for primary care, Volume 3, ed. by B.F. Crabtree and W. L. Miller. (Newbury Park, CA: Sage).

KVALE, S. (1996). Interviews: An introduction to qualitative research interviewing. (Thousend Oaks, CA: Sage).

LAMENDOLA, F. P. (1998). Patterns of the caregiving experiences of selected nurses in hospice and HIV/AIDS care (Immune Deficiency). PhD thesis: University of Minnesota, USA.

LAWTON, J. (1998). The disintegration of self: a study of patients in a day care service and a hospice in England. PhD Thesis. University of Cambridge.

LARSON, D.-G. (1993). The helper's journey: Working with people facing grief, loss, and life-threatening illness. (Champaign, IL, US: Research Press). 2

LaRUSSO, D. A. (1977). The shadows of communication: Non-verbal aspects. (Dubuque, Iowa: Kendall/Hunt).

LAVALL, G. ROISIN, D, and SCHAERER, R. (1997). Intractable pain in the terminally ill. European Journal of Palliative care; Vol 4 (2): 1-2.

LEICHTENTRITT, R. D., and RETTIG, K. D. (2000). The good death: Reaching an inductive understanding. Omega Journal of Death and Dying Vol 41 (3): 221-248.

LEININGER, M. (1981). The phenomenon of caring: Importance, research questions and theoretical considerations. In: Caring: An essential human need, ed. by M. Leininger. (Thorofare, NJ: Charles B. Slack).

LEFEVRE, C.J. (1992). Communicative needs of the terminally ill elderly and the role of the hospice volunteer. PhD thesis: University of Oregon, USA.

LEMON, N. and TAYLOR, H. (1997). Caring in Casualty: The phenomenology of nursing care. In: Doing qualitative analysis in psychology, ed. by N. Hayes. (Hove, East Sussex: Psychology Press).

LEPP, I. (1968). Death and its mysteries. (London: Burns & Oates).

LEVINE, S. (1982). Who dies? An investigation of conscious living and conscious dying. (New York: Anchor Books).

________. (1984). Meetings at the edge: Dialogues with the grieving and the dying, the healing and the healed. (New York: Anchor Books).

________. (1989). Healing into life and death. (Bath: Gateway Books).

LINCOLN, Y.S., and GUBA, E. G. (1985). Naturalistic Inquiry. (Beverly Hills, CA: Sage).

LUGTON, J. (1987). Communicating with dying people and their relatives. (London: Austen Cornish Publishers, Ltd.).

LUNT, B. and YARDLEY, J. (1988). Home care teams and Hospital support teams for the terminally ill. (Southampton: Cancer Care Research Unit. Royal South Hants Hospital).

LYNN, J. (1993). Travels in the valley of the shadow. In: Empathy and the practice of medicine: Beyond pills and the scalpel, ed. by H. M. Spiro, M.G. McCrea Curnen, E. Peschel, and D. St. James. (New Haven, CT, USA, Yale University Press).

MacLEOD, M. L. P. (1990). Experience in everyday nursing practice: A study of "experienced" ward sisters. PhD thesis: University of Edinburgh, Scotland.

MADJAR, I. (1991). Pain as embodied experience: A phenomenological study of clinically inflicted pain in adult patients. PhD thesis: Massey University, Palmerston North, New Zealand.

MAGNUSSON, D. (1981). Towards a psychology of situations. (Hillsdale, NJ, USA: Lawrence Erlbaum).

MAMALI, C. (1996). Interpersonal relationship processes in totalitarian societies. In: Communication in personal relationships across cultures, ed. by W. Gudykunst, S. Ting-Toomey, and T. Nishida. (Thousand Oaks, CA: Sage Publications).

MANNING, M. (1984). The hospice alternative: Living with the dying. (London: Souvenir Press).

MARSHALL, C. and ROSSMAN, G.B. (1989). Designing qualitative research. (Newbury Park, CA: Sage).

_____. (1995). Designing qualitative research (2nd ed.). (Newbury Park, CA: Sage Publications).

McCANN, I.L., and PEARLMAN, L.A. (1990). Psychological trauma and the adult survivor: Theory, therapy and transformation. (New York: Brunner / Mazel).

McCRACKEN, G. (1988). The long interview. (Newbury Park, CA: Sage).

McGRATH, P., YATES, P., CLINTON, M. and HART, G. (1999). "What should I say?": Qualitative findings on dilemmas in palliative care nursing. Hospice Journal; Vol 14 (2): 17-33.

McMANNERS, J. (1981). Death and enlightenment. (Oxford: Oxford University Press).

McWILLIAM, C.L. BURDOCK, J., and WAMSLEY, J. (1993). The challenging experience of palliative care support-team nursing. Oncol. Nurs. Forum; 20: 770-785.

MESLER, M.A. (1994, 1995). The philosophy and practice of patient control in hospice: The dynamics of autonomy versus paternalism. Omega: Journal of Death and Dying, 1994-1995, Vol 30 (3): 173-189.

MILLER, R. B. (1996). Love and death in a Pediatric Intensive Care Unit. Annual of the Society of Christian Ethics: 21-39.

MILLER, W.L. and CRABTREE, B.F. (1992). Primary care research: A multimethod typology and qualitative road map. In: Doing qualitative research, ed. by B.F. Crabtree and W.L. Miller. (Newbury Park, CA. USA: Sage Publications).

MISBIN, R.-J. (1990). Commentary - "Make Me Live": Autonomy and terminal illness. Hastings Centre Report: 42-43.

MISHLER, E.G. (1986). Research interviewing: Context and narrative. (Cambridge, MA: Harvard University Press).

MONTGOMERY, C.-L. (1991). The care-giving relationship: Paradoxical and transcendent aspects. Journal of Transpersonal Psychology; Vol 23 (2): 91-104.

MOORE, F.X., PHILLIPS, R., PIPALA, J., and BRAKARSH, S. (1992). The role of the house call in terminal care. Loss, Grief, and Care 6: 117-122.

MORGAN, D.L. (1997). Focus groups as qualitative research (2nd ed.). (Newbury Park, CA: Sage).

MOUSTAKAS, C. (1990). Heuristic research: Design, methodology, and applications. (Newbury Park, CA: Sage).

________. (1994). Phenomenological research methods. (Thousand Oaks, CA: Sage).

MUNNS, B. (1991). Factors that are important to the quality of life of dying patients: a study of the quality of life perceptions of terminally ill people in a hospice and the acute wards of a general hospital. PhD thesis: University of Surrey.

MURPHY, C.P., and HUNTER, H. (1983). (eds.). Ethical problems in the nurse-patient relationship. (Boston: Allyn and Bacon).

NEUBERGER, J. (1987). Caring for dying people of different faiths. (London: Austen Cornish Publishers Limited).

NEWCOMB, T.M., TURNER, R.H., and CONVERSE, P.E. (1966). Social Psychology: A study in human interaction. (London: Tavistock).

NORTON, R. (1983). Communicator style: Theory, application and measures. (Beverly Hills, CA: Sage).

PARKES, C.M.; RELF, M. and COULDRICK, A. (1996). Counselling in terminal care and bereavement. (Leicester: BPS Books)

PATTON, M.Q. (1990). Qualitative evaluation and research methods (2nd ed). (Newbury Park, CA: Sage Publications).

POSS. S. (1981). Towards death with dignity. Caring for dying people. (London: Allen & Unwin).

PRUYSER, P.W. (1984). Existential impact of professional exposure to life-threatening or terminal illness. Bulleting of the Menninger Clinic Vol. 48 (4): 357-367.

RAUDONIS, B.M. (1991). A nursing study of empathy from the hospice patient's perspective. PhD thesis: The University of Texas at Austin.

________. (1995). Empathic nurse-patient relationships in hospice nursing. Hospice Journal, Vol 10 (1): 59-74.

RAUDONIS. B.M., and KIRSCHLING, M. (1996). Family caregivers' perspectives on hospice nursing care. Journal of Palliative Care, Vol. 12 (2): 14-19.

REASON, P. (1981). An exploration in the dialectics of two-person relationships. In: Human Inquiry, ed. by P. Reason and J. Rowan. (New York: John Wiley and Sons).

REBER, A. S. (1985). The Penguin Dictionary of Psychology. (London. Penguin).

RHODES, C. (1987).Women in transition: From dependency to autonomy. A study in self development. PhD thesis: The Union Graduate School, 1986.

RIESSMAN, C.K. (1993). Narrative Analysis. (Newbury Park, CA: Sage).

ROMPP, G. (1987). Forderung und Sollen. (Demand and Obligation). Tijdschr Filosof (Deutscher Philosoph); Vol 49: 646-675.

ROSE, D. (1990). Living the ethnographic life. (Newbury Park, CA: Sage).

ROSENBERG, J.-A., and TOWERS, B. (1986). The practice of empathy as a prerequisite for informed consent. Theor. Med.; 7: 181-194.

ROSSMANN, P. (1977). Hospice: Creating new models of care for the terminally ill. (New York: Fawcett Columbine).

SANDER, C.P. (1991). Hospice Life. PhD thesis: New York University.

SAUNDERS, C., and BAINES, M. (1983). Living with dying. The management of terminal disease. (Oxford: Oxford University Press).

SCHILDER, E. J. (1986). The use of physical restraints in an acute care medical ward. PhD thesis: University of California, San Francisco, CA.

SCHWAB, J. (1994). Betreuung von Schwerstkranken und Sterbenden. (Care for the seriously ill and the dying). In: Kompendium der Gerontologie. Interdisziplinäres Handbuch für Forschung, Klinik und Praxis, ed. by E. Olbrich, K. Sames, and A. Schramm. (Landsberg/Lech, Germany: ecomed Verlagsgesellschaft).

SEKARAN, U. (1992). Research methods for business: A skill building approach. (New York: John Wiley and Sons).

SEULIN, C., GERIN, P., AMAR, A., and DUCLOS, A. (1989). Presentation d'une echelle d'engagement du patient dans la relation soignant-soigne. (Presentation of a scale of the patient's involvement in the care relationship). Information Psychiatrique; Vol 65 (9): 915-923.

SLOTE, M.A. (1975). Existentialism and the fear of dying. American Philosophy Quarterly, Fall, 12: 17-28.

SKIBOWSKI, R. (1984). Berufliche Helfer im Umgang mit sterbenden Patienten. (Professional helpers and their interactions with dying patients). In: A.M. Tausch and R. Tausch. Sanftes Sterben. (Gentle dying). (Reinbeck near Hamburg, Germany: Rowohlt Verlag).

SPINELLI, E. (1989). The interpreted world: An introduction to phenomenological psychology. (London: Sage).

________. (1994). Demystifying Therapy. (London: Constable).

STEDEFORD, A. (1989). Counselling, death and bereavement. In: W. Dryden et al. (eds). Handbook of counselling in Britain. (London: Tavistock / Routledge).

STERNBERG, R. (1986). A triangular theory of love. Psychological Review, 93: 119-135.

STEVENSON, C. and COOPER, N. (1997). Qualitative and quantitative research. The Psychologist, 10, No. 4: 159-160.

STILES, M.K. (1994). The Shining Stranger: Application of the phenomenological method in the investigation of the nurse - family spiritual relationship. Cancer Nursing: Vol 17 (1): 18-26.

STODDARD, S. (1978). The hospice movement. A better way of caring for the dying. (London: Jonathan Cape).

STONE, H.W. (1983). Crisis Counseling. (Philadelphia: Fortress Press).

STUHLMILLER, C. M. (1991). An interpretive study of appraisal and coping of rescue workers in an earthquake disaster: The Cypress collapse. PhD thesis: University of California, San Francisco, CA.

TAUSCH, A.M., and TAUSCH R. (1985). Sanftes Sterben: Was der Tod für das Leben bedeutet. (Dying gently: The meaning of death for life). (Reinbeck near Hamburg, Germany: Rowohlt Verlag GmbH).

THIBEAU, J.W., and KELLEY, H.H. (1959). The social psychology of groups. (New York: Wiley).

THOMPSON, D. (ed.). (1996). The Concise Oxford Dictionary of Current English. (9th ed.). (London: Book Club Associates).

TWYCROSS, R. (1999). Introducing palliative care. (3rd ed.). (Oxford: Radcliff Medical Press Ltd.).

UFFMAN, B. (1993). Living with dying: a qualitative study of hospice volunteers. PhD thesis: California Institute of Integral Studies.

VACHON, M. (1995). Staff stress in hospice/palliative care: A review. Palliative Medicine 9: 91-122.

________. (1998). Psychosocial needs of patients and families. Journal of Palliative Care: Vol 14 (3): 49-56.

VALLE, R.S., and KING, M. (eds.). (1978). Existential-Phenomenological alternatives for psychology. (New York: Open University Press).

van KAAM, A. (1959). Phenomenological analysis: Exemplified by a study of the experience of "Really feeling understood". Journal of Individual Psychology 15(1): 66-72.

_______. (1966). Application of the phenomenological method. In: Existential foundations of psychology, ed. by A. van Kaam. (Lanham, MD: University Press of America).

VEATCH, R.M., and FRY, S.T. (1995). Case studies in nursing ethics. (Boston: Jones and Bartlett Publishers).

von FRIEDERICHS-FITZWATER, M.M. (1987). The analysis of verbal immediacy in the communication of care providers and terminally ill patients. PhD thesis: The University of Utah, USA.

von GUNTEN, C. F., FERRIS, F. D., and EMANUEL, L. L. (2000). Ensuring competency in end-of-life care: Communication and relational skills. JAMA: Journal of the American Medical Association 284 (23): 3051-3057.

von MANZ, H.-G. (1994). Selbstgewissheit und Fremdgewissheit. (Self-certainty and Other-certainty). Fichte Studien; 6: 195-213.

WALKER, G., BRADBURN, J. and MAHER, J. (1996). Breaking bad news. (Poole: King's Fund; Bournemouth English Book Centre).

WARD, E. G. III, (1998). Boundaries in the heart: The sociology of distance and intimacy in hospice work. Phd thesis: Northwestern University.

WARNOCK, M. (1989). Existentialism. (Oxford: Oxford University Press).

WARWICK, D.P. and LINNIGER, C.A. (1975). The sample survey: Theory and practice. (New York: McGraw-Hill).

WARR, T. (1999). The physician's role in maintaining hope and spirituality. Bioethics-Forum; 15 (1): 31-37.

WATSON, J. (1979). Nursing: The philosophy and science of caring. (Boston: Little Brown).

WEIR, R. (1986). Ethical issues in death and dying. (2nd ed.). (New York: Columbia University Press).

WELLER, S. C., and ROMNEY, A. K. (1988). Systematic data collection. (Newbury Park, CA: Sage Publications).

WELLERSHOFF, D. (1983). Blick auf einen fernen Berg. (View towards a distant mountain). (Frankfurt am Main, Germany: Fischer Taschenbuch Verlag).

WENDULA, W. (1984). Erfahrungen medizinischer Helfer mit sterbenden Patienten. (Experiences by medical care workers with dying patients). In: A.M. Tausch and R. Tausch (1984). Sanftes Sterben. (Gentle dying). (Reinbeck near Hamburg, Germany: Rowohlt Verlag).

WERTZ, F.J. (1985). Method and findings in a phenomenological psychological study of a complex life-event: Being criminally victimized. In: Phenomenology and Psychological Research, ed. by A. Giorgi. (Pittsburgh, PA: Duquesne University Press).

WILBER, K. (1992). Mut und Gnade. (Grace and grit). (Frankfurt am Main: Scherz Verlag).

WILKINSON, S., ROBERTS, A., and ALDRIDGE, J. (1998). Nurse-patient communication in palliative care: An evaluation of a communication skills programme. Palliative Medicine; Vol 12 (1): 13-22.

WILSON, m. (1975). Communicating with the dying. Journal of Medical Ethics; 1: 18-21.

WILSON-BARNETT, J. (1994). "The nurse-patient relationship". In: Principles of Health Care Ethics, ed. by R. Gillon. (New York: Wiley and Sons).

WNOS, P. L. (1993). Behind the curtain: Nursing care of dying patients in critical care. (Oregon: Oregon Health Science University).

WOLCOTT, H.F. (1990). Writing up qualitative research. Newbury Park, CA: Sage).

WOOD, J. T. (1995). Feminist scholarship and the study of relationships. Journal of Social and Personal Relationships 12: 103-120.

YODER, P. (1990). Guilt, the feeling and the force. PhD thesis: (The Union Institute, 1989).

ZANER, R.M. (1970). The way of phenomenology. (New York: Pegasus).