

CARING FOR DYING PARENTS: AN EXISTENTIAL PHENOMENOLOGICAL APPROACH

**Submitted by
Lindsay Paul BSc (Adelaide), Grad Dip Community Health (La Trobe)**

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**School of Public Health, Faculty of Health Sciences
La Trobe University
Bundoora, Victoria 3086
AUSTRALIA**

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SUMMARY

The death of one's parents, irrespective of the age at which it occurs, is generally regarded as a life experience of considerable significance. The last few years of an elderly person's life are often characterized by increasing frailty, declining health and loss of independence. Responsibility for the spiritual and physical care of parents during that period is undertaken by many adult children. Current research in this area is generally informed by the requirements of social policy, which, by identifying and addressing the inherent difficulties in this so-called informal caring, is designed to support carers in the community. The research reported in this thesis represents a departure from this mode of inquiry and seeks, rather, to explore the existential aspects of caring in this particular situation, from the carer's perspective.

To achieve this objective, an existential phenomenological approach informed principally by the philosophies of Heidegger and Merleau-Ponty, and the adaptation of these philosophies by Schutz, Giorgi and van Manen to social science research, was developed to suit the particular requirements of the topic. In addition to the author's autobiographic material, primary sources include conversations with five people who had been principal carers for their parents during their final illnesses. In all cases caring had ended with the parent's death at least one year before the conversations took place. The principal secondary sources are Simone de Beauvoir's memoir, *A Very Easy Death*, and Philip Roth's account of his father's illness and death, *Patrimony: A True Story*. In addition, the argument is supported throughout by reference to other literary works. From these sources a number of major existential themes, including temporality, hope, suffering, and knowing the body, have been explored in depth, in conjunction with relevant existential theories. Synthesis of these topics suggests that in this particular circumstance, for the people involved in the study, the phenomenon of caring can be understood as an unconditional engagement with the life and concerns of their parent at the end of life, and can be interpreted within an existential framework as representing an authentic way of Being.

* * *

STATEMENT OF AUTHORSHIP

Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis for any other degree or diploma.

No other person's work has been used without due acknowledgement in the text of the thesis.

The thesis has not been submitted for the award of any other degree or diploma in any other tertiary institution.

All research procedures reported in the thesis were approved by the La Trobe University Faculty of Health Sciences Ethics Committee, Approval Number FHEC 96/200

Signed:..... **Date:**.....

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I thank the participants who have so generously contributed to the study, and without whom research of this type is not possible. Their experiences as carers cannot be quantified, and in this thesis I have attempted to present them in a form which celebrates caring as a feature of the human condition. I have benefited in many ways from our conversations during which they told of their experiences of caring, and trust that their inherent reflective attitudes serve them well in their future lives.

Finally, this thesis commemorates the life of my mother. The ultimate legacy of the experience of caring for her for the last few years of her life is that I have, through this study which was initiated in that experience, reached an understanding of the value of a phenomenological approach to life.

*With the drawing of this Love and the voice of this Calling
We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And know the place for the first time.*

T. S. Eliot: Little Gidding

Chapter One. Introduction

At the age of seventy-seven, Simone de Beauvoir's mother, who was crippled with arthritis, (although still living independently in her apartment in Paris), fell and broke the neck of a femur. She was alone at the time, and it took her two hours to reach the telephone and seek help. At first the doctors were concerned only with the injury, but at the beginning of what was intended to be a long period of rest and rehabilitation it quickly became apparent that she had a far more serious health problem. After the failure of the doctors to diagnose the illness with the help of X-ray examinations, an exploratory operation revealed the truth; a "huge tumour, a cancer of the worst kind" was blocking her bowel, and peritonitis had developed (de Beauvoir, 1966, p. 27). There was no hope that she could be cured, or even that surgery could alleviate her condition. The doctors made several attempts to prolong Mme de Beauvoir's life, but in the end these strategies served only to extend her suffering. De Beauvoir and her sister were constantly at their mother's hospital bedside for the five weeks during which she lay dying. In the course of this time the relationship between de Beauvoir and her mother, which had been somewhat strained for many years,¹ strengthened in response to the new situation. This was due in part, de Beauvoir explains, to a significant change in her mother's attitude:

My mother was awkwardly laced into a spiritualistic ideology; but she had an animal passion for life which was the source of her courage and which, once she was conscious of the weight of her body, brought her towards truth. She got rid of the ready-made notions that hid her sincere and lovable side. It was then that I felt the warmth of an affection that had often been distorted by jealousy and that she expressed so badly (de Beauvoir, 1966, p. 90).

Mme de Beauvoir died in December 1963, and shortly afterwards her daughter began to write her autobiographical account of the experience. The memoir, *A Very Easy Death*, was published in April 1964. It was generally well received by the public, although some critics accused its author of taking notes at her mother's bedside in preparation for writing the book. She states, however, that she used the notes only as a means of comfort,

¹ The reasons for this situation are explained in the first volume of de Beauvoir's autobiography, *Memoirs of a Dutiful Daughter* (de Beauvoir, 1963).

in much the same way as a religious person would find solace in prayer. She writes, "...I did not need [the notes] to remind me of the days I had just lived through – those days were imprinted upon me forever" (de Beauvoir, 1972a, p. 134). She continues:

At that particular time [when the book *Old Age* (de Beauvoir, 1972b) was about to be published] I hardly cared for the fate of my book at all. My mother had just been taken to hospital: her illness and her death filled my mind entirely. A few days after she was buried, I suddenly knew that I must write about her last days; I also knew what my account was to be called, how I was to dedicate it and what poem I would quote at the beginning. I spent that winter writing it. Almost every night I saw my mother in my dreams (de Beauvoir, 1972a, p. 134).

In a letter to Nelson Algren, dated April, 1964, she apologises for not writing to him for some time as she had been preoccupied with the new situation: "...I explained to you why [my mother's death] upset me and I had to tell it. It never happened that I felt so much compelled to do such a thing. Now it is achieved. Sartre likes it very much" (de Beauvoir, 1999, p. 573).

The research project: Caring for a dying parent

The research question

The aim of this research is to examine, by means of an existential phenomenological approach, the experiences of sons and daughters who, like de Beauvoir, had been intimately involved with the events surrounding the final illness and death of their parents. The objective of phenomenology, Michael Crotty explains, is to "...elucidate, first and foremost, the phenomenon to which people are attaching meaning. It pursues, not the sense people make of things, but what they are making sense of" (Crotty, 1996, p. 3). Existentialism is a variety of constructionist epistemology which is concerned with the ways in which we, as human beings, interact with other beings in our world; it is concerned with our "Being-in-the-world." From this perspective, and with the phenomenological objective in mind, the significance of de Beauvoir's memoir to a study of caring becomes clear. The urgent need to relate her story, the uncertainty (and ultimate irrelevance) of its factual correctness the sense of absorption in the events that it conveys, and the absence of any reference to "caring," are features common to such narratives. *A Very Easy Death* presents to the reader an image of a particular period in a person's life,

rather than a specific act identifiable as “caring.” Although de Beauvoir and her sister certainly did provide physical and emotional care for their mother, clinical description of these activities is not the primary objective of the book. Rather, it tells in an indirect way the story of a relationship between two people; it traces its growth, and its flowering, in a difficult and traumatic period of their lives.

Together these incidents, activities and emotional experiences constitute an overarching experience commonly known as caring, and by exploring these components it should be possible to construct a phenomenological description of caring in these particular circumstances. The purpose of this study is to elucidate such a phenomenon. It is not, however, concerned with grief, which constitutes an entirely different phenomenon.² In keeping with the objectives of phenomenological inquiry defined above by Crotty, the aim of the study is to describe and explore the nature of caring as far as this is possible using the materials available; it is not the intention to either theorise caring or to describe the act of caring. The research question that is addressed in this thesis can therefore be stated simply and unambiguously as: *“What is the nature of the phenomenon of caring experienced by adults caring for their dying parents?”*

In this introductory chapter, the significance of caring for a dying parent is considered from an existential perspective. A review of the interpretations of “caring” and “informal caring” commonly found in the academic literature is followed by an outline of existential theory, to the extent that it is relevant to the study. There is particular reference to Heidegger’s notion of phenomenology, the concept of the “phenomenon,” and his conceptualisation of *Sorge* as the fundamental way of Being. These ideas underpin much of the contemporary theoretical treatment of caring, and are used extensively in the development of the methodological approach employed in this thesis, and which is discussed in depth in Chapter Three. Finally an account of the significance of death in the totality of a person’s existence, particularly as envisioned in the works of Heidegger and Sartre, is presented. This is because the thesis deals specifically with the

² This difference is made very clear in C.S. Lewis’ *A Grief Observed* (1961), a work in which he documents the experience and resolution of his grief after the death of his wife (see also Charmaz, 1980, for further discussion on this issue).

care of a dying parent it is crucial that an existential understanding of death, both our own and that of others, is included. At the prospect of the death of one's parent we are inevitably confronted with our own mortality, and it is clearly incumbent upon the carer to endeavour to understand the experience of the dying person.

The study originated with my experience of caring for my mother for several years prior to her death. I did not become acquainted with *A Very Easy Death*, or indeed any of the other texts used in the study, until I began to seek an understanding of what had been at the time an extremely stressful situation. This reaction is, according to Jean-Paul Sartre (1969), a legacy of many human experiences, particularly such major ones as the death of a parent. Many people feel an overwhelming need to assign some sort of meaning to such events. As de Beauvoir explains to Algren in the letter cited above, she underwent such an experience, one of its outcomes being the memoir. I began my own reflective process by recording in a private journal incidents and impressions that were deeply embedded in the experience. Later this process extended to an investigation of both academic and autobiographical material on the subject of caring. The purpose of this inquiry is to further extend the understanding of the nature of caring through a fusion of interview transcripts, my personal writing, autobiographical accounts and theoretical material.

A Very Easy Death contains a number of graphic descriptions of human suffering and indignity. The shifting nature of the relationship between mother and daughter, and the awakening of new attitudes and emotions in de Beauvoir herself brought about by the traumatic events of the final month of Mme de Beauvoir's life, emerge as critical elements of the narrative. It is precisely such an existential understanding of a common situation, and the lasting legacy that such experiences convey, that are of concern in this research.

The idea of “caring”

De Beauvoir's book describes her involvement in the events surrounding her mother's illness and death. It is a story of the ambiguity of experience and the elusiveness of relationships; it is also a story of impending death. It does not purport to be a narrative of “caring”; yet offering physical and emotional support to another person (activities which engaged de Beauvoir almost exclusively during the last month of her mother's life) are implicit in the common understanding of caring. Why, then, does de Beauvoir not dwell upon the idea of caring in her memoir? Does her experience differ greatly from that of others who are said to be caring for their parents? A review of the variety of meanings that have been assigned to the word “caring” in social and political contexts, and of its existential significance, provides some answers to these questions.

To define “caring” is not a simple matter. For example, the verb “care” is described in the Macquarie Dictionary as “to be troubled, to be affected emotionally; to be concerned or solicitous; to have thought or regard” (Delbridge et al., 1997). Nurse researchers Patricia Benner and Judith Wrubel (1989) propose a broad definition which encompasses the range of experiences described by de Beauvoir, and which also falls within the dictionary definition. They consider caring to be a state (rather than an activity) in which “persons, events, projects, and things matter to people”, which means that it “fuses thought, feeling and action” (p. 1). In many respects this conceptualisation of caring resembles that of Milton Mayeroff (1971), who argues that although caring must be altruistic in nature, (being concerned with the “actualisation” of the Other), the benefits are in fact mutual, and the person providing care experiences “personal growth” through the process.³ Stated in such general terms, both the meaning of caring and its practice are open to interpretation depending upon the situation in which it occurs, and it is from such a sweeping understanding of caring that its creative or imaginative nature becomes apparent. There can be no prescribed or definitive way of caring; it can occur in a professional setting, between those who bear a familial relationship, or between people

³ Mayeroff's conceptualisation of caring is discussed in detail in Chapter Five (pages 139-144).

who are strangers to each other. Even within these particular settings the nature of caring varies widely.

Philosopher Stan van Hooft, in an exhaustive analysis of the meanings of “care” and “caring” with which he begins his work *Caring: An Essay on Caring and the Philosophy of Ethics*, reaches a similar conclusion. He argues that caring is a “fundamental motivational disposition” (van Hooft, 1995, p. 30), and that there is a “cognitive component” in caring that is expressed in the value the carer (the subject) places upon the object for which he or she cares; it must be important to the carer. He explains the significance of the motivational component when he writes that:

...finding something important is not simply a cognitive judgment but a practical one. It is the cognitive, evaluative, and motivational context upon which practical necessity is founded. To find something important is to make it apt to be acted upon. If caring, in its turn, is linked to finding something important, then it follows that caring is inherently practical. If we care for someone or something, then we are apt to act, as occasion demands, in pursuit of the benefit of that which is cared for. Merely being affected by the well-being of those objects is not sufficient. One must be inclined to act (van Hooft, 1995, pp. 36-7).

It is this interpretation that is the focus of the present study. Van Hooft describes other modes of caring; for example, as it is practised in the caring professions. He also examines the meanings of the terms “caring for” and “caring about,” although he does not consider that a clear distinction, either in theory or in usage, can be made between these terms. He does, however, make the important observation that the “motivational orientations” in a caring situation are specific to its particular circumstances, and thus inform the nature of the “specific notion of caring for” (p. 33).⁴

To say that de Beauvoir was caring for her mother is an entirely acceptable proposition in view of the flexibility (or ambiguity) of such a notion of caring. It is debatable whether de Beauvoir herself would have described herself as a “carer” during the five months covered in the memoir, although it is entirely possible that she would have viewed her behaviour and experience as inherent aspects of her role as a daughter, because the narrative is related from this perspective.

⁴ Van Hooft’s theory of caring is further discussed on page 32.

“Informal caring” or just “caring”? A question of semantics

Caring, like any other human activity, occurs within a social context. The type of caring in which the participants in this study, and de Beauvoir herself, were engaged is commonly known as “informal caring.” This term is a relative newcomer to the lexicon of health and social sciences, originating in Philip Abrams’ seminal study of the dynamics of community care networks in Britain between 1976 and 1981, which has been documented in detail by Bulmer (1986). Abrams was interested in the possibility of the deliberate optimisation of this modality of caring through social policies which encourage and foster environments conducive to informal caring between neighbours, and in this respect the structure and context of flourishing networks of neighbourhood care was recognised as being important. Abrams differentiated clearly between formal and informal caring. He defined formal caring as that “...provided within the ambit of bureaucratically structured agencies; it is a matter of tasks to be performed by specific persons whose work it is to carry out such tasks, within an overt hierarchy of accountability” (Bulmer, 1986, p. 4). Formal caring then, according to Abrams’ conceptualisation, does not necessarily refer to the practise of medicine, nursing, or caring enacted by other health professionals; it simply means that the providers of formal care are always responsible to a higher authority. Informal caring, however, is “...rooted not in commitment to tasks but in attachment to persons; it is a property of relationship, not of jobs; its dispositional base is involvement with other people, not the conscientious performance of a role” (p. 4). Informal caring is thus inherent within a relational role (that of mother, son, etc.) but does not in itself define a role. Abrams was careful to distinguish between informal care provided by friends and neighbours and that provided by relatives, recognising that relations are prepared to carry greater responsibilities and burdens than friends in caring for their kin.

Abrams identified four distinct bases for informal caring:

- *altruism*: the acceptance of the norm of beneficence as an absolute guideline for personal life;
- *tradition*: a practice of the taken-for-granted helpfulness strongly implanted in

childhood or earlier experience in adult life, and carried over as an unconsidered principle of present activity;

- *status*: the culling of self esteem from the patronage aspect of the relationship between donor and beneficiary or from the honorific connotations of being seen as a caring agent by the larger society; and
- *reciprocity*: this appears to be the principal motive for informal care, which can also be regarded as a form of altruism (adapted from Bulmer, 1986, p. 10).

Abram's study demonstrates the extreme complexity of human behaviour and suggests that altruism and reciprocity, as well as mutual and kinship obligations, are informed by a variety of factors. It also indicates that the rewards and exchanges involved in these activities elude definition; because of their subjective nature, such things as personal satisfaction derived from caring are almost impossible to identify precisely.

It is possible to envisage the principles identified here informing the behaviour patterns between two people, but applying them to a larger group, particularly those which do not share kinship ties, is an entirely different matter. Indeed, Abrams conceded that within neighbourhoods the reciprocity of altruism is not a "natural" occurrence, and an environment favouring its existence must be deliberately fostered. On this basis, he argued the moral tensions and contradictions between the provision of formal and informal care cannot be resolved completely; they simply need to be recognised and accepted. "...[T]he sensible course is to allow that any achievement of neighbourhood care is going to be based not on the unequivocal pursuit of this or that value or morality but on an accommodation of values, a more or less uneasy coexistence of moralities" (p. 225).

If social networks such as neighbourhoods and communities are understood as social constructs (in the manner of all social institutions), then the futility of trying to resurrect them once they have collapsed is obvious. It is even more difficult to create them in a deliberate attempt to synthesise a source of caring which can be called into action as

necessary, or be incorporated into public policies.⁵ Abrams found that the informal system of social caring between neighbours does not in fact exist “except as a system of care between kin,” and so Abrams concluded that informal care in the family could still be relied upon as a reality.⁶ Ultimately care is ambivalent: “Care can be seen as both natural and contrived, as at once needed and imposed, as simultaneously enhancing and impoverishing the lives of both those who receive and of those who give” (p. 224).

In an analysis of the emergence of the terms “carer” and “informal carer,” and of the carer discourse over the last thirty years, Heaton (1999) observes that the entry of informal caring into the political discourse has been associated with the rise in enthusiasm for community care (that is, care “in”, not “by” the community). In the United Kingdom, for example, informal carers are now officially recognised through legislation in the form of the Carers Act, while in Australia informal carers are acknowledged as legitimate clients of Health and Community Care (HACC) services (Palmer & Short, 2000). Heaton claims that the term “informal carer” was originally used almost interchangeably with “relation” (although this is not how Abrams understood the term), and now “carer” replaces “informal carer”. “Carer” no longer refers to professional carers, and there has been a polarisation of formal and informal caring roles in policy

⁵ Berger and Luckmann argue that because of their historicity, institutions “...cannot be created instantaneously. Institutions always have a history, of which they are the products. It is impossible to understand an institution adequately without an understanding of the historical process in which it was produced” (Berger & Luckmann, 1967, p. 72).

⁶ Whether the continued existence of the “family” itself can be relied upon, at least in Western cultures, is doubtful. Australian sociologist Michael Gilding (1997) for example, argues that the family can be defined variously as the site of socialisation, by spatial proximity of its members (sharing households and purposes), or as a group bound by “love, care and nurture.” But, he writes, “contemporary families are not defined by the quality of their relationship” (p. 23). Alternatively, families can be defined in ideological terms, as an “idea” or concept. In the era of assisted reproductive technologies such as In Vitro Fertilization (IVF), and the growing acceptance of surrogacy, the notion of biological kinship becomes absurd; thus the family is an historical and social construct, and its definition is neither certain nor enduring. In addition, despite the perception that the family is removed from public life, this is not so: however much we might wish to confine the activities of the family to the private world, they are ultimately directed by the public conception of the family and its “proper” activities. These activities (and duties) are not private; they only seem so but are in fact subject to the remote but deliberate manipulations of the State. What is entirely private and inviolable are the *meanings* of these activities to the individuals within the family, whatever form that may take. Such observations are similar to those of Donzelot (1979) in his history of the family in France.

literature. The politicisation of informal care through its changing public discourse is noted by Heaton, who writes that "...understanding the operation of discourses of care is central to comprehending the dynamics of care-related policies and their practical implications for individuals" (Heaton, 1999, p. 774). Although this aspect of caring is beyond the scope of this thesis, it is one that has the potential to affect informal carers in significant ways.⁷

An interesting outcome of the politicisation and associated exploitation of "informal caring" are the signs of dissent amongst those who are identified as "carers," or "informal carers," but prefer to think of themselves simply as mothers, brothers, daughters and so forth, who are carrying out their normal caring activities as part of their perceived familial roles.⁸ A compelling indication of this resentment appeared in the Spring, 2001 issue of *Carers in Victoria*, the newsletter of the advocacy and support organisation Carers Victoria, where an angry carer voiced concern about the term "informal carer" in a letter to the Editor (although he apparently had no objection to being recognised as a "carer"):

I was disturbed and disappointed to read in a Carers Victoria publication re Primary Care Partnerships, that my wife and I, having been carers for 45 years were labelled as "informal carers." (The Oxford Dictionary defines informal as being irregular). I can inform Carers Victoria and any organization or people that our caring role, like tens of thousands of other carers has been very regular and proper. During a conversation with one of your staff, I gained the impression that this term has been used in all PHP [Public Health Policy] literature. Carers in our area are very disturbed and angry that this term has been applied to them, and approved by Carers Victoria (Skinner, 2001, p. 8).

The editor replied:

I agree that the term "informal" is probably not a good one. We have used it occasionally to differentiate between paid care workers and unpaid carers (usually family members or close friends). Carers Victoria will endeavour not to use this term again, and will encourage others not to use it.

⁷ In the UK, this objective has been approached through the encouragement of traditional family values (and therefore responsibilities of family members to care for relatives) according to Finch (1989), Finch and Groves (1980; 1983), and Finch and Mason (1990).

⁸ Conversely, the author noted that some carers who spoke at the 1996 Carers' Association of Australia Conference (*It's About Time: Respite for Carers*) told the audience they were relieved to find themselves referred to as "carers," as this represents a form of officially sanctioned identity, rescuing them from the obscurity imposed by the public's indifference to their situations.

The moral indignation expressed by Skinner, and upheld by the Editor in this exchange, strongly supports Abrams' observation that caring is often intrinsic in a relationship. To this correspondent the notion that "caring" can be separated from, or added at will to the inherent features of his relationship with those for whom he is concerned, thereby recasting it as "informal caring," is absurd.

As socially constructed concepts, formal and informal caring can be understood as extremes of the continuum of care rather than as distinct entities. The term "informal care" is itself ambiguous and exhibits its own polarities; at one end of the scale informal care can be exploited as an agent of social control, while at the other it involves an intimate engagement with a family member.⁹ While the contentious nature of such an arbitrary distinction between different varieties of caring expressed in Skinner's letter to *Carers in Victoria* is acknowledged, in an existential phenomenological study the social and political meanings that inhere in the term "informal" are best avoided. For these reasons a meaning of the term "caring" which avoids all reference to such matters, and views caring as a state of being arising from a particular relationship is more appropriate. On these grounds, the decision has been taken to partially dispense with the word "informal," retaining it only if it is necessary to distinguish between caring in private and professional contexts. This is based on the premise that the study participants understood that they were simply engaged in "caring" for their parents. This thesis, then, has a role in hastening the end of the discourse of informal care which Heaton claims is inevitable.

An existential view: The phenomenon of caring

Throughout this work I will move constantly between narratives of caring derived from conversations with carers, notes written about my own personal experience, literary texts which illuminate and extend the understanding of caring, and theoretical texts which reflect the existential interpretation of caring, particularly the work of Martin Heidegger,

⁹ Dean and Thompson (1996) note the paradox that while "the family" is celebrated in some quarters, at the same time its very existence is called into question by ideologies of individualism currently in vogue. From a feminist perspective, policies of care in or by the community are regarded as a strategy to shift burden to women by "valourising" informal care and reinforcing patriarchy.

which underpins a great deal of existential thinking in this area. I stress, however, that despite its existential foundation, this research does not aspire to be a philosophical treatise; it is rather a qualitative inquiry informed by a particular philosophical concept. Indeed, since the inception of this endeavour the overarching influence has been the existential perspective upon which my personal reflection on the experience has been grounded. It has also informed the particular methodological approach chosen for the academic study of caring. In addition, by referring specifically to the existential dimension of informal caring, any quantitative connotations which are frequently (and, I believe, to a large extent inappropriately) associated with this style of care are eliminated.¹⁰ Despite the intrusion (at times vigorously pursued) by social and political forces into the private world of caring indicated in the above discussion, the narratives of caring used in the present study reveal that it is partly defined by existential features which inhere in the relationship between the people concerned, and consequently are not greatly affected by external factors. As a phenomenological study designed to investigate its existential characteristics, the point of departure then, is that caring be regarded as a “phenomenon,” in Heidegger’s sense of the term, rather than as an ordinary physical activity governed by social factors. The aim of this section is to examine some aspects of Heidegger’s thought which are relevant to the approach used in this study.

In his introduction to *Being and Time*, Heidegger explains why the “fundamental question of philosophy,” which he identifies as the nature of Being, can only be treated phenomenologically. To Heidegger, phenomenology is a “methodological conception,” which, he says, “...does not characterize the what of the objects of philosophical research as subject-matter, but rather the how of that research” (Heidegger, 1962, p. 50). He defines (albeit somewhat obscurely) the purpose of phenomenology as “to let that which shows itself to be seen from itself in the very way in which it shows itself from itself.” This, he says, means the same as the famous maxim, “to the things themselves.” Phenomenology differs from other sciences (e.g., theology, geology, anthropology) because it “...neither designates the object of its researches, nor characterizes the subject-

¹⁰ The difficulty of setting policy targets and devising policy evaluation techniques is one reason for the development of quantitative methodologies in this area. An example of this can be found in the “caregiving hassles scale” described by Kinney and Stephens (1989).

matter thus comprised” (p. 59). In all other sciences the object of concern is made clear in the noun’s prefix. The object of phenomenological research is simply any phenomenon of interest, and “phenomenology” merely tells us *how* to research something, not what that thing must be. The term “descriptive phenomenology” is thus a tautology because phenomenology is in itself a purely descriptive enterprise.

What, then, is a phenomenon? Phenomenology lets us see, or reveals to us, “that which is hidden”:

Manifestly, it is something that proximally and for the most part does *not* show itself at all: it is something that lies *hidden*, in contrast to that which proximally and for the most part does show itself; but at the same time it is something that belongs to what thus shows itself, and it belongs to it so essentially as to constitute its meaning and its ground (p. 59).

Heidegger illustrates the concept of the phenomenon with the example of symptoms of a disease, in which the presence of the disease (the phenomenon) is indicated by the symptoms which arise from it, although the disease is not apparent in itself.

By uncovering the hidden characteristics or properties of familiar things, phenomenology rescues its meaning from the obscurity of familiarity: “Thus that which demands that it becomes a phenomenon, and which demands this in a distinctive sense and in terms of its ownmost content as a thing, is what phenomenology has taken into its grasp thematically as its object” (p. 59). Thus phenomenology is a means of access, through various indicators, to phenomena which may be hidden in different ways.

Phenomena can be “covered up” (hidden) in several ways:

- they can be not yet found or discovered; or
- they can be buried over, having been once discovered or known. They may be still visible (apparent) but as semblance (“distortion”). To Heidegger this is the most “dangerous” way of being covered up as “here the possibilities of being deceived and misled are especially pertinacious” (Heidegger, 1962, p. 83).

The impossibility of concisely defining just what caring is (and particularly so-called “informal caring”) within the ordinary parameters of the social sciences, suggests that caring can most appropriately be regarded as an existential phenomenon for the purposes of research. The notion that caring is remote from (perhaps “above” is a better term) the social and political tensions described in the previous section, and is viewed by the carers involved in this study as an experience of great personal significance, invites a phenomenological treatment of the subject. Indeed, the objective of the study, and the epistemological attitude adopted by the researcher are driving forces in the selection of a methodological approach, a point that is elaborated in Chapter Three (page 61). In the spirit of Heidegger’s definition of a “phenomenon,” then, this study aims to uncover and explore the “hidden” features of caring that are essential to the constitution of its meaning.

The goal of this study is to explore the nature of the phenomenon of caring experienced by adults caring for their dying parents, and a number of limiting criteria are contained within the research question. First, caring takes place as the death of the ill person approaches. From an existential perspective this is a crucial factor because of the view that a life is incomplete before death; that is, life is circumscribed by birth and death. A consequence of this view is that it is likely that the impending loss of someone who has always occupied a place in another’s life-world represents an existential crisis. Second, the study is concerned with caring from the perspective of the person providing, not receiving, care. Third, the uniqueness of the filial relationship has a strong bearing on the nature of the understanding between the carer and the dying person.¹¹ A fourth, and implicit, factor in the study is that experience can only be viewed retrospectively; this requirement of phenomenological methodology means that the experience has been remembered, revisited, reconstructed and reinterpreted, perhaps many times, before its incorporation into the study. The stories of caring contained within all the research materials are not then to be regarded as “historical facts”; they are, rather, an outcome of reflectivity which defines the existential approach to life.

¹¹ By specifying the context of caring so precisely the familial bond can be subsumed into the study without fear of compromising it.

Heidegger's theory of Being and the existential meaning of death

Although it is not the only theory applied in this thesis, Heidegger's philosophy of Being is of primary importance. This study of the experience of caring for someone who is dying is to a large degree predicated upon the conceptualisation of the finitude of human existence, the significance of death in the totality of Being. This concept is fundamental to Heidegger's philosophical reasoning. Existentialists view humans as temporal beings, whose lives are circumscribed by birth and death. Our entire existence (Being) is thus grounded in temporality, the journey towards death; and so the end of temporality, or existence without time, is unimaginable. Indeed, it is the knowledge of inevitable death which defines consciousness and human identity; it is presumed that no other creature is aware of the possibility of their own future existence, or of death that extinguishes it. Before exploring this concept, it is necessary to consider the ways in which humans relate to each other, and to the world. This is the notion of *Dasein*.

Heidegger: Care and solicitude

Heidegger's philosophy of Being is grounded in the notion of *Sorge*, which is (somewhat unfortunately) translated as "care".¹² The following discussion explains that to Heidegger, not only is human existence governed by the inevitability or facticity of death, but it is also inextricably associated with the existence of other Beings and their worlds. Heidegger writes: "...[W]hen we interpret *Dasein* [Being] without any theoretical distortions we can see it immediately as 'being-alongside' the world with which it concerns itself..." (Heidegger, 1962, p. 156). As other Beings also occupy this world, they too are part of it, and our understanding of the world unavoidably includes their presence, even if they are encountered disinterestedly as "*Dasein*-within the world." In addition, this applies when others are not *actually* with us: "Being-with is an essential

¹² As previously mentioned, the Macquarie Dictionary defines the noun "care" as "worry, anxiety, concern, serious attention, solicitude, heed, caution." "Solicitude" is itself defined as "anxiety or concern; anxious desire or care; excessive anxiety or assistance," none of which descriptions can be applied entirely satisfactorily to Heidegger's concept (Delbridge et al., 1997).

characteristic of *Dasein* even when factually no Other is present-at-hand or perceived” (p. 156). We cannot ignore the existence of others, whether they are proximal or remote.

Heidegger examines different ways of Being-with the Other, concluding that “Only so far as one’s own *Dasein* has the essential structure of Being-with, is it *Dasein*-with as encounterable for Others” (p. 157). This interaction with others can be interpreted in terms of what Heidegger named “the phenomenon of *care*.” Krell explains Heidegger’s idea of *Sorge* (“care”) as that aspect of *Dasein* “preoccupied with itself or taking trouble concerning itself, advancing toward...*Sorge* or care” (Krell, 1993, p. 22). *Sorge* can be defined as relating to “...three basic elements of an individual’s *Dasein*: (1) the contingency of the individual’s existence (i.e., the possibility of death) which comes to awareness through *angst* (anxiety, dread); (2) *Geworfenheit* (thrown-ness), i.e., the sheer contingency of one’s existence; (3) decline, decay” (Moutner, 1997).

In *Sorge*, Heidegger is proposing something which is inseparable from absolute Being, or existence. The fundamentality of *Sorge* is reinforced by the understanding of *Dasein* as an expression of possibility, as Heidegger explains in the following passage:

Dasein is not something present-at-hand which possesses its competence for something by way of an extra; it is primarily Being-possible. Dasein is in every case what it can be, and the way in which it is its possibility. The Being-possible which is essential for Dasein, pertains to the ways of its solicitude for Others and of its concern for the “world”...As a modal category of presence-at-hand, possibility signifies what is *not yet* actual and what is *not at any time* necessary. It characterizes the *merely* possible (Heidegger, 1962, p. 183).

Care is revealed as “the primordial totality of Being” (p. 227), and the fact that Being is not ever wholly defined (until it is ended by death, as previously noted) because of its inherent character as possibility, care is similarly an expression of this possibility.

Being-in-the-world is essentially care, and our (unavoidable) interaction with others, which is a component of Being, must therefore be also considered as an aspect of care. Heidegger describes two aspects of Being-with: first, “concern” (*Besorgen*), which is “a character-of-Being which Being-with cannot have as its own, even though Being-with, like concern, is a *Being towards* entities encountered within-the-world” (Heidegger,

1962, p. 157); and second, “solicitude” (*Fürsorge*), which appears to be disinterested concern. *Besorgen* is introduced by Heidegger as a general term to cover both positive and negative “modes of concern” which arise from the ways in which a human being relates to the “entities of its world” (Kaelin, 1988). Drawing from Kaelin’s text, these are: having to do with something; producing something; attending to something and looking after it; making use of something; giving something up, or letting it go; undertaking; accomplishing; evincing; interrogating; considering; discussing; and determining. A clear definition of “care” in the Heideggerian sense is now possible:

The existential structure that gets expressed in these various ontic determinations of the ways in which we can express our concern is *care*. And so, the final answer to the question of how a human being exists in its world is “by caring.” Beginning with the entity we call distinctly human, we isolate its being as care, which has the structure of facticity or abandonment in the world, as a projection upon its possibilities, its *Existenz*, while existing carefully alongside the entities of the world (Kaelin, 1988, p. 60).

Although the distinctions between these concepts of “care” are somewhat lost in translation, the notion that they all arise from, or are even informed by, the nature and circumstance of the relationship between Beings is important. For example, our everyday relationship with Others who are of no concern to us, who merely share our world but have no other claim to us, who do not “matter to us” in any but a trivial or distant way, is still defined as solicitude, albeit negative solicitude. Heidegger does not see indifference as a way of Being in its own right; it is merely a particular form of solicitude.

For positive solicitude, on the other hand, there are two possibilities. “Leaping-in” is a mode of solicitude in which a person takes over the Other’s responsibility, or care, of himself or herself, and this can be temporary or have permanent repercussions in which the Other “disburdens” himself or herself of the problem completely. Clearly there is an inherent possibility of domination or control in this schema, although in some circumstances this could be a welcome outcome. It is, for example, an essential feature of some modes of professional caring (see, for example, Frank, 1991). Another possibility is that of the imposition of the culture and ideas of one person (or even a nation) over another (e.g., as in international aid programs). Heidegger claims that “welfare work,” which he termed a “factual social arrangement” (Heidegger, 1962, p. 157), is a result of

this type of solicitude, which he named *inauthentic* solicitude. The other form of positive solicitude Heidegger calls “leaping ahead,” and here care is “given back” to the Other in a process of facilitation or enabling which arises from a solicitude which enhances the Other’s Being. This is a sort of cooperative, mutually supportive encounter which creates, and at the same time springs from an authentic bond between two people.¹³ The special nature of the authentically solicitous relationship reaches beyond mere familiarity with the other: “The authentic relation is more than the accumulation of the specific histories of the two *Daseins*. My understanding of the Other is more than only my own, one-way intentional projection of him.” (Leman-Stefanovic, 1992, p. 226). The existence of this relationship means that it is possible to enter into experiences with the Other which we have not yet experienced ourselves (“because of the special ontological grounding of the relation”). According to Heidegger, this allows us to “give care back” to the Other. *Sorge*, then, “reveals that it is essential to the basic human constitution that there is always something-more to accomplish, something is always outstanding” (Leman-Stefanovic, 1987). We are not independent of one another (which is not to say that we are *dependent* on others). An authentic relationship is balanced and reciprocity is possible in this situation.

Clearly Heidegger’s “care” is not necessarily the same as the familiar understanding of care, and it is best to be wary of assigning philosophical meanings to activities described as “caring.” Nevertheless, the notion of “solicitude” as the individual’s concern for others (whether negative or positive), is a useful guide to the understanding of caring behaviour in everyday circumstances. Authentic and inauthentic solicitude, for example, could be viewed as private and public versions of caring respectively. The term “private” refers to an activity carried out away from the public gaze and influence, while in the public arena, as previously discussed, the activity is organised and directed by bureaucracies (see also Noddings, 1986). Change from authentic to inauthentic solicitude is always possible and should be guarded against, for example, in charitable and volunteer work, where altruistic

¹³ The relationship between client and counsellor can be understood as being characterised by a solicitude that resembles authentic rather than the inauthentic solicitude present in the professional encounter, although it will nevertheless be subject to professional constraints that are absent from informal situations.

sentiments can easily become corrupted. This point is supported in Arendt's argument that in modern societies the location of a human activity, whether occurring in the public or private domain, defines its value, and there is perceived to be a proper place where activities should occur. For example, Arendt explains that the Christian idea of "goodness," or "good deeds," requires that they exist and occur in private. Once removed to the public world (e.g., when private, altruistic work is appropriated by bureaucracies or the opportunity for self-aggrandisement beckons), they become an end in themselves and the innate quality of "goodness" disappears (Arendt, 1958). Similarly, Noddings writes:

The danger is that caring, which is essentially non-rational in that it requires a constitutive engrossment and displacement of motivation, may gradually or abruptly be transformed into abstract problem solving. There is then, a shift of focus from the cared-for to the "problem" (Noddings, 1986, p. 25).

In summary, from Heidegger's existential perspective our Being is unavoidably influenced by the relationship we have with Others, whatever their physical and emotional proximity.¹⁴ Interaction can take the form of negative solicitude, implying disregard or lack of concern for the Other, or positive solicitude, which can be either inauthentic ("leaping-in"), a transient relationship involving the provision of practical necessities, or authentic ("leaping-ahead"), within which reciprocity is possible as a moral enterprise. Caring about, as an expression of an authentic relationship, is directed towards a particular outcome or future, even if the person cared for eventually dies and will exist only in memory. Caring for the Other, then, does not necessarily end with his or her death.¹⁵ Public perceptions of caring, even of informal caring, however, are not generally concerned with this existential aspect.

¹⁴ From a broader sociological perspective, Hannah Arendt writes that it is the consciousness of the conditions of existence, and the historicity in each human life, which render humans unique among living things, both as individuals and as a species, and are what enable the perpetuation and development of the human psyche. Through production (of deeds and words) we have the potential to shape the existences of later generations. More immediately, we contribute toward the condition of others by our presence and action, and this is what makes us human beings (Arendt, 1958).

¹⁵ The link between caring and remembering identified by Edward Casey (2000) is referred to again on page 83.

The existential understanding of death

...to die is to exist only through the Other (Sartre, 1969, p. 544).

* * *

“...death does away with time” (de Beauvoir, 1972, p. 539).

* * *

The significance of death in this view of existence is obvious: indeed many claim that existentialism is the philosophy of death because its founding observation is that we proceed always to death, and death is thus the ultimate purpose of life (Charmaz, 1980). This study is concerned with a particular type of caring involving only mature adults; the care provided by one adult for another who is dying. Existential thought indicates that in this context there will be a unique relationship between the living and the dying, and it is reasonable therefore to assume that the caring experience is substantially different from, for example, childcare, or the care of a disabled person. It appears that those enmeshed in the world of caring can become detached from the everyday world of others, and therefore the nature of the relationship,¹⁶ and the certainty and closeness of death, both dominates and defines the experience.

Despite the carer's immersion in the fact of the ill person's approaching death, ultimately death must be faced alone, and this limits the possibilities of empathy. It is impossible to penetrate the dying person's isolation. De Beauvoir, for example, is appalled at her mother's suffering, but cannot really share it: “[Maman said] ‘I’m so utterly miserable,’ in that child’s voice that pierced me to the heart. How completely alone she was! I touched her, I talked to her, but it was impossible to enter into her suffering” (de Beauvoir, 1966) p. 72. Similarly, C. S. Lewis, writing of his wife's dying, agonises over the impossibility of sharing her pain:

You can't really share someone else's weakness, or fear or pain. What you feel might be bad. It might conceivably be as bad as what the other felt, though I

¹⁶ The remarkable insularity of the carer's world is evident in Edelman's account of her mother's dying, in which she sees the minutiae related to her mother's illness as being integral to her experience, but to the outsider her mother simply died. She writes: “When people ask how my mother died, I say, ‘She had breast cancer.’ ...I may be able to tell you what my mother died from in only four words, but their subtext fills the page” (Edelman, 1994, p. 67). This experience is discussed in detail in Chapter Five.

would distrust anyone who claimed that it was. But it would still be quite different....I had my miseries, not hers; she had hers, not mine (Lewis, 1961, p. 13).

The profound significance of one's own death lies in the fact that it belongs to us alone, it cannot be shared with another person. The death of another, however, does not necessarily remove that person from our "world." After death, the Other's Being-in-the-World becomes past but can still be remembered by those left behind. According to Leman-Stefanovic, (1987, p. 12), death "...does not represent a mere end-point which is not-yet, but it is the mark of each individual's life; it is that which defines us in our temporal, finite being-in-the-world." Heidegger's view is that, at the death of another, their "Being-in-the-world" past can still be imagined; it has a certain reality for those left, but cannot be a "corporeal encounter." The implication from Heidegger's existential concept that caring is to project into the future, is that care is still a possibility after the death of the Other, because he distinguishes between the "dead person" and the "deceased" person, who is still "an object of concern" (being the subject of funeral rites and mourning). Thus the living can still in this sense "be with" the person who has died, and they are not necessarily removed from memories. Paradoxically, when the possibility which resides in *Dasein* has been extinguished, *Dasein* is complete but ceases to exist. Heidegger writes that "[Dasein's] Being is annihilated when what is still outstanding in its Being has been liquidated" (p. 280). In other words, we cannot know Dasein in its entirety because it is always projected onwards towards death, and death is nothingness, which we cannot know. If *Dasein* ceases to exist then "it can never again be experienced *as an entity*." Only the death of another can be experienced (but objectively) because of this paradox. Their Being-in-the-world becomes "Being-no-longer-in-the-world." In experiencing this change from one kind of Being to another we can experience a "remarkable phenomenon...[and]...the *end* of the entity *qua* Dasein is the *beginning* of the same entity *qua* something present-at-hand" (p. 281).

Sartre, writing that "...[t]he unique characteristic of a dead life is that it is a life of which the Other makes himself the guardian," also alludes to the possibility of the continuing involvement with the dead person which can be interpreted as the continuation of caring. The life of the now dead person can be reconstructed "through the memories of relatives,

in the historic environment” (Sartre, 1969, p. 541), but can, of course, equally be consigned to oblivion. This would not mean that the life is “lost,” but rather that it becomes part of a *collective* past, part of a “generation” or a class of people. The plurality of a person’s life after death depends upon our relationship with them and how we interpret their life, or as Sartre puts it: “The dead life does not thereby cease to change, and yet [paradoxically] it is *all done*.” And, in a more sinister vein: “To be dead is to be the prey for the living” (p. 543). The living who remain, and who were most involved with the dead person, are charged with the responsibility of dealing with this memorialised being, and are free to reconstruct the persona of the dead person; to invite the dead person to persist in their lives, as it were. This so-called “dead life” changes, without in any way being itself responsible for the changes; it changes only through the meaning that the living read into it, or place upon it. Death “dispossesses us” of the ability to present our own lives to others in particular ways, and that life now becomes the property of others. But this “dead life” is still a reality, a real and “unique dimension” which continues to exist. The past lives of the dead:

...are objective and opaque beings which are reduced to the single dimension of exteriority. In this capacity they will pursue their history in the human world, but they will never be more than transcendences – transcended in the midst of the world (Sartre, 1969, p. 544).

A person’s death transforms and redefines the life that is now ended (but always in any case past): “...death deprives [life] of all subjective meaning in order to hand it over to any objective meaning which the Other is pleased to give it” (Sartre, 1969, p. 544).

Confronting death

Death is something that stands before us – something impending (Heidegger, 1962, p.294).

* * *

Because the existentialists see “confrontation with death as the central issue in human existence” (Charmaz, 1980, p. 44), it is accepted as something to which our entire existence is ultimately and unavoidably directed, and we are consequently charged with the responsibility of deriving our own meaning from death. Social and other factors do, however, conspire to encourage denial of the inevitability of death, and existentialists

argue that people tend to “flee from reality” by accepting other people’s interpretations of death (p. 45). The enormous existential significance of death is perfectly expressed by Heidegger who observes that “...[d]eath is the possibility of the absolute impossibility of Dasein” (Heidegger, 1993, p. 294).

It is difficult to accept that our world, our *consciousness*, will cease to exist when we are dead, but according to Maeterlinck the fear of death (or rather what exists beyond death) is absurd because the “nothingness” of death, “...is but a negative infinity” and it is ridiculous to fear that which does not exist (Maeterlinck, 1977, p. 36). Similarly, Koestenbaum doubts the “reality” of death, in the sense that we have to “invent” it because it is impossible to actually experience it, and it is a “problem” for which we seek to avoid responsibility. He writes: “Because dying is difficult to manage within our subjectivity, we expel or project it outside our consciousness” (Koestenbaum, 1976, p. 201). Thus as we reach old age and death becomes imminent, we look for ways of dealing with it which are external, and can be objectified; hence the success of the medicalisation of death, where we can relinquish control by handing responsibility to doctors. According to de Beauvoir:

There is no such thing as a natural death: nothing that happens to a man is ever natural, since his presence calls the world into question. All men must die: but for every man his death is an accident and, even if he knows it and consents to it, an unjustifiable violation (de Beauvoir, 1966, p. 92).

Nevertheless, death has a supreme purpose, in that it “...transforms life into a destiny: in a way it preserves it by giving it the absolute dimension...” (de Beauvoir, 1972b, p. 539). Sartre, too, reaffirms this existentialist view when writing that death “...is the final phenomenon of life...[which]...becomes the meaning of life as the resolved chord is the meaning of a melody” (Sartre, 1969, p. 532). The acceptance of the reality and meaning of death, both our own and that of others, is essential if we are to live in a state of “ontological security.” Mellor describes this as having “...nothing to do with atemporal, non-social assumptions about subjectivity, but the maintenance of a personal identity which is acquired and maintained through interaction with others in communal frames of meaning” (Mellor, 1993, p. 28).

Although we will all eventually die, and existence is directed towards death, there are different ways of thinking about this. Usually death is not something that immediately threatens (although it is always “impending,” as Heidegger writes), and so it is not normally part of our understanding of what is going on in our lives. It is understood as “...an indefinite something, which, above all, must duly arrive from somewhere or other, but is proximally *not yet present-at-hand* for oneself, and is therefore no threat... ‘Dying’ is levelled off to an occurrence which reaches *Dasein*, to be sure, but belongs to nobody in particular” (Heidegger, 1992 p. 297; emphasis in original text). In this schema “dying” is denied its real significance or real meaning, and impersonalised; we relinquish our hold of it as our own possession and transfer it to the public domain as something which is general and of reduced importance or significance, and “[d]eath gets passed off as always something ‘actual’; its character as a possibility gets concealed...” (p. 297). In this way the reality of death faced by a person who is actually dying is often denied by others, as they imagine and tell the person that he or she will soon return to the everyday world. The denial of death in the face of certainty is common:

Such “solicitude” is meant to “console” him. It insists on bringing him back into *Dasein*, while in addition it helps him to keep his ownmost non-relational possibility-of-Being completely concealed. In this manner the “they” provides [besorgt] a *constant tranquillization about death*. At bottom, however, this is a tranquillization not only for him who is “dying” but just as much for those who “console” him. And even in the case of a demise, the public is still not to have its own tranquillity upset by such an event, or be disturbed in the carefreeness with which it concerns itself. Indeed, the dying of Others is seen often enough as a social inconvenience, if not even a downright tactlessness, against which the public is to be guarded (Heidegger, 1962, p. 298; emphasis in original text).

This process of denial “forces *Dasein* away from its death.” Heidegger’s thinking here relates to the social construction of death and dying in which behaviour (both public and private) is informed by this turning of *Dasein* away from its death, that is, the denial of death; death and dying become “unacceptable” despite the facticity of death. He is putting it in an existential perspective. *Dasein* is directed always towards its death but it is forever “coming to grips” with this, in what Heidegger calls a “fugitive” manner. He then argues that “Being-towards-death is grounded in care.” The evasion of the facticity of death (in the face of dying) is an inauthentic way of Being. Authentic existence (Being) signifies the anticipation of death. Anticipation, Heidegger states, is “...the

possibility of understanding one's *ownmost* and uttermost potentiality-for-Being – that is to say, the possibility of *authentic existence*” (Heidegger, 1962, p. 307; emphasis in original text). Authentic Being-towards-death is projected existentially as follows:

*[A]nticipation reveals to Dasein its lostness in the they-self, and brings it face to face with the possibility of being itself, primarily unsupported by concerned solicitude, but of being itself, rather, in an impassioned **freedom towards death** – freedom which has been released from the illusions of the “they,” and which is factual, certain of itself, and anxious. (Heidegger, 1962, p. 311; emphasis in original text).*

Thus authentic existence is not possible without coming to terms with one's own death. The death of another also represents an existential crisis. Although a being that is part of our own Being continues to exist, this existence is in a radically changed form. The understanding of death, and the temporality of existence outlined in the above discussion is crucial in defining the experiences of those caring for dying people. They become even more significant when the person about to die bears the closest of all biological relationships to the carer.

* * *

Plan of the thesis

When conceptualised as an existential phenomenon, the vastness and complexity of the phenomenon of caring, even within the well-defined boundaries of this project, soon become apparent from the material collected for the study. In order to control a mass of information that continually threatens to blur the focus of such an undertaking, the following structure has been devised. The thesis has been divided into two sections: Part One, (Chapters One to Four), comprises the formal section, which deals with the fundamental existential theory that informs the thesis, and the methodological issues arising from this perspective; while Part Two (Chapters Five to Eight) contains the phenomenological part of the study. Three chapters in this section represent an exploration of existential themes arising from the research material, framed in terms of theoretical treatments of these themes. The objective of this approach is to impose some order upon the mass of anecdotes and accounts of emotional experiences and memories

that make up the stories of caring; in other words, to avoid the danger of drowning in a mass of data, or, as Edward Casey puts it, “spinning out in free space” (Casey, 2000, p. 20). Synopses of the individual chapters are as follows:

Chapter Two, *Phenomenology and Caring in the Nursing Environment*, is a review of phenomenological research on caring. The vast majority of this type of research is concerned with caring in the nursing environment, most of which examines experiences of nurses themselves. The reason for this focus is apparent from the nature of popular nursing theories. The chapter begins with an outline and critique of several major nursing theories, including those of Parse, Benner, Watson, as well as theories of Campbell and Bradshaw, which are based on a spiritual interpretation of nursing. This is followed by a review and critique of phenomenological research informed by these theories.

In Chapter Three, *Methodology*, the suitability of existential phenomenology as an approach to the study of caring is justified. The theoretical foundations of phenomenology, and the influential adaptations of philosophical theory to human science research developed by Schutz, Giorgi and van Manen are outlined. This is followed by a brief review of the phenomenological studies of Moustakas, Toombs and Casey, whose methodological adaptations have influenced the development of the method employed in the present study. This method, and the hermeneutic process by which the final phenomenological description of caring was attained, are then described in detail.

Chapter Four, *Research Material*, presents the primary and principal secondary sources used in the study. The chapter begins with an account of the author’s experience of caring for her mother. There are five other major, and two less important, primary sources, all of which are presented as follows: first, a brief biographical statement outlines the participant’s story; an introductory note provides additional information about the circumstances of the conversation; and finally, the conversation itself is summarised from the transcripts, with some additional comments where deemed necessary. Because of the length of the transcripts and the fact that not all of the material contained in them was relevant to the study, complete transcripts are not included in the thesis, although

extensive extracts appear in the subsequent phenomenological section. The two principal secondary sources are Simone de Beauvoir's memoir *A Very Easy Death* and Philip Roth's autobiographical account of his experience during his father's illness and death, *Patrimony: A True Story*. These works are summarised, with additional comments about the authors' stated reasons for writing such personal accounts of their experiences.

The phenomenological section begins with Chapter Five, *The World of Caring*. The aim of this chapter is to examine the ways in which caring is conceptualised in theory and practice. As an introduction to the stories of caring which are cited throughout the chapter, Mayeroff's theory of caring is discussed in detail, including a comparison of some aspects of the theory with the works of Fromm and Marcel. The examination of features of caring experienced by the carers, and which also appear in the literature, begins with a brief account of how caring is perceived by those receiving care. The carer's experience itself is explored according to a number of themes: a comparison between nursing and informal care, upholding the truth, nourishing body and soul, ways of communicating, the issue of self-deception as denial, simple and difficult tasks, and temporality. Finally, the carers reflections upon their caring experience are considered.

Chapter Six *Hope and Suffering*, begins with an overview of the existential view of suffering, including the ideas put forward by Kleinman, Scheler, Frank and Frankl. This is followed by a review of existential theories of suffering and hope, in particular those of Heidegger and Merleau-Ponty. Morse's bio-psycho-social theory of transitions between states of suffering and endurance is briefly discussed in comparison with existential theories of suffering. Examples of hope and suffering which appear in the research material are grouped under the following themes: suffering without hope, finding a new purpose through hope, overcoming fear through hope, and explaining illness as a means of coping with fear and despair.

Chapter Seven, *Ways of Knowing the Body*, is concerned with an issue that affects the carer, health professionals and the ill person in different ways; the way in which the ill person's body is experienced. There are three main sections. The first section (*The*

Hidden Body) deals with the ways in which medical technology reveals the body's interior by means of X-rays and other procedures, and how these images are interpreted by medicine, the sick person, and the carer. In the second section, (*The Naked Body*), shame and embarrassment, and ways of overcoming them are examined. The final section is concerned with medical specialisation, which has so narrowed the focus of interest that the body has become metaphorically deconstructed, its parts excised from its totality.

Chapter Eight, *Being There*, consolidates the themes developed in the previous three chapters as a phenomenological description of caring as experienced by the participants in the study. It is argued that the importance of this type of qualitative research lies in its potential as a means of extending the range of knowledge of human experience.

Chapter Two. Phenomenology and caring in the nursing environment: A review

The existential conceptualisations of care discussed in the previous chapter indicate that care (if not caring) is a central characteristic of human existence, yet little qualitative research dealing specifically with caring as it is practised in everyday life has developed within this discourse. Early preparation for this research project included a survey of the literature of care and caring. This revealed the absence of phenomenological research on caring in general; the most significant body of research on the phenomenology of caring appears in the nursing literature. In view of such a lack of phenomenological literature in the area of concern, it became clear that the development of a methodology specific to this particular project would be necessary. Nevertheless, a gauge to the extent and objectives of this type of research, and a critical review of the methodologies used has proven most useful in the development of a methodology specific to this project. The purpose of this chapter is to provide a foundation and justification for the development of the methodology described in Chapter Three.

Nursing theories, in which the phenomenological concepts of philosophers such as Martin Heidegger, Maurice Merleau-Ponty and Paul Ricoeur feature prominently, have developed rapidly over the last three decades. This is partly a response to fears that the traditional humanistic and spiritual components of nursing are in danger of disappearing in an increasingly technological environment, in which priority is placed on technical skills and scientific knowledge. The dilemma that now confronts nursing is that it must engage simultaneously with the discourses of technology and human existence, and of disease and illness. Whether existential phenomenological approaches advocated in these nursing theories succeed in bridging such dichotomies is a contentious issue; enthusiastic reception of such theories by some nurse researchers is often tempered by criticism from

the same quarter. Without question nurses must command technical and scientific expertise in the modern health care setting, but there is disagreement about which other qualities are appropriate or desirable in this environment.

The aim of this section is to critically examine some nursing theories founded upon existential and phenomenological thought which have evolved in response to this debate. It begins with an account, from an existential perspective, of ideas about the nature of the caring relationship which underpin the theories discussed. The distinction between caring for and caring about is outlined, and an introduction to Mayeroff's theory of caring (which will be dealt with in more detail in Chapter Five) is presented. This is followed by an outline and critique of several major nursing theories, including those of Parse, Benner, and Watson, as well as theories of Campbell and Bradshaw, which are based on a spiritual interpretation of nursing. Finally, a review of recent empirical research concerned with the phenomenology of care in nursing which is informed by these theories is presented.

Caring for and caring about

Because nursing is informed by the disparate paradigms of disease and illness, or by biomedical thought and humanistic perspectives, thus demanding expertise in both, defining the caring role of modern nursing is problematic. The conceptualisation of care as being either "caring for" or "caring about" allows us to interpret this situation within Heidegger's existential framework. These modes of care are enacted in ways which reflect their principal concern. Caring *about* a person who is ill is an holistic enterprise involving psychological and spiritual, as well as physical factors, while caring *for* the person is concerned mainly with the physical aspects of the condition. "Caring about" can be regarded as corresponding in general to Heidegger's authentic solicitude (see page 16), being concerned for the welfare of another person in an encompassing manner. "Caring for" is primarily concerned with the provision of therapeutic interventions and

other services in a professional, but impersonal way; this can be interpreted as an example of inauthentic solicitude.

Caring for and caring about are therefore different endeavours and this is reflected in the fundamental conceptual distinction between illness, which Kleinman (1988) described as the “innately human experience of symptoms and suffering”; and disease, “the physiological manifestation of a condition” (p. 6). Illness cannot be experienced entirely in isolation, however, because it is affected by wider cultural and social norms and the almost inevitable impact of the biomedical model espoused by medicine; nevertheless it remains essentially a subjective concept. This may be contrasted with disease, which is the biomedical assessment of a person’s health status, and refers to the deviation from what is considered by medicine to be a normal healthy state. It is a construct which reflects not only the values of medicine, but also the value which society invests in medicine. To medicine, disease is something which should be corrected. Disease “...is what the practitioner creates in the recasting of illness in terms of theories of disorders,” and: “In the broader biopsychosocial model...[of]...primary care, disease is construed as the embodiment of the symbolic network linking body, self and society” (Kleinman, 1988, p. 6). The caring role of medicine differs substantially from that of informal caring and it is governed primarily by the objective principles of science and professionalism. Nevertheless, the roles of patient and doctor are interdependent and, as Eric Cassell writes, “Physicianhood is a role – a set of performances, duties, obligations, entitlements, and limitations connected to a function or status” (Cassell, 1991, p. 70).

Is the distinction between caring for and caring about, and between informal care and professional care, as clear as the discourse implies? Dalley and Finch (1988) and Abel (1990) write that according to public discourse, caring for and caring about can only coexist in the family, which is the realm of informal care. This may be challenged primarily because of the complexity of roles in the modern caring professions, and particularly in nursing, which seeks to include both types of caring. Furthermore, if morality is linked solely with caring about, as some writers (for example Noddings, 1986) suggest, such a simplistic view would deny the moral dimension of some caring

professions. Van Hooft, however, states that it is possible to care for someone without actually caring about the person; caring in this sense can be carried out adequately, for example in a professional capacity, without interpersonal involvement. Looking after someone's physical needs does not necessarily involve a particular relationship between two people. For van Hooft, the term to "care for" "...embraces both a motivational and a behavioural component," while to "care about" is "limited to the attitudinal" (van Hooft, 1995). Mayeroff (1971) argues, however, that both moral integrity and practical capability are essential for the effective practice of any type of care and that in the absence of one of these factors care will be deficient in some way. Despite major social and philosophical differences, the boundaries between formal and informal care are in many respects indistinct, and it is difficult to define a clear dichotomy because most caring practice does rely to some extent upon the exercise of both.

The caring relationship

The existence of a unique, intimate relationship between the person needing care and the carer is a common theme, and is one that has been documented and explored phenomenologically in an earlier publication relating to the present study (Paul, 1999b). Charmaz also claims that ill people and their carers enter a private world and embark upon a shared journey. She writes: "Illness can become an odyssey to unfamiliar emotional and social terrains filled with passion, pain, and renewed purpose. Ill people and their intimates enter worlds with concerns, feelings, and problems removed from conventional adult worlds" (Charmaz, 1991). Writing from the ill person's perspective, Arthur Frank also implies that a special relationship develops between the carer and the recipient of care as a result of the situation in which they have been thrown. He argues that carers are "...the other halves of illness experiences. The care they give begins by doing things for the ill persons, but it turns into sharing the life they lead." (Frank, 1991, p. 6). Here caring is understood to be intrinsically associated with the empathic understanding between the two people to such an extent that it becomes an expression of their relationship.

Frank and Charmaz believe that caring develops within, and is nurtured by, a particular relationship, while to Mayeroff, the relationship itself is a precursor to caring. The idea of a special caring (and authentic) relationship gives rise to the notion of reciprocity, an important principle in Mayeroff's existential model of care, in which caring is seen as being mutually self-actualising and therefore inherently a moral activity which conveys meaning and purpose to the participants (Mayeroff, 1971). To Mayeroff, caring is not a power relationship; it is rather one of trust, and the carer is a facilitator who encourages and nurtures development in the Other. Mayeroff posits caring as a fundamental component of the human condition, and proposes that if this quality is not exercised our humanity is compromised. Both parties must be receptive in this situation; giving and receiving care are merely two integrated aspects of a moral activity, and therefore caring for others is both a right and a privilege because of its reciprocal moral dimension. This requirement for sharing in the caring relationship is echoed by Frank when he states: "Care is inseparable from understanding, and like understanding, it must be symmetrical. Listening to another, we hear ourselves. Caring for another, we either care for ourselves as well, or we end up in burnout and frustration" (Frank, 1991, p. 49). In a similar fashion, Pearlin and his colleagues claim that caregiving cannot be regarded as a role because it is intrinsic to the human condition, and therefore should be regarded more accurately as an inherent feature of a particular social role, for example husband or wife, mother or daughter; it develops within a relationship (Pearlin, Mullan, Semple, & Skaff, 1990).

Continuing his analysis, Mayeroff claims that caring is "primary," inferring that the activity or process of caring, not the future result of it, is of primary and intrinsic importance; it should not be subordinated to the future and be treated merely as a means towards an end (Mayeroff, 1971). The primary nature of caring is examined in greater depth by van Hooft who also develops the concept of care as a "motivational structure" (Van Hooft, 1995). His thesis is that "...commitments ground our subsequent caring in that they are as often expressed in...feelings of solicitude and concern as they are expressed in our actions" (p. 29). Van Hooft describes a "caring person" as one who acts upon concern for another person, and this can extend to what he terms "deep caring,"

which is defined as “...an inchoate level of commitment” (p. 39), and which he considers to be authentic solicitude. Therefore, when present, deep caring is an incipient factor upon which expressions of caring are founded, and “...[d]eep caring is present as a horizon rather than a content of consciousness or an *a priori* postulate” (p. 45). Deep caring, from this perspective, is instinctive and therefore primary, signifying that it is present even before cultural identity is formed. The unavoidable fact of social interaction with others ensures the existence of deep caring: “Solidarity with others involves this deep caring; deep caring is a self-project, although it always involves others.” Van Hooft proposes that “some sort of caring-about-others is a central preconscious motivational element in any analysis of our caring” (p. 75). We need to acknowledge that others matter to us as a part of our self-project, and this provides a minimal basis for ethics. He suggests that ethics is grounded on deep caring.

Nursing theories

Van Hooft and Mayeroff do not specify any particular context in their analyses of the existential aspects of caring, but it is difficult to envisage the sort of relationship implied in their theories thriving in a professional environment where no pre-existing personal knowledge is shared by the actors. Nevertheless, this is precisely what some nursing theorists, for example Parse (1981a; 1981b), Benner and Wrubel (1989) and Watson, (1985; 1989) signify when they postulate the primary nature of caring in the nursing environment. It is also considered important in therapeutic situations, for example, as Carl Rogers suggests, in psychotherapy (Rogers, 1961).¹ The authors of the three theories outlined below have turned to existential theories for enlightenment as they address the problem of intersubjectivity in nursing and seek to justify the centrality of care to nursing. These theories have proved immensely popular with nurse researchers, and this popularity is demonstrated in the review of the phenomenological literature of nursing care included in this chapter. The following brief critique of nursing theories is not

¹ By definition, however, the professional encounter cannot feature an authentic relationship between the expert and the patient because of the inherent imbalance of power (Kleinman, 1988).

intended to be inclusive, and is confined to those which feature most prominently in the phenomenological research reviewed later in this chapter.

Parse's nursing theory; the idea of human becoming

Parse's (1981a & 1981b) theory of nursing, which focuses strongly on the spiritual, or existential, aspects of the nurse/patient relationship, is held in considerable esteem by many nursing researchers. Perhaps following Heidegger's example, Parse has created distinctive rhetorical devices to accommodate her theory of "human becoming," in which she states: "That man experiences coexistence while coconstituting rhythmical patterning with the environment means that man and environment move together mutually and simultaneously in the inevitable 'ebb and flow of the dance of life'" (Parse, 1981a, p. 130). Building upon this statement, she defines caring as "risking being with someone towards a moment of joy" (p 130). The "moment of joy" is described as "the complementary rhythm of suffering-joying all at once."

Phenomenology is important to Parse, who claims that "...the primary research method to uncover modes of caring in families from a human science perspective is the phenomenological method. *Phenomenology is a method of inquiry which focuses on the unfolding of a phenomenon as it is lived.* It is hypothesis generating" (Parse, 1981a, p.131; emphasis in original text).² Parse claims that her theory of nursing is "grounded in the human sciences," and in developing her theory, she draws mainly on the works of Sartre, Merleau-Ponty, and Heidegger, and her rhetorical style also reveals her indebtedness to Martha Rogers' theory of nursing science (Rogers, 1970). For this reason, the interpretation of some of Parse's assertions is challenging, although they appear to refer to the constitution of the Self through interaction with other beings and the environment, which Merleau-Ponty (1962) and Sartre (1969) have expounded so transparently.

² Johnson (1999), however, has reservations about Parse's "mystical" approach to phenomenology and her use of extravagant rhetoric, as well as in her deductions about the nature of nursing taken from quite ordinary experiences.

Benner and Wrubel's theory of nursing: The nurse as advocate

The problem of entering into the world of the patient, and understanding the patient's experience of illness, also occupies Benner and Wrubel (1989) who, like Parse, observe that in the phenomenological tradition a person's history and situation are incorporated into their experience of illness, and this must be recognised by health professionals. Benner and Wrubel claim that the primacy of care in nursing is demonstrated in three ways. First, if care is understood as "having things matter," then the act of caring immediately defines something which caring must alleviate or address. Caring defines stress, because without care, the concept of stress would be meaningless. The second confirmation of the primacy of care is that it is "enabling" in the sense that the caring relationship aids the recognition of problems and presents possibilities for solving them.³ The third way in which Benner and Wrubel see caring as primary is because it offers the opportunity for reciprocity.⁴ The implication is that none of these things can occur prior to a caring relationship between nurse and patient. Care is the vehicle through which nurses acquire knowledge of the patient's world and as a result are equipped to act as their advocates.

As advocates, then, nurses must share the patient's world in order to communicate effectively with both patient and physician, whose relationship with the patient is constrained by his or her professional role.⁵ In order to carry out their task effectively, nurses must appreciate the patient's "situated freedom," which defines the degree to which patients are free to act within the circumstances of their illness. An important contingency of this premise (i.e., that the nurse must be able to empathise with the patient in a phenomenological way), is that the patient's needs, emotions and feelings can be interpreted by the nurse. This enables the nurse to act as a mediator in interactions between patient and physician. Benner and Wrubel write that as a consequence the nurse

³ Benner and Wrubel offer "parenting techniques" as an example here; "...parenting techniques are not even useful or possible unless the parent is already engaged in the parenting situation through caring" (Benner & Wrubel, 1989, p.4).

⁴ Kuhse (1997) and Morrison (1992) do not agree, however, that reciprocity is, or even should be, a feature of nursing care.

⁵ In this construct nurses appear to be implicitly familiar with the physician's world.

must “become not just someone who understands but an interpreter of the situation for the client” (Benner & Wrubel, 1989, p. 16). They also claim that:

Because personal concerns determine what is at stake for the person in any situation, the challenge for the health care provider is to interpret those concerns that influence the person’s understanding of his or her own illness. Just as with background meaning, because we share a culture we have shared meanings. Even when those meanings are not personally held by the interpreter, they are understandable as possible ways of being in the world because of shared culture. Caring for a patient enables the expert nurse to be a participant in the sub-culture of being a patient. In this way, the expert nurse can have access to a patient’s meanings and concerns without directly having the illness experience (p. 88).

In this way the “lived experience” of nurses is paramount, the patient’s experiences being interpreted through the eyes of the nurses as part of that lived experience. Benner and Wrubel argue:

Concern is a way of caring about patients that enables taking care of patients. Concern situates the nurse so that what is salient about the patient and about the patient’s situation is apparent. Concern determines salience and is the basis for gaining knowledge that is both generalizable and yet specific. A nurses’ concern can make both the patient and the patient’s medical situation interpretable. A nurse’s concern can make medical interventions possible for and understandable to a patient. And a nurse’s concern can lead her or him to understand a patient’s concern and champion that patient when further interventions are known to be painful and useless. Concern is caring, and without caring there can be neither cure nor comfort (p. 96).

In other words, they claim that through concern that caring and advocacy are possible.

Watson’s theory of nursing: Transpersonal caring

Watson (1985) also argues that an understanding of the lived experiences of both patient and nurse contribute to effective nursing practice. In formulating her theory, Watson draws upon an eclectic array of theories and as a result, Falk (2000, p. 35) remarks that her proposal “...strongly reflects the influences of consciousness theory, noetic sciences, quantum physics, transpersonal psychology, Jungian psychology, and feminist theories, among others.” A distinguishing feature of Watson’s theory is the transcendental element, which in some ways resembles Maslow’s concept of self-actualisation (Maslow, 1968; 1971). This transcendental experience is supposedly manifested in the transpersonal relationship between nurse and patient when they come together in a psychic manner in the “caring moment.” The supreme value with which this transcendent

aspect is endowed is reflected in Watson's statement that the Spirit is related to "...a higher degree of consciousness, an inner strength, and a power that can expand human capacities...and cultivate a fuller access to the intuitive and even sometimes allow uncanny, mystical and miraculous experiences" (as cited in Falk, 2000, p. 36). The development of ten so-called "carative factors" which inform nursing care in this paradigm are crucial in Watson's theory. These factors are related to a humanistic-altruistic system of values, faith and hope, sensitivity to self and others. John Walters, in his review of nursing theories, concisely lists the ten "carative factors" as:

- "humanistic – altruistic system of values
- faith – hope
- sensitivity to self and others
- helping – trusting human care relationship
- expressing positive and negative feeling
- creative problem-solving caring process
- transpersonal teaching-learning
- supportive, protective and/or corrective mental, physical, societal and spiritual environment
- human needs assistance
- existential-phenomenological spiritual forces" (Walters, 1994. p. 28).

As in the Nightingale era, the status of care in modern nursing practice is once again paramount, and in this paradigm it is therefore difficult to isolate "care" from other nursing activities. Watson (1989), for example, claims that intersubjective contact, both physical and spiritual, which defines care, overcomes the technology which dominates modern healthcare. She writes:

Because subjective involvement in another's suffering is possible only where caring, compassion, and concern exist, empathic touch is concern made tangible. The caring relationship not only overcomes technology and objectivity by touching the self of the other, it also precludes a person's succumbing to the isolations of pure subjectivity – retreating totally into self (Watson, 1985, p. 129).

The concept of "transpersonal caring" alluded to in this statement refers to a process by which the care provider enters into the world (the "life space") of the patient (and *vice*

versa), and is thereby able to detect the other's condition (suffering). There are similarities here to Mayeroff's (1971) existential account of caring. Mayeroff also posits the intersubjective activity, or state, of care as an inherently moral interaction which facilitates the opportunity for mutual growth of the persons involved. Montgomery agrees with Watson's understanding of nursing care, asserting that

...in a caring encounter, the caregiver and the client experience union, but...this union occurs beyond the level of self, at the level of spirit. Spirit can be understood as a common humanity, the fundamental sacredness and unity of all life...or shared phenomenological fields as suggested by Watson (1985) (Montgomery, 1991, p. 95).

A concept common to these three existential nursing theories is the acknowledgment of the lived experience of the patient as a primary factor in the caring process. In Parse's account of the dynamics of a person's health and illness experience there is an assumption that the nurse must be attuned to this experience in order to interact and facilitate the process of "human becoming" which defines her theory. The role of patient advocate which Benner and Wrubel stress in their theory of nursing presupposes the entry of the nurse into the patient's world of "lived experience," while Watson's nurses and patients share a transcendental experience in reaching the "caring moment." Although such theories inform phenomenological inquiries that investigate the structure of nursing in general and the nature of care in nursing, seek to understand the experiences of patients, and explore the learning process in nursing education, questions do arise concerning their suitability for nursing practice. To what extent, for example, is it realistic to expect health care providers to transcend the mundane world of disease and pain, or even to enter into the world of the patient while providing care? Is this indeed a desirable aspiration in nursing? Is the adoption (and adaptation) of existential theories of care by nursing appropriate? Ways of overcoming these problems, while still acknowledging the intersubjectivity of care in nursing, have been suggested by other theorists who favour an alternative conceptualisation of caring as a spiritual endeavour, or covenant.

Nursing care and spirituality

Theories such as those described above have emerged from the conceptual shift associated with scientific advances in health care which has occurred in the latter half of the twentieth century. The 1960s heralded an escalation of nursing research and the development of nursing theory which was centred upon issues of altruistic nurturing and caring traditionally associated with nursing, as nurses sought a balance between the increasingly technical aspects of their profession and its essential, fundamental humanity. Both nursing theory and practice have therefore evolved in response to contemporary social and medical perceptions since the pioneering days of Nightingale.

Nursing as a covenant

In her overview of the history of nursing theories, Bradshaw comments on the relatively recent development of formal nursing theory. In traditional nursing education its theory was implicit, whereas today she observes that it occupies a position of such prominence that it threatens to displace other aspects of nursing practice. To Nightingale nursing was a calling or vocation, and in the Nightingale tradition, "...[t]he importance of excellent physical care...was rooted in the nurse-patient relationship which was itself grounded in an objective moral framework. Science and art were held together" (Bradshaw, 1996b, p. 90). Bradshaw observes that the relationship was a covenant rather than a contract, which "...depended not on mutual return but on a self-giving love derived from a warmed heart, the classic ethic of care, that was rooted in a spiritual, metaphysical dimension." (p. 90). Bradshaw argues that these traditional notions of caring have since been devalued as a result of their reinterpretation within modern frameworks.

Campbell's concept of nursing as skilled companionship

Campbell proposes that what nursing is really offering is "a love which is skilled companionship" and is constantly exposed to the tension between "being with" and "doing to" (Campbell, 1984, p. 35). He insists that the stereotypical images of nurses as the doctor's "handmaiden" and the patient's "angel of mercy," which persist despite, or perhaps because of, the efforts of theorists like Benner and Wrubel, Parse and Watson should be abandoned. Campbell declares that the adoption of the medical model in

nursing theory which prevailed until the 1970s was dangerous, because the use of technical terminology distances the nurse from the patient's understanding of their condition. The nurse needs to be attuned to the concept of illness as the patient experiences the condition, rather than just disease. Conversely, the idea that nursing is like mothering should not be entertained either, and he writes that

...we need to understand the nature of nursing as a relationship which combines tenderness and care for the body with respect for the individuality of the patient and consistent effort to promote independence and self-maintenance...The trained nurse, as opposed to the unskilled bedside helper, should have learned to perceive the needs of patients more objectively and to define goals for the nursing care which is offered (p. 42).

Although, as indicated above, caring is conceived by many to be central to nursing, Campbell says it is difficult to "hold that focus." A fine balance between various aspects must be maintained:

What is required is an account of nursing which is not caught up in sexual stereotypes, which is professional without being distanced and manipulative, which is close to the realities of bodily care, yet also sees the personal potential of the patient, which protects the nurse from overwhelming demands, yet which gives every patient full consideration. In short, to understand nursing correctly we need to understand the tensions implicit in all human acts of care... (p. 49).

Campbell sees that the answer to the problem of the love/care relationship in nursing lies in the idea of companionship, which fulfils the criteria mentioned above. Companionship arises from the existence and nurturing of a mutual goal, and "[t]he good companion is someone who shares freely, but does not impose, allowing others to make their *own* journey" (p. 49). There is clearly a parallel here with Mayeroff's idea of caring as well as Heidegger's solicitude in which caring involves the facilitation of the Other's development. However, the "being with" that characterises good nursing entails some risk for the nurse. It means being with and helping a person, even one who is dying, on a journey rather than keeping them in a state of "living death." The nurse must always be able to inspire hope in the patient, even if it is hope only for a dignified journey towards death.

Campbell lists four points which characterise nursing as companionship:

1. nursing can be "bodily presence" that is not sexual;
2. nursing is a companionship which helps a person forward;

3. “[t]he closeness of contact between nurse and patient means a costly mutuality for the nurse”; and
4. companionship is a limited relationship; it is not the same as love (adapted from Campbell, 1984, p. 50).

He emphasises the importance of control in the professional situation. Empathy, love and the like must always be under control in order to maintain a “critical distance” between patient and health professional. The love that professional carers offer is therefore moderated, a measure which enables the objective provision of care to vulnerable people. Campbell cites Rollo May who points out the shortcomings of a purely existential concept of caring in nursing when he writes that: “A rather sentimental existentialism unfortunately assumes that it is enough for human beings to be ‘present’ to one another. But in crisis the ill person needs not simply presence but skill, not just personal concern but highly disciplined services targeted on specific needs” (as cited in Campbell, 1984, p. 92).

The understanding of nursing as a covenant derives from this notion of the existence of “moderated” love between nurse and patient. The fact that nursing can involve touching another person’s body in a particular way (for example washing) distinguishes it from medicine where the reason for touching is more often for investigative or scientific purposes. A contract, as in the medical encounter, is limited by the professional, consultative relationship, and the rigid criteria inherent in the agreement between the two people. Conversely, a covenant is not limited but is continuing and the relationship grows and is nourished. Despite this distinction, however, the professional must respect and acknowledge the vulnerability of the patient.

Reciprocity, which is a feature of existential theories of care both within and outside the nursing environment, is also recognised by Campbell. The professional carer is not simply performing a job, but chooses the profession for a particular reason; namely, the desire to help others. Therefore he or she, as well as the patient, gains from the encounter, although in entirely different ways. Campbell refers to this as “the need to be needed.” The altruistic nature of this style of caring is reflected in the concept of “grace,” in which,

Campbell writes, care is “not offered by anxious people trying to earn love, but by sensitive people who release us from bonds of our own making in spontaneous and often surprising ways. The gracefulness in caring is as closely connected to bodily expression as it is to an intellectual understanding or emotional awareness” (p. 108).

As in Benner’s and Wrubel’s interpretation, the nurse acts as advocate and interpreter of both the physician’s and the patient’s needs. Finally, the difference between the love which inspires care as a feature of nursing as covenant (*agapê*), and ordinary love (*eros*), and the importance of physical contact between nurse and patient in this interpretation of nursing is unequivocal:

But although...the love of professional care is a *moderated* one and so should not be confused with the more intimate forms of love we receive from parent or friend, there remains the important element of gracefulness in caring, whose similarity to maternal tenderness and sexual intimacy must not be overlooked. The covenantal relationship, which promotes trust and mutuality, requires bodily mediation in order for its true value to be appropriated by helped and helper alike. The sacrament of caring is the use of the physical closeness of bodies to therapeutic end, the overcoming of weakness and the restoration of hope which another human presence makes possible (p. 111).

The spiritual dimension of nurse caring is not necessarily religious in nature: Montgomery, for example, interviewed nurses who claimed to have had “spiritual” experiences while interacting with patients. She writes:

There is a distinct qualitative difference between helping relationships connected at the level of the ego and those connected at the level of something greater. [The study] suggests that in a caring encounter, the care-giver and the client experience union, but that this union occurs beyond the level of self, at the level of spirit. Spirit can be understood as a common humanity, the fundamental sacredness and unity of all life...or shared phenomenological fields... (Montgomery, 1991, p. 95).

Montgomery argues that her study demonstrates the possibility of “spiritual transcendence” in the nursing encounter, which “serves as an important resource for self-renewal and motivation for the care-giver.” (p. 93). Narayanasamy and Owens arrive at a similar conclusion from a study involving narrative analysis of nurses’ responses to the spiritual needs of their patients. It appears that both religious and emotional spirituality in nursing is important in that “...patients’ faith and trust in nurses produces a positive effect on patients and families, and nurses themselves derived satisfaction from the

experience of giving spiritual care” (Narayanasamy & Owens, 2000, p. 46).

Bradshaw: Spiritualism in the Christian tradition

By contrast, Ann Bradshaw (1996a) examines nursing in terms of Christian traditions. She observes that humans differ from other creatures in their relationship with God, who always offers (even if it is rejected) a covenant relationship. She writes:

For the patient, health is the strength to reflect this humanity, his/her createdness in the image of God, and to respond freely to the love offered by the covenant relationship. Human life therefore has an absolute value regardless of subjective judgments of worth or personal responsibility for illness. Physical and mental sickness are hindrances to covenant actualisation. The promotion of health and the removal of ill health are absolute priorities, both for the individual and for society. Yet because health is the strength to be human and thus to have a fulfilled relationship with God, it follows that a person with a frail and diseased body or mind may have such a health, while the physically or mentally fit person may not (Bradshaw, 1996a, p. 20).

Thus the covenant model of care depends on a purely spiritual definition of health: “From a covenant perspective, sickness, pain and death are real and not illusions. They are the result of chaos breaking into creation and thus are not ultimately under personal control” (p. 21). Nurses with this view (including Nightingale), argue that the care of the body and the soul are inseparable, and that nursing is fundamentally spiritual in nature. Like Campbell, Bradshaw stresses that the important distinction between the spiritual approach in a covenant model of nursing and that of, for example, Watson or Parse, is that it is inspired by *agapé* rather than ordinary love. This elevates it to a different level and circumvents the problem of love as care:

This is not a contractual duty but a covenant service, nor is it detached self-denial; rather it is because the nurse is herself created in love and for love that she is able to reflect that love to others. As a nurse, whether she knows it or not, she is fulfilling her own createdness by this commitment which asks for neither satisfaction nor return because it does not depend on the capriciousness and fallibility of personal human feelings and sentiments but on the steadfastness of covenant love. This is that nature and definition of love as *agapé* and the ground for the equality of the nurse-patient relationship which safeguards the intimacy of the relationship against any manipulation, however unintentional (p. 22).

In this model, “...the nurse herself is not an autonomous, isolated individual seeking personal empowerment, but a limited human being who is also in complementary

relationships with her colleagues and with whom care needs to be shared in a spirit of mutual cooperation” (p. 23).

Bradshaw shows that by grounding nursing theory in *agapé* rather than in love in the ordinary sense of the word, a serious flaw which stems from its spiritualistic aspirations can be overcome. The transcendental claims of some nursing theorists, exemplified in Watson’s work, are exposed by Bradshaw as being ludicrous and unnecessary, and in addition they undermine the scientific and technical skills that are undeniably important features of modern nursing practice.⁶

A critique of existential nursing theories⁷

Bradshaw states that there was a “sea change” in nursing practice and theory in Britain during the 1970s, and the “...long-held, Judaeo-Christian, ethical tradition of caring for the sick as an altruistic spiritual calling was now seen as an archaic, irrelevant and even dangerous myth...” (Bradshaw, 1996a, pp. 2-3). She claims that the rejection of the religious aspect of spiritualism, the idea that nursing is a “spiritual vocation resting in the biblical principle of the light of God” has resulted in the “fragmentation of care, a splitting apart of the personal and relational from the technical and functional, and with it the loss of the moral foundation for nursing care itself” (p. 3). Caring as a moral imperative, the “response to the divine call to love and thus a vocation to love one’s neighbour as oneself” (p. 18), which is essentially the principle which informed Nightingale’s approach to nursing care, is not a feature of modern existential nursing theories.

⁶ Conversely, it could be argued that not all nurses are open to, or even desire, the spiritual experience or knowledge described by Campbell and Bradshaw, and this would leave them with the somewhat barren prospect of nursing in a purely scientific manner.

⁷ Walters (1994) also offers a useful critique of the use of existential and phenomenological theories in nursing care from the Australian perspective, remarking that it is “disappointing” that most of the literature at the time of writing was American. By this criticism he means that the health care systems of Australia and North America are so different that observations in one country cannot necessarily be extrapolated to another.

Bradshaw claims that paradoxically modern nursing theory is founded upon philosophical principles which celebrate the spiritual (that is, the existential) qualities of human Being and human caring, and transcendental theories of care have developed from an “existential phenomenological strand of theory” (Bradshaw, 1996a, p. 4). It is the use of so-called Heideggerian existentialism, and the concept of *Sorge*, as a foundation for nursing theory that Bradshaw finds disturbing. The intellectual integrity of Benner’s and Wrubel’s theory of nursing, which they claim is grounded in Heideggerian hermeneutics, has been disputed by both Crotty (1996) and Bradshaw (1996a; 1996b), who question Benner and Wrubel’s interpretation of Heidegger’s philosophy. Crotty’s most devastating criticism, which also extends to much of the research which is informed by Benner and Wrubel’s theory, is that they misuse Heidegger’s concept of care, which is not at all compatible with their own idea of care (Heidegger, 1962).⁸ Bradshaw finds that Benner and Wrubel fail to appreciate the implications of what she believes is the inherent solipsism in Heidegger’s work. She writes that “Heidegger is not primarily concerned with care for others but rather care for self, for personal authenticity, for self-concern” (Bradshaw, 1996a, p. 9). Benner and Wrubel, she claims, focus on the experience of nurses, and the patient’s experiences are interpreted only through the eyes of the nurses.⁹ Self-actualisation and empowerment consequently are directed to the nurse, leaving no external way of evaluating the nurses’ interpretation of experience. In addition, the interpretation of Heidegger’s concept of authenticity as being entirely solipsistic means to Bradshaw that it is fundamentally a quest for “personal authenticity” and “self-concern” (p. 9). As such, she does not believe it can sustain objective moral principles of care.¹⁰

⁸ It could be argued that the exercise of normal humanitarian principles in which the patient’s interests are paramount (as prescribed in the professional charter of most nursing organisations) would ensure that high quality nursing care is provided, without the necessity of clothing it in the rhetoric of transcendentalism.

⁹ This is an important aspect of Benner and Wrubel’s theory. For example, they write that the nurse must “become not just someone who understands but an interpreter of the situation for the client” (Benner & Wrubel, 1989, p. 16).

¹⁰ Bradshaw does not however, indicate how this can be achieved in isolation, and without regard for the Other’s interests. Van Hooft’s assertion that what he describes as “deep caring” is a “self-project” certainly indicates that this is a solipsistic enterprise, but he then contradicts this by pointing out that its objective must always involve the interests of the Other (van Hooft, 1995).

Jean Watson (1985), however, in her transpersonal approach, sees caring itself as the moral essence of nursing in which care and love are universal and primal psychic energy. She argues that human beings are capable of transcending time and space through the universal spirit or essence which transcends the self to a higher degree of consciousness. Health is this harmony between mind, body and soul. The role of nursing is to “actualise this caring consciousness.” (Bradshaw, 1996a, p. 15). Morse and her colleagues (1990) are critical of Watson’s theory, saying that it focuses on the humanistic, altruistic conceptualisation of care to the detriment of other essential nursing attributes like technical expertise and the provision of basic personal care such as washing. They also remark that in the short space of time that a nurse usually has to deal with a patient in a hospital setting there is no time to establish the intimate relationship Watson implies in her theory.

The scientific basis of Martha Rogers’ (1970) theory, which informs Parse’s concept of nursing, is left in tatters by Bradshaw’s critique. Bradshaw claims that a new science which declares the indivisibility of the human being from nature or a universal spirit is postulating a “fourth dimension” and it is “not verifiable [but] rather is experienced through the paranormal” (Bradshaw, 1996a, p. 16). In this four-dimensional world, such things as clairvoyance, psychometry, therapeutic touch, telepathy and the like, are valid. Bradshaw warns that this approach represents a return “...to the Dark Ages of medieval Western society which tainted medicine with magic and astrology in place of observation and experiment” (p. 17). Modern nursing cannot deny its scientific component, and there is little room for a reconciliation between this sort of spiritualism and science. Sourial’s (1996) evaluation of Watson’s theory shows that in addition to the inconsistency of its philosophical underpinnings which Crotty and Bradshaw reveal, it needs further development, and has not been thoroughly tested.¹¹ Bradshaw finds it “ironic” that nursing is trying to recapture the spiritual aspect of the occupation when the original basis of care was, in fact, its “spiritual dimension.” This spirituality has been marginalised as a result of scientific and technological advances, and nursing has, as result, become

¹¹ Sourial is also guilty of inconsistency by moving away from the holistic approach to health when claiming that the therapeutic effectiveness of the caring relationship has not been proven (Sourial, 1996).

intensely technical. The implication is that nursing has turned its back on tradition but at the same time is trying to explain or revive the spiritual aspect of the profession through flawed methodologies in which philosophical theories are used inappropriately.

Helga Kuhse (1997) is also concerned that the preoccupation with caring in nursing could threaten its primary purpose. She argues that the role of nurses is to provide for the health care needs of patients, although she does not dispute the need for sensitivity to their emotional needs. She argues that aspiring to the interpersonal and transcendental objectives endorsed in the theories discussed above is potentially dangerous to the nurses themselves, as well as nursing practice. Referring to Watson's work, she writes:

Many a nurse who aspires to such ideals will think that she has failed when she finds it impossible to enter into the "life space" of (most of) the patients for whom she cares, or is not able to "form a union with the other person on a level that transcends the physical." To exhort nurses to strive for such unattainable goals is not only to imbue them with a sense of failure; it is also to make them ask themselves why their professional nursing skills – that is, careful and skilled attention to the health-care needs of the patient – should count for so little (Kuhse, 1997, p. 149).

Kuhse throws further doubt upon theories which celebrate existential and transpersonal attributes as being primary to nursing when she cites a study which indicated that many patients value the professional expertise of the nurse more highly than interpersonal factors (Komorita, Doebling, & Hirschert, 1991).¹² Similarly, Bradshaw argues that in focussing on the patient's existential understanding of suffering it is possible that the scientific aspect of nursing could be marginalised. She states:

A primary focus on the patient's search for the meaning of suffering may not only be ethically questionable, given the unequal nature of the nurse-patient relationship, and impractical for many patients and nurses within the time limitations of this relationship, but, significantly, may also mean the scientific alleviation and even cure of that suffering becomes a secondary consideration (Bradshaw, 1996a, p.13).

¹² An earlier review by Morse and colleagues (Morse et al., 1990) found that most of the nurse researchers believe that "the ultimate outcome of nursing is to alter patient responses" (p. 10). The question of whether caring (in nursing) is actually therapeutically essential in the curative process has not been addressed, according to these authors. They argue that it is therefore possible that cure can be attained without the caring element at all.

In relation to the critique of the theories themselves, Bradshaw (1996a) and Morrison (Morrison, 1992) argue that there cannot be a “theory of nursing” because nursing is contextual, multidisciplinary and complex. Morrison considers the notion of an encompassing theory of nursing to be as ludicrous as that of a theory of medicine, or of sociology; nevertheless there is widespread acceptance of theories which purport to inform both nursing practice and research. Morrison and Bradshaw are supported by Johnson (1999) who questions the notion that nursing is deserving of its own unique epistemology, and that nursing, which, he observes, is a “human phenomenon,” cannot really claim ownership of any particular epistemology. Nursing research should be accessible and of value to other disciplines, but Johnson doubts that this is the case. Theory building in the manner of Watson (1985), in which caring is supposedly central to nursing is flawed, according to Morrison, because care in its many forms is present in a variety of activities, including other health professions. Caring cannot therefore be brought under a single unifying umbrella. Morrison’s most severe criticism of generalised nursing theories is that they have been developed within particular cultures (mostly North American) and nursing practice and teaching methods in that country do not necessarily bear much similarity with those in other countries.¹³ Referring specifically to phenomenological studies of nursing care, Morrison observes that few such studies in this area relate their findings back to nursing theories of care. He attributes the lack of theoretical development partly to the disenchantment with positivist approaches which have in the past contributed to nursing theory, but which nevertheless should not be ignored. Many theories have also developed through a social psychology perspective, and the lack of familiarity with psychological research among nurses renders them inaccessible. A further problem is that nurses and patients often differ in their idea of indicators of excellence in nursing care. Nurses “...tend to perceive expressive behaviour as a more positive indication of caring than do patients; in contrast, patients tended to perceive instrumental nursing behaviour as a more positive indication of caring than do nurses...” (Morrison, 1992, p. 46).

¹³ At the time of writing his book, Morrison called for a study of nursing care in UK, and a search of the most recent literature on nursing care indicates that this has yet to occur.

The final word on nurse researchers' enthusiasm for Heideggerian philosophy is reserved for Holmes (1996) who claims that Heidegger's association with Nazism, and the relationship between his philosophy and fascism is incompatible with the humanistic aspirations of nursing. He writes that "...because of its immanent fascism, Heideggerian phenomenology is at odds with the general value orientation publicly espoused by the nursing profession, and...this may render it not only unsuitable as a means of understanding and elaborating nursing knowledge, but also [be] actively counter-productive to the conventional aspirations of nurses" (Holmes, 1996, p. 579). Although Bradshaw (1996b) shares Holmes' distaste for Heidegger's philosophy, her reasons have more to do with Heidegger's particular variety of existentialism than with his professed political ideology.

In summary, existential nursing theories which seek to explore the nature of caring in nursing are a relatively recent addition to the research armoury, yet despite the fact that there are serious doubts about their validity, they have been accepted with alacrity by many nurse researchers and practitioners. Because of its somewhat uncertain foundations, the research itself has also been criticised. The search for phenomenological studies about care, however, leads in the majority of cases to the nursing literature which accepts the centrality of care in nursing practice. Bradshaw appears to be seeking a balance between spirituality and science in nursing but does not acknowledge the relevance of existentialism to nursing. She claims that the spiritual aspect of nursing has been marginalised by technological advances, but conversely, a spiritualism founded on Christian principles is threatened by existentialism. Kuhse's objection to nursing theories, particularly transcendental theories, is based on her doubts about the desirability or possibility of such experiences in the nursing situation. Morrison and Crotty question nursing theorists' interpretation of existential theories, and others, like Holmes, are convinced that the credibility of Heidegger's work is under a cloud because of his infamous flirtation with Nazism.

Phenomenological nursing research: A review

Evaluation of the less definable elements of nurse caring in the above theories is particularly challenging, and researchers have approached this by a variety of qualitative methods, including phenomenology. Many assert that this approach is compatible with nursing's "implicit paradigm" because it apparently respects the uniqueness of the individual's experience and life-world (see for example Thibodeau & MacRae, 1997). In addition to concern over the philosophical foundations of the theories themselves, however, serious criticisms of the methodological soundness of many so-called phenomenological studies into aspects of nursing, including caring, can be made. Misunderstanding of philosophical concepts and terminology which are claimed to underpin the research leads inevitably to methodological flaws. These are sometimes fundamental; for example, in addition to Holmes' warning, Walters (1995b) cautions that the use of Husserlian phenomenology, which retains aspects of Cartesian dualism, gives an entirely different interpretation than Heideggerian hermeneutics which emphasises the notion of the person in and of the world. This warning has not been heeded; three years after the publication of Walters' paper, Paley's survey of phenomenological nursing research reveals that much is what he calls "lived experience research," which betrays rather than exemplifies Heidegger's phenomenology (Paley, 1998).

Paley's (1998) claim that so-called phenomenological nursing research can be more accurately described as lived experience research is vindicated in some of the examples cited below. The validity of lived experience research is not questioned by Paley, but he does point out that findings derived from it are entirely subjective and cannot be extrapolated to other contexts. This is not, according to Paley, a characteristic of phenomenology. Crotty agrees, pointing out that what he terms the "new phenomenology" (which corresponds to Paley's "lived experience research") practised by many nurse researchers, adds little to the work of symbolic interactionism, because it merely describes phenomena uncritically. The new phenomenology "...simply describes the state of affairs instead of problematising it." Lived experience is "...a code for a narrow band of subjectivity which is immune to external correction, alternative ways of

construing” (Crotty, 1996, p. 7; see also Corben, 1999; Drauker, 1999). Paley (1998) also argues that lived experience research is incompatible with Heideggerian philosophy. These critics are not denigrating qualitative nursing research *per se*, but they are concerned by the misuse of philosophical concepts which undermines its credibility (Maggs-Rapport, 2001). They suggest that nurses who wish to pursue this type of research abandon their attempt to link it to phenomenological concepts and develop a narrative literature which does not distort the principles of traditional phenomenology (Crotty, 1996; Drauker, 1999; Paley, 1997). Corben (1999) is critical of many so-called phenomenological methods, including Benner’s, which set out to extract generalisations from interview material, as this is not the purpose of phenomenology. There is nevertheless no need to abandon Heidegger; Drauker (1999) suggests that nurses seek another way to utilise Heidegger’s philosophy as a foundation for their research in a convincing and scholarly fashion.¹⁴

Conversely, the views of phenomenological purists have been attacked by researchers who are unconcerned by the relaxation of strict methodological principles. Beech (1999), for example, counters some of Crotty’s criticisms by claiming that the type of “bracketing” used in this research is similar to that used in phenomenological psychology rather than in philosophy and is therefore an acceptable compromise when this method is adapted for use in the social world (Beech, 1999). He does not, however, address the issue of whether the research is actually phenomenology rather than lived experience research. Similarly, Johnson (2001) claims that “purity of method is uncommon” in many qualitative nursing studies, including phenomenological studies, and this is a fact that should be accepted rather than frowned upon.

Despite strong criticism of the methodological rigour of some phenomenological nursing research, it remains popular, with some writers claiming that phenomenological research

¹⁴ A qualitative method which could serve the purposes of some nursing research is “phenomenography”, which has been developed by Swedish researchers. This method aims to describe how people conceive a phenomenon, rather than elucidate the phenomenon itself, which is the aim of phenomenology. (For some examples of the application of phenomenography in health sciences, see Hyrkas, 2001; Martensson, Karlsson, & Fridlund, 1997; Marton, 1988; Nordgren, 2001).

itself is a caring act (Milligan, 2001; Nelms, 1996). Van der Zalm and Bergum also state that when applied to nursing research, phenomenology “contributes to empirical, moral, aesthetic, personal, and socio-political knowledge development.” Van der Zalm and Bergum comment on the connection between “aesthetic knowledge” and phenomenological accounts or description which underpins moral reasoning and decision-making in nursing, and enhances the readers’ ability to act in a morally responsible manner. They write: “Phenomenology gives personal knowing of the self, through recognition of the meaning ascribed to various aspects of the individual context, and through an awareness of the manner in which the self may affect other individuals in interaction with them” (van der Zalm & Bergum, 2000).

The attraction that phenomenology, particularly in its existential interpretation, holds for nurse researchers is understandable. For most people, including its practitioners, nursing represents much more than the mere provision of services (however specialised they might be), expected in the medical encounter. The quest to identify the intangible qualities that make nursing unique in the caring professions lends itself to the phenomenological perspective, and although some of the studies reviewed in the next section are flawed, most of them do extend the understanding of nursing care.

The nature of caring in nursing

For many researchers caring has multiple identities, and in some cases is equated not only with love, but with nursing in its entirety. Clarke and Wheeler (1992) discover that “...care is the response to a continuous process of need that is experienced through the giving of oneself to another, creating friendship through trust, love and value for each other” (Clarke & Wheeler, 1992, pp. 1287-8). They claim that their study “clearly captures the informants’ experiences of the closeness of love to caring” (p. 1288). Caring is not always easy for the nurse, however: “...empathy facilitated the nurses to identify in their experiences that being a patient can create anxiety. The reasoning was why people may appear difficult to care for at times” (p. 1287). Unfortunately in writing that “...[t]he process of obtaining descriptive data and then reducing it can therefore lead to an essential structure of caring” (p. 1284), the authors reveal a misinterpretation of the term

“reduction” in the phenomenological sense. Ray also argues that care and love are one and the same. She writes: “I have spent much time researching and reflecting on the nature of caring and feel intensely that it is the way of compassion, a journey of love. Caring and love are synonymous” (Ray, 1991, p. 181).¹⁵

Forrest’s study of the “experience of caring” results in a “phenomenological description” of caring in nursing in which it is claimed that “caring is inextricably bound to the belief system and practice of nursing” (Forrest, 1989, p.815). Forrest declares that the “essential structure of caring” has been elucidated in her study. In claiming that “reduction” of the nurses’ stories resulted in the identification of four major categories derived from “theme clusters,” Forrest reveals a misunderstanding of the meaning of the phenomenological reduction similar to that of Clarke and Wheeler.

A common misapprehension in nursing research is, as Crotty and Paley note, confusion about the actual purpose of phenomenology. Thus Sadala (1999) claims that her existential phenomenological study of “taking care in the isolation ward” facilitates the description of the structure of this “phenomenon.” Although Sadala’s research leads to a clear and useful account of the fears and problems that characterise this type of nursing, it does not provide a phenomenology of nursing caring in this, or any other context. Beck’s study of nurses’ experiences of caring for cognitively impaired elderly patients, in which the nurses’ narratives were subjected to phenomenological analysis, reveals that nursing students experienced a range of emotions (e.g., frustration, fear, empathy, sadness) in this situation. Again the value of the research is not questioned, but it is not a phenomenology of caring (Beck, 1996). Bertero, using a method inspired by Ricoeur’s (1981) phenomenological hermeneutics to explore the experience of “caring for and about cancer patients,” arrives at a primary theme: “Developing and maintaining a helping-trusting interpersonal relationship,” and associated sub-themes: “Creating an interaction with patient and next of kin; acting to satisfy the needs of the patients and their next of kin, feeling frustrated in the role of caring, being affected by time aspects; developing self and acquiring insights” (Bertero, 1999, p. 414).

¹⁵ The link between love and care is discussed on pages 144-146.

The “Heideggerian hermeneutic technique” employed by Nelms (1996) in a study of “living a caring presence in nursing” is more attuned to the existential perspective than Bertero’s and Sadala’s works. This author finds that although “care” is accepted as being central to nursing and to life in general it is usually taken for granted and its constitution not understood. Themes identified as being implicit in nursing care are: “the timelessness and spacelessness of caring, creating home, and the call to care as the call to conscience” (Nelms, 1996, p. 368). Echoing Watson’s idea of care overcoming the impact of technology, one participant in Nelms’ study said: “Caring is something you give and receive. Caring makes your understanding richer and deeper. All of the mechanical, scientific technology may save lives, but it doesn’t create bonds. Caring does” (p. 373).

The drama and stress of providing nursing care can be considerable, as Loftus finds in her research into the experiences of student nurses whose patients died suddenly and unexpectedly (Loftus, 1998). She applied interpretive analysis to the students’ narrative accounts, from which the following themes emerged: nurse-patient relationship, communication difficulties, ethical dilemmas relating to sudden death, sudden deterioration, mechanistic care, resuscitation policies, and student support systems. The primary value of the study appears to lie with its therapeutic value for the participating students.

The notion that nurse caring is necessarily an intersubjective process is to some extent undermined by some investigations into the nature of nursing care in unusual situations. Walters observes that nurse caring as practised in the intensive care unit challenges the connection between caring in nursing and the patient as person because of the technological nature of critical care. Two themes, “balancing” and “being busy,” emerged from the study, and these are experienced as “unification of the objective and subjective dimensions of the intensive care environment” (Walters, 1992; see also Walters, 1995a). Intersubjectivity is again challenged in the interpretive study carried out by Pearson and colleagues, where powerful narratives reveal the emotions and experiences of nurses in the traumatic situation of caring for brain dead people prior to organ donation (Pearson,

Robertson-Malt, Walsh, & Fitzgerald, 2001). Crotty's (1996) account of the nature of intensive care nursing, although concerned with the nature of nursing rather than caring in particular, also throws doubt on the importance of interpersonal relationships in nursing care. Finally, Chard (2000) demonstrates the importance of caring for perioperative nurses, even though their pre- and post-operative patients are often surrounded by machinery and barely conscious. "Caring tasks" involved touch and talking to the patient, holding their hands, and similar activities. The study "...delves into the lives of perioperative nurses from the angle of what they believe their work lives reflect." Because this type of nursing is not particularly visible, the author believes that phenomenology gave the nurses an opportunity to tell their stories (Chard, 2000).

Despite indications from these studies that caring does not necessarily require the active participation of the patient, it is generally acknowledged that nurse caring does have existential characteristics, and emotion plays an important part in nursing care. Hochschild's notion of the feminist construct of "emotional labour" (Hochschild, 1979; 1983) is potentially of great interest to nurses, and Bolton's study (although it resembles narrative analysis more than phenomenology) indicates that:

Nursing has an ideological image which is generally associated with the feminine qualities of being loving and kind and the vocational drive to care for people. Many of the expectations which arise from this idealized representation centre around the way nurses manage their emotions, they must always appear kind and caring but also calm and detached (Bolton, 2000, p. 583).

This is not an innate skill. Also from a feminist perspective, Staden shows in her research into the "alertness to the needs of others" which is described as "an attempt to deliberately revalue the caring component of nursing," that because emotional work is a part of caring, and caring is central to nursing, then emotional labour is also integral to nursing (Staden, 1998, p. 147).

For male nurses, the feminist perspective on nursing caring is problematic.¹⁶ Paterson and colleagues (1995) address this issue in their study titled *How Male Nurses Learn to Care*.

¹⁶ According to Gilligan (1982) women learn to care from interactions with other women, implying that learning to care is not a natural process for men.

The method used in their study involved “paradigm analysis and interview,” and although not primarily designed to give a phenomenology of caring, the researchers used a phenomenological rationale to analyse the stories. Students were asked to write a story of an incident in which they learnt how to care as nurses:

As the students progressed through the nursing programme they moved from the lay person’s generic view of caring as a human trait to the recognition of professional caring, directed towards conserving and restoring the well-being of patients and their families. Students developed a personal and relational ethic of care throughout the programme (Paterson et al., 1995, p. 606).

In another study on the experiences of male nurses, Milligan (2001) found that sensitivity to the male stereotype makes it difficult for men to cope with the “care in nursing” ideal which is based on feminist perceptions that caring is a female trait. The nature of caring appears to be elusive; most of the twenty-five participants in the study had difficulty defining “caring.” When asked to describe occasions which exemplified caring to them, many of the male nurses chose scenarios involving very ill or dying patients, and it was clear that to them much of caring involved helping the “significant others” or families of the ill people. According to Milligan, this point is not often mentioned in descriptions of nursing caring but it was significant to the male nurses in his study (Milligan, 2001).

Although the emphasis placed by the male nurses on interaction with the patients’ families might suggest they have a unique perspective on nursing, Tarzian’s (2000) study shows this is an important part of nurse caring in general. The study was designed to investigate the experiences of nurses who cared for dying patients who suffered what they called “air hunger” (presumably apnoea, although this is not explained in the paper). Tarzian interviewed nurses as well as two relatives who had been with their dying spouses, and found important themes were: “(a) patients look-panic beckons, (b) surrendering and sharing control, and (c) fine-tuning dying.” This process included “calming patients and families...and attending to family members’ needs.” Caring is multifaceted, and “encompasses knowing what to do as well as how to stay present during suffering” (Tarzian, 2000, p. 137). This is useful information, especially for nurses dealing with the problem of deciding when palliative measures become a means of the deliberate hastening of death, but again does not constitute a phenomenology of caring.

A similar criticism can be made of King who went to impressive lengths to devise “bracketing strategies” in order to conform with the Husserlian phenomenology she claimed to use in her study of nurses caring for anorexia nervosa patients. These measures included delaying the literature review until after the study, avoiding discussions with colleagues about the topic, putting aside her own thoughts on the topic, and removing herself from the care of anorectic patients. The findings of the study indicated that nurses found their values and nursing principles challenged because of ambivalence towards the patients who were often deceitful and uncooperative. She claims that the essence of this type of nursing was contained in the themes: personal core values of nurses; core values challenged; emotional turmoil; frustration; turning points; and resolution (King, 2000).

In addition to the focus upon caring from the nurse’s perspective, there are many studies which seek to understand the nature and requirements of nurse caring less directly, through the experience of the patients. In Dunneice’s descriptive phenomenological study of the experience of nurses being present at a patient’s diagnosis of cancer, for example, she demonstrates the fusion of patients’ and nurses’ caring experiences and concerns. This is reflected in the identification of seven “core themes”: “what if it were me?, divergent feelings, being there, becoming closer, method of disclosure, time as an influence, and learning by reflection” (Dunneice, 2000). In a slightly different fashion, Koch and her colleagues try to identify the parameters which contribute to ideal nursing home care by interviewing geriatric patients (Koch, Webb, & Williams, 1995). It is doubtful that this study is phenomenological despite the author’s claim, but it does provide useful information which could contribute to the quality of geriatric nursing care.¹⁷

¹⁷ Other recent studies of this type include those of Allen & Wellard (2001), Bernstein (2000), Billhult & Dahlberg (2001), Burton (2000), Edwards, Mulherin, Ryan & Jester (2001), Forsberg, Backman & Moller (2000), O’Mahony (2001), and Thibodeau & MacRae (1997).

Finally, some nurse researchers see a need to understand the experiences of informal carers. One example can be found in Ward-Griffin's study of the relationship between nurses and informal carers. By a method based more on narrative analysis within a "socialist-feminist perspective of caring" than phenomenology, this writer found that district nurses were often concerned about the well-being of the carer only because they saw the need to keep them caring, rather than to relieve the stress and workload. The nature of the relationship between nurses and informal carers with whom they came in contact were described as: nurse-helper, worker-worker, manager-worker, nurse-patient (Ward-Griffin, 2000). The somewhat pragmatic findings of this research are offset by Gates' "phenomenological study" which was designed to reveal what it is like for the family members caring for the frail elderly. She writes:

The meaning of caring for an elderly relative is surfacing poignant remembering while doggedly continuing with nurturant giving and confirmatory receiving, as swells of enjoyment merge with tides of sorrow amid uplifting togetherness and valleys of aloneness (Gates, 2000, p.54).

The influence of Parse's theory of nursing is evident here.

Summary of the phenomenological perspective of caring in nursing

The quality of research which is concerned with understanding the phenomenon of caring in nursing is inconsistent, and often bears more resemblance to "lived experience research" than the phenomenology that its authors claim. Nevertheless, it does give a clear indication of the diversity of understandings of caring and of its complexity, particularly when caring is considered as a component of nursing practice. Nursing faces an ethical dilemma in reconciling its unique style of caring with that of professional caring governed by a biomedical paradigm, which nurses must practise in parallel. Professional caring in such a context is governed by objective, scientific principles in which the embodiment of disease is privileged, rather than an expression of illness, while nursing seeks also to respect the individuality and illness experience of the patient (Leininger, 1981). Nevertheless, nursing cannot emulate informal caring because of the restrictions of professionalism; the relationship between nurse and patient is always unbalanced because of the superior technical knowledge of the nurse. Indeed, Kuhse

expresses doubt that ill people need such a relationship as they have different expectations of a nurse than a family member (Kuhse, 1997).

It is likely that the tension between the instrumental requirements of nursing and the existential aspects which are generally understood as caring have contributed to the methodological problems which beset nursing research. Warelow argues that a further complication is that for nurses caring is a moral principle, and because nursing (and caring) are highly complex it is not feasible to link the two or assume that they are synonymous; caring is “context-specific.” He argues that the common assumption that caring is an essential component of nursing is “dangerous” because when nurses find it impossible to care (and he is referring here to “caring about”) if, for example, a patient is violent or unpleasant, then they will feel a sense of failure when in fact they might be providing the best care possible under the circumstances.

In direct contradiction to Watson’s (1985) suggestion that nursing aspires to care and therefore care is seen as an ideal, Warelow concludes:

It would seem that nursing needs not to articulate its philosophy of care better than it already has, or to define its concept of care and caring as an ethical ideal, but to perhaps make care more visible both as a principle of practice and of moral action. In the process, the thought that caring is a superior ideal to the others would be cast aside, in favour of a more balanced view which benefits both the cared-for and the carer, with health being the focus (Warelow, 1996, p. 660).

Nursing needs to refocus on the business of nursing rather than become obsessed with the yearning to care above all other things even though this is not necessarily possible nor even desirable. Walters (1994) argues that there is a tendency to polarise nursing as either being intellectual (emotional) or physical (concerned primarily with bodily care), and few theorists seem to combine the two aspects. This review indicates that a critical appraisal of nursing research and theory is developing, and as a result an approach which embraces both its physical and intellectual aspects, rather than treating them in isolation, may evolve. Should this occur, it should indeed be possible to resolve the tension between the physical and intellectual aspects of nursing.

Summary and Conclusion

The interest in existential theories of nursing can be interpreted as a reflection of the continuing tension between the scientific and humanistic discourses of nursing. This situation is intensifying in the current explosion of sophisticated medical technology which demands considerable technical expertise in nurses. The danger of losing touch with the human caring aspect of nursing in such an environment, either through lack of time, or through the medicalisation of illness that it fosters, is of concern to many nurse researchers. This chapter began by examining concepts of the caring relationship that are important in many nursing theories. This was followed by a review and critique of a number of the more popular nursing theories. A critical review of the so-called existential phenomenological research these theories have inspired indicates that the technological advance of nursing is balanced by a similar advance in existential inquiry. It also showed that many of these studies are methodologically flawed, their authors often confusing existential phenomenology with “lived-experience” research.

In Chapter Three the suitability of existential phenomenology as an approach to the study of caring in the situation selected for this study will be justified. The theoretical foundations of phenomenology, and the influential adaptations of philosophical theory to human science research developed by Schutz, Giorgi and van Manen are outlined. This is followed by a brief review of the phenomenological studies of Moustakas, Toombs and Casey, whose methodological adaptations have influenced the development of the method employed in the present study. This method, and the hermeneutic process by which the final phenomenological description of caring was attained, are described in detail.

Chapter Three. Methodology

[Phenomenology] is the search for a philosophy which shall be a “rigorous science,” but it also offers an account of space, time and the world as we live them. It tries to give a direct description of our experience as it is, without taking account of its psychological origin and the causal explanations which the scientist, the historian or the sociologist may be able to provide (Merleau-Ponty, 1962, p. viii).

* * *

The review of the literature of caring presented in the preceding chapter indicates that for the purposes of this study, that phenomenological research in this area does not provide a sufficiently sound basis for the development of a methodology appropriate for this study. The main focus has been upon caring in a nursing environment; informal caring has not been explored phenomenologically. The chapter examined a number of the more popular nursing theories, including those of Parse, Benner and Wrubel, Watson, Campbell and Bradshaw. The subsequent review of the critiques of this research shows that in many instances there is every reason to question its validity. It was therefore deemed necessary to develop a methodology specific to the aims and context of this study.

For the methodological purposes of this thesis, the point of departure is the understanding that caring is an existential phenomenon, and as such, it resists definition in quantifiable terms. The early part of this chapter is concerned with the problem of researching the existential aspects of human experience and is designed to demonstrate its scientific validity through the examples and discussions of a number of researchers, including Polkinghorne and Gergen. This is followed by a brief outline of transcendental phenomenological theory and then proceeds to a more detailed discussion of application of existential phenomenology to social science research. Because of the relevance of these approaches to the present research, the works of Schutz, Giorgi, and van Manen are discussed in some detail. Some examples of research in which these principles have been applied, and which have informed the methodology developed for this research project are then presented. These include works by Moustakas, Toombs, Casey. This background material is then followed by a comprehensive explanation and methodological

justification of the present research. The problems of validity in vicarious experience and the remembered past, which are an essential aspect of this particular project, are dealt with before a detailed account of the precise process undertaken is given. Finally, the selection of participants, the use of secondary sources and identification of themes is explained.

Science and qualitative research

The selection of a qualitative research methodology is not generally problematic. In their text on in-depth interviewing in qualitative research, for example, Minichiello and his colleagues claim that in each project of human science inquiry the entire process is virtually preordained by the epistemological position of the researcher. They state:

Methodologies and methods are not constructed or chosen in isolation from ontological or epistemological positions. Rather, the manner in which we gain access to knowledge and our choice of the techniques for collecting evidence are directly related to our image of reality and the way we think we can know it. Obviously, our choice of research topic or question will be influenced by our world views or meaning systems (Minichiello, Aroni, Timewell, & Alexander, 1995, p. 180).

This observation has indeed been borne out in this particular study. The acts of reflection upon past events, and their subsequent reconstruction through writing, which I pursued in an effort to understand caring as an experience distanced from its more conventional association with factors such as stress, burden, satisfaction, and the like, are the hallmarks of an instinctively existential way of thinking. The existential view of experience rests upon the assumption that all experiences occur within a particular situational framework, and that they take on a meaning which depends entirely upon the individual life-world of the person undergoing the experience. In other words, a phenomenon cannot exist alone; the experiencing of the phenomenon is essential for its existence, and the nature of experience is dependent upon contingencies. Experience and perception, as well as the phenomenon, are unique to each particular circumstance. They stand out from the contextual background, yet are inseparable from it (Pollio, Henley, & Thompson, 1997). From its origins as a mode of philosophical thought, existential phenomenology has entered the realms of social and psychological sciences as researchers and practitioners

find in it a way of acknowledging the importance of social as well as individual factors to peoples' lived experiences. Indeed, the fruits of existential thought *invite* phenomenological investigation; the difficulty lies within the details of a procedure which must compromise neither the phenomenological spirit of the project, nor the integrity of the phenomenon itself.

The present study is concerned to examine the existential aspects of the human act of caring in a particular context. The elucidation of emotional experience and pure thought to which such an enterprise aspires, however, is of concern to some empiricists, who believe that sense experience is a truer reflection of reality, and consequently they do not regard the study of subjective reality as true science. This view has been seriously questioned by the philosopher of science, Paul Feyerabend, who advocates a liberal approach to scientific inquiry that embraces a variety of methodologies. He writes that "[s]cience is an essentially anarchistic enterprise: theoretical anarchism is more humanitarian and more likely to encourage progress than its law-and-order alternatives," arguing here that once a particular theory or concept has become accepted as reality (i.e., proven "beyond reasonable doubt"), it is virtually impossible to shake that conviction because all subsequent inquiry is informed by the conclusion itself. This then becomes a "means of further solidifying the myth" and tends to "preserve the *status quo* of intellectual life" (Feyerabend, 1975, p. 45). The proof or verification of scientific theories is based upon empirical observation, which in turn is nonetheless based upon assumptions of one kind or another, and so the label "scientific method" does not categorically confirm that data obtained through its processes are any nearer the truth than those resulting from any other method. In casting doubt upon the validity of universal laws, Feyerabend's criticism strikes at the very heart of positivist thought.

The claim that phenomenology can be legitimately classed as a "science" which purports to reveal unquestionable truths has been effectively defended by Feyerabend in this argument. In a similar fashion, Merleau-Ponty argues that the task of science is never-ending, being constantly in need of clarification and refinement. He observes that scientific laws are derived from what has been before, and are refined in terms of what

goes beyond. They are not “ultimate truths,” but rather are expressions of a “cultural epoch,” but as such should not necessarily be discredited. Scientific laws can therefore be regarded as being dependent upon a dynamic knowledge context or field, rather than as immutable facts. In a similar fashion, perceptual certainty at a particular time does not mean that this certainty cannot be contradicted at some other time. The certainty of a perception is tenuous, meaning that perception cannot be finalised, denying subsequent perception of the thing or object; we can always perceive something afresh, within a new context or circumstance (Paul, 1999a; see also Farber, 1970; Merleau-Ponty, 1962; 1964).

Similarly, Donald Polkinghorne points out that phenomenological research method differs from Western scientific method in that it

...reminds us that the research journey needs to attend to the configuration of experience before moving on to the assumptions about independent natural objects. Because the descriptions of natural objects are derived from experience, experience itself must be clearly understood before a firm foundation can be established for the sciences studying the natural world (Polkinghorne, 1989, p. 41).

Western science depends upon observation of “directly perceived objects,” the researcher being a “passive recipient of reflective sensations from natural objects.” Polkinghorne continues:

Phenomenological philosophy, however, calls this assumption into question. It holds that experience involves the operation of active processes that encompass and constitute the various contents that become present to awareness. These contents include not only the objects of perception but also those of memory, imagination, and feeling (p. 41).

This involves a shift in focus from the description of objects to the description of experience, and this is what leads us to the understanding of the phenomena which are being experienced. The reality of human experience cannot be reduced to “...either the sphere of the mental or the sphere of the physical” (Polkinghorne, 1989, p. 42).

Kenneth Gergen also observes that traditional empiricists do not accept that experience is a representation of the truth. He asks: “From what grounds do they derive their truth warrants? Are the so-called ‘reports of one’s experience’ not linguistic constructions

guided and shaped by historically contingent conventions of discourse?” (Gergen, 1985, p. 272). He claims that if properly constructed, the experiential account is validated by a different route:

However, the success of such accounts depend primarily on the analyst’s capacity to invite, compel, stimulate, or delight the audience, and not on criteria of veracity...Although some methods may hold the allure of large samples, others can attract because of their purity, their sensitivity to nuance, or their ability to probe in depth (pp. 272-3).

Such arguments support the intellectual legitimacy and scientific rigour of a qualitative approach to human experience, and both Merleau-Ponty and Polkinghorne are referring in particular to phenomenology. The purpose of descriptive phenomenology, of which the present study is an example, reaches beyond the purely aesthetic and seeks to present the reality of lived experience in a way that is convincing and, at times, confronting. It does not, however, contribute to theory-making (van Manen, 1990). By uncovering and accepting as reality the nuances of human experience, it is fundamentally a critical methodology (Crotty, 1996, 1998; Zaner, 1975), which, as van Manen (1990) argues, can also be regarded as an artistic enterprise. The link between art and existentialism, and their long history as devices for social and political comment owes much to these qualities.¹

The above brief review of the place of qualitative, and specifically phenomenological methods, serves to justify the chosen methodological approach (and its reputation); it also supports the view taken in this thesis that the methodology that addresses the purposes of this research most closely, that is, to elucidate and describe a particular phenomenon, is one founded upon the principles of existential phenomenology. Other qualitative methodologies are often defined within particular disciplines, and therefore have implicit, if not explicit, objectives; they can also arise from different theoretical frameworks. For example, within a symbolic interactionist perspective, an ethnographic methodology

¹ Here the music of Shostokovich, a great deal of which was composed as subversive protest against the contemporary political regime in the Soviet Union, immediately springs to mind. Similarly, for centuries the art of painting has served as a means of both secular and religious communication to a generally illiterate population; the works of the highly political Peter Paul Rubens, and later Rembrandt, exemplify this role, while Picasso’s *Guernica* is a more recent example of art as revelation and protest. The French existentialist writers, Sartre, de Beauvoir and Camus employed their literary talents to great effect to alert the world to their political causes.

would be an appropriate way to study caring behaviour in a particular social or cultural context, while a feminist perspective would inform a feminist methodology which might, for example, examine caring as a predominantly female occupation in a patriarchal society (Crotty, 1998; Grbich, 1999). Such clearly defined aspects of caring, however, are not the concern of this study. Its objective, which is to examine and describe caring from an existential phenomenological perspective which seeks neither an explanation nor a theory of caring, is, as Minichiello and his colleagues state, most appropriately approached through a method directly derived from that theoretical perspective; that is, descriptive existential phenomenology (see page 63).

Phenomenological theory

The application of philosophical principles and techniques to so-called “lived experience” research does, however, present some difficulties. This is particularly evident in research that claims a basis in Husserlian transcendental phenomenology.² Existential phenomenology, which acknowledges the relevance of individual life-worlds to experience, thereby respecting the uniqueness of every person’s experience, lends itself more readily to human science research. The development of existential phenomenology from Husserl’s original concept is discussed briefly in the next section.

Transcendental phenomenology.

Transcendental phenomenology seeks to describe experience directly, dissociated from prejudgments, preconceptions, or other biases that normally inform the way in which we experience the world. In other words, it is concerned with pure consciousness. This is the fundamental goal of the phenomenology that Edmund Husserl developed early in the twentieth century (Husserl, 1964; 1970). In an effort to transcend the presuppositions that are inherent in the attitudes of all human beings, and which would compromise this objective, Husserl, (employing terminology that reflected his mathematical background),

²Crotty (1996) cites examples of nurse researchers who claim to follow Husserl’s phenomenological method by engaging in “bracketing”, a process that he claims is difficult in philosophy and virtually impossible to achieve, even in philosophical endeavours.

devised the philosophical procedure that he called “bracketing” or “reduction”. Through this process he sought to literally bracket out all other perceptions in the effort of uncovering the essence of the phenomenon of concern, achieving a state termed the *epoché*.

Central to Husserl’s phenomenology is the concept of intentionality, which Crotty (1998) explains as, “referentiality, relatedness, directness, ‘aboutness’” in the world of constructionism. This is a fundamental concept in phenomenology, one which should not be confused with the more usual meaning of intention as purpose, or deliberation. Within the framework of existential philosophy, Crotty writes, “Not only is consciousness intentional, but human beings in their totality are intentionally related to their world.” In addition, “[i]n existentialist terms, intentionality is a radical interdependence of subject and world” (Crotty, 1998, p. 45). Thus in this conceptualization, intentionality demands that subjectivity and objectivity are inseparable: in studying the phenomenology of an experience, we are using the subjective experience to describe an objective phenomenon. The importance of the constructionist way of thinking exemplified here is that there is no correct interpretation of anything; all interpretations are equally valid and therefore demand respect. Interpretation of a phenomenon is not fixed or determined by the phenomenon itself, but is the result of the interaction between the phenomenon and the person observing or experiencing it, and that depends in its turn on the unique and particular circumstances of the person concerned. Within the limitations of prevailing circumstances we are free to make what we will of an experience.

Existential phenomenology

Although Ernesto Spinelli (1989) reminds us that Kierkegaard and Nietzsche are sometimes regarded as the first existentialists, the foundation for existential phenomenology is the work of Husserl’s assistant, Martin Heidegger (1962). Heidegger did not believe that the perceived world is reducible to a set of physical phenomena; indeed the foundation of his philosophy, as expressed in *Being and Time*, is the idea of *Dasein*, or Being-in-the-world; as individuals we are “thrown” into a situation and it is the interaction with that world, and its influence, that shape our understanding of it.

Merleau-Ponty also recognises the inextricable association between human perception, or consciousness, and environment. With the first words in *The Phenomenology of Perception* he asks, “What is phenomenology?” It is, he answers, “a matter of describing, not explaining or analysing.” However, in his view, this task cannot be addressed in isolation from the world:

I am not the outcome or the meeting-point of numerous causal agencies which determine my bodily or psychological makeup. I cannot conceive myself as nothing but a bit of the world, a mere object of biological, psychological or sociological investigation. I cannot shut myself up within the realm of science. All my knowledge of the world, even my scientific knowledge, is gained from my own particular point of view, of from some experience of the world without which the symbols of science would be meaningless (Merleau-Ponty, 1962, p. viii).

Memory and reflection are the dynamic sources of perception; the past is crucial in constructing the future, but the past also can be reconstructed in terms of later events. Our lives, then, undergo continuous change as things unfold and events past and present interact with each other, and the past may be reinterpreted in light of present events, securing significance because of an occurrence of the present. In this way, historicity is introduced into our lives. The fluidity of existence is expressed beautifully in this passage:

My hold on the past and the future is precarious, and my possession of my own time is always postponed until a stage when I may fully understand it, yet this stage can never be reached, since it would be one more moment, bounded by the horizon of its future, and requiring in its turn further developments in order to be understood (Merleau-Ponty, 1962, p.346).

We are born into a particular cultural environment, which naturally informs our behaviour; the customs of society are internalised from the earliest moments of perception; they are learned through observation of others, and these other beings are therefore also integral with our being. The relationships we have with others are supremely important; without others we cannot exist as human beings, and cannot develop and learn the norms of society. In other words, we are essentially social beings. The past, even when we do not recall it, still exists for us:

If anything of the past is to exist for us, it can only be in an ambiguous presence, anterior to any express evocation, like a field upon which we have an opening. It must exist for us even though we may not be thinking of it, and all our recollections must have their substance in and be drawn from this opaque mass (Merleau-Ponty, 1962, p. 364).

From the outset, the descriptive purpose of phenomenology is stressed by Merleau-Ponty. This is not a method that will generate theory or establish explanations of human phenomena. It is, rather, a means of uncovering the perceived world through an “archaeological” process (see also Hammond, Howarth, & Keat, 1991; Ihde, 1977; Merleau-Ponty, 1964; Pivcevic, 1975; Spiegelberg, 1975, 1984; Spinelli, 1989).

Human science practice and research

Existential phenomenological theory informs research and practice in many areas of the human sciences that reject positivist paradigms.³ The defence of phenomenology’s scientific credibility, and acknowledgement of the relationship between reality and the individual’s life-world, contained in the works of Heidegger, Sartre and Merleau-Ponty, pave the way to existential interpretations in the human sciences, and legitimise research and practice which respect the uniqueness of the individual. Existential psychotherapy and counselling is one area of practice that is founded upon existential principles. (See, for example, Frankl, 1969; Giorgi, 1985; Moustakas, 1994; Spinelli, 1989; Valle & Halling, 1989; van Kaam, 1969); van Manen (1990) applies it to pedagogy, while Schutz (1967) adapted it to the social sciences (see also Natanson, 1970; Pollio et al., 1997). Nurse researchers, (for example, Benner, 1994; Koch, 1996; van der Zalm & Bergum, 2000; Walters, 1995b) have also discovered in existential phenomenological methodology a means of reaching into the existential dimensions of nursing practice. It has also proved popular as a means of exploring the experiences of nurses in a variety of situations, for example, the study of learning processes in student nurses (Green & Holloway, 1997); while Madjar and Walton (1999) provide a collection of phenomenological studies that involve both nurses’ and patients’ experiences. Further topics of research into patients’ perspectives include the experience of living with stroke (Burton, 2000); liver transplant (Forsberg et al., 2000); social support (Natturlund & Ahlstrom, 1999); breast biopsy (O’Mahony, 2001); alcoholism (Smith, 1998); and breast

³ An exhaustive account of the development of phenomenological philosophy and methodology can be found in Spiegelberg’s history of the subject (Spiegelberg, 1984).

cancer survival (Thibodeau & MacRae, 1997). Phenomenology even appears as the unlikely methodology in a study of quality assurance in nursing homes (Koch et al., 1995).

The application of philosophical procedures to practical research.

The application of mental processes developed originally as philosophical techniques to praxis is not easy, and this is illustrated by the use of bracketing. The absolute focus, through the exclusion of all other influences on perception that bracketing demands, is difficult to comprehend, let alone attain. Even Husserl eventually conceded defeat in his efforts to achieve the *epoché*,⁴ but this has not dulled the enthusiasm for “bracketing” shown by many modern exponents of phenomenological research. Peter Ashworth’s survey of phenomenological psychology during the 1980s and 1990s, for example, reveals that this procedure is still embraced despite the fact that it is a purely philosophical device, and indeed he shows that it is a crucial aspect of this branch of psychology (Ashworth, 1996). Crotty’s critique of phenomenology in nursing research shows a similar faith in Husserl’s technique by nurse researchers, although it is not always interpreted rigorously (Crotty, 1996). Crotty and other authors (for example, Corben, 1999; Paley, 1997), do not deny the importance of bracketing in phenomenological research, but they do stress that the variety of phenomenology that is adapted to research and practice in the human sciences (for example, psychology), demands a more liberal interpretation of the procedure in accordance with the circumstances; indeed, as Giorgi writes: “...the philosophy to be adopted, however helpful, cannot be handed over ready-made. It has to be mediated” (Giorgi, 1985, p. 46). The phenomenological foundation of this study, as well as the majority of those reviewed by Ashworth and Crotty, is existential, not transcendental, and this distinction has been the source of confusion over the application of bracketing. Existentialists acknowledge that because humans are “active in the world,” that is, they are not simply passive observers of the world, they interact with the world, and interpret it as it develops around

⁴ In the Preface to *The Phenomenology of Perception*, Merleau-Ponty mentions Husserl’s reference to “constructive” and “genetic” phenomenologies in his *Cartesian Meditations*, and that in his later work he identified the *Lebenswelt* as “the central theme of phenomenology” (Merleau-Ponty, p. vii; see also Ashworth, 1996).

them; there is a “radical interdependence between the subject and the world” (Hammond et al., 1991, p. 97). As Koestenbaum (1971) stresses, phenomenology is a philosophical methodology, while existentialism is a theory of mind emerging from the application of phenomenology, which is concerned merely with description of the human condition.

While major difficulties are encountered in the execution of the *epoché* in practice, anthropologist Arthur Kleinman identifies another fundamental problem. He remarks:

The chief problem with phenomenological theory is that it has over time become a special language whose conventions, accepted by initiates, are opaque to general readers. The neologisms invented by Edmund Husserl, Martin Heidegger, Maurice Merleau-Ponty, Helmut Plessner, and others obscure more than they illuminate about the felt quality of the flow of experience, and ultimately take on an essentialist tenor that is unacceptable for social analysis. Indeed, phenomenological theory often hides behind these abstruse terms. It has not taken on the responsibility of popularising its conceptual advance through a rapprochement with broader intellectual currents (Kleinman, 1995, p. 276).

The neologisms to which Kleinman refers do indeed serve to isolate phenomenology, whether by accident or design, from the reality of lived experience which it purports to describe. Some researchers appear to be entranced by this intellectualisation of human experience (see for example, Montgomery, 1991), but in fact it should be acknowledged from the outset that what phenomenology aims to elucidate always has its origins in the experiences of ordinary people. This is not to say that without exception the ordinary person can, or even wants, to reflect upon their experience in an introspective manner, rather it merely means that those who are reflective should not have their experience appropriated by a discipline which translates it into unintelligible jargon.

If the problem lies with the original writers mentioned by Kleinman, then surely it is the duty of subsequent researchers interested in the existential aspects of human experience to use the techniques that phenomenology offers in order to describe and enhance experience, thereby making it more accessible to all. In addition, the legitimacy of finding deep significance in the most ordinary things in life should be acknowledged. Undaunted by, or perhaps oblivious to, this challenge, phenomenologists have produced a great deal of research, some of it quite profound, which examines lived experience within an existential perspective.

Another controversial methodological issue is that of the management and interpretation of research material. Research that involves in-depth interviews, conversations and various forms of written text has the potential to generate an enormous amount of so-called “data.” In an effort to control this, and perhaps even legitimise it in the eyes of advocates of positivist research, computer programs have been developed as a means of organising and sorting data into “themes.” These trends are not without their critics (see, for example, Grbich, 1998, 1999).

How, then, do exponents of phenomenological research and practice in the human sciences overcome these problems? A great many phenomenological methods, some of which are highly structured (for example, those of Colaizzi, 1978; Van Kaam, 1969), have been developed by researchers in a variety of disciplines. Only three examples, all of which have been important in defining the eventual design of this study, will be discussed in any detail here; these are the works of Alfred Schutz, who applied Husserl’s phenomenology to social sciences, Amedeo Giorgi, who adapted Merleau-Ponty’s philosophy to psychology, and Max van Manen, who understood the literary nature of the phenomenological descriptive process.

Alfred Schutz: *The Phenomenology of the Social World*

Schutz’s understanding of social relations prompted him to find a way of adapting phenomenology to the social sciences. Admittedly Schutz’ work, which stems from Weberian thinking and is based upon Husserl’s phenomenology rather than that of existential philosophical thought, but it does constitute an important foundation for existential studies as well. In his introduction to a collection of Schutz’ essays, *On the Phenomenology of Social Relations*, Helmut Wagner explains that Schutz’ “phenomenological baseline” rests with the works of Husserl and Weber. Husserl’s idea of experience is that it is “attention ‘directed’ upon objects, whether real or imagined, material or ideal; and all such objects are ‘intended’” (Schutz, 1970, p. 5). The process of bracketing by which prior beliefs in the outer world (“ontological assumptions”) are suspended, leaves only the inner world of “intended objects” which are now “no longer

understood as objects in the outer world but as ‘unities’ of ‘sense’ or ‘meaning’ in the ‘inner world’ of the conscious individual” (p. 6). The “sociological baseline” is Weber’s idea of social action:

Action is human conduct which may consist of physically tangible activities, of activities of the mind, of deliberately refraining from acting, or of intentionally tolerating actions of others. In each case, however, human conduct is considered action only when and insofar as the acting person attaches a meaning to it and gives it a direction which, in turn can be understood as meaningful. Such intended and intentional conduct becomes social if it is directed upon the conduct of others (Schutz, 1970, p. 8).

This reasoning offers Schutz the bridge between sociology and phenomenology, and in this respect Schutz’ work can be regarded as a “synthesis of Husserl and Weber.”

Schutz believes that because phenomenology is a discipline which “refuses to accept uncritically the givenness of sensory perceptions, of biological data, of society and environment as the unquestionable point of departure for philosophical investigation” (p. 55), it is admirably suited to the study of sociology. The point of departure for the social sciences is the acceptance of humans as social beings. Intersubjectivity is accepted as fact, as are the “so-called social and cultural objects created by men” (p. 56). Schutz looks beyond these accepted phenomena:

How is it possible that man accomplishes meaningful acts, purposefully or habitually, that he is guided by ends to be attained and motivated by certain experiences? Do not the concepts of meaning, of motives, of ends, of acts, refer to a certain structure of consciousness, a certain arrangement of all the experiences of inner time, a certain type of sedimentation? (Schutz, 1970, p. 56).

Thus phenomenology does not examine social structures, but rather the structure of the phenomena which inform social structures. Husserl argues that in living our ordinary lives we are unconscious (that is, unaware) of these underlying phenomena, and in order to examine them it is necessary to reflect upon our experiences. By bracketing out the “natural” world it is possible to attend to that which remains: “...neither more nor less than the concrete fullness and entirety of the stream of our experience containing all our perceptions, our reflections, in short, our cogitations” (p. 59). The benefit of this phenomenological reduction in phenomenological psychology rests with the assumption that it is only by these means can some hidden underlying structures be revealed; but

...since to each empirical determination within the phenomenological reduction there necessarily corresponds a parallel feature within the natural sphere and vice versa, we can always turn back to the natural attitude and make use of the insights we have won within the reduced sphere (Schutz, 1970, p. 59).

Schutz, like Merleau-Ponty (1962), argues that reflection isolates experiences and renders them meaningful as they are “apprehended, distinguished, brought into relief, marked out from one another,” and, “...the act of attention...presupposes an elapsed, passed-away experience – in short, one that is already in the past...” (Schutz, 1970, p. 63). Only past experiences are meaningful because only they can be subject to reflection. The present and future are meaningless; the present because it is ephemeral and not yet interpreted, the future because it has not yet existed.

Clearly such an understanding of the social world implies that it is accessible through phenomenological methods (albeit indirectly through the experience of others), but the researcher (or psychotherapist, as the case may be), has access to such data only through vicarious experience; the written or spoken accounts of others must be regarded as credible. The historian of the phenomenological movement, Herbert Spiegelberg, explains how this stumbling block can be overcome through what he terms “imaginative self-transposal” (Spiegelberg, 1975, pp. 35-53). He admits that the data obtained through this process is not “perception,” but rather “vicarious imagination”; nevertheless his argument supporting the acceptance of phenomenological information from others as being legitimate is convincing and underpins all phenomenological research that relies on the experiences of people other than the researcher. The world consists of multiple realities, but because we cannot see the world through another’s eyes a phenomenology that extends beyond the researcher’s individual experience must proceed through a cooperative endeavour with other people. Writing that “...between firsthand phenomenology and merely hypothetical construction there is a middle ground which calls for cautious and critical cultivation” (p. 52), Spiegelberg stresses the need to incorporate accounts of other people’s experiences into the phenomenological enterprise, but at the same time warns that it is (or can be) open to criticism. On the other hand, too wary an approach to this “middle ground” would restrict the possibilities of phenomenology. The argument is supported by the example of a psychiatrist whose

patient describes hallucinatory experiences. By endeavouring to understand the experience, the patient is encouraged to describe and explore it in detail, thus leading to a fuller understanding by the psychiatrist and also, of course, by the patient.

Acceptance of the validity of vicarious experience is of course fundamental to any investigation of experience outside that of the researcher; methodologies developed in psychology are also reliant upon this presumption. According to Ashworth, the rise of existentialism, particularly through Merleau-Ponty's work, signified a shift from Husserl's concepts in which the transcendental realm does not need to be regarded as "disengaged from the world." It does, however, "...retain bracketing as the process of return to the pre-reflective life-world, putting out of play the various interpretations and prejudices which would cloud its analysis, especially those of objective science" (Ashworth, 1996, p. 9). Ashworth acknowledges, however, the limitations of bracketing in psychological research. He writes:

The touchstone throughout [the investigation of the life-world] is clear. Just as bracketing must be applied to all presuppositions which hamper the phenomenological quest for entry into the life-world of the research participant, so necessary decisions of procedure or interpretation in the investigation of the life-world must always be made in such a way as to elicit the communication of rich descriptions of the phenomena of interest (p. 23).

Amedeo Giorgi: *Phenomenology and Psychological Research*

There are many variations of phenomenological procedures in psychological research (for example, Colaizzi, 1978; John, 1997; Koestenbaum, 1971; Rowe et al., 1989; Spinelli, 1989; Taylor & Brown, 1988; Van Kaam, 1969; Von Eckartsberg, 1989; Wertz, 1989) but for the purposes of this study it is most useful to consider that of Amedeo Giorgi (1985), as his work has influenced that of many other phenomenological researchers. To Giorgi, the adaptation of Merleau-Ponty's philosophy to psychology is a logical step because of the philosopher's profound understanding of psychology. He describes Merleau-Ponty's phenomenological method of having the following characteristics:

- it is descriptive, and analysis follows "naïve description";
- the reduction, or *epoché*, is attained by bracketing "theoretical prejudices" and ensuring that we do not "naïvely prejudge the nature of our experiences";

- it is a search for the essence, the structure of experience, that is, “what meanings must necessarily belong to the phenomenon”; and,
- intentionality is uncovered through “description within the reduction” (Giorgi, 1985, pp. 43-44).

Giorgi places great emphasis upon the fact that phenomenological psychology is science, not philosophy. He writes:

A psychological perspective is an originary one, and it cannot be reduced to other perspectives. It must discover its own methods, procedures, rules of interpretation, and so on by a direct contact with its own phenomena of interest and by working through whatever is necessary to achieve stable and significant psychological findings (p. 46).

Merleau-Ponty's criteria must then be adapted to make them relevant and attainable in both psychological practice and research. Like Schutz, Giorgi needed a way of justifying the incorporation of other people's experiences into the phenomenological process, and he did this by regarding such descriptions as a form of “text,” which, he claims, “presumably phenomenologists would find acceptable” (p. 47). He overcame the problem of the reduction by understanding it as “the difference between the way in which a situation is and the way it is experienced” (p. 49). In contrast to the transcendental reduction, then:

With a phenomenologically inspired psychology, we have the mixed case, a partial reduction – objects of consciousness are reduced but the acts are not – but the fact that psychology in this interpretation does not make the total transcendental move should not eliminate it from the movement altogether. Again, it is a compromise between the criteria for being phenomenological, which is seen to be desirable, and the exigencies of meeting human scientific psychological criteria (Giorgi, 1985, p. 49).

Merleau-Ponty's third characteristic, the “search for essences,” the invariants that universally define the phenomenon, must also be compromised in psychology, because psychologists are concerned with essences that are “context related.” Giorgi justifies the acceptance of this alteration by saying that “...regardless of the fact that the essences are limited, they still transcend the facts upon which they are based – just as universal structures do” (Giorgi, 1985, p. 50).

Finally, intentionality is reinterpreted for psychology in terms of behaviour. By this Giorgi means that "...behavior is always directed towards something that is not behavior itself, which we can best characterize by saying that it is directed towards a situation." Importantly, he concludes that "...[t]he emphasis on behavior also converges with the need for descriptions from others for phenomenological psychology, since one of the poorest perspectives for accurate *behavioral* description is the perspective of self-description" (Giorgi, 1985, p. 51).

Max van Manen: *Researching Lived Experience*

Both Giorgi and Schutz show that it is possible, albeit with a degree of compromise, to apply the principles of phenomenological philosophy to the human sciences; shifting the techniques of individual reflection that philosophy entails to the examination of the social world. Any compromise to the details of phenomenological process is balanced by the value of the approach to human science inquiry. Max van Manen, on the other hand, is more concerned with the literary processes that must occur throughout the phenomenological project, and their essential role in the construction of its final form as a written phenomenological description, than the adaptation of the original philosophical processes to his methodology. His work, subtitled *Human Science for an Action Sensitive Pedagogy*, is concerned with the application of hermeneutic phenomenology in this field, and the importance he places upon the artistic merits of this approach is reflected in his words:

Human life needs knowledge, reflection and thought to make itself knowable to itself, including its complex and ultimately mysterious nature. It is a naive rationalism that believes that the phenomena of life can be made intellectually crystal clear or theoretically perfectly transparent. That is why a human science that tries to do justice to the full range of human experience cannot operate with a concept of rationality that is restricted to a formal intellectualist interpretation of human reason. Likewise, the language of thinking cannot be censured to permit only a form of discourse that tries to capture human experience in deadening abstract concepts, and in logical systems that flatten rather than deepen our understanding of human life (van Manen, 1990, p. 17).

The principal methodological themes which characterise van Manen's approach are:

- turning to the nature of lived experience; this always involves *real* people in real situations (within certain contexts);

- investigating experience as we live it; it is about the “practice of reliving, which results from having lived life deeply” (p. 32). The researcher is actively involved in this process;
- reflecting on essential themes – a grasping of what it is that renders a particular experience significant to a person; phenomenology distinguishes between appearance and essence, things of experience and “that which grounds the things of our experience...Phenomenological research consists of reflectively bringing into nearness that which tends to be obscure, that which tends to evade the intelligibility of our natural attitude to everyday life” (p. 32);
- the art of writing and rewriting; phenomenological research is a “bringing to speech”, the application of language (speech) to a phenomenon;
- maintaining a strong and oriented relationship; it can be difficult to remain focussed on the experiences of interest and not become distracted by coincident areas; and
- balancing the research context by considering parts and wholes; be aware that theories can overlay the actual experience (the reality).

From an existential perspective, lived experience cannot be grasped at the time it happens, but only upon reflection, and meaning cannot be grasped unless the experience is placed temporally within the whole life experience (see also this chapter, page 73). Memory, then, is crucial in the phenomenological process: “Lived experiences gather hermeneutic significance as we (reflectively) gather them by giving memory to them. Through meditations, conversations, daydreams, inspirations and other interpretive acts we assign meaning to the phenomena of lived life” (van Manen, 1990, p. 37). It is not enough simply to recall experiences; we need to find the “meaning structures” of the experience.

Information from participants in phenomenological research frequently takes the form of anecdotes, which van Manen describes as stories that illustrate a phenomenon, an incident that is of special significance and which reveals the meaning of what is happening in the lived experience. Even if anecdotes are not historically factual, they are

important in that they illustrate what is factual to a person; they “form a concrete counterweight to abstract theoretical thought” (p. 119).

Van Manen examines the role of writing in phenomenology in considerable detail. Writing, he says, involves more than the mere production of text: “Writing fixes thought on paper. It externalizes what in some sense is internal; it distances us from our immediate lived involvements with the things of our world” (p. 125). The significance of writing to van Manen’s interpretation of phenomenological method can be understood in this summary of what he argues are crucial features of the writing process:

- Writing separates us from what we know and yet it unites us more closely with what we know.
- Writing distances us from the lifeworld, yet it also draws us more closely to the lifeworld.
- Writing decontextualizes thought from practice and yet returns thought to praxis.
- Writing abstracts our experience of the world, yet it also concretizes our understanding of the world.
- Writing objectifies thought into print and yet subjectifies our understanding of something that truly engages us (adapted from van Manen, 1990, pp. 127-129).

Van Manen recognises the fact that considerable responsibility rests with the researcher to express the findings of the inquiry, that is, the phenomenological description, in a way that makes it both accessible and believable to the reader. This implies a degree of literary proficiency in the researcher. The reader, however, also bears a certain responsibility in that he or she must understand its purpose as a phenomenological description in order to properly grasp its content and meaning, in much the same way that a novel is read with the understanding that it represents a particular literary genre.

Thus van Manen argues that writing can be understood as a process which fixes description and meaning in a way which renders it accessible to others, and this process forces the researcher (or writer) to express things in a meaningful way. The writer needs to understand the phenomenon and be able to transfer this understanding to others. The

phenomenologist has a responsibility to create a true representation of the phenomenon as experienced by others, not influenced by his or her own presuppositions. It is not a process of reducing another's experience to one's own.

The validity of phenomenology also relies to some extent upon its literary quality, and, van Manen writes, "A good phenomenological description is collected by lived experience and recollects lived experience – is validated by lived experience and validates lived experience" (p. 27). The usefulness of phenomenology lies in its value to ourselves. Collecting data from others allows us to become more experienced; phenomenology is, then, an educational process for both people involved. The primary interest in phenomenology is not merely in the description of an experience, as in ethnography or case studies, but in describing the phenomenon itself. Finally, phenomenology is a never-ending task, an "attempt to accomplish the impossible"; it must always be kept in mind that "to construct a full interpretive description of some aspect of the life world, and yet to remain aware that lived life is always more complex than any explication of meaning can reveal" (van Manen, 1990, p. 18).

Applications of phenomenology

This overview is intended to demonstrate the adaptability and ingenuity of researchers who have seen phenomenology's potential as a tool for the investigation of the phenomena of lived experience. Certainly numerous methods based on these and other variations of the original philosophies have evolved, offering ways of exploring the phenomena of ordinary human life that, without such a stringent scholarly foundation, might be relegated to mere subjective description. I turn now to a number of phenomenological studies that demonstrate the versatility of the approach.

Clark Moustakas: *Loneliness*

Psychologist Clark Moustakas describes the method he uses in his study of loneliness as "heuristic research" (Douglass & Moustakas, 1985; Moustakas, 1990). Heuristic research is an autobiographic endeavour, in the sense that it originates in the researcher's personal experience of a particular phenomenon, but calls upon other sources through which

understanding of the phenomenon is explored. These sources can include the accounts of other people, written documents such as diaries, as well as literary and art works. The method itself involves a number of distinct phases: initial engagement, immersion, incubation, illumination, explication, creative synthesis and finally, validation. The participants are referred to as “co-researchers,” and by reading the syntheses of their interviews, are asked to confirm the validity of this portrait as a true representation of their experience. Moustakas describes the first stirrings of his interest in the topic of loneliness:

My interest in loneliness began at a critical time in my life when I was faced with the problem of whether or not to agree to major heart surgery that might restore my daughter to health or result in her death...The urgency of making a critical decision plunged me into the feeling of being utterly alone, and pushed me to deliberately cut myself off from the advice or guidance of others (Moustakas, 1990, p. 91).

Material from a variety of sources, including his psychotherapy clients and a number of written accounts, was added to his own thoughts on the topic, and he arrived at the following “synthesis” of loneliness:

There is a power in loneliness, a purity, self-immersion, and depth which is unlike any other experience. Being lonely is such a total, direct, vivid existence, so deeply felt, so startlingly different, that there is no room for any other perception, feeling, or awareness. Loneliness is an organic experience which points to nothing else, is for no other purpose and results in nothing but the realisation of itself (Moustakas, 1961, p. 8).

Moustakas’ book was intended primarily for a lay readership and is therefore not highly academic in structure or content. As a consequence it has always been freely available to the public, rather than remaining confined to the shelves of academic institutions. It has proved immensely popular, and he reports that he has received validation of his elucidation of loneliness by the numerous letters of appreciation from readers who recognized their own experience in his description (Moustakas, 1961).

Kay Toombs: The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient

Philosopher Kay Toombs’ phenomenological investigation into the disparity between the patient’s and the doctor’s understandings of illness was inspired by her own experience

as a multiple sclerosis sufferer (Toombs, 1992; see also Toombs, 1987). Throughout the study she relies heavily upon Schutz' work on the interpretation of the social world, and also upon Merleau-Ponty's account of embodiment. The central issue of the study is the fact that although patients and physicians have common understandings of some aspects of illness experience,⁵ when the physician adopts a scientific attitude to the disease he or she is treating in another person, there is no longer any communication possible through a shared world of typifications. Both physician and patient assume that because they are communicating information about the illness, they each understand it through a shared reality, but Toombs posits that such a common reality does not exist. Toombs is not saying that this is simply "a matter of disparate interpretations of a common object" because "the lived experience of illness is such that it cannot represent a common object" (Toombs, 1992, p. 23): it is primarily a subjective experience. What the physician and the patient are talking about and experiencing are not at all the same things. The complexity of the meaning of illness, and its remoteness from the physician's understanding of disease, "underscores the philosophical importance of the difference between meaning which is grounded in lived experience and meaning which represents an abstraction from lived experience" (p. 42). The principal existential issue, then, in the doctor/patient relationship, is that of sharing experiences; the doctor (or anyone else for that matter) cannot share the patient's experience of illness, and therefore it is imperative that communication be established through some common ground. The way to achieve this, Toombs proposes, is through the establishment of an "eidetic interpretation of illness...[which]...discloses certain essential characteristics that pertain to the experience of illness *per se*, regardless of its manifestation in terms of a particular disease state" (Toombs, 1987, p. 219).

In an effort to uncover these eidetic characteristics, Toombs embarks upon an existential exploration of the broad issues that are involved in the understanding of illness. These are the separate worlds of the patient and physician, the experience of illness, the understanding of the body, and the healing relationship. Although the experiences of

⁵ For example, both are aware of the physical sensations associated with fever, sore throat and so on, these being seen as "representing a more or less typified instance of an objective, disease process" (Toombs, 1992, p. 22).

others are not entirely absent from this work, gathering information from a number of participants is not part of her method. Instead, she methodically explores the differences between the patient's and physician's experiencing of their separate worlds, the illness, the body, and the healing relationship, in terms of the principal existential components of spatiality, corporeality, temporality and relationality.

The extent to which Toombs' work has been embraced by physicians has not been examined in the course of the present study, but certainly her project of bringing together two different understandings of illness through a phenomenological process is potentially of great value in addressing a problem that is endemic in medical practice (see, for example, Frank, 1991; Kleinman, 1988).

Edward Casey: *Remembering*

The final work of particular relevance to the present study is philosopher Edward Casey's phenomenology of remembering (Casey, 2000). As with Moustakas' and Toombs' works, the study originated in the author's own thoughts and experience. *Remembering* was originally intended as a companion book to Casey's phenomenology of imagining because he saw many similarities between these processes (Casey, 1976). Casey's fascination with the existential characteristics of remembering is not difficult to understand; he begins the Preface to the first edition of *Remembering* with these words:

In the case of memory we are already in the thick of things. For this reason there can be no preface to remembering: no pre-facing the topic in a statement that would precede it and capture its essence or structure in advance. Memory itself is already in the advance position. Not only because remembering is at all times presupposed, but because also it is always at work: it is continually going on, often at several levels and in several ways at once (Casey, 2000, p. xix).

Following this introductory observation is a highly detailed and scholarly examination of the seemingly inexhaustible facets of this rich topic. Casey launches the discussion by identifying several different modes of remembering through accounts of his own deliberate excursions into the phenomenon. He discovers that remembering is multifaceted. The exploration of the topic reveals that it is represented in mnemonic modes (reminding, reminiscing, and recognizing), and in the pursuit of memory beyond the mind (body memory, place memory, commemoration). Casey examines these aspects in great detail, with constant reference to philosophical, sociological and literary texts. He

does not, however, refer to the experiences of other people; this is primarily a philosophical work. It is, nevertheless, highly readable and, no doubt because remembering in one or more of its forms is absolutely inseparable from consciousness and the way in which the world is experienced, has the potential to greatly extend the reader's appreciation of the construction of the life-world.

The present study

Explanation and justification of method

There are numerous other phenomenological studies that employ variations on the above techniques, but I cite these three in particular because in many ways my own approach bears some resemblance to them. I am encouraged by Polkinghorne's declaration that because of the recognition of the individuality of experience, and the aim of this type of research being to "produce clear and accurate descriptions of a particular aspect of human experience," there can be no fixed method which can be faithfully followed, as in other scientific research. He writes: "Methods based on phenomenological principles ...function as general guidelines or outlines, and researchers are expected to develop plans of study especially suited to understanding the particular experiential phenomenon that is the object of their study" (Polkinghorne, 1989, p. 44). The examples cited in the previous section serve as guidelines for this study.

The aim of the present study is to uncover the structure and the nature of caring contained in the accounts and stories of caring that I have collected, rather than through naked, factual description of caring as an activity, which could threaten to obscure its existential nuances. The task is defined by the requirement to preserve the existential dimensions of caring, and to respect its contextual foundation. This can be approached through an exploration, or perhaps teasing out, of the components that constitute caring for the participants, and immediately this presents itself as a creative endeavour. Indeed, as Casey (1998), Game and Metcalfe (2001) and van Manen (1990) explain, caring itself is creative, or rather it requires imagination to be successful or true to its purpose, and it can be seen that the elucidation of caring through the stories is also a creative exercise. It is first and foremost something that calls for a degree of artistic expression; it is not

something that presents itself immediately as complete and defined. My concern lies not with its overt expression as a collection of physical (or even mental) activities, but with its elucidation by means of a phenomenological process.

An important factor that relates to this artistic theme is that existentialism recognises the validity of artistic representations of human experience, and therefore it is not the role of the researcher to question individual interpretations or accounts of phenomena. Peterson, for example, contends that some modes of qualitative research, particularly phenomenology, can be "...seen to be advancing more the domain of rhetoric and poetry than that of science" (Peterson, 1994, p. 174). He thus claims that the results of phenomenological studies are often regarded as an end in themselves, rather than the stimulus for further inquiry. In response to this statement, it could be argued that the "domain of rhetoric and poetry" is indeed an appropriate and effective way of expressing human experience, which is ultimately, as Merleau-Ponty (1962) observes, the basis for all scientific inquiry. Phenomenological endeavours which draw upon a variety of sources, literary and otherwise, of which the present study is an example, therefore rely upon the "rhetoric and poetry" of those who have undergone experiences and described them through a variety of media. Perhaps the most powerful of all arguments in favour of the existential phenomenological approach rests with Simone de Beauvoir herself. The authors of recent studies argue that many of her works, including the autobiographies and memoirs (*A Very Easy Death* being one of these), are best understood as being informed by her own distinctive variety of existential phenomenology, rather than as they are more commonly read from a feminist or Sartrean existential perspective.⁶

Accepting the validity of these interpretations allows the researcher to utilise them when investigating the richness and variety of human experience. In this schema, the veracity of artistic endeavours of any kind, not only literary works, ranks equally with that of verbal accounts of experience, because all art originates from human experience and is merely a form of representation of experience through the skills of the artist. The literary

⁶ O'Brien and Embree (2001) have edited a collection of essays on this topic; see also Pilardi (1999).

sources which contribute to this study do not serve merely as extensions or embellishments of the oral accounts of caring available for use in constructing the phenomenological description. In a variety of ways they corroborate the participant's stories, but more importantly, through their artistic qualities they have enriched the ways in which caring can be apprehended. In this way the understanding of human experience becomes a process of continual enrichment and validation through the accounts of others. To question the motivation of the authors of such accounts is therefore not a profitable exercise because, as Ricoeur (1971) argues, all description, whether it purports to be academic or artistic, is reinterpreted by the reader within the context of his or her individual life-world.

In explaining the development of my own research it is useful to turn to Casey himself, whose meticulous phenomenology of remembering provides an explanatory background to my initial tentative excursions into the understanding of my own experience. These were simply acts of remembering, and this was accomplished through a process of writing and rewriting my memories of certain incidents that were impressed upon my memory. In his phenomenological study, Casey writes:

Remembering *is* caring for what we remember – intensified, once more, in commemorating. Indeed, it can be loving as well...Moreover, both caring and loving *take time*; neither can occur instantaneously; both require the fullness of time. Yet neither, when fully enacted, become time's fool: each represents a triumph *within time*, not a subordination of it. And in this "sweet victory" each is autonomous in its memorial action, realising itself through the density of its immersions (Casey, 2000, p. 274).

In this passage, Casey conveys the sense that remembering is an unhurried, creative act; one that requires patience and a certain degree of dedication (for whatever reason). He also shows that remembering is a selective, hermeneutic process through which an attempt is made to derive significance from certain remembered details, an observation that certainly applies in my own case. This opens the way to further examination of the remembered episodes, and perhaps even to their reconstruction. They are really only broad, undefined memories in which fine details are lost, perhaps because details are unimportant to this process. There is an implicit significance in a remembered episode, and this is sharpened by revisiting it.

In order to illustrate this, I refer to the story of bathing my mother, which appears in the phenomenological section on page 239:

Bathing my mother should have given me the chance to observe the deterioration of her body, the encroachment of the disease, but in fact this was wholly internal, and to my relief, invisible. Virtually the only outward sign of the cancer was the small pale scar on her breast, and when she was undergoing radiotherapy, the targets drawn on her hip by the therapist. Over time she just became smaller, until the skin lost its underlying support, revealing at last the enduring skeletal structure. (But this was an illusion; the X-rays told me that the bones were in reality mere shadowy vestiges of what they had once been). The skin on her back was white, unchallenged by the sun, as the skin on her hands was after years of gardening. On her back it was like the skin of a baby, white and pure and fine. Clothed, and with her hair neatly combed, she looked frail, but not particularly unwell...(Extract from author's notes).

In remembering the baths I consciously and quite deliberately expand upon the original blurred memory; for example, I had merely noticed the perfection of the skin on her back but now I look for a deeper meaning in this consciousness. I remember *noticing* it, but carrying it further to wondering about the bone structure has nothing to do with memory – it is an elaboration of the picture which remained in my mind. This retrospective reading is made possible only because of more recently acquired knowledge. At the time I certainly did not reflect upon the condition of her bones. The memory has become a foundation from which arises a picture of caring, or at least some aspects of it. The picture can be used for an endless variety of purposes; to reinforce, enhance past emotions, to keep them alive or reconstruct them. For what is left now? The events cannot be changed but what I do with the memories of the events is my prerogative. I am free to do as I please with them if they are my private memories.

Memorials, as concrete reminders of the past, are used not only to keep memories alive, but also to anchor them so they can be revisited in terms of the present. In this way the memory of the bath has been fixed in text, and I can now revisit it endlessly and seek more meaning in it, and I can also use it as a means of accessing newer ideas. I can play with the idea that the state of her skin belied the skeletal disintegration; as Casey writes, “the past develops” (p. 275) and takes on new meaning in light of later events. The past is precious, and what is precious about these memories is the fact that they are not just

recollections of events but that they can be used as we wish and can lead us on to unexpected realms. Schutz and Luckmann (1973) describe “meaning” in these words:

Meaning is not a quality of certain lived experiences emerging from a stream of consciousness – that is to say, of the objectivities constituted within it. It is rather my explication of past lived experiences which are grasped reflectively from an actual now and from an actually valid reference schema. As long as I am engaged in lived experiences and directed toward the Objects that are intended in them, these experiences have no sense for me (apart from the particular meaning – and time-structure of action!). Lived experiences first become meaningful, then, when they are explicated *post hoc* they become comprehensible to me as well-circumscribed experiences. Thus only those lived experiences are subjectively meaningful which are memorially brought forth in their actuality, which are examined as regards their constitution, and which are explicated in respect to their position in a reference schema that it is at hand (Schutz & Luckmann, 1973, p. 16).

The act of writing effectively disentangles events from the mass of memories that populate our consciousness; the effort required in writing clarifies to some extent the images of the past and grants time and space in which they can be scrutinised.

Remembering is not only an integral aspect of the phenomenological process which characterises this project, it also acts through my own writing as the catalyst for the further exploration of caring (in a phenomenological sense), through the experiences of other people. In addition to my own material, a number of literary narratives of caring were collected, the most important of which are those of Simone de Beauvoir and Philip Roth, and these were supplemented with spoken accounts obtained through informal interviews, or (more correctly), conversations with five people who had cared for their parents as they were dying. These accounts are all products of remembering; this material has already been reconstructed (some probably many times) and interpreted by the authors or speakers as being part of caring. Even the conversation transcripts, although faithful representations of my conversations with the carers, tell of episodes revisited many times. For this reason the stories would have undergone extensive examination and refinement. Nevertheless such revision, even to a minor extent, does not detract from the veracity of the stories, because phenomenology is concerned with the meaning of subjective experience and not with “objective” truth.

The tendency, and the need, to order experience in the search for meaning is explained by Paul Ricoeur in his idea of life as a narrative (Ricoeur, 1986). He has this to say about remembering:

But what is it to remember? It is not just to recall certain isolated events, but to become capable of forming meaningful sequences and ordered connections. In short, it is to be able to constitute one's own existence in the form of a story where memory as such is only a fragment of the story. It is the narrative structure of such life stories that makes a case history (Ricoeur, 1981, p. 253).

De Beauvoir's compulsion to record the events surrounding her mother's death and explore her own feelings and relationships is, as Nancy Miller writes, not an unusual sequel to the death of a parent. In the book she wrote after her own mother's death, Miller observes that these memoirs constitute "...a narrative of mourning that gives grief a story, loss a semblance of closure" (Miller, 1996, p. 14). Remembering and writing about the past can be undertaken as a means of resolving grief (see, for example Andrew Hall's poems written after the death of his wife, poet Jane Kenyon [Hall, 1998], and C. S. Lewis' journal of grief at the loss of his wife [Lewis, 1961]), or it can be a way of exploring the character of the dead person, as exemplified by Raymond Gaita's *Romulus, My Father* (Gaita, 1998). Miller warns, however, that memory is fluid, and, "the biography of a parent is always an act of remembering, and like all effects of memory, vulnerable to omission and distortion" (p. 17). As Edward Casey writes in his phenomenological study of remembering, memory is "polymorphic" and, in addition:

...remembering makes a very considerable difference in how we relate to the past. Indeed, through its action of uncovering the past as ever-different, it *makes all the difference*. In remembering we do not repeat the past as self-identical, as strictly unchanging and invariant. We regain the past as different each time (Casey, 2000, p. 286).

But it is not at all certain that the truth, the past that involved our parents, is ever revealed; as Miller writes: "Nonfiction does not guarantee that the enigmas of family history will be solved" (Miller, 1996, p. 108). The constant restructuring of the past, and the differences in perspectives of the actors from that past, ensure that any unchanging historical account is an impossibility.⁷

⁷ The disparity in perspectives is illustrated by the reaction of Sartre's mother when she first read her son's account of his childhood in Sartre's autobiography *Words* (Sartre, 1967): "'He understood nothing about his own childhood,' she said to a friend" (de Beauvoir, 1972a, p. 106).

Thus the notion of “truth” in autobiographies is problematic, a fact which two of de Beauvoir’s biographers, Francis and Gontier (1985) failed to understand. While interviewing Simone de Beauvoir, her biographers soon realised that the events recorded in her memoirs did not always accord with what she herself said: “We were aware of twilight zones and topics that were taboo. We had discovered that she had wilfully blurred some parts of her life or reconstructed the circumstances surrounding people who were dear to her” (Francis & Gontier, 1985, p. xii). Indeed even on different days her accounts of events differed, as they certainly do in the memoirs, *A Very Easy Death* (de Beauvoir, 1966), and in her letters to Nelson Algren (de Beauvoir, 1999). When taken to task about these discrepancies, she said to them: “For you it is easy, you just have to cross it out, but it creates a real problem for me, a problem concerning the errors you make when you write [a long silence] and yet I was in the heart of things” (Francis & Gontier, 1985, p. xv).

Francis and Gontier claim that because of their factual inconsistency, de Beauvoir’s memoirs are really “works of art” created by reconstruction of “aspects of her personality and her life” (p. xv). The purpose of a memoir is, Catherine Brosman reminds us in her critique *Simone de Beauvoir Revisited*, to create “a record of what happened to and around the self, not the interpretation of the self” (Brosman, 1991, p.135). Jo-Ann Pilardi also defends de Beauvoir’s autobiographical depictions of both her younger self and other people from her past as creations “...made possible by Beauvoir’s ‘lending’ them her present consciousness, the freedom that is activated through and in the process of writing” (Pilardi, 1999, p. 115). De Beauvoir herself claimed that her autobiographical works (which she described as memoirs) were not intended to be “works of art,” but rather they were written as a medium through which she could explore her own character and persona as a writer. Pilardi observes that de Beauvoir’s approach, “to explain her life as a writer by its details rather than in generalities,” is not only existential, but it is fundamentally a “phenomenological project” (Pilardi, 1999, pp. 111-12).

There are many similarities between the illness narratives of Philip Roth's *Patrimony* and de Beauvoir's memoir; for example in both accounts the authors tried to protect their parents from the truth about their illnesses, and early symptoms were wrongly attributed to less serious conditions. Roth's book has also been described by Jay Halio (1992) as a "memoir," and both authors have constructed narratives in which their parents' biographical material is included as a means of examining relationships through remembering the past, and by trying to understand their parents' characters. Unlike de Beauvoir (who only took notes at her mother's bedside), however, Roth tells us: "...in keeping with the unseemliness of my profession, I had been writing all the time while he was ill and dying" (Roth, 1991, p. 237)

Because I had consolidated my own understanding of caring through a process of remembering and putting the various significant incidents into place within that particular context, I was interested in exploring this process in others. The writing of authors Roth (1991), John Bayley (1998; 1999), and particularly de Beauvoir (1966), led me to speculate that perhaps there was a way of considering caring phenomenologically that avoided problems of "thematizing" (my "themes" are very broad and indistinct) or decontextualising the material which are, as previously indicated, common features of many phenomenological methods. My own writing and way of thinking suggest that plucking themes from various accounts or stories of caring destroys the very concept under scrutiny. For example, the story about the baths is so deeply associated with the fact that at the time I was caring for my mother that it would be meaningless, or take on a different aspect, in any other context.

The principal issue informing the method of dealing with the variety of available material was the view that, although the lived experiences of other carers were crucial to the project, they were ultimately only intended for the furtherance of the project itself as an academic enterprise. In other words, all material, including my own, was treated as "text." A text, according to Ricoeur, is "any discourse fixed in writing." But, in fixing discourse, the act of writing irrevocably alters its nature:

Dialogue is an exchange of questions and answers; there is no exchange of this sort between the writer and reader. The writer does not respond to the reader.

Rather, the book divides the act of writing and the act of reading into two sides, between which there is no communication. The reader is absent from the act of writing; the writer is absent from the act of reading. The text thus produces a double eclipse of the reader and the writer. It thereby replaces the relation of dialogue, which directly connects the voice of one to the hearing of another (Ricoeur, 1981, pp. 146-7).

When both the participants and I were satisfied with the content and value of the transcripts of the conversations, the view was taken that it was justifiable to treat them as texts. No further examination through subsequent discussion with the participants was deemed necessary. The transient roles of the participants in this approach imply that it was neither possible nor desirable to collaborate in any way with the participants once the conversational records had been obtained. This represents a departure from many phenomenological methods, for example that described by Moustakas, (1994), in which the participants are regarded as “co-researchers.” The present research has at all times been directed by myself, and the texts (including my own) have been used as means of access to some factors which have then been explored from an existential perspective. This is, however, by no means a revolutionary approach: Moustakas’ (1961) “heuristic” phenomenology of loneliness builds upon a variety of personal and written stories; van Manen (1990) emphasises the value of literary and other artistic material in his phenomenological pedagogy; Scheler does not acknowledge, or even mention, his sources in his study of shame (Emad, 1972); Crotty (1996) relies entirely upon his own observations in his study of intensive care nursing; while Casey (2000) utilises his personal recollections as prompts for his phenomenology of remembering. These, and other researchers, show that the production of a phenomenological account does not necessarily demand the continuing involvement of those who contribute to the research material. The solitary phenomenological enterprises of Husserl, Heidegger and Merleau-Ponty need not be the province only of philosophers, as these researchers have shown.

It should be mentioned here that the collaboration of participants as “co-researchers” facilitates verification of a study. By returning to the participants with the final phenomenological account, it is possible to ask if in it they recognise their own experiences. Again, however, I refer to phenomenologists like Casey, Toombs and Scheler, who could not seek confirmation of the veracity of their work which stands on

its academic merits. Such studies rely to a large extent upon the integrity of the methodology employed by the researcher for validation.

Selection of participants

The importance of selecting participants who are reflective, and whose experience of caring was sufficiently distant for them to have overcome their exhaustion and grief was made very clear after an early “pilot study”. The edict that phenomenology can only really be understood through actually engaging in the process was certainly verified by this experience.⁸ The participants in these exploratory interviews were contacted with the help of the facilitator of a grief support group at a metropolitan hospice. She mentioned my study to the group and gave the members the opportunity to contact me if they wished to participate. I was contacted by every member of the group within the next few weeks, but interviewed only two of the carers, although I did have lengthy telephone conversations with them all. There were serious methodological problems with this method of sampling. First, it was very clear that these people were all deeply influenced by their experiences as members of the support group. A common understanding was that by attending the group they were “given permission to grieve” and this was encouraged in quite structured ways. For example, as it was nearing Christmas at the time, the group members were given ideas of how to cope with the absence of their parents at this important family gathering (e.g., by making sure that frequent reference was made to the dead person, and in the participant Kerry’s case, to hang stars on the tree symbolizing her dead parents). Another important issue was that as most of the people had lost their parents within the past six months (the grief support group was available to relatives up to one year after the person’s death) they were still in the grieving phase and could not separate grief from caring.⁹ As a result it was difficult, if not impossible, for them to

⁸ Van Manen, for example, observes that there is no method in phenomenology (or in hermeneutics); instead they are guided by “a body of knowledge and insights, a history of lives and thinkers and authors” (van Manen, 1990, p. 30).

⁹ This is not surprising; deep emotions are easily confused as they can resemble one another in their physical manifestations. C. S. Lewis, for example, begins the account of his journey through grief at the loss of his wife with the words: “No one ever told me that grief felt like fear. I am not afraid, but the sensation is like being afraid. The same fluttering in the stomach, the same restlessness, the yawning. I keep on swallowing” (Lewis, 1961, p. 5).

reflect on the actual experience of caring as a past activity. I was delighted at the strong response to my strategy to find participants, but soon realized that their eagerness arose from the misconception that the interviews were actually “counselling sessions” despite my clear assertion that I was not a psychologist, but a student conducting social science research. My reluctance to proceed with the hospice people after two interviews was due partly to this unwanted and potentially dangerous responsibility. At the same time my interest in caring became more focussed upon its existential aspects, and the semi-structured interview format I used at that time did not offer the carers the freedom to explore the existential dimensions of their experiences. Nevertheless, these carers did contribute to my understanding of caring, and the grief that is for many people inseparable from it. Some information provided by one of these early participants (Kerry) is used in the phenomenological discussion.

The five carers (one man and four women, two of whom are sisters) who eventually provided the first-hand accounts of their experiences that appear in the study, were contacted by word of mouth, through friends and colleagues. One participant managed a team of volunteers in a palliative care facility attached to a large Melbourne hospital, and when he informed one of the volunteers of the study, she subsequently also offered to participate. Another participant is a colleague, who also suggested her sister could be interested in taking part as they had both cared for their mother. The fifth person was at the time writing a thesis about nursing homes in Victoria and expressed interest in the project when we met to share our knowledge in an academic capacity. The recruitment of participants for a study of this nature is governed to a large extent by chance, but by this stage I had a clear idea of the type of person I was seeking (i.e., those who are reflective), and the material provided by these people proved invaluable to the project. The sample of four women and one man reflects the gender ratio of informal carers in Australia (Australian Bureau of Statistics, 1998), but this balance was not a primary concern. As previously indicated, of greater concern was the ability of the participants to think about their experiences in a phenomenological way so that their stories were appropriate for the fundamentally descriptive and creative purposes of the project.

Phenomenological inquiry does not demand a large number of participants. It is possible to conduct such research with as few as one participant, or the researcher can proceed alone (Gergen, 1985). In this instance, I decided after studying the five transcripts, that together with the secondary material, sufficient material was at my disposal to initiate examination of a number of issues within an existential framework to suit the purposes of the thesis. This decision was reviewed at a later stage and found to be sound.

Conversations with carers

After locating the participants, and confirming their willingness to take part in informal conversations about their caring experiences, I spoke to them by telephone prior to meeting them, explaining the aims and structure of the study. Informed consent forms and a written description of the project were posted immediately following this conversation (see Appendix A, page 267). The signed consent forms were collected at the subsequent meetings with the participants. In the preliminary conversation with the participants I suggested they reflect upon their experience, recalling, and perhaps writing about incidents that represented or epitomised caring for them. This was intended as a means of directing the focus in a particular way upon the issue in which I was interested, and also as an “icebreaker” should it be difficult to initiate conversation. It proved unnecessary to direct the conversation beyond this; the participants appeared pleased to have before them a listener who was interested in the significance of their caring experiences. In fact, the participants were not interested in writing about caring; they were far more interested in talking about it and they had all clearly found the reflective process extremely useful as preparation for the meetings. I conducted one conversation, of about an hour and a half duration, with each person. With the permission of the participants, the conversations were tape recorded and transcribed by myself within a few days of the meetings. After reading through and discussing the transcripts with me, all said that they felt that they had little to add to them as they had exhausted the topic. Thus, although the opportunity was offered, we did not engage in further face-to-face conversations.

The hermeneutic process: Identifying the themes

The transcripts were read many times, in conjunction with *A Very Easy Death* and *Patrimony* as well as my personal stories, which had by this time been refined and edited by means of a hermeneutic process over a period of about a year. I also extended my other reading, both academic and literary, in the area. Over a period of several months, a number of existential themes that seemed particularly important in the stories emerged. Although sometimes they appeared in several accounts, this was not necessarily a prerequisite for their selection. The primary reasoning for the choice of themes was that they had been presented in a particularly powerful manner in the primary sources, that they invited further exploration through existential (and other) texts, and were indeed represented in those texts. For example, the image of the body's interior that medical technology makes possible evokes a wide range of emotional reactions in the carers. Not only does this topic feature in several of the primary accounts, but it also appears in literature and also boasts an extensive theoretical treatment in academic literature. Consequently, it seems appropriate and fruitful to pursue this particular aspect of caring (See Chapter Seven).

In Chapters Five, Six and Seven the results of this analysis are presented in a manner that links theory with practice, while Chapter Eight comprises a summarised phenomenological description of caring based upon the findings of these chapters.

Chapter Four. Research material

Closely related to mourning is caring: how could I mourn for what is indifferent to me? Caring also implies remembering, that is to say, keeping the other person (or thing) in mind...(Casey, 2000, pp. 273-4).

* * *

The previous chapter outlined the theoretical foundation In this chapter the primary and secondary materials used to develop the phenomenological analysis of caring are presented in summarised form. Primary sources consist of interviews or more correctly, conversations, which were carried out between the researcher and individual carers in single sessions of around two hours duration, and these are summarised in this chapter. Also included is a summarised version of a journal which one of the carers (who was also interviewed) maintained intermittently throughout her caring experience. All participants have been assigned pseudonyms in order to protect their privacy. The principal secondary sources, Simone de Beauvoir's *A Very Easy Death* and Philip Roth's *Patrimony*, are presented in abstract form with a brief commentary on the historical and biographical circumstances under which they were written. A number of themes arising from this material are linked to theoretical discourse and developed in the following section of the thesis.

Primary sources: Conversations with carers

The transcripts of the conversations with carers contain a considerable amount of material that was not used directly in the study. For that reason, rather than reproducing the conversations in their entirety, the participants' stories are presented as summaries which incorporate a limited number of extracts from the transcripts. Further direct quotations from the stories are to be found in the analytical section of the thesis. Although the circumstances of the carers are not particularly relevant to the study itself, each story is preceded by a biographical sketch, and other comments, which are intended to convey to the reader an understanding of the range of circumstances and emotional involvement experienced by the carers.

The author's experience of caring: Joan's story

Biographical note

At the age of seventy-two, Joan, who at the time lived alone in Adelaide, suffered a minor stroke as a result of arteriosclerosis, which had restricted blood flow to the brain. She underwent emergency surgery to repair a damaged carotid artery. The operation was successful, but it was clear that Joan would need some care in the future as the stroke had left her with minor brain damage. She sold her home, and moved interstate to live close to her daughter in Melbourne. Her new home was a ten-minute walk from her daughter's house. She settled in well, and for several years enjoyed setting up her home and establishing a new garden, frequently returning to visit her old friends, and also entertaining them in her new home. At her age, however, it was difficult to establish new friendships, and her social world, apart from these contacts with her Adelaide friends, was centred entirely on her daughter, son-in-law and three grandchildren. At age seventy-eight, breast cancer was diagnosed, and after apparently successful surgery, she made a good recovery. Her eightieth birthday was celebrated in style with her friends and family. About nine months later she underwent a hysterectomy, and during a protracted and complicated recovery she experienced pain in her hip. The cancer had spread to her bones, and radiotherapy was recommended as a palliative measure. Despite the devastating side effects of this treatment, Joan regained some mobility and a degree of independence after some months, but this was only temporary, and she eventually died at the age of eighty-two. Despite her increasing frailty, with assistance she was able to remain at home until her last six days, which were spent in a metropolitan hospice. During these final ten years of her life, she relied heavily on her daughter for support and companionship, and in the last two years was highly dependent upon her as her primary carer.

Introductory note

Joan's story is my mother's story. When the illness had first been diagnosed, her dependence upon me involved little more than companionship, but as the episodes of serious illness became more frequent, the nature and intensity of this dependence

changed. It gradually but relentlessly eclipsed other aspects of my life, and finally extinguished them; I became saturated in caring. Eventually, my entire existence was concerned with this one person, controlled by the routine of seemingly endless medical treatments and doctors' appointments which are the essential components of the modern cancer experience. About a year after her death, I began to explore the more persistent images of the experience through writing. The objective of this process was to seek an understanding of the reasons for their persistence. Throughout the thesis they are referred to as "extracts from the author's notes."

On reflection, it became clear to me that the anticipation of death altered completely and permanently the meaning of the caring experience. At which point, then, did my involvement with my mother change from one of mere companionship to caring? It might appear from "Joan's story" that this was a gradual, imperceptible process, growing over the ten years from the time I first assumed responsibility for her well-being. But this is not how it really happened: it was the discovery of my mother's cancer that redefined my situation and threw us together in a novel way, transforming me into her "carer" at that instant. The absolute certainty that the future will be irrevocably predestined comes with the diagnosis. It is very probable that, because of the slow progress of cancer in the elderly, her body had harboured the cancer for some time, perhaps even years, but it was unsuspected until the authority of medicine confirmed the truth. Remission provided no real escape, only brief respite before the next wave of illness overtook us. Before the diagnosis, death did not threaten immediately and could be pushed out of mind as we saw before us a future, albeit of some unknown quality. The diagnosis meant that we could not return to what we had been the day before, even the hour before; we could not retrieve our old relationship in any guise whatever because it was forever past. She immediately became ill and at that instant I became her carer.

The diagnosis: Becoming a carer

We had arranged to meet outside the fishmonger after my mother's regular appointment with her GP (she had high blood pressure at that time which was monitored at monthly intervals). I was trying to choose between the salmon and trout which rested on their beds of ice. Suddenly, my mother appeared next to me; her face looked blank, stunned, and she said to me: "I've got breast cancer."

I was unable to immediately comprehend the import of this terrible news. I turned away and together we left the fish shop to find a coffee shop. We hoped that the ordinary surroundings would restore the world, but of course they could not. Apparently during the consultation she casually mentioned to the doctor that she had noticed a sore spot on one breast, which she clearly was not concerned about as she had not mentioned it to me. The doctor took one look and just said: "You've got breast cancer!" Medicine and humanity do not always coexist. Together we faced the certainty of death and the uncertainty of dying (Extract from author's notes).

This anecdote describes the exact moment at which I assumed my new role. There were two crucial features of the experience which distinguished it from other caring activities I had undertaken. First, this person was my mother, to whom I owed my very existence. And, despite our sometimes uncertain relationship, she had in one way or another always been part of my life; she was *always there*. The second defining feature of this episode was that I was, from that moment, charged with the care of a person who could anticipate no future except that brief, uncertain time which I alone would share with her before she died. The discovery of her illness threw us together, and we could not escape from each other until she died. And even now that she is dead, and has truly escaped, I myself can never be without her. I cannot ever shrug off her influence or remove her from my memory.

The time during which Joan received treatment for metastatic cancer was relieved by several periods of relatively good health, when it was almost possible to forget that she could never overcome the illness, interspersed by periods of extreme sickness and suffering. Thus hope was always tempered by the certainty that at any time the illness would manifest itself, but in unexpected, unpredictable ways.

* * *

Conversation with Anne. 19/2/1999. Anne and her sister Zoe (see following conversation), both cared for their mother while she resided in a metropolitan nursing home.

Biographical note

Anne is a highly trained nurse who has a great deal of professional experience in both practical and academic capacities. Her familiarity with the professional care of the elderly has been strengthened by her involvement with the Alzheimer's Association. She and her elder sister (Zoe) were born in a large rural town in the Gippsland district of Victoria, and Anne's widowed mother was still living there until just before she died. She did not suffer from any particular life-threatening disease, but died from the cumulative effects of various complaints of old age. Although she managed to remain independent for some time, albeit with the help of her daughters, eventually she became too frail and was transferred to a nursing home in Melbourne where both daughters lived. Despite the fact that she did not at any time reside with either of her daughters, they spent a great deal of time at the nursing home with her, and they both considered themselves "carers." Neither sister was present when their mother died, although they had both been with her shortly beforehand. Her body was taken back to the country, and the funeral was held in her home town. The large attendance was testament to her popularity.

Introductory note

About a week before the interview I had asked Anne to think about some times which she thought signified caring to her. I suggested that she might find it helpful to write some of it this in preparation for the discussion. She did try this, but had just written a few brief notes, to which she referred from time to time during our conversation; she found it easier to talk about her experiences than to write about them. She was extremely articulate, and had clearly given a great deal of thought to the subject. She did not present a continuous narrative of caring; her experience was presented as a series of chronologically unrelated incidents which she regarded as representing her caring experience.

Conversation summary

Anne began by saying, “The first thing that I wrote down was that...it was a privilege to care for my mother” and, “Caring...is a very private relationship.” She had from the time of her childhood enjoyed a loving relationship with her mother, and even as a child a special knowledge and empathy existed between them. She chose three scenes as representing caring: playing recordings of her own (not necessarily her mother’s) favourite music, in particular Richard Strauss’ *Four Last Songs*; writing letters and cards telling her mother how much she loved her; and just sitting in Macdonald’s car park, eating potato chips and reminiscing about the past and the people they used to know. She thought they were all “simple” and easy ways of caring. A fourth event, moving her mother from her home town, was added later in the discussion.

Because Anne is by profession a nurse, and by nature a reflective person, her story provides an opportunity to explore the existential differences between professional and informal caring. She possesses practical expertise and technical skills which she was able to call upon when she wished, and which were used to enhance and facilitate the informal role when she felt she was able to use them within that sphere. The activities and processes of informal caring are not “clearly defined” in the same way that nursing is normally defined, or more precisely, bounded by the constraints (both cultural and social) of less intimate and personal relationships. Conversely, when acting in the capacity of nurse, she found that being able to draw upon the privileged relationship she had with her mother altered the nursing experience: “...it was a totally different way of doing it, and a sort of connecting.” Although the informal role did not encroach upon the professional role, the converse was not necessarily the case, and professional skills could be incorporated into the informal role. To some extent, they were complementary.

The nursing home staff frequently invited Anne to share the professional nursing care (for example, by administering medication), which she willingly did at times. “At certain times”, however, she simply did not wish to assume that particular responsibility because she felt that the emotional involvement was too great. At these times she preferred just

“being there”; she said: “I think it was a time when I didn’t want that heavy, intense connection. This is when she played the Strauss songs to her mother.

The letters that she wrote to her mother were meant to be read “over and over”, a constant reassurance that she was deeply loved and cared about. Anne said that this process helped them both because caring had mutual benefits, strengthening them both. She continually referred to the apparently imperceptible transition from being simply a daughter to becoming a carer. She said:

Perhaps there is an element in the caring role that is not highly intellectual, or examined. What I’m saying is that what I learned about that relationship with my mother is that it just flowed. (Conversation with Anne).

The experience of caring, in retrospect, was for this person something which became integrated with her life. After her mother’s death, she said that she felt “extremely sad, of course, but also *extremely empowered*.” Anne was responsible for arranging a funeral which celebrated her mother’s musical talents and her popularity. In defiance of convention, the pallbearers were all women, whose lives had been touched by Anne’s mother in the course of her involvement in the community. The contrast with her father’s funeral, over which she had little authority, and which she considered “inappropriate” for a number of reasons, did not have a “therapeutic” effect in the way that her mother’s did

* * *

Conversation with Zoe, 1/3/99. Zoe and her sister Anne (see previous conversation) both cared for their mother.

Biographical note

Anne's sister Zoe is a widow, her husband dying suddenly, although not unexpectedly (he had for many years suffered from a form of lymphoma, although this was not the cause of his death), before her mother became ill. She and her husband had been living in Sydney, but when he died she moved to Melbourne where her children lived. She has three grandchildren. She lives in a neat, comfortable old apartment, and although it is on a busy highway it is peaceful despite (or because of) the constant background hum of traffic. She said that her sister Anne bought the flat for her without her having seen it. The stipulation was that it be on a busy road because she was afraid of the isolation and possibility of intruders in a quiet side street. She said she doesn't feel at all afraid living there. Zoe and Anne shared the care of their mother when she entered a nursing home.

Introductory note

This conversation took place about a week after I spoke with Zoe's sister Anne. Anne herself suggested that it might be interesting to talk to her sister, as they had shared the care of their mother, and Anne thought that her sister had cared in a totally different way, being the "practical one". I had suggested during the initial phone conversation that jotting down some notes about her experience of caring might help, as Zoe seemed rather nervous and reserved. She seemed to think there was a "correct" way of doing things; for example, she was anxious to be seen to fit into some sort of pattern, asking me later if her description of caring fitted into the "general setup" of carers I had spoken to. She constantly compared her style of caring with her sister's, which she considered "special", and of a higher quality because her expertise was of a practical nature. Towards the end of our conversation she did concede that both contributions to their mother's care were of equal importance. There was a large arrangement of gerberas in the fireplace, which Zoe said were her mother's "favourites," and which she often bought for her: "Whenever I could, when she was at the nursing home, I'd bring her gerberas, and I still like to." Zoe's conversation consisted of reflections about her experience, rather than a narrative of events.

Conversation summary

Zoe's relationship with her mother appears to have been one of mutual support and interdependency, but the emphasis was on its practical aspects. Zoe understood that her role involved her "just *being* there" for her mother, and the fact that she would worry ("got a bit funny") if there was no contact for a couple of days meant that the relationship was in some ways almost symbiotic: "So I guess that I was pretty important to her." The lives of Zoe's family and her mother were intertwined and concern for each other was a constant feature of this pattern of dependency. When Zoe's husband was ill, she said that "She was a big part of our family," and "She worried as much about me as I worried about her." Later in the conversation (although in reference to an earlier time when her children were young) she again emphasised this dependency on her mother.

Although Anne attended to the practical aspects of caring when her mother required it later in life, it would appear that in many important ways Zoe was more closely associated with her than was her sister over a long period of time. The different patterns of caring appear to mirror the caring inherent in the two mother-daughter relationships. Zoe was able to reciprocate when the time came with the same sort of assistance and support that her mother had provided for her over a long period of time. Even the way the two daughters helped their mother when she was sick differed; the sickness had been virtually deconstructed, in order that different aspects of it, and responsibility for them, could be allotted to different sisters. It is only at the very end, when her mother was dying, that Zoe felt capable of providing the spiritual care that she considered her sister could offer so naturally:

Zoe referred constantly to the difference between the caring styles, and her impression that the spirituality of her sister's caring elevated it to a different, higher plane. Zoe saw herself as the provider of security, while Anne's role was directed towards the provision of comfort. Listening to music and writing letters to her mother were seen as "beautiful, expressive things," which somehow sprang from the special closeness of their

relationship. Zoe said: “They did have a different, a *very*, very close relationship in lots of ways.”

Zoe frequently referred to the death of her mother as being a positive experience for her: “When she was dying, that was a wonderful experience” and, “I think it was just lovely.” Later she said that “Mum’s death (it sounds stupid!) was just lovely, in a way.” Indeed there is no mention of distress at all. Zoe said that Anne (still acting as a nurse) continued to provide comfort after their mother had died: “We went back [to the nursing home when told their mother had died], and Anne fixed her up, made her comfortable until the doctor came...I couldn’t have done what Anne did when she died, and I sort of stood back because I knew she needed to do this for Mum.”

After our conversation Zoe said that she supposed the way she cared was not “real” caring, and that she couldn’t have cared in the same demonstrative way that her sister did. All the same, she considered that she had loved her mother as much as her sister did. They both were very close to their mother, but in different ways.

* * *

Conversation with Brad 17/5/99. Brad cared for his mother in her own home during the last few weeks of her illness.

Biographical note.

Brad is a counsellor who currently oversees a volunteer program at a palliative care institution associated with a large metropolitan public teaching hospital. I had initially approached him as a possible contact for participants, but he himself offered to participate in the project as he had cared for his mother who died in 1993 after suffering from breast cancer for two years. At the time of the diagnosis he lived in Sydney, and flew to Melbourne frequently to be with his mother, staying at her home with his father and a brother during the last few weeks when she was very ill. He is the oldest of five siblings, having three brothers and a sister, who is the youngest.

Introductory note

Brad had clearly reflected a great deal about his experience, and told me in a later conversation that he used episodes from it to illustrate points to his volunteers. Most of the volunteers are health care students (mainly nursing and psychology) and they are actively recruited in a deliberate strategy to expose them to situations arising from the care of the dying and their families.

Conversation summary

Brad's narrative of caring is inseparable from the history of his relationship with his mother. He began with a brief, clinical description of the final stages of his mother's illness; "There had been fairly significant cognitive loss in the last week," and: "[S]he had secondaries in the lungs, and she also got bony secondaries." Because Brad had been travelling at the time of the initial diagnosis he was the last sibling to learn of it, and indeed treatment had already begun when he finally spoke to his mother. He said the cancer was by then at an advanced stage, and: "They immediately put her on to chemotherapy." Brad refers to an "estrangement" as a possible reason for the abrupt tone of his mother's phone message, which was waiting for him when he returned from his holiday. The message was odd, indicating that "something was wrong...I knew from the

tone of voice to ring immediately.” Brad knew instinctively from her description of events that his mother would die from the cancer, which upon diagnosis had already metastasised. His partner at the time (a GP), whom Brad had invited to overhear the conversation, confirmed this. Despite the difficulties of the relationship with his mother, Brad said: “[I] reassured her that I loved her,” and was prepared to do anything necessary to help her.

Brad sees himself as the “family truth-teller,” a person who values openness and honesty as high priorities in his personal construction and sense of self. He said: “My role in the family has been as the truth-teller. I’m the one who says things when nobody else wants to.” Such scrupulous honesty was the cause of the initial estrangement from his parents; he had confronted his father (Mr Morris) with an accusation of physical abuse of him as a child, and when the rest of the family were informed of this, they joined forces against him, supporting Mr Morris. Brad did attempt to redress the situation, but could not understand his mother’s ambivalence. Before the cancer was diagnosed, his attempts to show affection were rejected: “When I...went to hug her, she winced, and froze, and that clearly was partly about me being the way I am, but it was also because she was in physical pain, and she of course made out it was all physical pain.” Brad realised in hindsight that the tumour was already evident, but concluded that her refusal to seek a proper diagnosis or treatment was directly linked to his behaviour, that “denial of her breast cancer and the growth of the tumour was directly related to her needing to be closed down emotionally because of what else was going on in the family, because of my challenging of the [family mythology].”

The problems within the family were not really resolved until a few months before Mrs Morris died. A “non-aggression pact” was observed, and concern for his mother’s health displaced the disagreement that had dominated the family for a few years. Brad says that he “didn’t feel that this was the time to challenge her about her parenting of me,” but the relationship was still not as secure as it had been. It was “more superficial,” but the illness was a crucial conciliatory factor in that Brad now “got on better with everyone because of what was going on with her.”

A few months later, at Christmas time, the cancer had progressed alarmingly, and Brad's decision to spend the holiday with the family as a surprise ("That was in a sense going to be my Christmas present to my parents") appears to have abruptly ended the feud. There is no more mention of it in the narrative; up to this point it had been a dominant theme, but the certainty of his mother's impending death displaced all other concerns. Brad's role as "truth-teller" was still very important, but now the effects of his inflexible honesty were positive. His willingness to expose what is usually hidden, and to discuss things that are often left undisclosed, were the foundation for his role as carer. The tone of the narrative shifted at this point. Brad did not return to the earlier times, but provided a quite detailed description of the intense caring which now consumed the whole family. Brad emerged as the person who held the family together, faced the truth, and also helped them face it.

After Christmas Mrs Morris' condition deteriorated rapidly, and Brad moved back to Melbourne to help with the caring during the last two weeks, although he spent each weekend with her before that. During one of these trips he raised the subject of her dying, saying, "You know, we really ought to talk about the fact that you're dying." After her initial shock and surprise at his directness, Brad and his mother discussed funeral arrangements, the distributions of favourite belongings, and so on. This crucial episode restored the original bond between them, and affirmed the importance of his role as carer. It was an emotional scene, but one which led to new understanding between them; she said, "I never thought I'd be able to talk to anybody about things like this." For Brad the outcome was significant: "And that was probably the closest we'd become again. That was, from my point of view, the time that I realised, that despite everything, despite all the conflict there'd been, with the estrangement, that I was still *loved*, and certainly that I still loved her...and to realise that I was doing this thing for her which nobody else *could* do, was really important." Not only were arrangements discussed with his mother but they were also finalised with all the people who would be involved in the funeral. This is what Brad called "primary care": "So, from my point of view, *that's* primary care. That has to happen. *Somebody* has got to do it. And for my mother, it was *immensely*

important that it not be my Dad. She...didn't want him to have to do it. She knew he would just break down, it would break him up."

Brad describes his mother's death in some detail, and also what happened just after she died, while her body was still in the house. Brad's role was then still important, but no longer central. Arranging the funeral and attending to the flowers as his mother had requested was a result of caring that occurred while his mother was alive, about which his mother knew, and in which she participated to some extent. It was more important for Brad to be with her before she died, rather than to have left it until after she died: "The thing is, I don't want to take leave after she's died, I want to be there with her while she's alive."

In the end, Brad has "no regrets": "I'm proud of that. I did all I could, to make a good living when she was still alive, and good dying when she was dying, and so did we all". By supporting her in her request that treatment be ended, the situation was controlled, and his mother's dying happened in the way they wished, which was how she wanted it herself. "The outcome of it all was that she died relatively pain-free, in her own home, surrounded by her family, knowing what was going to happen to her belongings, and [what would happen] at her funeral was as she wanted them to be. So that's pretty big."

* * *

Conversation with Susan 27/5/99. Susan cared for her father in his own home for the last two months of his life.

Biographical notes

Susan is a single mother whose son was four years old at the time of the conversation. She and her child now live at home with her mother. Her father, who died of lung cancer about two years previously, only two months after diagnosis, was cared for in his own home until the last two days of his life, which were spent at a hospice facility attached to a large metropolitan hospital. After living away from home for a few years, Susan returned with her little son, just before Mr Reid had become ill and cancer was diagnosed. Although she has a number of siblings, it was Susan and her mother who were the primary carers. Susan's role was different from her mother's, but, she believes, just as important. She was so impressed by the palliative care nurses, and her caring experience, that she has decided to undertake a nursing course next year.

Introductory note

Before our meeting, I had asked Susan to reflect upon her caring experience, using writing to assist her in the process. She did not however, write any notes but was very articulate and had no trouble recalling important events during her time as a carer. The overall impression conveyed by Susan's story of caring for her father is that it had been a joyful experience, which she had found "uplifting." It provided her with an opportunity to get to know her father and to develop a loving, understanding relationship with him, and also with her mother, with whom she still lives. After living away from home for a few years, she had returned with her little son, just before Mr Reid suddenly became ill and cancer was diagnosed. A theme that continues throughout the story is that the whole episode seemed "planned". Her return home was fortuitous, as was the assembly of relatives and friends at the bedside just before he died.

Conversation summary

Ten years earlier, at the age of fifty-eight, Mr Reid had survived a previous encounter with cancer. He had been a heavy smoker for forty years and also drank heavily. Susan

said that he was in fact an alcoholic, although he did not behave as a drunkard (he was not violent or aggressive). The throat cancer was apparently cured by surgery, although at the time he was not expected to survive and had been unconscious for three weeks after the surgery. Secondary lesions (in the lungs) did not arise for ten years. Mr Reid retired after the initial bout of cancer, their “first taste of death,” and during this time he apparently “mellowed”, grandchildren arrived, and his relationship with Susan (which had previously been indifferent) improved to the extent that he welcomed his daughter home after her absence of several years. She had had very little involvement with her father’s care during this first episode of cancer, saying that at eighteen she was too young (“I didn’t know how to react. I was just so young to deal with it. So I ran away from that one a bit, and let Mum do it all – let her do all the caring and worrying”). With maturity came a greater respect and affection for her father, as well as a sense of responsibility for her father’s care during his illness.

The extra ten years was seen as a “bonus.” The cancer was regarded as a presence which was “just sort of in there waiting to grab him,” and “it was shadowing him,” so it was not unexpected when it finally reappeared, this time in an extremely aggressive form. When Mr Reid did not recover from what initially appeared to be a bout of influenza, he took it upon himself to consult his oncologist, losing patience with his GP, who apparently did not recognise the cancer symptoms. Caring was shared with Mrs Reid, who had the “night shifts”. These “shifts” are mentioned several times; even when Mr Reid was dying in the hospice mother and daughter took shifts to be with him.

Susan was very concerned about her father’s actual experience of death, and his “well-being” after he died, afraid that he would be left alone not knowing what to do. However, Mr Reid appeared to undergo a spiritual experience just prior to his death and having witnessed this, Susan is convinced her father’s death was a good one.

Because mother and daughter had shared the caring there was a special understanding between them and they counselled each other. Susan said that “there are certain things that no one else can understand, because we went through that experience together,

although her experience was really quite different from mine, even though they were simultaneous”. Susan comments on the difference between her reaction to the experience, and her mother’s now, eighteen months afterwards. She feels uplifted, having shared significant spiritual experiences with her father, while her mother can feel only sadness. She understands that the joy that she derived from the whole experience is out of reach for her mother. Susan’s current role as a volunteer at the hospice has strengthened this awareness of the individuality of grief and caring. Her initial thought was that because she herself had experienced the same emotional experience that these people were feeling, that she would be “really good at this, because I know how those people feel,” but she soon realised that this was not the case. She feels “detached” but this detachment enables her to assist them without becoming too involved with their distress.

Susan’s father’s favourite piece of music was *Nessun Dorma* sung by Pavarotti. Mr Reid had an eclectic taste in music, and enjoyed listening to a variety of music when he was sick. But although Susan did not share his interest in opera, she indulged her father’s love of this piece and whenever it was played on the radio she turned up the volume to please him: “Because you know the person so well, you do what you know is good for them. You know, Pavarotti *full blast*! That was one of the nicest times with Dad...I’d go and lie on the bed [with him] and we’d lie there and listen to *Nessun Dorma* full blast”.

Susan felt that her siblings were not helping in a substantial way. Her sister would “breeze in” from time to time, offering to do some housework but not actually doing anything effective. (Susan repaid this by playing the opera aria at high volume: “She was one of the ones I used to assault with the opera”). Two brothers were living overseas at the time but the one who lived locally “actually went on a holiday to Queensland” when his father was very ill. In retrospect, however, Susan realised that they were probably dealing with things in their own way, and she feels that she may have been possessive of her role as her father’s carer: “I got a bit selfish there towards the end because I was the main one. I thought that nobody else was making much of an effort, so I got to a point where I tried not to let anyone else in.”

Several times Susan remarks how thankful they were that the whole process was so quick, saying; “It was good because we didn’t have to go through an awful lot of misery.” Susan described the “worst experience” as when Mr Reid hallucinated after taking drugs prescribed by the GP. (The GP emerges as the villain, having misdiagnosed the lung cancer in the first place). Although this was traumatic for all, Susan felt that she could manage this episode well, while her mother was unable to cope at this time, because Mr Reid became aggressive to her mother but not to her. Susan saw her father as being afraid, rather than aggressive, and in that condition he was “just a scared little man.”

At the end, caring consumed her life to the extent that she took measures to remove other responsibilities in order to devote as much time as possible to caring for her father (e.g. by placing her little son in day care). After her father died, the rest of the family took over (“I was obsolete”). She tried to cling to the fading remnants of her role: “I’m useless. It’s all over...I had his pillow, and I was smelling him on it. ‘I can smell him, why can’t I do anything?’ I was focused on one thing, and all of a sudden it was gone”; she “felt a bit ripped off once it happened.” The rest of the family now became the focus of her mother’s concern, because they had not been there, had not been the carers. They needed to be drawn in because their loss was (paradoxically) seen to be greater because of this distance. Caring had put Susan and her mother in privileged positions. But the urge to remain involved was very strong. Susan did not want her role to finish abruptly with her father’s death; there were still important things to be attended to in her special way. Having spent the last few months in close contact with her father she felt that she alone knew him (having “found” him), and therefore “she had a lot to offer them.” This is not how her mother saw the situation. She felt that because “they weren’t here, she had to comfort them. They were the ones who had lost the most.” In fact Susan had gained by getting to know and understand her father, which at the same time left her with more to lose when he died.

Despite the lack of understanding of the effect of Susan’s role as carer, she was permitted to have an important role in the funeral ceremony. She arranged the music (which

included songs which were not necessarily her father's favourites, but which reflected his Irish heritage), helped carry out the casket to the triumphant strains of *Nessun Dorma*, but she decided to leave the reading of the eulogy to her brother because of her emotional involvement, although she contributed to its writing.

Susan's caring role was not appreciated or understood by her siblings. Months after the funeral she received a "thank you" card from her sister, "saying thank you for being with Dad at the end." But to Susan, "the end was nothing!" The significance of the two months of caring and intense involvement was not appreciated by her sister. It was in some respects a solitary role. Susan knew that her siblings would have cared if they had had to, but in different ways, and she feels that the way in which she cared was "right." Caring was regarded as a privilege; "I found the whole caring thing to be a great privilege, and I feel so proud and I feel *privileged* and I do feel happy about the whole thing. And, "I'm very proud of his last couple of months, and there was a lot of *joy* in there."

* * *

Conversation with Alice, 23/6/99. *Alice cared for her mother who had been a nursing home resident for several years before her death. During her mother's illness Alice kept a journal which is also used in this study.*

Biographical notes

Alice is a mature age student who is currently engaged in writing a thesis in history. Our husbands work together and they discovered by accident that we are both interested in the care of the aged. Alice is looking at the role (or more accurately, the lack of a role) of feminism in the area of aged care facilities, most of whom are staffed by women, and most of whose residents are also women. Alice had a traumatic experience when her own mother, a retired schoolteacher from a small Victorian town about three hours' drive from Melbourne, developed an unidentified disease during which her mobility and communication skills were gradually eroded. In the end she could no longer feed herself, and needed constant care. Alice brought her mother to Melbourne to be cared for in a nursing home run by the Uniting Church. Because of the nature of the condition, Alice needed (and wanted) to spend a great deal of time caring for her mother, but this was not encouraged by the staff at the home. This led to immense frustration, and the feeling that even though it was not possible for Alice herself to provide the sort of nursing care necessary, she had failed her mother when she was in a particularly vulnerable state.

Introductory note

Alice's experience prompted her to pursue the issue of caring and the role of relatives in nursing home care of the elderly. She is now involved in the Community Visitors Program, which is a group of voluntary members of the community who visit various institutions and report back to the Office of the Public Advocate on the conditions they find there. Alice herself is a retired high school teacher, having returned to work when her three children became independent, but resigning soon after because of the pressure of major re-organisation in the school system. She is, as expected, highly articulate, and became quite emotional when describing the conditions at the nursing home. She kept a diary for about four years while her mother's condition deteriorated, and has provided a copy with permission for its use in this research. It has been used in conjunction with the conversation.

Conversation summary

Alice's mother (Mrs Sandow) did not respond to her daughter's care, and was "dreadfully unhappy" throughout the entire four years of her illness, but at no time did Alice waver in her efforts to care for her. Despite finding caring anything but uplifting (as my other participants have) she still "would never not have done it."

Alice's difficulties began as soon as her mother moved out of her family home. Alice was "a little judgmental of her" at first. When Mrs Sandow first moved to the hostel in a neighbouring small town (H—), she appeared to "down tools." The once strong and independent woman seemed to retreat into herself: "It was almost as if [by] moving out of her home, she lost her persona. Her identity was all tied up with her home, her plants." The medical staff never identified the cause of her decline, and Alice assumed that it was partly due to arthritis, from which she had suffered for many years. Communication became a major problem when she "started to lose the capacity to say what she wanted to," for which Alice said she could "hardly blame her." Her mother's lack of appreciation of conditions in the hostel was disappointing, and Alice thought "that it would have been possible for her to have been a bit happier there." She could not understand why her mother failed to agree that it was better for her to be cared for by friendly staff, whom she evidently liked, than to struggle on in her own home. She had refused the invitation to live with Alice in Melbourne, and this gave Alice no alternative; the hostel was the only option now that her mother was incapable of living at home.

Alice's mother's medical condition was never identified. Although she suffered from several medical problems ("she had always been arthritic, she'd sort of stiffened up"), and had a hiatus hernia, these conditions were certainly not fatal. The prospect of a long decline became clear as she gradually lost her independence. It seems that the entire town had been mobilised in an effort to maintain her at home, but in the end this would have depended upon regular contributions from her other daughter, who suffered from mental instability. There was, then, no sudden crisis; the situation developed slowly, and Mrs Sandow did not at any time agree to leave her home. Alice says that "...she never wanted to move out of her own home. She neither agreed nor disagreed, but if you had asked her

she would have said ‘No.’” By the time she left the hostel, Alice was travelling to H— twice a week to be with her mother, and eventually a series of falls prompted her carers to send her to the district geriatric centre, in a large rural centre, for assessment and treatment. The contrast with the H— hostel, (“a most fabulous place,” and, “a lovely country informal place”) was devastating: “...it was the most appalling place! The physical layout of the hospital was so Spartan; a big old hospital with those floors, and iron beds, and hallways, and cold bathrooms – a *terrible* place!” An attempt was made to alleviate her misery by a program of physiotherapy (presumably it was thought to be due to her immobility), but Alice was excluded from this process and was not informed of any diagnosis resulting from these investigations.

Alice had no idea whether her mother’s loss of speech was due to dementia or some other process. A psychogeriatric examination revealed that Mrs Sandow was depressed, and the outcome of the trip was that she was immediately excluded from the hostel system, and was not permitted to return to H—, even for one night, and Alice began a desperate search for nursing home accommodation near her home in Melbourne. The lack of communication and consultation continued throughout the whole period. Alice’s mother herself began to question her own sanity (At one time she asked her daughter, “Tell me, am I getting cuckoo?”). This unwillingness, or inability to enlighten Alice about her mother’s condition was a constant source of frustration. The possibility of dementia was particularly significant. Alice remarks, “I think I would have been better if I’d known how much Mum had dementia.” Brain scans revealed nothing, but as the nursing home staff were of the opinion that dementia was probably present, Alice was left in a state of uncertainty, unable to attribute her mother’s idiosyncratic and aberrant behaviour to any definite medical cause. All she could do within this context (i.e., with the assumption that her mother was “normal”) was to continue to treat her as if she were still her old self, even though it was patently clear that this was not so.

In retrospect, Alice saw her efforts to please her mother as an instinctive attempt to fix things, to reverse the situation; a futile battle to restore things. She persisted in pursuing avenues that were not appreciated: “I’d take her out in the wheelchair around the block.

She didn't really enjoy that." The shell of stoic suffering was impenetrable, however, and Alice realises now that all she wanted to do was break into this shell and restore her mother's self: "I don't know that it was I wanted to please her; I wanted to fix her up." Later, she said, "I'm one of those people that tends to think that if I do something I'll be able to fix up somebody else's problems, so I worked very hard in the end to accept the situation, for what it was...I could see that what I was doing all the time was trying to fix her up and sort of make her old age, and this terrible time of her life, better."

Throughout this sad and depressing story there is a concurrent narrative of the nursing home experience. In some ways this is separate, Alice's mother having "closed down" when she left her home in R—, and decisions about institutionalisation being made by her daughter. She refused to live in Melbourne with her daughter, and endured her stay at the local hostel with stoic indifference. When the geriatric assessment team at the rural health facility declared her unfit to return to the hostel, the search for a nursing home in Melbourne began. The inherent stress of this process would have been exacerbated by the knowledge that her mother would never accept any care outside the family. A further problem for Alice was that she was the youngest of three siblings and found it difficult to assume an authoritative role, particularly after enjoying a happy relationship with her mother for so long.

Alice describes vividly how the desperate hunt for a nursing home bed reduced decent people to predators: "...we saw some most dreadful places. I met all these middle-aged women like myself all in a similar state, all sort of weeping and getting upset. I got that way that when one of them asked me if I'd seen a nice nursing home, I wouldn't tell them, because if I did they would put their name down too and they might get it first! I was just *horrified* with myself!"

While the nursing home in which a bed was finally found was of a high standard, "clean and bright and cheerful," and well run by qualified staff, there were many issues which troubled Alice. Indeed, so concerned was she that she and her husband became active members of the board and she tried to instill a degree of professionalism into the staff.

The endemic problem of staff treating residents as “non-persons,” or at best as children, prompted Alice to spend a great deal of time at the home with her mother. Despite her constant presence, her authority over, and involvement in her mother’s care was frequently overlooked, and certainly her mother’s wishes were ignored. A continual source of frustration was the lack of communication with medical staff. Alice was rarely consulted about her mother’s medication; indeed she had difficulty meeting with the doctor at the Melbourne nursing home. She accidentally discovered at one time that he had prescribed Prozac to counteract her mother’s depression, something her mother would never have agreed to had she been consulted. Because of her mother’s desperate unhappiness, Alice decided to see if Prozac would relieve the depression. It was ineffective, however, and Alice demanded that all medication be discontinued.

For Alice, then, caring was an horrific experience of unrelieved stress and despair. It has taken a long time for her to accept the fact that she had little alternative, and that the situation was beyond her control. At one stage she thought that it might have been better if she could have cared for her mother at home, rather than in the nursing home. She says, “I kept thinking that if I had her here [at home], I could control the situation, and that I would be able to do it better.”

Mrs Sandow resented Alice’s attention to other people in the hostel; “The way she dealt with it was ‘stoical suffering’...If I was talking to the others she might say, ‘Take me back to my room!’” At this time, when she first left her home in R—, she “stopped smiling and laughing,” and rarely showed affection in spite of the fact that they had previously enjoyed a very close relationship. Only once did she thank Alice for her care, and asked her to care for the collection of family documents. She told her then that she loved her, and recalling this scene was an emotional moment for Alice.

It was difficult to escape this burdensome situation. Alice had returned to study, and at the time was working towards a Graduate Diploma, later a Masters degree. She found this to be a useful escape from her oppressive situation, calling it “brain stuff” and “mind stuff.”

There was a change in her role at the very end. It was a relief when she realised that she could no longer try to help her mother: “In some ways, when Mum got really bad, and could only just lie on the bed and could barely eat, it was better for me because the worst thing was when I thought that more could have been done for her.” At this stage her futile attempts to care for her mother, to make her life more bearable, had come to an end. She said that “...in the last two or three months, because my task had been done, and [I realised] that she was going to die soon, and that I could just sit with her, try to help with her feeding, give her drinks, there wasn’t much more I could do.” The exhausting effort of trying to penetrate the barrier behind which her mother had retreated, to restore her original personality, could be relinquished when she understood that there was no hope of reaching her.

* * *

Alice’s journal

Explanatory note

I first transcribed the interview with Alice, and I read the journal soon afterwards, as she herself had suggested. The journal, with its dated entries, gives a sense of time which is not apparent in the conversations. It documents a period of about four years, beginning at the time when her mother was still living in her own home (at R-) but required constant attention. The entries are irregular, sometimes with gaps of several months between them. Many things that were mentioned in the journal had also been referred to in the interview, but of course not in such detail, and, most significantly, sometimes with different emphasis. Alice had re-read the journal herself just before our conversation.

Introductory note

The conversation with Alice did not prepare me for the oppressive nature of the journal, and the relentless, unrelieved despair of the story it told. The immediacy of events such as these, documented soon after they happened, is overwhelming. At first the journal is concerned with the search for an explanation of the changes in her mother’s behaviour, as well as a way of caring to which she will respond. Later there is despair at the realisation

that neither of these quests will succeed. In the latter part of the journal, Alice continually reiterates the conviction that her mother is failing rapidly and the nightmare will be over soon. It is as though she is trying to convince herself that it is really happening, to will her mother to die so that the suffering will end, but in fact the process continues for many more months. This story of tragedy and frustration is immensely moving, and is made more so by Alice's sister Greta's violent suicide towards the end of the narrative. The real tragedy seems to lie with the fact that her mother found it impossible to accept Alice's care, and in doing so denied her daughter the "privilege" of caring. The account includes many other distressing and frustrating circumstances, but the fact that her mother had become closed and inaccessible caused the greatest grief. Alice strove throughout the whole episode to provide the care she thought her mother deserved, but could not understand, let alone alleviate, her mother's distress. She had become untouchable, consumed by unhappiness.

Journal summary

General overview.

Because there are a number of well-defined themes running through the journal, it has been summarised according to these themes, rather than in a chronological fashion. The journal begins when Alice's mother is living in the hostel at the town of H-, and the stress of endless trips from Melbourne to visit her is invading her life ("the need to go again on that trip to see her is creeping over me" (p. 1). As her mother's condition deteriorates, Alice is faced with the awful dilemma of what to do next. She is torn between the idea that her mother should be living with her in Melbourne, but at the same time wondering whether it is too late for this because her mother may have reached a stage where full-time nursing care is necessary. There is also a fear that there would be little "back up" to support her at home, and as her husband said, she could become an "all day prisoner to Mum."

The nursing home experience motivated Alice to actively try to improve things, especially for the families of the residents whose concerns were often overlooked. She

was shocked at the “lack of professionalism” displayed by many of the staff, and said she was “itching” to start professional development programs for them.

Alice received little support from her (much older) brother and sister. Her brother showed little understanding of the dreadful experiences that both Alice and their mother were experiencing. Even at the end, he left for an overseas trip the day before their mother’s death, leaving Alice to attend to the funeral and other affairs.

A few weeks after the funeral, her entry states: “I have now dealt with most of the things that had to happen after Mum’s death. I put aside one day to deal with her clothes. They had such a strong smell of her and I could hardly bear to do it. The worst thing was that [the nursing home in Melbourne] continued to bungle right until the end. Mum’s teeth fell out of the bag of clothes as I set about dealing with them. [The nursing home] had not put them in her mouth before she was sent to the undertakers. I had to put her teeth out in the garbage with the nighties...I am still having trouble coming to terms with the nature of Mum’s last week on this earth. The image of Mum lying dying is very strong” (p. 29).

Principal topics

Alice’s sister. The story of Alice’s mentally disturbed sister is a tragic thread running through the story. During a visit to her mother, Alice’s sister had evidently threatened to kill herself. Alice’s remark in the entry for that day is that this behaviour “is symptomatic of the state that Greta is in.” Alice remarks that “I know that I am a help to Mum on these visits (to H—). I also know that she is not as close to me as she is to Greta” (p. 4). Later she writes, after a visit to H—: “[My mother] also told me that Greta had said something nice – that she was the only mother she had. Unfortunately that was what I said last time I was there. I guess that Mum wished Greta had said it. It took me a while to get over that.” It appears that her mother had bequeathed an extra \$5000 to Greta, for some reason, and Alice resents this when she is not compensated for her trips to and from H— (p. 8).

Alice always regrets the breakdown in the relationship with her sister, wishing she could share the burden. For instance, after a particularly stressful visit to H—, during which her

mother is rude and uncooperative, she writes: “This is where if Greta and I were working together we could be of so much help to each other” (p. 8).

When her mother reached the age of ninety, two years before her death, Alice decided to go ahead and arrange a birthday party, even though she doubted if her mother would either enjoy or appreciate it. It was successful, though, because many family members were there, her sister did not come, however, the excuse being that “she wanted to remember Mum as she used to be.” A few weeks later their brother said that Greta had “got religion,” to which Alice replied that “it was hardly very Christian not to see your mother for four to five months.”

In April 1997 Greta committed suicide. Thus the seriousness of Greta’s mental condition was not understood until it was too late. Abruptly Alice’s tone alters: “I now realise how sick she was and believe the crisis with Mum was a trigger for even more mental distress from which she never recovered.” Despite this, and the realisation that she was “never treated properly for her mental illness, and as with Mum, IT WAS NOT HER FAULT,” Alice remains bitter about lost opportunities; “How good it would have been to have become closer in the care of our mother. I feel as if I can hardly forgive her for this – for leaving me with the total responsibility for Mum and for not being the sister for which I yearned” (p. 20).

A few months before her mother’s death, when it is clear that there is not much time left, and little communication exists between them, Alice writes: “Tonight I am missing Greta and Mum so much. I feel deserted. I cannot help feeling that Greta and I should be doing this together and I don’t know how she could have left me and Mum the way she did” (p. 26).

Confusion about Mrs Sandow’s condition. “Mum sits helplessly while others move her body. This drives everyone mad. I feel it is indicative of her mental attitude. I wonder how much of her negative attitude in relation to living in a hostel has contributed to her

physical condition” (p. 4). While being dressed her mother does not help in any way: “She seems at times to expect just everything to be done for her – and not to mind.”

Alice is never sure just what has caused her mother to lose the ability to speak. Perhaps it began when she had to leave her home: “One of the things that my mother has done as she moved out of her own home was to stop talking” (p. 16). Originally, in her younger days, this had been a technique she successfully used to avoid conflict, but eventually Alice wondered if it was a result of dementia. On March 9, 1995, she writes: “[I] showered and dressed Mum today – but she had little energy this morning and was barely able to speak to me.” The inability to communicate is seen as an obstacle to Alice’s caring: “If Mum could say how bad she feels and how powerless she feels and say that in fact she feels betrayed by her family maybe this stuff could be dealt with. OR on the other hand maybe we would all feel worse. Who knows?” (p. 7). Alice has had to guess what is troubling her mother, and imagines the worst thing possible, betrayal.

Five months before she died, after a silence of six months, Alice’s mother spoke clearly, although the family couldn’t comprehend what she wanted. Again Alice is desperately seeking a reason for her mother’s silence. “It seems that no-one really has a clue what happens to the brain during the ageing process. Why can’t Mum speak?” (p. 24). Her brother still doesn’t understand, and “seems to come up with unrealistic notions,” suggesting they hire a speech therapist for their mother (now ninety-two years old and with an undiagnosed condition).

The body. Her mother has no sense of modesty, but Alice finds it “very hard and distasteful to wipe Mum’s bottom.” She writes that her mother asks her to do it, and “she thinks nothing of this request and what it means (p. 4). A description of her mother eating is distressing: “Meals with her are now terrible. She grunts and puffs and her face goes red as she eats. She sucks and slurps her food. It is awful” (p. 19).

The institutions. As soon as Alice’s mother began living at the hostel, she seemed to abandon any effort to take part in the hostel activities, and Alice implies that the

opportunity to establish a good relationship with the staff and other residents has now been lost. Alice is concerned, saying that “Mum’s attitude is not good,” and, “Mum’s effort to join in the life of the hostel was spasmodic at first and now she can’t.”

The staff at the nursing home, although “not bad” people, had little time to help the residents with their meals. The outcome was that she said she “felt more tied to Mum than ever” (p. 19). Mrs Sandow’s efforts to speak were often ignored by the staff. Instead of encouraging her to communicate, this lack of interest, particularly at the nursing home, was frustrating for Mrs Sandow, and the result was that she gave up trying not only to communicate with the staff, but also with her daughter (p. 17).

Alice feels that her presence at the nursing home is essential, because she did not believe that her mother would be properly fed without her help. “I know that if I wasn’t here she would be on vitamized food. No staff member would have the patience to feed her as I do. I do not feel inclined to leave her” (p. 23). The stress of caring for her mother in the nursing home environment is nevertheless difficult to deal with: “All I know is that it is dreadfully hard to look after Mum without upsetting people along the line”(p. 24).

There was little opportunity to discuss her mother’s condition with the doctor; despite the fact that Alice spent a great deal of time at the nursing home, she rarely met the doctor, and was annoyed when she discovered he had declared she was anaemic but did not carry out blood tests to confirm this: “It was decided that it was not worth taking blood tests on her.” (p. 25).

Nursing home food was disappointing, and despite its abundance in the shops, fresh fruit was rarely provided to the residents. Earlier, when she was searching for a suitable nursing home, she was appalled when one of the managers implied that it was “something special that they provided fresh fruit and vegetables” (p. 11).

The nursing home staff were not helpful at the end; it seemed that the entire burden was carried by Alice, and her wishes were ignored. Two months before her mother died, Alice

arrived at the nursing home to find an Agency nurse about to shower and dress her mother. She “had to ask that she stay in bed” (p. 26).

After her mother’s death she writes: “Now I am not only grieving for my dear mother, but also wracked with dismay, and to some extent guilt, about how this last week of her life was managed. No-one seemed to me to take charge – or even to show much interest in Mum at this time” (p. 28).

Suffering and death. At one stage (September 1997) Alice found herself searching the obituary notices for her mother’s death. She now wanted her mother to die because she suffered so greatly, and was “filled with despair” at the thought that Mrs Sandow might remain living for a long time. (In fact it was another eight months before she did die). She writes: “I have now become obsessed with when Mum is going to die and how long it will take” (p. 22); and, “I lie in bed willing her to die” (p. 23). The terrible responsibility rests with her alone, as her brother has no idea of the reality. He simply does not understand Alice’s predicament, expecting her to visit him in M— (a Victorian country town about three hundred kilometres from Melbourne), not understanding that she cannot leave her mother.

The uncertainty is difficult to cope with: “If one knew the length of time that it would take one could act accordingly.” As death draws closer the entries show the despair that leads Alice to hope that her mother will soon die. For example, on October 21, Alice remarks that it is Spring, the time when nursing home people die (“One woman died yesterday and another is expected today”). Alice can expect no such release, though, because her mother’s physical condition is quite good, although “[s]he is just sick at heart” (p. 23). After Christmas she says, “I sincerely hope that this is her last [Christmas].”

When her mother’s much younger brother Jerry died at this time, it was left to Alice to tell her mother, just as it had fallen upon her to break the news of Greta’s death. Alice writes: “She had shown little emotion at the death of Greta and so I was surprised that she

was very upset about the death of Jerry. It was very sad and once again I was stirred with pity and sadness for her situation. I felt as if this was just another thing to add to her well of sorrow” (p. 22).

The entry dated August 28, 1997 seems significant; Alice thinks her mother has reached a state of sadness and peace. Her mother had made a “supreme effort” to speak to her, saying “I’m finished.” The writing here itself seems peaceful, as though Alice believed her mother would soon die, and the nightmare would be over. This does not happen, however, for another eight months. In September, the customary grim silence had been resumed, and Alice writes: “She has said her bit to me and now I think is waiting for it all to be over. I deeply wish for her sake that it was. The thought that she might have to wait still more years like this fills me with despair” (p. 22)

Her mother’s condition continued to deteriorate, and Alice is still wishing the horror would end. On January 28, 1998 she writes, “Mum is very pale and somehow I feel that surely she will not live much longer. However maybe this is me just wishing – as I can’t bear her (who was always so full of courage and hope) being so hopeless” (p. 25).

On her ninety-second birthday (January 1998) the family visited Mrs Sandow. They took her flowers and champagne, and sang “Happy Birthday” to her, but because she showed little response, her eyes being closed the whole time, Alice writes that “I just hope that it was nice for her to have us, all of us, in her room on her birthday.” There was no way they could tell; they were continually groping in the dark, seeking some sign of recognition or appreciation.

In February 1998 Alice writes, “Mum seems to me to be fading. For the last few days she has been asleep most of the time and is very hard to feed....Despite my best efforts I continue to be overwhelmed by the sadness of such a long drawn out end to a courageous life” (p. 26).

In April 1998 Alice was told by a new nurse that her mother would probably die within three days, and so Alice prepared the family for “Mum’s imminent death.” She felt “devastated” by the prospect, despite having expected, and wished for it for years. However, it was another three weeks before she finally died. Alice comments, “It is all beyond my understanding.”

The last week was very difficult, and Alice was given little direction by the doctor or staff. Her mother could no longer swallow, and after five days without food or fluids, Alice offered her some ice-cream, which “she took very eagerly.” She was still conscious at times, and Alice writes, “At this time she was often wide awake – looking at me with frightened eyes” (p. 8).

The mother-daughter relationship. After enjoying a good relationship with her mother all her life, the descent into rudeness and impatience is difficult to tolerate. “I was less patient with Mum on this trip. Her lack of manners and the way she spoke to me really got me down....Her authority over me is still powerful. I would not put up with this from anyone else” (p. 8). A friend told her, “That is not your real mother, Alice.” And later in the diary she reminds herself, “IT IS NOT HER FAULT” (p. 20, emphasis in manuscript). It was difficult, however, to accept that this silence was due to the effects of illness (especially as she had no definite diagnosis to support this notion). At times Alice demanded that her mother “open her eyes and speak to me,” although she knows that the speech difficulties are “not all a matter of choice” (p. 17).

An entry written nine months before her mother’s death tells of Alice’s despair at the loss of the mother she once knew and loved: “At this stage I hoped for Mum’s death. I will miss her so much but she has no life left now. There is no control and nothing of interest to her...I have grieved for her so much and wept so many tears over the past two years...Although Mum is still alive she is not the mother I once knew and I have lost my mother and my sister” (p. 1).

The few times that Alice's mother communicated with her were moments of great joy. "On Xmas Day [1997] she smiled and tried to speak to me. She also smiled at me on my birthday. This is the first time she has done this for many months and the transformation of her face was miraculous. On my birthday I said to her that her smile was the best present I could ever have and she smiled at me again" (p. 24).

* * *

Additional primary material

Conversation with Kerry 19/12/96. (*This was one of four semi-structured interviews conducted very early in the project*).

Biographical note

Kerry's mother, who had been a widow for three years before her death, became ill with lung cancer and Kerry had been her primary carer for twelve months before she entered the hospice where she died. Kerry's mother apparently missed her husband a great deal and Kerry believes that she "more or less gave up" and became ill as a result. The chest X-rays were negative until after her husband's death. Kerry does not think that her mother fully understood the "implications" of lung cancer, and because she felt a strong sense of responsibility towards her mother, took twelve months off work to care for her while she was still at home. Kerry's sister has a young family and therefore has other responsibilities, so the caring role fell to Kerry who was single and without children at the time. The interview took place six months after the mother's death. I had contacted her through the grief counselling group at a large metropolitan hospice, which Kerry was still attending at the time. In the hall near the front door was a large artificial Christmas tree with a few presents underneath it. There were two stars on it, which she said were for each of her dead parents.

Conversation summary

Kerry's primary concern was the happiness, independence and integrity of her mother, and she was prepared to see some aspects of professional care compromised in order to maintain these factors. She found the experience fulfilling in that she considered it to be a worthwhile enterprise which helped someone whom she loved. Caring for someone in an informal capacity was seen as a noble action involving a certain amount of sacrifice, an aspect which Kerry valued highly even before she herself became a carer. She said:

I always felt that anyone who could do that was wonderful, because you are making sacrifices. For instance, if you were working, you might have to give that up, and you might be doing something that you really like doing - a lot of people wouldn't even do that [give up working]. So I always thought it was wonderful. I

think until you actually do something, you've been through it, you tend to have a superficial appreciation of what's going on. It's not until you actually partake of the experience that you become aware of the various facets that the experience has to offer.

... [W]e have become a disposable society, dehumanised. It is nice that we can care for our relatives, as a sign of love and respect, and also because most people prefer to stay in their home environment rather than go to a strange environment, particularly when they know that the writing's on the wall. Particularly if there's somebody you love, and who brought you up, and looked after you when you were little; I think it's nice if you can do that. But you need support.

I asked Kerry if there were any incidents that came to mind when she reflected on her caring experience, and she described her mother's death. Kerry seemed to find comfort in what the nurses told her

Well, there's a thing that I think of a lot, but it's not directly related to [caring]. I think of when she died, and we were there, during the night, and she'd been fighting it for quite a while - it was about ten days she was really fighting it. And it had been explained to us that quite often this is the case with people who are dying. Mum said she was ready to face death. The nursing staff said that what happens is that people sometimes feel that they haven't quite got their business finished, and they don't really want to leave you...They were giving her medication, but the palliative care is quite good. They medicate you, but it's not as though they'll try to zonk you out, knock you out totally.

Yes, well, what happened was she was there on her side, and she was having difficulty breathing, and she was so, so thin, she was so thin, and those last few gasps-. But the nursing sister that was on, she was so lovely. She said, "You know, she really has died. They're just reflex actions". It's not so bad now. I'd go to bed and I'd see that - I'd just sort of acknowledge it - I just let it - I just pass over, go on to something else, because I don't particularly like that. Probably because it was so graphic.

Afterwards they ask you to go away, and they straightened up Mum's hair and they put a couple of flowers [on the pillow near her face].

* * *

Secondary sources

Why do we write about the dead? To tell the story that only we can tell and therefore to keep the work of memory alive (Miller, 1996, p. 119).

* * *

In addition to the narratives related by the participants and my personal writing, reference is made in this study to several literary works, the most important being Simone de Beauvoir's *A Very Easy Death*, and Philip Roth's *Patrimony: A True Story*. In these books, both of which are biographical as well as autobiographical, the authors document the progress of their parents' final illnesses, while exploring the relationships they had with their parents throughout their lifetimes. This process is in itself an act of caring, as Casey (2000) explains in the quotation at the beginning of this Chapter.

Simone de Beauvoir: *A Very Easy Death*

In December 1963, Simone de Beauvoir explained in a letter to her lover Nelson Algren why her correspondence with him had lapsed during the past months:

Novembre was a long sad month for, indeed, my mother was dying, and at last, she died. But, as you say, how these old women cling to life! My mother fell down and broke a bone in her hip; she was taken to a clinique, and there, was discovered having a cancer; she would die within a few months, or days. We did not tell her, indeed. They operated on her, and then she felt much better; she was sure she would soon recover. She had two very happy weeks, everybody taking care of her, my sister and myself spending our days and night in her room. Not from love, in my case, but from a deep and bitter compassion – she wanted so much to live! She began to feel very tired, pains began, too, and we *ordered* the doctors to give her a lot of morphine, and in fact to kill her slowly. They were obedient: no hope, anyway...Interesting thing was that she never wanted to see any priest, none of her old pious friends: she wanted young faces and smiles around her. During this month she was nearest my heart she had ever been since my early childhood. And I had an irrational guilty feeling of cheating her, promising she would see spring and summer and long years, and knowing she would not (de Beauvoir, 1999, p. 571).

De Beauvoir succeeded in reducing those five weeks during which she witnessed the rapid deterioration of her mother's health as death approached, to this skeletal account that Algren received in the letter from his distant correspondent. *A Very Easy Death* gives a very different account. Here de Beauvoir examines her changing relationship with her mother, and explores her mother's personality in relation to her past life, while at the

same time providing the reader with deeply disturbing images of pain and suffering.

Mme de Beauvoir was frail and in poor health when she fell and broke a femur, but de Beauvoir was not overly concerned at the time, believing that although with rest she would probably recover from the injury, she was reaching the end her life. She remarks: "I was not very much affected. In spite of her frailty my mother was tough. And after all, she was of an age to die." This somewhat heartless observation becomes revised as the story unfolds, and at the end de Beauvoir writes:

If I had met a woman of fifty overcome with sadness because she had just lost her mother [before this experience], I thought her neurotic: we are all mortal; at eighty you are quite old enough to be one of the dead....

But it is not true. You do not die from being born, nor from having lived, nor from old age. You die from something. The knowledge that my mother's life had come to an end did not lessen the horrible surprise: she had sarcoma (de Beauvoir, 1966, p. 92).

Initially, before the cancer was discovered, Mme de Beauvoir had been taken to a Paris hospital in readiness for an operation on the femur, but this plan was soon abandoned and instead she was moved to a nursing home where it was thought that she would recover in about three months with adequate rest and care. At the nursing home she did indeed receive excellent care; a "vibrating mattress" supposedly averted the possibility of bedsores developing, she had a private room overlooking a garden, a physiotherapist visited her daily, and she reported that the meals were excellent. However, this brief spell of relief was shattered when within a few days she developed peritonitis. Despite the involuntary (and hastily smothered) plea from one of the nurses ("Don't let her be operated on!"), and against the wishes of de Beauvoir's sister Hélène ("Poupette"), an exploratory operation was performed and the bowel cancer was discovered. Subsequently, Mme de Beauvoir's condition deteriorated rapidly and she required constant attention from the nurses and her daughters. De Beauvoir describes a typical day:

I had to help Maman to spit; I had to give her something to drink, arrange her pillows or her plait, move her leg, water her flowers, open the window, close it, read her the paper, answer her questions, wind up the watch that lay on her chest, hanging from a black ribbon. She took a pleasure in her dependence and she called for our attention all the time. But when I reached home, all the sadness and horror of these last days dropped upon me with all its weight (de Beauvoir, 1966, p. 50).

The final days were terrible: the sisters watched in horror as bedsores appeared despite the vibrating mattress, and her organs failed as they were invaded by metastases.

Throughout *A Very Easy Death* de Beauvoir intersperses the account of her mother's illness with reminiscences about Mme de Beauvoir's past. The differences between them, and de Beauvoir's loss of religious faith which caused her mother such anguish, and which de Beauvoir describes in the first of her autobiographical works, *Memoirs of a Dutiful Daughter* (1963) are resolved during her mother's illness as de Beauvoir comes to understand how her mother's character was shaped by her history.

Philip Roth: *Patrimony: A True Story*

In *Patrimony* Roth describes the emergence and progression of his father's fatal illness, and at the same time examines the sometimes tormented relationship he shared with his father, and the powerful influence that Herman wielded over his son. Roth writes in his autobiography which was published in 1988, a year before his father's death, that it is "[o]nly after nearly forty years of living far from home, I'm at last equipped to be the most loving of sons..." (Roth, 1988). Previously Roth's estrangement from his father appears to have stemmed both from awe of his father's imposing physical stature and from the clash between Herman's essential "Jewishness" and Philip's more Americanised version of his cultural heritage. Old age and frailty had reduced the imbalance in their relationship, and Roth writes that

...now, when he no longer commands my attention by his bulging biceps and his moral strictures, now, when he is no longer the biggest man I have to contend with—and when I am not all that far from being an old man myself—I am able to laugh at his jokes and hold his hand and concern myself with his well-being (Roth, 1988, pp. 16-17).

Roth's account, like de Beauvoir's, begins with a story of misdiagnosis. At the age of eighty-six, Herman Roth suddenly developed facial paralysis which was at first deemed to be caused by Bell's palsy. The true nature of his illness was discovered after an MRI examination revealed a massive brain tumour. Roth also tried to protect his father from the truth, keeping some hope alive in Herman while all the time knowing that removing the tumour presented immense dangers, and that its removal would not in any case

restore the damage that had already been done. Over the next year, the tumour progressively spread and damaged other nerves; he became blind in one eye and his hearing failed, and eventually he could not swallow or breathe normally. Herman became dependent upon his son for the most intimate personal care, and this once proud and difficult man overcame his reserve and accepted his son's help. But despite this apparent capitulation (at one time Roth overheard Herman say to a friend: "Philip is like a mother to me") the relationship was fundamentally the same as it had always been:

You can say that it doesn't mean much for a son to be tenderly protective of a father once the father is powerless and nearly destroyed. I can only reply that I felt as protective of his vulnerability...when I was still at home and he was powerfully healthy and driving me crazy with advice that was useless and strictures that were pointless and reasoning that caused me, all alone in my room, to smack my forehead and howl in despair. This was exactly the discrepancy that had made repudiating his authority such an oppressive conflict, as laden with grief as it was with scorn. He wasn't just any father, he was *the* father, with everything there is to hate in a father and everything there is to love (Roth, 1991, p. 180).

Finally, as his father was dying, and the doctor was about to begin "extraordinary measures" to keep his father alive, Roth made the difficult decision to discontinue medical treatment, saying to the unconscious Herman, "Dad, I'm going to have to let you go." Herman Roth died on October 25, 1989, with his son holding his hand. He was buried in one of the prayer shawls that he had kept neatly folded in his bureau, despite having been a non-practising Jew for most of his life.

Conclusion

The biographies and personal narratives which form the backbone of this study are, as de Beauvoir's biographers Francis and Gontier claim of *A Very Easy Death*, all to some extent "works of art."¹ They have all been written or related by people for purposes which are unlikely to have anything to do with recording faithfully and in detail the precise events surrounding the death of their parents. These accounts arose from the desire to examine a relationship and to understand the significance of caring for someone at the most vulnerable point of their life. It is highly possible that are all embellished and

¹ The issue of "truth" in autobiography is discussed in Chapter Three.

enriched because they are coloured by subsequent events and introspective processes. The revisited past does not diminish in importance; on the contrary, its constant reconstruction ensures that it has a place in the present and future.

In the next chapter, the first of the phenomenological section of the thesis, conceptualisations of caring that emerge from the conversations with carers and other sources are examined in detail, from both theoretical and practical perspectives. The broad picture of caring established in this chapter serves as a foundation for the following two chapters, which move to more obscure regions of the experience, existential significance of the body and of suffering, fear and hope, all of which are constituents of caring experience.

Chapter Five. The world of caring

I think there are two type's of (among people) Philosophies. People who care, and those that don't, People who do and people who Procrastinate and never do or help...You wanted a house. I went at once and got you the money to buy it. Why? Because I cared. Phil needed an operation for Hernia, I took him to the Dr. and he was operated on. Same with mother after she suffered for 27 years. Why because I cared and am a doer...I have many battles with my conscience, but I fight my wronge thoughts. I care, for people, in my way (Extract from a letter written by Herman Roth to his son Sandy, quoted in Roth, 1991, pp. 80-81; original text unchanged).

* * *

This chapter begins the phenomenological analysis of the material presented in the preceding chapter. Chapter One introduces the phenomenological understanding of caring and explains the epistemological direction of the thesis; the existential framework within which the researcher experienced caring and which emerges from the material selected for the purpose of expanding this understanding. An exhaustive review of the literature of caring, which constitutes Chapter Two of this thesis, reveals a lack of attention to informal caring, and it was therefore deemed necessary to develop a specific method to address the issues contained within the research question set out in Chapter One, pages 2-3; that is, “*What is the nature of the phenomenon of caring experienced by adults caring for their dying parents?*” The development of this method is explained in Chapter Three. It involves a process in which a number of existential themes are identified through thorough and continual review of the selected research material, these themes then being examined in conjunction with the theoretical material which is presented throughout the thesis. The research material, which includes both primary (interview transcripts) and secondary (literary accounts of caring) sources, is presented uncritically in Chapter Four.

The aim of this chapter is to examine in detail the various ways in which caring is apprehended both theoretically and in practice. As a point of reference for the examples that follow, this chapter begins with an account of Milton Mayeroff's understanding of caring, which incorporates the major existential aspects of caring in general, many of

which can be found in the carers' stories and anecdotes used in the study. Included here is a brief survey of some of Gabriel Marcel's related concepts which are supported in Mayeroff's work. Similarities between Erich Fromm's concept of love and Mayeroff's concept of caring are also considered. Following this theoretical section there is a brief account of caring from the recipient's perspective, which highlights the intersubjective, empathic character of caring that Mayeroff emphasizes throughout his work. The manner in which these factors are enacted is then revealed as the carers themselves describe the nature of their caring experiences.

The extract from Herman Roth's letter to his elder son quoted above identifies a salient point about caring; that is, it does not necessarily conform to any objective definition. Herman's idea of good caring was to assess the needs of the person and to immediately spring into action to address these needs, fulfilling his role as a "doer." Herman Roth envisages someone who cares as being a decisive person, one who does not procrastinate. There is nothing soft and gentle about this approach. It would be difficult to discover an existential component in Herman's conception of caring, but this does not detract in any way from the fact that his actions were motivated entirely by his concern for others when they were in need, and that he fulfilled those needs in the way he thought most appropriate, yet within his capabilities.

Although many carers resemble Herman Roth in lacking a reflective attitude, this lack in no way diminishes their skill and dedication as carers. The contributors to this research however, were chosen to fulfill the methodological requirement that they were reflective, which means that they look back upon the experience in a particular way (see Chapter Three, pages 93-95). In order to initiate conversations with the participants, they were asked if there were any particular incidents which seemed to represent caring as they had experienced it. The variety of the responses evoked by this suggestion supports the notion that caring is a highly subjective concept, covering an enormous range of activities, and making any categorization of these activities a difficult, if not impossible, task. Like Herman Roth, the carers acted, as far as they were able, in accordance with their individual understanding of the situation. Often so-called informal carers, having special

and privileged knowledge of the ill person have a heightened degree of empathy, a unique advantage from which to approach their task. Sometimes the techniques they use can be extremely simple, for example reminiscing about a shared past; others can be abstract, like listening to music; while still others can be physically difficult or mentally stressful.

Milton Mayeroff: *On Caring*

Caring, as helping another grow and actualize himself, is a process, a way of relating to someone that involves development, in the same way that friendship can only emerge in time through mutual trust and a deepening and qualitative transformation of the relationship (Mayeroff, 1971, p. 1).

* * *

One of the most frequently cited and comprehensive descriptions of caring is philosopher Milton Mayeroff's work *On Caring*. The strong moral overtones, and the complete absence of reference to related material that characterise this work, suggest that it could be intended as a book of instruction rather than a theoretical treatise; yet the exhaustive examination of the components of caring and their bearing on human experience and relationships contained in the work constitute a standard of caring behaviour with regard to both its practical and existential aspects. It is above all a philosophical work, one which is commonly regarded as a foundational text, a point of reference for the theoretical treatment of caring.

Mayeroff's major premise is that caring is a process that, as a function of a particular relationship, imparts order to life, is central to its integrity, and is both the source and expression of meaning in a person's life: in short, caring is an essential element of the human condition. In caring (and here Mayeroff includes as the possible objects of caring such inanimate things as ideas, creative works and the like, along with human beings), a person is "in place" or "at home" in the world, rather than aimlessly drifting in search of stability and meaning in life. Mayeroff argues that the dynamics of a caring relationship are governed by the understanding of caring as a symmetrical, reciprocal activity which must always be of mutual benefit to both parties. In particular, the caring relationship is characterised by mutual trust and respect for integrity, factors which implicitly preclude

any imbalance that would cause the relationship to degenerate into one of power and control. The entire caring process is informed and perpetuated by these requirements:

Any direction that I may give the other is governed by my respect for its integrity and is intended to further its growth, and I show that respect by the interest I take in determining whether my actions do in fact further growth and by being guided by what I find (Mayeroff, 1971, p. 5).

Mayeroff does not confine his idea of caring in this way to any particular relational category. He claims that such a symbiotic state can exist in a variety of situations: for example, in the relationship between parent and child, or informal carer and ill person; it is found in encounters between health professionals (e.g. psychotherapists) and their patients; and also, as previously mentioned, between humans and their creative projects such as artistic endeavours, philosophical ideas and plans for the future. The interpretation of the notion of “growth” posited here is thus entirely subjective; there is no formula that defines either the context of caring or the particular benefits that it conveys. “Growth” itself has far-reaching implications for the individual, and for his or her associates. Mayeroff writes:

A man grows by becoming more honest with himself and more aware of the social and natural order of which he is a part; in coming to see himself with a minimum of illusion, he also comes to appreciate better the objective structure of means and ends (p. 8).

Mayeroff offers an exceptionally broad interpretation of the meaning of “caring.” The professional encounter, for example, is generally seen as being an asymmetrical power relationship in which medicine plays the dominant role;¹ while to “care for” an inanimate object or abstract idea appears at first an improbable concept. Closer examination of Mayeroff’s theory shows, however, that his interpretation of caring is entirely valid and is a useful framework in which any type of caring, and informal caring in particular, can be situated.

The subtle balance between the interests of the actors which exists in the caring relationship can be understood as a form of reciprocity, but at a spiritual or existential

¹ See for example, Frank (1991, 1995); Toombs (1987, 1992); Turner (1995). From a sociological perspective, this phenomenon has been explored at length by Freidson (1970, 1988, 1994), and also by Willis (1989).

rather than at a literal level. The primary concern is the integrity of the Other, and it is this that directs action, rather than the will, or desire, or even the preferences of the Other. This concern is driven by what Mayeroff terms “devotion” to the Other, through which the carer is committed to the Other’s future (even if this future is unforeseeable). However difficult the tasks associated with caring may be, and Mayeroff admits that caring is “sometimes frustrating and rarely easy” (p. 52), their moral status elevates them above the category of burden. Mayeroff summarizes his “basic pattern of caring” as being

...understood as helping the other grow: I experience the other as an extension of myself and also as independent and with the need to grow; I experience the other’s development as bound up with my own sense of well-being; and I feel needed by it for that growing. I respond affirmatively and with devotion to the other’s need, guided by the direction of its growth (p. 6).

Clearly, artistic and other creative endeavours can satisfy these criteria. The broad terms in which Mayeroff’s model is expressed, which leaves the meaning of “growth” and “reciprocity” open to interpretation, does indicate that caring is possible in an enormous variety of human situations, including within the contract between health professional and patient. In support of this observation, Adrian Moulyn argues that treating the sick can be highly rewarding, although, he writes, “...[t]he relationship between doctor and patient is necessarily one-sided and compartmented, because he is the dominating authority while the patient is the passive, ‘patient’ partner who looks up to the doctor, as if he were standing on a pedestal” (Moulyn, 1982, p. 200). This relationship does end, however, with the recovery of the patient, after which both actors are left only with its memories. This applies also to long-term therapeutic relationships, for example, in psychotherapy. Nevertheless, strictly within the professional context (and in this respect Mayeroff’s model of caring has certainly proved remarkably popular with nursing theorists), elements of mutual benefit can no doubt prevail in some instances, and Mayeroff does not demand permanency in the caring relationship.

Mayeroff lists the “ingredients” of caring as comprising:

- *Knowing*. This involves both implicit and explicit knowledge of the subject of care. Implicit knowledge, meaning that which is verbally inexpressible, resembles empathy.

- *Alternating rhythms.* This term has two meanings. First, it alludes to the incorporation of previous experience into present activities, that is, the acquisition of skills over time. The second meaning is concerned with “the rhythm of moving back and forth between a narrower and a wider framework” (p. 11). By this Mayeroff is referring to the shifting foci of caring, whether the activities are viewed at an individual level or within a broader, perhaps long-term perspective.
- *Patience.* Of this “important ingredient” Mayeroff writes: “Patience is not waiting passively for something to happen, but is a kind of participation with the other in which we give fully of ourselves” (p. 12). Patience does not necessarily have a temporal aspect, as it is concerned with encouragement, tolerance and understanding, rather than with merely disinterested companionship.
- *Honesty.* This is envisaged as “something positive, and not as a matter of *not* doing something, not telling lies or not deliberately deceiving others” (p. 13). This responsibility applies equally to the carer, who must be honest and frank with himself or herself as well as the person cared for. The episodes recounted by de Beauvoir (page 203) and Roth (page 204) provide evidence of the existential consequences of evading this criterion. Self-aggrandisement and vanity are detrimental to caring:

Pretending to be what I am not interferes with being able to relate to the other as an individual in its own right; I cannot be fully present for the other if I am more concerned about how I appear to other people than I am with seeing and responding to its needs (p. 14).

- *Trust.* The nurturing of another person’s “growth” means that the carer must have confidence in his or her judgment on what behaviour and action is most appropriate for that particular situation, but this also means that trust is accompanied by an element of risk. Being over-protective, or doubting the capacity of the Other to cope, stifles the participation of the Other in the caring process.
- *Humility.* This quality ensures that the carer learns from previous experience, and has the creative capacity to adjust to changing situations.
- *Hope.* Mayeroff’s description of hope is similar in many respects to Marcel’s, which is discussed below. He writes:

There is hope that the other will grow through my caring which is more general than hope as a specific expectation; it is akin, in some ways, to the hope that accompanies the coming of spring...Such hope is not an expression of the

insufficiency of the present in comparison with the sufficiency of a hoped-for future; it is rather an expression of the plenitude of the present, a present alive with the sense of the possible (Mayeroff, 1971, p. 19).

Hope, unlike wishfulness, is grounded in a realistic understanding of the present, but most importantly, it “enlarges the significance of the present” (p. 19).

- *Courage*. This final element of caring derives from hope; it takes courage to look to the future in a realistic and honest manner. The interrelation between hope, courage and trust is expressed as follows:

Trust in the other to grow and in my ability to care gives me courage to go into the unknown, but it is also true that without the courage to go into the unknown such trust would be impossible (Mayeroff, 1971, p. 20).

It is not always possible to care as we might wish. The reciprocal nature of caring ensures the mutuality of actualisation, or growth, but this is impossible in the event that a person is unwilling to accept care, or deliberately rejects it. Alice’s experience (described on pages 197-199) is an example of such a situation. It is important to realize, however, that caring does not *always* involve reciprocation; for example, as mentioned in an earlier section, nurses providing post-mortem care undoubtedly regard this as genuine caring.² It does, however, require that the carer does not neglect his or her own well-being, as caring requires both physical and mental strength.

The primary purpose of caring is to assist the Other’s growth, or actualisation, but such apparent altruism is rewarded by self-actualisation. Through the fundamental selflessness which motivates caring, its moral dimension is established. The notion of the “primacy” of caring (a theme which nurse researchers, for example Benner and Wrubel (1989) have employed in theorising caring in professional encounters), resides with the understanding that caring *in itself* is of value, rather than simply some envisaged outcome of caring. The intrinsic worth of a person (or thing) must be understood and valued, quite apart from the value that the caring activity may have to the carer. Despite its intrinsic value, caring cannot be an end in itself; its fundamental purpose is to nurture the growth of the Other (or of a thing) in an appropriate way. In an environment characterised by trust, openness

² The idea of caring for a dead person can be rationalised in terms of the theories of Heidegger and Merleau-Ponty, who argue that although the dead have no material existence, they have an existential significance. This perspective is outlined in Chapter One, pages 19-25.

and patience, the carer acts as a facilitator who encourages and nurtures development in the other.

The ways in which we care for the various objects of concern in our lives, and this includes ourselves, must be compatible in order that a state of “harmony” prevails. Mayeroff refers to this state of affairs as being “in-place” in the world. The ordering of our lives which arises from caring creates this state, which Mayeroff describes as being “as much temporal as spatial.” Being in-place is thus an existential state which is not clouded by conflicting interests and in which the person’s caring capabilities are utilized to their full potential.

Patience, love and caring: Marcel and Fromm

Gabriel Marcel’s conceptualisation of “patience” bears a strong resemblance to many of Mayeroff’s “caring ingredients.” Marcel has this to say about patience:

[Patience] consists in placing our confidence in a certain process of growth and development....Patience seems, then, to suggest a certain temporal pluralism of the self in time. It is radically opposed to the act by which I despair of the other person, declaring that he is good for nothing, or that he will never understand anything, or that he is incurable. That is, of course, the same despair which makes me proclaim that I shall never be cured, that I shall never see the end of my captivity, etc. It seems, strangely enough, that, in hoping, I develop in connection with the event, and perhaps above all through what it makes of me, a type of relationship, a kind of intimacy comparable to that which I have with the other person when I am patient with him (Marcel, 1962, p. 40).

Respecting and accommodating the rights and sensibilities of the Other is paramount. Patience with oneself, (e.g., by “taking one’s time” to do something) and with others, has a temporal aspect, as it means to adjust to one’s natural “rhythm.” Patience with another means that the Other’s rhythm is not forced, or ignored; a concept that appears to be similar to Heidegger’s notion of the “leaping ahead” of authentic solicitude (see pages 17-18). Such “non-interference” (which is not at all the same as indifference), is constructive and serves to preserve the “vital rhythm” of the Other. It must come from within the individual, and thus contains a spiritual element:

In so far as I hope, I detach myself from this inner determinism which is rather like a cramp, threatening, when the trial is upon me, to change me into one of those degraded, abnormal, and in the end perhaps hypnotised expressions of human personality produced by despair...(Marcel, 1962, p. 41).

Marcel links hope with risk-taking, in that risk-taking is a feature of the “human condition.” To have no hope means that we are not prepared to risk anything (by having those hopes dashed) in an effort to avoid disappointment. Hope therefore involves a certain amount of risk-taking; being devoid of hope has the effect of “chaining reality down in advance” (Marcel, 1962, p. 55). Indeed, Marcel and Mayeroff appear to be writing about very similar processes, and the distinction between the “caring ingredients” (even among themselves) and Marcel’s “patience” is somewhat blurred. The idea of risk-taking, which features in both Marcel’s and Mayeroff’s work, appears to be an inevitable consequence of dedicating oneself to the well-being, or care, of another person (or thing).

There are also noticeable similarities between Mayeroff’s description of caring and the psychoanalyst Erich Fromm’s account of loving, which predates Mayeroff’s work by more than a decade (Fromm, 1957). For example, similarities between Mayeroff’s concept of the caring relationship, discussed above, as being one of “mutual trust and respect for integrity” can also be found in this passage from *The Art of Loving* in which Fromm describes the mutual effects of love in a relationship:

Love is an active power in man; a power which breaks through the walls which separate man from his fellow men, which unites him with others; love makes him overcome the sense of isolation and separateness, yet it permits him to be himself, to retain his integrity. In love the paradox occurs that two beings become one yet remain two (Fromm, 1957, p. 16).

Referring to Spinoza’s notion of active and passive affect (action and passion), Fromm writes: “Love is an activity, not a passive affect; it is a ‘standing in’, not a ‘falling for.’ In the most general way, the active character of love can be described by stating that love is primarily *giving*, not receiving” (pp. 17-18). What does giving mean? Fromm says that the idea of “giving” is complex, its most important aspect being the giving of one’s self: “he gives of that which is alive in him; he gives him of his joy, of his interest, of his understanding, of his knowledge, of his humour, of his sadness – of all expressions and manifestations of that which is alive in him” (p. 19). Fromm sees this as a reciprocal process, in that there are benefits to both the giver and receiver of love. Moreover, “the ability to love as an act of giving depends on the character development of the person” (p.

20). He believes that there are four “mutually independent” elements which constitute love; these are care, responsibility, respect and knowledge, and together they represent

...a syndrome of attitudes which are to be found in the mature person; that is, in the person who develops his own powers productively, who only wants to have that which he has worked for, who has given up narcissistic dreams of omniscience and omnipotence, who has acquired humility based on the inner strength which only genuinely productive activity can give (pp. 25-26).

It is important to realise that Fromm is referring to any type of love, not necessarily romantic or sexual love (*Eros*). Echoes of Fromm’s words, “*Love is the active concern for the life and growth of that which we love*” (p. 21; emphasis in original text) can be detected in Mayeroff’s statement that caring is a dynamic state existing between two people, and, like caring, love requires constant attention and cannot survive in an unbalanced relationship. In Fromm’s words: “There is only one proof for the existence of love: the depth of the relationship, and the aliveness and strength in each person concerned; this is the fruit by which love is recognised” (p. 80).³

In summary, Mayeroff regards caring as a particular state of being or existence, a process rather than an act, which can be created and nurtured in one person through the agency of another. It represents the synthesis of a range of interrelated caring “ingredients”: in short, caring is the primary component which underpins the integrity of human condition and in so doing, creates meaning in our lives. The comprehensive picture of caring that Mayeroff paints, which is supported obliquely in the works of Marcel and Fromm, reaches beyond the specific everyday tasks that are usually associated with caring, and encourages the exploration of caring’s less tangible aspects within an existential framework. The following extracts and examples examine some of the more significant components of the experience of caring, and demonstrate their place within the framework established in the above theoretical discussion.

* * *

³ In view of the remarkable affinity between the concepts of love and caring formulated by Fromm and Mayeroff respectively, which is evident in this comparison, one might ask if they are one and the same thing; alternatively, this could merely reflect the difficulty of assigning specific terminology to concepts that elude concise definition.

Receiving care: The ill person's experience

There are many autobiographical accounts of illness experiences,⁴ but few offer a significant exploration of the nature of the author's interaction with informal carers. A notable exception is sociologist Arthur Frank's work *At the Will of the Body: Reflections on Illness*, in which the author describes and analyses his experiences of suffering, and eventually overcoming, two episodes of life-threatening illness. Frank's concern lies with the way in which illness altered not only his own perceptions, but also those of the people around him. He observes that "the responsibilities of the caregiver⁵ have no bounds," and that the enormous involvement of carers in the everyday life of the sick is frequently disregarded by the health professionals. They are also unwilling to acknowledge the nature of the unique relationship between carer and sick person:

Being a caregiver is doubtless an opportunity, but the dangers of losing herself, her energies and appetites, and her sense of a future may be even greater for the caregiver than for the ill person. As little as we know of illness, we know even less of care. As much as the ill person's experience is denied, the caregiver's experience is denied more completely (Frank, 1991, p. 107).

So intense is this involvement that, according to Frank, caregivers "...are also the other halves of the illness experiences. The care they give begins by doing things for the ill persons, but it turns into sharing the life they lead" (p. 6). Being a carer, Frank explains, is far more complex than merely providing treatment, which, he claims, "...gets away with making a compromise between efficiency and care by creating an illusion of involvement" (p. 45). Instead, Frank refers to caring as an "art," its purpose being to assist the sick person to express his or her needs, which can then be acted upon within the boundaries of the carer's capabilities. The uniqueness of each carer's experience, which is intimately shaped by the sick person's experience, is made clear by Frank's observation that "...[t]erms like pain or loss have no reality until they are filled in with

⁴ Some examples are Stewart Alsop's account of his experience of leukemia (1973), Jean-Dominic Bauby's description of the nightmare of stroke (1997), Robert Murphy's book in which he describes his experience of encroaching paralysis as a benign spinal tumour gradually destroys his nervous system (1990), Oliver Sack's story of the loss and rediscovery of his injured leg (1991), and William Styron's account of his experience of severe depression (1990).

⁵ Throughout Frank's work, the term "caregivers" is reserved specifically for informal carers.

the ill person's own experience. Witnessing the particulars of that experience, and recognizing all its differences, is care" (p. 49). In contrast, medical staff are often hampered by their professional commitment as providers of treatment and lack the time to be "caregivers." Frank argues that although caregiving and treatment provision are of equal importance, they are fundamentally different.

The symmetry of the caring relationship, and the circularity of its effects, are central to both Mayeroff's model and Frank's understanding of informal care; for example, Frank writes:

Care is inseparable from understanding, and like understanding, it must be symmetrical. Listening to another, we hear ourselves. Caring for another, we either care for ourselves as well, or we end up in burnout and frustration (Frank, 1991, p. 48).

The ideas of companionship and understanding contained in this passage are also expressed eloquently in Jeremy Warburg's diary, which he wrote during the time between the diagnosis of inoperable cancer and his death six months later.⁶ Warburg was well loved and cared for, and he died surrounded by his wife and adult children. The importance of being home in familiar surroundings is a theme which permeates his experience. Returning home after spending time in a hospital for respite care, he writes: "Back at home. Ecstasy. At last in my own house, in our dining room. View of our garden from the french windows. [My wife] Teil's cooking. Euphoric. My wife and daughter round me. Heaven" (Warburg, 1988, p. 184). Towards the end of his illness, he felt secure in the presence of loved family members:

Notice Teil and I talk less. Often just sit. Hold hands if Teil can get near enough. Say nothing much. A word here and there. Nothing much to say. Just want to be left alone with each other. Calm. Loving. Silent (p. 140).

To be able to enter and share the sick person's world is of overwhelming importance to some carers, and the inability to achieve this communion can be a source of considerable anguish. Suffering itself, however, cannot be shared.⁷ What is of importance to Warburg

⁶ The diary was edited and completed by his wife, who took notes for that purpose when Warburg himself was unable to write.

⁷ Merleau-Ponty discusses this, and related issues in his account of the shared "interworld" of different Beings (Merleau-Ponty, 1962, pp. 346 ff).

as he nears the end of his life is simply the presence of his wife; the requirements of caring had gone beyond words and action.

Providing care: The carers' experiences

Nursing and lay perceptions of caring.

Frank (1991) and Warburg (1988) show that although the provision of instrumental assistance is unquestionably important in caring, it is the unique style of caring that is made possible through the agency of what Mayeroff terms "implicit knowledge" that the ill person values most highly. This knowledge also affects the manner in which ordinary, everyday, tasks are conducted and has the additional effect of investing these activities with significance, or meaning, beyond a mere practical value. Anne, one of the study participants, is an experienced nurse, and during our conversation she explored the significance of the shift between formal and informal caring roles in which she engaged while caring for her mother. Anne considered herself fortunate in that she had always loved her mother, a factor that she realised had, in all probability, considerably enhanced her caring experience. She also realised that her professional role could have influenced her style and appreciation of caring, which she said had been a "privilege":

Anne: I was really lucky, and in fact I wrote down here [in my notes] I felt that what I was doing was keeping her more comfortable, and I really felt that. And I feel that for me that was terrific feedback; do you know what I mean? That the role was as much for me as for her, and yet when I was thinking about it, I was wondering how much of a power relationship it was, you know. And one of the things I said was, well, it was so easy, but also I received so much. But the role I played was more, not - clearly defined. It was more to sort of talk, listen, and when necessary, wash her, and help her because I had those skills. And it would be interesting to know, if I hadn't been a nurse, what that would be like. But it was quite different to the nursing role. (Conversation with Anne).

At times the professional carers invited her to take over their roles, but when she did perform tasks that called upon her nursing skills she experienced them differently; she said that the "essences" of the two types of caring were different, and that informal caring was performed in a different spirit than nursing. Because of the depth of her nursing experience, she was capable of performing any nursing tasks, nevertheless there were times when she withdrew from them, because, she said, "...it was almost as if the

overload of caring by me would increase the burden of my mother having to stay well. You know - something to do with that.” She continued:

Anne: I can think of um – Well, a lot of it was to do with energy – physical and emotional energy, because - even massaging; when you’re massaging, ordinarily, it still takes a lot of energy, I think, but you are so connected, and I think you need energy. Sometimes, I felt too tired. And also, not so much tiredness, but emotion, that she was going to die, you know, that she would let go. And I guess that happened prior to the time when I was helping her let go. You know, where I was saying well you know “Let go. It’s all right.” That sort of thing. (Conversation with Anne).

There were, nevertheless, advantages in having nursing skills and knowledge:

Anne: The thing is that the feedback is absolutely tripled, because you can anticipate – because of the relationship with my mother - I would know that she would want this to be happening to her, even though it might be painful. So, I think it’s something to do with knowledge of the person, and connectedness with that person, that is quite different. When you’re a nurse, of course you care about the person, but you don’t know that this person may have had suppositories, and been discomforted, and did not even agree with the use, or whatever. You know, you actually have a background of – a full background to draw on. Likes and dislikes. But then you don’t think about that at the time...I enjoyed caring – I’ve always enjoyed that. I get a lot out of it. But it is different, what happened with Mum. It’s almost a part of yourself. (Conversation with Anne).

In this way, the special knowledge that the mother-daughter relationship (in this case) fosters effectively redefines nursing care within its own criteria; the acts themselves are invested with different meanings because of what Anne described as the “loving giving” of treatment that was possible because of the relationship. Yet at the same time nursing skills serve to enhance the informal aspect of caring because of the extra skills acquired through nursing practice. Nevertheless, Anne’s account indicates that formal and informal care are at all times distinguishable from each other. The frequently offered invitation to share in professional nursing caring was not always accepted. “At certain times” Anne simply did not wish to assume responsibility for activities in which, at other times, she willingly took part. These were the times when she felt that the emotional input required to displace these activities to the informal sphere was too great. These are things like just “being there”: “I think it was a time when I didn’t want that heavy, intense connection,” and: “That’s when I really felt I was caring.”

Stepping across the boundary between informal and professional caring, and participating in nursing home activities, are common occurrences, particularly in institutions where the staff are often pressed for time. For example, while her mother was resident at the nursing home, Alice and her husband became heavily involved in the administration of the home, and the staff had a great deal of respect for Alice's care of her mother, and the time she spent at the home:

Alice: ...in fact I had the friendship of most of the nurses, who could not help but respect the way I'd looked after Mum. Occasionally they'd tell me this stuff: "Go away, we'll look after her!" And sometimes they did that. We went away for weekends, we had a week's holiday every now and again. I was sensible enough to know that I needed breaks, but they actually did have a lot of respect for the way I was so consistent in my care. (Conversation with Alice).

This involvement continued after her mother's death, when she kept in contact with the relatives of some of the other residents, and attended the funerals of those who had died. Alice also spent a great deal of time assisting her mother at mealtimes because she knew that this was time-consuming for the staff and was often neglected for that reason (see page 157).

Zoe, who shared the care of their mother with her sister Anne, seemed to struggle with the notion that her contribution to the care of their mother was in some way inferior to Anne's. Zoe had spent a great deal of her life living near her mother when Anne had moved away from their home town. It fell to Zoe to take care of practical issues:

Zoe: So, I guess Mum's been just a part of my life, whereas Anne hasn't been with her all the time, so she has cared for her in a different way. I suppose I've been the one who has taken her to have her feet done, and pay the bills, and...[I took] her to buy dresses...but I hadn't sat and talked deeply, and – you know what I mean?

LP: Yes, I do.

Zoe: I'm not that sort of person, I suppose. I wouldn't think to go down to Mum's...to bring one of her favourite tapes down to play. I'd probably think more of: "Now, what I can take her to eat? I wonder what bills she needs paying." Those sort of things. (Conversation with Zoe).

Later, when her mother became very frail and entered the nursing home in Melbourne, Zoe explained how again she felt that her skills were inadequate:

Zoe: That was another area, the sickness bit, that I didn't cope terribly well with. I was all right taking her to the doctors and all that, but to talk, to sit and talk to her about it, and things like that, *not* very good. (Conversation with Zoe).

Zoe's self-criticism was centred primarily upon the notion that her sister's relationship with their mother was of a more spiritual nature, defined by their shared love of music and the letters she wrote to her mother, although in this incident she also attributed some of Anne's perceived advantage to her nursing skills. Although Zoe realised that in general she had superior practical skills, she continually underrated these during the conversation. During the final weeks of her mother's life, however, she said she found the courage to express her feelings to her mother:

Zoe:...I wasn't even much good at the talking. But I did *learn* in those few days. You know, I learnt to say things that probably I'd never said, that I'd never been able to say before, that I wanted to say.

LP: What sort of things did you say?

Zoe: Oh, just how much I loved her, and how wonderful she was, and how the kids were so proud of her, and how proud we all were of her. Things that I guess I don't find it all that easy to say...I couldn't have done what Anne did when she died, and I sort of stood back because I knew she needed to do this for Mum.⁸ So I suppose in caring for Mum I was more on the practical side in a lot of ways...It's still part of caring. It's a *big* part of caring. But then, the other side of caring, just playing her music, and I've learnt, from looking at Anne, the way she - They're *beautiful* things; and like writing, and, I think that's lovely, for a daughter to be able express herself. But they did have a different more of a - You know, it's not saying that one loved their mother more than the other, that's not it! But they did have a different a *very*, very close relationship in lots of ways. I feel that she got *special* caring from Anne. The things that she was able to say to her - I'm not saying that her caring was any better than mine, and if it was all over again, that's still the way I would do it. But I still think that Mum was lucky, to have had that *other* [style of caring]. (Conversation with Zoe).

The balance between nursing and informal caring and between practical and spiritual elements of caring feature strongly in these accounts. Zoe in particular seemed to regret that she did not have the assurance that Anne possessed in expressing her deepest feelings; indeed, she apparently aspired to a style of caring that did not come naturally to her. Here the issue of honesty with oneself which Mayeroff includes in his "ingredients" can be detected. Here too can be seen the vexed issue of "roles"; Zoe aspired to a caring role that exhibits her sister's qualities that she admired (or perhaps even envied), yet it is

⁸ Neither of the sisters was present when their mother died, but they returned to her bedside as soon as they were told of her death. The story ends with Zoe expressing her respect and admiration for Anne's caring skills: "So we went back [to the nursing home], and Anne fixed her up, made her comfortable until the doctor came. I'd just felt that it was lovely, and I think that's what Mum would have wanted too."

only at the very end, just before her mother died, that she found the resources to overcome inhibitions and in telling her mother how much she loved her, acted more or less like Anne.

Upholding the truth.

Not everyone shares Anne's concern with other people's perception of their caring role. Brad had assigned himself the role of the "family truth-teller" in much the same way that Herman Roth saw himself as a "doer," and this unflinching honesty sustained his ability to broach difficult topics with his mother, and also with other members of his family. He described several incidents when through this strict honesty he encouraged his family to face the inevitable. Once, when he and his father were visiting his mother (who was at the time in hospital for treatment), and desperate for information about her condition, Brad forced the issue with the doctor:

Brad: Basically I said: "I haven't seen my mother since September, and obviously she's a *lot* worse." I chose my words very carefully, because I was standing there with [the doctor], with my Dad standing next to me. And I said to him: "It seems to me that it would be a reasonable assumption for us to make that Mum's probably going to die within the next six months," and he realized; "Oh! It's *that* talk!" Because doctors have no training in this shit, which is very unfortunate for them. He saw that I knew what I was on about and he said: "I think that would be a useful assumption for you to be working with at the moment." I said, "Yes, that's useful for us to know. Thank you." And asked him a few more questions about the treatment, and he said the nurses could deal with that. We just wanted to know how long she would be here for. Is it painful?, What could we do to prevent the pain?...So I then took my Dad down the corridor, and he cried on my shoulder for about half an hour, because it was the first time anybody had mentioned out loud that she was going to die. (Conversation with Brad).

Having elicited the truth from the doctor, Brad now considered it his duty to inform his siblings. His mother was apparently aware of the terminal nature of her illness, but had not discussed it with anyone. Brad said that although his brothers and their partners accepted the news they were understandably upset, but his sister was both devastated and angry:

Brad: I saw my little sister, and she was angry with me for saying that, and said, "Mum can still fight it!" And I said, "I know Mum can fight it, and will fight it, and it's useful for us to recognise that it's not a battle she's likely to win. I hope she wins it, I'll support her attempts to win it all the time, and she's not likely to win it, and it's likely to end soon. I want to tell you that out loud, so you know

that is the indication the doctor gave me.” When I got back to Sydney, Number Three, my little brother, was up in Sydney on holiday with his girlfriend...[and]...I rang them from the airport. I knew they’d be going home the day after the next day. I said, “I’m back in Sydney, I’d love to see you, I’ve got some news about Mum.” And they came around to my flat, and again I had both of them crying on my shoulder. So, this is what I mean about it’s my role in my family to - certainly nobody else volunteered to tell the other siblings.

LP: None of them had actually tried to nail down one of these professionals to find out?

Brad: Well, my Number Two brother might have if he’d been around. He would have fronted, but he was very glad he hadn’t had to. My father wouldn’t have in a million years. Mum didn’t want him in there with her discussions with the doctor, and made that very clear, which he didn’t like....And my three younger siblings wouldn’t have done it. (Conversation with Brad).

Finally, he succeeded in turning the conversation with his mother to the difficult matter of her death.

Brad: I said to [my mother]: “You know, we really ought to talk about the fact that you’re dying.” She was pretty taken aback that I would say that. I said: “Well, I figured that you’d probably want to organise things, and you might well have organised some stuff, but there’s probably other stuff you haven’t had a chance to, and I want to be of help, be of assistance.” So, what she and I did over the next five hours was went through all the details of her funeral, and worked out exactly what it was she wanted, where she wanted it, how she wanted it, down to what sort of casket she wanted, what kind of flowers, who she wanted to have do the flowers, and then other things – Who had to be notified immediately she died. So we went through all that sort of stuff. And then I wheeled her into her room (she was in a wheelchair at this stage), so we went through her jewellery. And so I was able to go through all her jewellery with her...

We were about half way through it, still sitting in the lounge room, when she said: “I never thought I’d be able to talk to anybody about things like this.” I’d been quite emotional, but quite controlled about it, but that was the point at which I lost it and I said, “Well, I just want to make sure that everything’s as you want it to be. It’s not that I want you to die. I’m really sorry that you’re dying.” And then I started crying, and she had a bit of a cry too. And that was probably the closest we’d become again. That was, from my point of view, the time when I realised that despite everything, despite all the conflict that there’d been, with the estrangement, that I was still *loved*, and certainly that I still loved her...and to realise that I was doing this thing for her which nobody else *could* do, was really important. (Conversation with Brad).

Not only were arrangements discussed with his mother but they were also finalised with all those who would be involved in the funeral. These were tasks that both Brad and his mother knew would devastate his father, and this is what he called “primary care.”

Nourishing body and soul.

Offering special delicacies and favourite foods to the sick person is for many a cherished act of caring. The poet Doris Brett, for example, saw in the soup she prepared so carefully for her mother the distillation of her love and care:

Mum now has a partial bowel obstruction. She can only hold down tiny portions of food and water. I am cooking soup. I put in everything nourishing I can think of, then I simmer and sieve it. The evaporation has reduced it until it is almost solid - essence of soup. It is like compressed love, I sometimes think (Brett, 2001, p. 374).

Alice, however, found that attempts to reach her mother through offering her special foods were rejected. Any images she did have of her mother enjoying food were marred by their context and implications, as this extract from Alice's journal explains: "My prevailing memory of Mum after this visit is of her in bed – almost in the foetal position, eating a 'comfort biscuit.'" Much later, when her mother was living in a nursing home, Alice was appalled at the lack of fresh fruit provided to the residents, despite its abundance in the local stores at the time. However, Alice persevered in trying to recapture simple pleasures her mother once enjoyed:

Alice: I'd go [to the nursing home] at about 4.30; initially I'd take – I'd have a bottle of sherry up there, and we'd have a sherry and biscuits and cheese, and then I'd help her with her meal, maybe read or something, and they'd come in to put her to bed, and I'd go home, and say goodnight. She would never answer me, and then if [my husband] Peter was there, she'd say; "Goodnight, Peter!" (Conversation with Alice).

The staff at the nursing home, although they were "not bad" people, had little time to help the residents with their meals. Alice arrived at dinner time one evening (at 5.20 pm) to find:

Alice: Mum was sitting in her chair with food everywhere. She did not have her plate guard or special spoon. She could not eat her mornay, and was tackling her pavlova with her hands....I felt more tied to Mum than ever...I know that if I wasn't here she would be on vitamised food. No staff member would have the patience to feed her as I do. I do not feel inclined to leave her (Alice's journal, pp. 19 & 23).

Even when death is very close, nourishment, perhaps symbolising life, continues to offer hope. Alice offered her mother, who had not taken either food or fluids for five days at the time, some ice-cream, which she "took very eagerly."

Brad's sister, who was at the time training to be a nurse, was distraught when her mother lost the desire for food. Brad said:

Brad: [My sister] wanted to be there feeding Mum. That was her job of an evening, and her coming in to the lounge room where I was sitting, and so angry, and crying, really angry about the fact that Mum couldn't eat. Of course she couldn't chew, she didn't have the voluntary muscle control. She'd been trying to get her to just sip some drink with protein in it or whatever. I said, "She's dying, she's going to die in the next couple of days. She doesn't need to eat. Your going in there to help her is your way of showing that you love her." Then of course she cried. (Conversation with Brad).

Even the nursing staff find it difficult to accept that there is a time beyond which nourishment is pointless. The day my own mother died, I was with her at lunch time, when a nurse tried to persuade her that she should eat some blancmange as it would "slip down easily." Like Brad's mother, she could not swallow, and clearly had only a few more hours to live.

Ways of communicating

Communicating through reminiscence

Anne, who has been involved in a professional capacity with the Alzheimer's Association, understands the importance of reminiscence in helping old people remain connected with their past lives and acquaintances. She spent many enjoyable hours with her mother remembering the past she had shared with their her and her sister Zoe. Anne described an often-repeated scene as follows:

Anne: And then I used to travel down there when she was in T- [a large rural town about three hours' drive from Melbourne], this is before we moved her. That is when I would get her into the car – just me – and go to Macdonald's which is on the corner where – T—'s a place where everything's changed. My mother and father lived there – we all lived there, so we knew every block. So we would sit, facing the traffic, in the Macdonald's car park. She'd eat about three or four little chips, and a bit of the thing, and a bit of ice cream – she liked the ice cream! and we would talk about who used to live here, and that sort of thing. So I suppose they are very reminiscent stuff. (Conversation with Anne).

Communicating through writing

Anne communicated with her frail mother in an unusual way. Throughout her life they had enjoyed a good relationship, which, through caring, Anne said "just got better and better." Whenever they had been separated, she had always written to her mother, and she

continued to write even when she was caring for her. This natural continuation of a familiar activity added a unique flavour to this woman's perception of caring, and indeed this was what first sprang to mind as representing caring to her:

Anne: The very first [caring act I thought of] was that I wrote a letter to her every week. This is before I did that intense caring. And I would buy cards. You know, really beautiful cards, like, you know, really lovely, little cards, and I'd spend, every time I went into town or into a shop I'd buy another card and I'd put it my pile. And in those letters I wrote, and I've got some of them - I told her how much I loved her, you know, I really talked to her. I think that was a really caring sort of thing, and it was very simple.

LP: And did she read these letters?

Anne: Yes! She read them. She never spoke about them much, but she had them, and she could read them over and over again. The staff, and my sister, it was all a bit unsaid, because really - you know - bold, really saying how I felt. But you see, it was easy for my mother and I because I'd always done that. At boarding school I used to write to her, and tell her that I missed her. So, it was very easy for me, but you know, it was something for me that was almost - it helped me and it helped her. (Conversation with Anne).

Communication on such a personal level depends upon the special knowledge of the sick person; it is difficult to imagine such intimate interactions such as these taking place within a professional encounter. Such simple acts are supremely significant for both people, and for that reason they will always remain privileges of informal care.

Communicating through music

Most people enjoy some sort of music for a variety of reasons, and for two of the participants in the study, and for myself, it was an important factor in our caring experiences. I used music not as an escape from the stress caring sometimes brought, or as a means of communicating with my mother, who shared my taste in music, but to deliberately heighten my emotional state:

I have always been puzzled by the sort of music I invariably chose to listen to whenever I was overwhelmed by our situation. I never chose anything remotely happy, certainly nothing exuberant. I had no desire to counteract my sadness; quite the opposite, in fact. I needed to enhance my sadness and grief, to deliberately sharpen it in a way that seemed almost masochistic. I liked to sit at the dining table, earphones on, lost in the sublime creations of Schubert's imagination, or Bach's incomparable expressions of his faith. This was an aesthetic experience which transcended my own sadness, and in doing so resolved it. Music does not have the power to obliterate suffering, but it does has the power to resolve it. Afterwards, I would feel stunned, emotionally exhausted,

not really relieved of the frustration and sadness (because after all, that could not be entirely removed until the situation itself had come to an end), but equipped to face caring again. (Extract from author's notes).

People find a variety of ways that are not as self-serving as my own, in which to incorporate musical experience into caring. Anne, for example, when asked when she most felt she was caring for her mother, related an entirely different experience, which may or may not have been shared with her mother:

Anne: I played Strauss' *Four Last Songs*⁹ to her, and I would put the tape recorder close to her ear. She was a singer, a soprano. That was really the picture....That's the picture that I've really got, of Kiri Te Kanawa singing the *Four Last Songs*.

LP: It is just the most superb music!

Anne: Isn't it beautiful! And now, one of the things about that is that I love that, but my mother and I hadn't actually listened to them together. We'd listened and played a lot of music together, but my family I think thought "This is not really her music." She sang light opera, and – but it was so beautiful, particularly the one – *Morgen*.¹⁰ That was the one that I played a lot, and I just felt, and again – I guess I would have liked to have known- because she didn't actually talk to me about it. This was when she was – And I'd play it to her – One day I thought, "Gee, am I forcing this upon her?" But at the same time, that was – that's the song – those songs, and music in general was what I played to her, and I suppose that was really to me the highlight of – That's when I really felt I was caring. (Conversation with Anne).

I asked Anne if she still listens to the Strauss *Songs*:

Anne: Well, just recently – I used to play them – when she died, every day I'd play them and cry. I mean they were a great help to me. I love them, but just recently I've been avoiding them. It's very interesting, and I adore them, but I don't feel that same response to them, but yes, that was part of the process afterwards for me. (Conversation with Anne).

The image of Anne leaning close to her mother, hoping, but never really knowing that she too could benefit from the serene calmness of the *Songs*, is powerful indeed. After her mother had died, Anne seemed to use the music in a different way, perhaps to consolidate her grief, or, in Merleau-Ponty's terms, to keep her on the "horizon of life" (Merleau-Ponty, 1962, p. 81).

⁹ The *Four Last Songs* are about Death; they are the last works of Strauss, and demonstrate a shift in his compositional style to simplicity, and are quite different from his other late works.

¹⁰ Here Anne is mistaken; *Morgen* is not in fact one of the *Four Last Songs*.

Moulyn writes that music

...can express the struggle of suffering without words...[and]...in these exalted moments¹¹ we are torn between feelings of deepest sorrow, expressed in most ethereal and beautiful tonal form. We suffer as we hear this music because we synthesize extreme aspects of our human existence. We feel at the same time the hurt of our human misery and also its conquest through exquisite beauty. Music can fulfill this earthly gift of healing the dichotomies and the fractures of our existence because this form of art exists, mostly, in subjective time-space, while objective time-space stays in the background (Moulyn, 1982, p.270).

The power of music, or any art, for that matter (although Moulyn places music at the pinnacle of art forms), lies in the fact that it can portray the fracture in existence artistically (aesthetically) so as to mirror the fracture in real life existence of the listener, bringing suffering into the foreground and (perhaps) hastening its healing effects. In addition, according to Moulyn, the creative act itself which gives rise to music can be interpreted existentially as a form of resolution of suffering (that is, the suffering experienced in the vacuum before creativity arrives), and it therefore has the power to produce an echo of this process in the listener.

The choice of music was extremely important to Anne at her mother's funeral, which, she said, "...was also part of the caring role, I think. I just thought – but it was probably more to do with me. I had all these young women that she'd known all their lives, as the Pall Bearers, and I had the *Messiah*. People thought it was Mum singing, because she really could sing." Anne does not seem to be able to decide whether the music was really for her own benefit, although the connection with her mother is clear.

One of the other participants, Susan, indulged her father's love of Pavarotti's operatic renditions, although she herself thought it was "terrible stuff."

Susan: Because you know the person so well, you do what you know is good for them. You know, Pavarotti *full blast*! That was one of the nicest times with Dad. I'd put it on in here, and just turn it up full up. His room's just this room here, and I'd go and lie on the bed, and we'd lie there and listen to *Nessun Dorma* full blast. He had all these opera CDs he never really played because he knew it bothered everyone else. But when it got to that stage I just -
LP: So you put up with the operas!

¹¹ Moulyn is referring at this point to Beethoven's late string quartets.

Susan: Yes, I even actually started to enjoy it! He'd lie there and translate it, because he was a real opera buff. *Nessun Dorma* was the all-time favourite. A couple of times in my life he'd translated it, and I'd thought, "Boring, boring, boring!" But then, because it was such a poignant moment, and it meant, you know, it's about victorious death, it became a *lot* more meaningful. We played that at his funeral. I thought, "He's going to love this!" And I told the girls to play it *loud*. And they did!

LP. Have you listened to it since then?

Susan: Yes. For quite some time I couldn't. There were certain songs that, because I did the music for the funeral – there were certain songs that I just couldn't bear, and I started forcing myself to listen to them, and I would just listen and listen until I could listen without crying. I've got quite a heavy sort of rock tape in the car, and the last song is *Nessun Dorma*, and it's got to be loud! - *Nessun Dorma* is the only one that I actually do like.

LP. You haven't tried to like anything else?

Susan: Terrible stuff! It just doesn't do anything for me! But he used to love it. when it's very very loud, it's not too bad. We'd have people sitting in here (it was all a bit selfish really, but we'd be here drinking tea and trying to talk), and I'd say, "Sorry! It's got to be loud!" And they'd just have to sit here, while Dad and I would be having a concert. (Conversation with Susan).

The significance of *Nessun Dorma* lay not with its temporal or existential qualities, but with its direct connection with her father's passion for a certain type of music, and that aria in particular. In playing the record after her father's death, perhaps Susan, like Anne, found a way of keeping him on her "horizon." Again, the music chosen for the funeral (although there was a variety, including Irish music to celebrate her father's Irish heritage) was chosen with great care, and of course *Nessun Dorma* was included.

I, too, spent a great deal of time selecting music for my mother's funeral. Although there were few people at the service because Victoria was not her home State, they were treated to a feast of the organ music of Bach and Buxtehude which was intended to somehow bridge loss and renewal, with a spirituality which bore only faintly Christian overtones.

Self-deception.

In stories of deception the carer indulges either in self-deception (Merleau-Ponty, 1962), or faces an ethical dilemma of major proportions by deliberately deceiving the sick person. The latter situation has been discussed earlier; (XR Roth and de Beauvoir in

“Hope”). Donald Hall’s deception is of the former variety. In a poem about the death of his wife, poet Jane Kenyon, Hall writes:

He hovered beside Jane’s bed, solicitous. “What can I *do*?”
It must have been unbearable
while she suffered her private hurts
to see his worried face
looming above her, always anxious to *do*
something when there was exactly nothing to do. Inside him,
some four-year-old
understood that if he were good – thoughtful, considerate,
beyond reproach, *perfect* – she would not leave him.
From *The Porcelain Couple* (Hall, 1998, p 13).

Alice’s account at one point reflects Hall’s childlike attitude that good behaviour (in this case, caring), would somehow be rewarded by the elimination of unpleasant truths. She remarks: “I don’t know that it was I wanted to please her; I wanted to fix her up.” Later, she said,

I’m one of those people that tends to think that if I do something I’ll be able to fix up somebody else’s problems, so I worked very hard in the end to accept the situation, for what it was...I could see that what I was doing all the time was trying to fix her up and sort of make her old age, and this terrible time of her life, better. (Conversation with Alice).

These incidents seem to resemble a fleeting return to a distant childhood belief that atonement can be gained through bargaining with some higher being or authority, the illness being a form of punishment for some imagined misdeed.¹² These sentiments are probably not seriously entertained by Hall and Alice, they appear to be merely offered to explain the yearning, or wish, for the restoration of health. Distinguishing this process from hoping, Heidegger explains that

Wishing is an existential modification of projecting oneself understandingly, when such self-projection has fallen forfeit to thrownness and just keeps *hankering* after possibilities. Such hankering *closes off* the possibilities; what is ‘there’ in hankering turns into the “actual world.” Ontologically, wishing presupposes care (Heidegger, 1962. pp. 239-240).

“Hankering” is not a constructive emotion because it “closes off the possibilities,” but fortunately for Alice (and no doubt for Hall as well) it was ephemeral, and later

¹² An alternative interpretation of this attitude can be found in Kubler-Ross’ theory that grief can be understood as a series of stages, this sort of “bargaining” being one of them (Kubler-Ross, 1969).

abandoned in the face of reality. Marcel's notion of "natural optimism" provides another way of looking at this phenomenon. He explains it in this way:

We might say that a natural optimism exists, which reflects before everything else the perfect functioning of the organism, but which may also correspond to a thoroughly egotistical desire to husband one's forces, to save oneself useless anxiety for as long as possible; it goes without saying that this natural optimism is not to be confused any more than theoretical optimism with hope (Marcel, 1962, p. 44).

The "natural optimism" or yearning displayed here, which denies reality, and looks to the inauthentic future is based on fantasy, or wishful thinking. As explained on pages 191-192, Marcel tells us that optimism constructs an imaginary, benign future, and wishing (which is probably what Hall and Alice were engaged in) is to imagine that future as actually happening.

Simple comforts

Although Susan did not seem at any time to entertain the illusion that exemplary care would somehow restore her father's health, she nevertheless delighted in pampering her father, and was rewarded with his response:

Susan: At one time I was – he was sitting in that chair – I was putting his woolly socks on. I loved to dress him, and groom him, and do his hair, and shave him. I did a *terrible* job of shaving him! That was one of the things that I *loved* to do, to pamper him. I'd be brushing his false teeth – But yes, I was putting his socks on one day, and he said: "I don't deserve this. So many good people around me!" (Conversation with Susan).

When her father had entered the hospice a few days before he died, Susan had to relinquish this task, but she gained vicarious comfort from the nurse's care:

Susan: [The nurse] Phyllis (she's left now) she was just lovely – the doctor came in and wanted to talk to me, and Phyllis had a big basin bubbling away, full of lavender water. She said, "Yes, off you go, you go out there and talk!" And she kicked me out, and when I got back there was this – Oh! she'd lavendered him all over. She gave him a good wash. That was on the first day, when I got back he was quite comfortable, and I felt OK. (Conversation with Susan).

Susan's father accepted and enjoyed the care lavished upon him, but Alice, who tried in innumerable ways to please her mother, and in desperation even experimenting with tactics that she knew were unlikely to succeed found her care was rejected (see page 167).

Difficult tasks

Shame and embarrassment: Intimate caring

Being unable to cope with normal bodily functions can be a source of shame and repulsion for both carer and patient, but overcoming these feelings brings unexpected benefits to the relationship. In Roth's powerful (and familiar) description of the scene in which Herman "beshat" himself, he explains the meaning of "patrimony." Herman Roth is devastated when he has to allow his son to clean up the mess: "In a voice as forlorn as any I had ever heard, from him or anyone, he told me what it hadn't been difficult to surmise. 'I beshat myself,' he said." When he had been showered and wrapped in a clean towel, he said it again: "'I beshat myself,' he said, but this time he dissolved in tears" (Roth, 1991, pp. 172-3).

He begged Philip not to tell anyone, so great was his sense of shame. Roth describes in detail the cleaning operation necessary to remove all traces of the incident, but cautions against a symbolic interpretation of the episode:

I felt awful about his heroic, hapless struggle to cleanse himself before I had got up to the bathroom and about the shame of it, the disgrace he felt himself to be, and yet now that it was over and he was so deep in sleep, I thought I couldn't have asked anything more for myself before he died – this, too, was right and as it should be. You clean up your father's shit because it has to be cleaned up, but in the aftermath of cleaning it up, everything that's there to feel is felt as it never was before....[O]nce you sidestep disgust and ignore nausea and plunge past those phobias that are fortified like taboos, there's an awful lot of life to cherish (p. 175).

However, Roth admits that the ennobling effects of this sort of activity might very well pall if it were repeated too often. But here he learns the meaning his patrimony, that the thing that he inherits from his father that means most, or is the only meaningful thing, is the "aftermath" of cleaning up his father's mess, that the activities of caring, however repugnant, bring rewards.

Situations such as this are perhaps more difficult to deal with because both people are obliged to overcome their shame at the same time. If Scheler is correct in saying that shame cannot be shared empathically, the carer needs to enable the patient to accept the

situation without feeling ashamed (Emad, 1972). They are, nevertheless, important because they represent steps towards the state in which concern for the niceties of social conventions can be cast aside. It is not just the carer and patient who are constrained by convention, however, as this passage from de Beauvoir's memoir indicates:

[The paid nurse] Mademoiselle Leblon and a red-haired nurse tried to put her on a bed-pan; she cried out; seeing her raw flesh and the harsh gleam of the metal I had the impression that they were setting her down on knife-edges. The two women urged her, pulling her about, and the red-haired nurse was rough with her; Maman cried out, her body tense with pain. "Ah! Leave her alone!" I said. I went out with the nurses. "It doesn't matter. Let her do it in her bed." "But it is so humiliating," protested Mademoiselle Leblon. "Patients cannot bear it." "And she will be soaked," said the red-head. "It is very bad for her bed-sores." "You can change the clothes at once." I said (de Beauvoir, 1966, pp. 47-8).

When she returned to her mother and told her not to worry, that there would be "no sort of difficulty about it," Mme de Beauvoir remarked, "The dead certainly do it in their beds" (p. 48).

An experience that my mother initially found devastating, and I had some difficulty in overcoming, was not quite so dramatic (or unpleasant), but it was nevertheless a watershed in my caring career.

Every morning I called in at my mother's house to help her bathe and prepare her for the day ahead. She was still fairly independent at the time and I usually found her sitting at the table eating her breakfast. This time, however, she was not there, and I found her in the bathroom, clutching the basin and crying. "I can't clean my teeth!" she sobbed. She must have suffered a slight stroke, perhaps during the night, and her right hand was now useless. I have (or did have) a strong aversion to dentures (the prospect of needing them myself would appal me) but here I had no choice; the issue had to be dealt with. I could see immediately that her distress was due to her inability to perform this ordinary, but private, task; not because she had suffered a stroke. (I do not believe she considered that possibility, and for weeks she massaged the useless hand in an attempt to bring life back to it). I took the dentures from her, led her back to her chair, and said, "Don't worry, Mum, I can easily clean them for you." It is difficult to convey the degree of revulsion with which I regarded this task, but I knew that it was most important that she did not sense this and I forced myself to treat it as something of little consequence. After a few days I become used to this new task and it just became another part of my routine. At first my mother was embarrassed, apologising every day, but after a time she came to think little of it, although it meant that there was one less thing she could accomplish every day. (Extract from author's notes).

The vulnerability and powerlessness of the ill person means that it is the carer's

responsibility to dismiss, or neutralize, the shame surrounding intimate bodily care; in these situations carers (and patients) are not protected by the emotional distance upon which professional carers are able to call. Both Roth and I were acutely aware of the distress our parents were suffering, and pity helped us pretend that attending to these matters was not especially arduous.

These incidents involve a mutual revision of entrenched inhibitions so that the feelings of revulsion or embarrassment that hamper caring can be overcome. One task that a vulnerable person often faces is to accept care, to allow a person to help them. Brad, for example, was able to help his mother overcome her shyness by being direct and unpretentious during this incident:

Brad: She was a very private woman physically, so for her to allow me to wipe her bottom and things like that was, she was very humiliated by that at first, until I said to her; “Well, come on Mum, I came out of here!” (laughter) “I came out of all this stuff, so you know!” (Conversation with Brad).

Incidents like these of course require a certain strength and self-confidence in the carer.

Decision making

Being responsible for another person frequently involves making decisions on their behalf. Several of the carers, as well as Philip Roth and de Beauvoir, found this to be an extremely stressful aspect of caring. Anne and Zoe, who were both living in Melbourne at the time, decided that instead of moving their mother to a nursing home in her home town, they would bring her to Melbourne where they could both spend more time with her. To Anne, making this decision was of major importance in her caring experience, a “huge caring thing.” Her sister also thought of it in a similar way, and explained the circumstances:

Zoe: Well, she had to get out of the nursing home. It was a hostel, in T—...and she was just about ready for Nursing Home care, and I’d bought this unit, and [my husband] had died, and Anne was [in Melbourne], and we made the decision. I don’t know if it was the right or wrong decision, We won’t ever know that, I suppose. To shift her from where she’d been married (she was married in T—).

LP: Yes, it’s a very hard decision to make. How do you think she – did she have any say in it? How was the decision made?

Zoe: Oh, yes, she did. But I really don’t think she was well enough to care particularly. Anne did most of it because she was up with all of that. That was

another area, the sickness bit, that I didn't cope terribly well with. I was all right taking her to the doctors and all that, but to talk, to sit and talk to her about it, and things like that, *not* very good. I can still see her, bless her heart! They brought her down in an ambulance. I can still see her perched up there, being wheeled into this strange place where she knew nobody. In T— she'd been a member of the Church, and a member of *everything*, the Red Cross, she played cards with friends, and the bowling club...It was a *big decision*, and Anne said to me: "Now don't be surprised if there's a change. Mum might go downhill." But then again, we didn't know. She might have if we'd gone to all that – of shifting her to somewhere else in T—. (Conversation with Zoe).

Alice, too, agonized over a similar decision she had to make for her mother. Once she had left the hostel in the small Victorian town near where she had lived, it was made clear that her mother would not be able to return, as she now needed nursing-home care. Although she was much younger than her siblings, the care of her mother, including the decision to relocate her in Melbourne, fell on her shoulders:

Alice: That [I would have the greatest responsibility] was becoming increasingly clear to me, and I would also say that I was the youngest in the family by a lot, and I found actually taking the role very very difficult: the role of the authoritative figure when you've been the baby. So that was another thing that was hard. So anyway, we tore around here, and saw some most dreadful places. I met all these middle-aged women like myself all in a similar state, all sort of weeping and getting upset. I got that way that when one of them asked me if I'd seen a nice nursing home, I wouldn't tell them, because if I did they would put their name down too and they might get in first! I was just *horrified* with myself!

LP: They were probably all doing the same thing!

Alice: I just didn't realise that I could have got so *desperate*, and that was the word. (Conversation with Alice).

Alice describes how she and her husband tried to work out the best solution (Alice's mother had refused to live with them, despite their offer to care for her at their home):

Alice: We sat down, and got a whole lot of butcher's paper out, and we worked out the places, and we went over it again, whether we should bring her down here, or whether we should try to get her into the R- Nursing Home, and so on and so forth. We had a whole scenario worked out. (Conversation with Alice).

Decisions about treatment options on behalf of another person are particularly difficult to make, as they are often complicated by deception.

Temporality and spatiality

What is past or future for me is present in the world. It is often said that, within things themselves, the future is not yet, the past is no longer, while the present,

strictly speaking, is infinitesimal, so that time collapses (Merleau-Ponty, 1962, p. 412).

* * *

The final aspect of caring considered in this section is that of temporality. Cassell (1985) remarks that when someone is dying they and their carers seem to enter a different world (or at least lose contact with the “real” world) and, he says, “the passage of time, the orderly progression of life for the other actors, will not resume until long after death” (Cassell, 1985, p. 187). Illness and dying are of such importance that it is not surprising that those concerned with these issues become immersed in them and isolated from other people and activities. A stranger phenomenon is the oddly surreal, but entirely physical world, in which health professionals move, but which even the ill only fleetingly penetrate. Hospitals and other institutions are themselves further subdivided, each section or department devoted to a single ailment or condition, being connected only through the occasional mingling of the staff.

The Women’s Hospital was like a giant sandwich, each layer revealed in turn as the doors, like solidified curtains, opened when the lift stopped at each level. A disembodied, mechanical voice kept us informed of our progress as we ascended: “Level 2, Maternity; Level 3, Theatre Suites; Level 4, Recovery...” and so on, until we reached my destination, the top level, where I alighted to visit my mother. At one level, when the door swished open, we would see pregnant women in dressing gowns strolling to and fro, some wheeling structures which supported their intravenous drips, and others stood clutching packets of cigarettes while they waited for the lift to take them to the ground floor where they could escape outside for a smoke. The view of the next floor took us rapidly through time, and labour; here the babies were already born, wheeled past the open lift door in tiny trollies covered in pink or blue blankets. A far more serious atmosphere prevailed at the surgical level; here important people (who sometimes even broke away from their duties and joined us briefly for a ride) strode past in green crinkled gowns, their heads encased in paper caps and their feet silent in white booties. Groggy patients were being wheeled through the swing doors with round windows into the theatres, unconscious ones out again. Whenever the staff and patients joined us in the lift they exchanged jokes and remarks about the weather in a peculiarly stilted, self-conscious fashion. On one occasion someone had pinned a notice in the lift which read: “Happy birthday Prof. Pepperil”. Everyone who rode in the lift, staff and patients alike, was linked through this familiar greeting; we were all friends of the professor. (Extract from author’s notes).

This little scene, repeated in identical fashion over a period of six weeks, never failed to impress me. Being only a visitor, I had no real connection with this medical, and

medicalised world; I was simply an observer who shared the conduit linking the layers of activity and their participants.

Later, when my mother was dying of cancer, I found that the medical environment had constructed another world, this time one my mother and I shared, although I do not know what she thought of it.

Waiting rooms are places where we pretend, and we are all on our best behaviour; it is not acceptable to reveal to other waiting people what we are really thinking or feeling. One does not even allow oneself to speculate about other patients' conditions. It is enough to know that oncologists are concerned with only one type of patient. The oncologist shared his waiting room with several other doctors in a new building next to the private hospital. We parked in the car park at the rear of the building, made our way slowly and carefully to the lift door, our conversation confined to the inconsequential. We did not speculate about the possible outcome of the consultation. We didn't have any specific questions prepared; the visits were part of the game of sickness. The lift quietly elevated and then deposited us at the second level. We walked past several silent, unpopulated waiting rooms, expectant indoor plants ready to serve their therapeutic purpose when waiting patients finally filled the rooms. We finally reached the oncologist's domain (the journey took longer and longer, as the months passed). He shared the waiting room with several other doctors, but they were usually invisible, perhaps busy in the hospital. Waiting rooms have their own particular stamp, depending upon their purpose. This one was defined by the focal concern with cancer. There was no pathological variety among the patients; the only variable was age. The waiting room was an artificial world where the separation between doctor and patient and carer was carefully contained. Four closed doors indicated that there were other worlds besides the waiting room, but we were permitted only fleeting views of them. When I opened the secretary's door, for instance, it was with a sense of relief to discover that there were other people there; a desk decorated with a bunch of flowers, photos of the family, papers, a computer. I would exchange pleasantries with the secretary, who would announce our arrival to the oncologist, and then we would take our place in the waiting room next to our own potted palm tree. The once-again closed door re-established the strange suspended time and place of waiting. No one looked directly at anyone else, the quietness threatening to expose our innermost thoughts. The waiting patients and their carers, all of them no doubt covertly harbouring the seeds of despair, were briefly relieved of this despair during their time of occupancy in the waiting room. The calm waiting room provided respite from reality; it was a time to be savoured, it was a refuge in the midst of the relentless progress of life towards death. More importantly, here we were secure in the knowledge that none of us would succumb without the ritual of consultation and treatment.

Eventually this illusion of unreality would be shattered when the doctor himself would open his door, cheerfully welcoming us into his office as we greeted him with platitudes. Afterwards we retraced our steps, through our waiting room (rendered unfamiliar because its purpose was ended for the time being), past the other, empty waiting rooms and into the silent, carpeted lift, back out into the

world of ordinary people, noise, normality. Once home again, we did not talk about the cancer, or of dying, or about hospitals. We simply resumed our living; the monthly excursion was over. Waiting for the interview with the oncologist, and the consultation itself had the ironically, paradoxical effect of temporarily blotting out the cancer's presence. The visit had become a purpose in itself, a sort of sanctuary, and it was only upon returning to our own homes again that the true perspective was restored. (Extract from author's notes).

Although at first glance it would seem that these "worlds" constructed by medicine around the illness experience are purely physical in nature, this is not really the case. There is certainly an impression here of a world existing in parallel to reality, but there is also a feeling of timelessness about the world of the hospital, or the waiting room; that they are always there, unchanged and unaffected by visits from outsiders, who constantly come and go.

Retreating from the outside world does offer a chance to divest oneself of other responsibilities in order to concentrate on caring. Roth, for example, writes that the circumstances at the time his father was ill, made it possible to concentrate wholly upon his father's illness. During this time he was living in an hotel while his partner, Claire Bloom, was away in London, and he was unable to pursue his writing because of the preoccupation with his father's condition. This was, he wrote, a "peculiarly opportune fortuity" (Roth, 1991, p. 16). Bloom offered to come back and help, but Roth declined, writing that he preferred to be alone to "be concentrated on what has to be done." There are, however, disadvantages in withdrawing from the normal world: "Though all the concentration isn't so wonderful either. I can't read, God knows I can't write – I can't even watch a stupid baseball game. I absolutely cannot think. I can't do a thing" (p. 129). There is room to concentrate only on one thing; caring for his father. Escape through leisure is not possible.

De Beauvoir was also trapped, but at the same time comforted, by the monotony of routine:

I, too, grew used to this way of life. I arrived at eight in the evening; Poupette told me how the day had passed; Dr N came by. Mademoiselle Cournet appeared, and I read in the lobby while she changed the dressing. Four times a day, a table loaded with bandages, gauze, linen cotton-wool, sticking plaster, tins, basins and scissors was wheeled into the room; I studiously looked away when it was wheeled out again. Mademoiselle Cournet, helped by a nurse she knew, washed

Maman and made her ready for the night. I went to bed. She gave Maman various injections, and then she went off to drink a cup of coffee, while I read by the light of the bedside lamp. She came back and sat down near the door:...she read and knitted. There was the slight sound of the electric apparatus that caused the mattress to vibrate. I went to sleep. At seven, time to get up (de Beauvoir, 1966, p. 63).

Mme de Beauvoir herself benefited from the regularity of her new life, saying to her daughter: "I like this routine very much" (p. 64). The familiarity of routine and surroundings brings a certain comfort, despite the associations. On the final journey to the hospital (to pay the bill), de Beauvoir tells herself that she will never again need to make that journey or see the hospital room, but she would willingly have faced these hated images again if she could have her mother restored to health. The spatial and temporal world contracts as preoccupation with the dying person consumes the daughter:

The transition of my mother to a living corpse had been definitely accomplished. The world had shrunk to the size of her room: when I crossed Paris in a taxi I saw nothing more than a stage with extras walking about on it. My real life took place at her side, and it had only one aim – protecting her (p. 64).

In a variety of ways these stories reflect Cassell's notion of the separate world which seems to form around illness. Even the "parallel universe" of the hospital environment really illustrates the exclusiveness of the medical world, which temporally welcomes and absorbs the ill, only to expel them as soon as their health is recovered, or becomes unrecoverable. The purely physical barrier erected by medicine is reflected at an existential level in de Beauvoir's account of the monotonous routine of hospital procedure; the nightly ritual of changing the dressings and preparing the patient for the night, the night itself characterised by the mesmerising sound of the vibrating mattress which was designed (unsuccessfully, as it transpired) to prevent bedsores. The waiting room story again tells of the alienating medical environment, but here it is not even populated; the staff themselves are invisible until they have been deliberately sought and exposed. On the other hand, de Beauvoir had embraced that world so completely that the outside, everyday world, away from her mother's bedside, had taken on the air of unreality or illusion that characterizes the theatre.

How can these notions of shifting and parallel worlds, which we may or may not be able to enter and leave at will, be explained existentially? And why is it that the ability to

focus completely upon a task is restrictive in that it precludes us from continuing to function in the broader public world? These questions can be answered to some extent by the phenomenon of temporality, and also by the work of Mayeroff, who tells us that caring has the effect of “ordering” our lives by bringing to the foreground those things which are concerned with caring:

Such inclusive ordering requires giving up certain things and activities, and may thus be seen to include an element of submission. But this submission, like the voluntary submission of the craftsman to his discipline and the requirements of his materials, is basically liberating and affirming (Mayeroff, 1971, p. 38).

Reflections on the caring role

Reflecting upon their experience as a whole, most of the carers expressed satisfaction with the way in which they had performed their role. The question of when the caring role ends cannot be answered categorically. For example, Brad reports he has “no regrets” about how he conducted himself when his mother was dying, saying: “I’m proud of that. I did all I could, to make a good living when she was still alive, and good dying when she was dying, and so did we all”. By supporting her in her request that treatment be ended, the family was able to control the situation, and his mother’s dying happened in the way they wished, which was how she wanted it herself.

Brad: The outcome of it all was that she died relatively pain-free, in her own home, surrounded by her family, knowing what was going to happen to her belongings, and her funeral was as she wanted then to be. So that’s pretty big. (Conversation with Brad).

Susan, too is proud of the way she cared for her father, but understands that her mother’s grief gives her a different perspective on the episode.

Susan: [My mother and I] were “co-caring,” but the way she looks back on it, now that I look back I realise that yes, it was the same sort of thing. It’s all very very sad for her, whereas I feel quite joyful about the whole thing. I’m sad, and I miss him, and I’d love to have him back, but I’m very proud of his last couple of months, and there *was* a lot of joy in there. Even the day he died I felt quite uplifted. It really is opposite sides of the coin. (Conversation with Susan).

Interestingly, at times her father responded more positively to Susan’s care than his wife’s:

Susan: But Dad was so *scared* with the hallucinations. He got aggressive with Mum; he never got aggressive with me. He was just a scared little man. It was just a matter of holding on to him, and trying to keep him focused until he came out of it. (Conversation with Susan).

Anne's caring continued after her mother's death, when, in her sister's words, she "made her comfortable," the notion that their mother would somehow be aware of this special attention resounding strongly in Zoe's words. Alice, despite the trauma of her experience, still "would never not have not done it," and although certainly not uplifting, she said that "it was certainly a very meaningful experience, and I learnt a lot."

Conclusion

This chapter deals with the overarching concerns of caring, aspects which cannot easily be defined, or, as Anne puts it, be "intellectualised". Milton Mayeroff's foundational text, *On Caring*, introduces the idea that caring involves a number of fundamental and interrelated "ingredients" (knowing, alternating rhythms, patience, honesty, trust, humility, hope and courage), notions that also interest Fromm and Marcel. Evidence of these characteristics is found in the experiences of the carers taken from the primary and secondary sources used in the thesis. First, the ill person's experience of care is considered as a background to the carer's experiences. A comparison of nursing and lay perceptions of caring indicates that they are fundamentally different, to the extent that it is possible for a person to "switch" from one modality to another at will. Other broad aspects of caring that emerge are the problem honesty with the dying person, the deeply symbolic significance of nourishment in caring, and the variety of ways through which communication is possible between carer and the ill person. Music appears to offer a particularly potent and important means of communication between the two people. The strategy of self-deception is sometimes used by the carers to overcome the anguish of accepting the fact that their parents are dying, while the provision of simple comfort to the dying proves highly satisfying to the carer. In contrast, other tasks associated with caring can be extremely difficult and stressful, particularly those which signify the dying person's loss of control over everyday functions such as personal care and decision making. Finally, it appears that carers frequently experience their role as taking place a unique space and time frame which is removed from everyday life.

The meaning of caring for someone who is dying, particularly someone so well known as a parent, can only be appreciated and understood fully through the experience itself. Brett writes that from an observer's perspective, caring for a frail parent appears onerous in the extreme, but she found that when she herself undertook the care of her own mother, she realised "what a blessing it was to have that grace-time; to give back some of the love and nourishment that she had given to [Brett and her sister] over the years" (Brett, 2001, pp. 17-18). Anne's words, which capture the understanding of caring that is conveyed through the stories and examples cited in this chapter, are a fitting conclusion to this chapter:

Perhaps there is an element in the caring role, that it is not highly intellectual, or examined, what I'm saying is that what I learned about that relationship with my mother is that it just flowed. (Conversation with Anne).

Chapter Six. Hope and suffering

Suffering isn't noble - it's awful, often horrifyingly so. Suffering in itself is a terrible thing. But suffering has a context; the experience of suffering is coloured and changed by the meaning we ascribe to it. I don't want to just "suffer." I want to create something from it, learn something from it, do something with it (Brett, 2001, p. 183).

* * *

The discussion in the previous chapter suggests that caring is comprised of a range of activities and emotional experiences which are unique to each individual, although there may be superficial similarities amongst different carers. The concern for the sick person's comfort and welfare apparent in such activities as the sharing of reminiscences, can also be manifested as a preoccupation so intense that it represents a virtual fusion of the two people's worlds. In supporting their parents as they face increasing debility and ultimate death, while at the same time knowing that they themselves are about to be confronted with a great personal loss, the carers may experience suffering and anguish of a similar magnitude to that of their parents. It cannot, however, replicate the parent's experience.

The aim of this chapter is to explore, from the carer's perspective, the meaning of suffering and of hope that can emerge from suffering. It builds upon this observation that at times carers can undergo vicarious suffering as they see their parents dying in addition to suffering through their own unique anguish and despair. The clear and powerful relationship between suffering and hope is found in the primary and secondary material used in this study, and in this chapter the nature of suffering and the emergence of hope is examined. To support these findings, a number of the theories which deal with the notion that suffering is fundamental to human development are discussed, in particular those found in the works of Kleinman, Scheler, Frankl, Marcel. Following this, the theoretical arguments, established by Heidegger and Merleau-Ponty, that hope and suffering are inextricably linked are then explored.

A note on the ordering of material in this chapter is necessary here. The significance of these issues in the caring experience emerged strongly during the initial study of the primary and secondary material, but because of their existential complexity it was deemed more expedient to enter into a theoretical survey of the concepts before discussing their presence in the stories of caring used in the thesis.

An existential view of suffering

At a basic level, suffering is understood as a purely sensory experience, manifested as physical sensations which can be experienced by organisms whose nervous systems possess a degree of complexity sufficient to register sensations of pain. In this schema, suffering and physical pain are considered to be synonymous. The Macquarie Dictionary defines “pain” as “bodily or mental suffering of distress (opposed to *pleasure*).” The distinction between pain and suffering is somewhat blurred in these definitions, the two words being used interchangeably. The concern here, however, is with the “phenomenologically different” understanding of suffering as a spiritual or existential phenomenon, which is endowed with social and moral dimensions, and whose *causal agent* is pain (either physical or mental). (See for example, Cassell, 1991; Scheler, 1974; Young, 1997).¹

Kleinman and Kleinman (1997) describe suffering as “one of the existential grounds of human experience,” a phenomenon which is always understood and experienced within particular cultural, social and historical frameworks. The constantly changing nature of these values over time, and their enormous variety throughout the world’s communities and nations, means that it is impossible to define suffering objectively. David Morris, for

¹ The separation of suffering from physical pain is exemplified in Brian Keenan’s experience of being beaten by his captors while held hostage for four and a half years in Beirut during the 1980s. He writes:

...[I]t was the psychological and emotional shock of the beatings, rather than the pain, that struck each man. The beatings were not merely a bodily encounter. The mind engaged itself with another kind of intensity quite unrelated to the event; it fused with something previously unknown. For such experiences one developed strategies of mind to hold oneself together (Keenan, 1992, p. xv).

example, writes that “[s]uffering...is not a raw datum, a natural phenomenon we can identify and measure, but a social status that we extend or withhold. We extend or withhold it depending largely on whether the sufferer falls within our moral community” (Morris, 1997, p. 40). Kleinman, Das and Lock also argue that the recognition of suffering’s moral (and political) connotations indicates that such “social suffering” can occur on a grand scale, as in “the suffering of a nation” (Kleinman, Das, & Lock, 1997). Nevertheless, suffering remains essentially an individual experience, and can be understood existentially only through the narratives of individuals.

Max Scheler (1974) observes that the understanding of the meaning of suffering is the basis of all great religions and philosophies, and that they instruct their followers how to “suffer correctly,” and to overcome suffering in order to reach a state of grace, or to achieve some sort of redemption. This type of suffering is fundamental to the human condition, and its deep significance in the development and construction of the Self is reflected in this universal recognition of its transcendental nature. Indeed, Adrian Moulyn (1982) claims that suffering is essential to life, in that humans must suffer in order to develop in a moral and spiritual way.

Scheler, however, views suffering as an opportunity rather than a necessity for personal development. He observes that human experiences and emotions are never without reason. For example, fear warns us to avoid danger, while fatigue warns us to rest, and shame calls on us to act to preserve the integrity of the person. These phenomena prompt behaviours which enable the individual to cope with a particular situation, and in this respect suffering is similar. An important point Scheler makes here is that the meanings that bring about the new attitude or behaviour are separate from the original event that caused them. He also alludes to the cultural and historical nature of suffering when he writes: “The stimuli that cause the physical pain to which the emotions react are constant in history. But the capacity for enduring and tolerating pain, which are quite different from the stimuli, can be very different in the history of civilization” (Scheler, 1974, p. 122). In other words, the nature of suffering and its effects are subjective, and are shaped by historical, cultural and individual factors.

Victor Frankl (1969) and Gabriel Marcel (1962) agree that suffering, interpreted as loss of integrity and freedom, is not (or at least should not be), without purpose. Marcel observes that overcoming suffering, and the restoration or growth of the Self is achieved through hope; it is hope's "mission" to relieve us of the anguish of suffering. Hope is, however, not directed towards a concrete goal; it is directed towards an abstraction. Hope cannot be equated with optimism, which is a confident imagining of a particular (and favourable) outcome; it is more than this. Hope is a kind of mysterious "super-rational" process or, as Marcel tells us, "hope is a mystery and not a problem" (Marcel, 1962, p. 35); in other words, hope is not something that can be simply solved; it is inexplicable.

Kleinman (1988) examines the link between hoping and the construction of an illness narrative as a mechanism through which sick people overcome suffering to find meaning in their experience of illness. He found that narrative construction is facilitated by the involvement of others in what he calls "empathic witnessing" (Kleinman, 1988). Kleinman defines this as "the existential commitment to be with the sick person and to facilitate his or her building of an illness narrative that will make sense of and give value to the experience" (p. 48). The illness narrative, around which hope develops, needs to be communicated in some way with another person, so that validation of a new narrative can occur.² The role of the carer is crucial in this process, which rarely happens in isolation. Arthur Frank (1995) envisages a continuum in narrative construction in which chaos and order are the opposite extremes. The "absence of narrative order" in a person's story signifies what he terms "chaos narrative." In fact, however, the order of events which appears in a story is imposed retrospectively. Events are arranged in order to construct a meaningful narrative; that is, to make sense of things. The purpose or function of telling a story is to construct a meaning of what has happened, to be able to look at events from a distance, separate oneself from them and locate them in the wider context of life. Seemingly random and disconnected events can have no meaning in isolation, and the chaos narrative "has no narrative sequence, only an incessant present with no memorable

² Michael White and David Epston have developed a narrative therapy on this principle, which also involves participation of an audience to "perform meaning" (White & Epston, 1989; 1990).

past and no future worth anticipating,” and is disturbing in its disjointedness (Frank, 1995, p. 99). The teller of the chaos narrative is the “wounded storyteller,” for whom there is no “space,” no time in which to reflect and impose some order upon what is happening.

Defining suffering is clearly a difficult task, and this is especially so in the third person. Such vicarious understanding of suffering can be achieved only “by the methods of extrospection, identification, empathy, and projection” (Moulyn, 1982, p. 277). In the following section, the theories of suffering briefly reviewed above are examined more closely, with particular reference to the writing of Heidegger and Merleau-Ponty.

Theories of suffering and hope

[Maman said] “I’m so utterly miserable,” in that child’s voice that pierced me to the heart. How completely alone she was! I touched her, I talked to her, but it was impossible to enter into her suffering (de Beauvoir, 1966, p. 72).

* * *

Happiness flees to always greater distances from one who hunts it. Suffering approaches the fugitive the more quickly the more rapidly he flees from it Marcel, 1962 #633, p. 154].

* * *

Heidegger and Merleau-Ponty

From an existential point of view, suffering, as a state of being, is an innate feature of caring, experienced by both the carer and the ill person. It is possible that the relief of suffering and subsequent restoration of hope in the ill person are the carer’s primary objectives, and the informal carer, because of privileged knowledge and understanding of the sick person, is uniquely placed to do this. If this proves impossible, that in itself becomes a source of suffering to the carer. In the following discussion, suffering is interpreted primarily as a state arising when, for some traumatic reason, the individual’s life and future expectations have been torn asunder, cast adrift from their customary foundations. Hope, a vision for the future, is once more possible when the sufferer comes to acknowledge and accept these new circumstances.

According to Heidegger, (1962) the envisaged future is differentiated into the “authentic future,” which is “anticipated,” and the “inauthentic future,” which is “awaited.” The authentic future is related to Dasein, and is revealed through resoluteness. The inauthentic future is projected through everyday, that is, superficial concerns which are dissociated from the reality of Being: “The authentic coming-towards-itself of anticipatory resoluteness is at the same time a coming-back to one’s ownmost Self, which has been thrown into its individualization” (p. 388). If the “potentiality-for-Being” is forgotten and only the facts of the immediate present are taken into account, we await the inauthentic future.

This schema suggests the existence of some type of dynamic mechanism whereby it is possible that our potentiality for Being, which derives from and incorporates all past experiences, can in certain circumstances be forgotten. In this event, it needs somehow to be retrieved or disclosed, so we can move away from merely awaiting an inauthentic future to the anticipation of the authentic future. “Awaiting” appears to be a static or stagnant state: the future, although envisaged, cannot eventuate because it is founded upon inauthentic data. Awaiting such a future, trapped by the inauthentic concerns of the present, and not yet able to reach into the resources of Dasein’s “ownmost potentiality-for-Being” (p. 386), resembles suffering.

Fear, which would appear then to be a primary cause of suffering, is, according to Heidegger, an “inauthentic state-of-mind” which arises in the face of something concrete (an “oncoming evil”) that threatens us, and is detrimental to our potentiality-for-Being. Heidegger asks: “Is not the primary meaning of fear the future, and least of all, one’s having been?” (p. 341). Citing Aristotle, he likens fear to a “a kind of depression or bewilderment,” which has the effect of making one leap randomly from possibility to possibility, both authentic and inauthentic. The person who displays fear becomes lost (“forgetting oneself”) amongst the plethora of possibilities. In this way, fear induces suffering: “The having forgotten which goes with such bewilderment modifies the

awaiting too and gives it the character of a depressed or bewildered awaiting which is distinct from any pure expectation” (p. 392).³

Anxiety is similar to fear, except that it is concerned with something undefined rather than concrete: “Anxiety is anxious in the face of the ‘nothing’ of the world.” But, Heidegger warns, that does not mean that anxiety stems from the absence of what is present-at-hand. It means, rather, that “[t]he present-at-hand must be encountered in just *such* a way that it does *not* have *any* involvement *whatsoever*, but can show itself as an empty mercilessness” (p. 393). He continues:

The forgetting which is constitutive for fear, bewilders Dasein and lets it drift back and forth between “worldly” possibilities which it has not seized upon. In contrast to this making-present which is not held on to, the Present of anxiety is *held on to* when one brings oneself back to one’s ownmost thrownness. The existential meaning of anxiety is such that it cannot lose itself in something with which it might be concerned. If anything like this happens in a similar state-of-mind, this is fear, which the everyday understanding confuses with anxiety. But even though the Present of anxiety is *held on to*, it does not as yet have the character of the moment of vision, which temporalizes itself in resolution. Anxiety merely brings one into the mood for a *possible* resolution. The Present of anxiety holds the moment of vision *at the ready* [auf dem Sprung]; as such a moment it itself, and only itself, is possible (Heidegger, 1962, p. 394).

Fear, then, has “environmental” origins, while anxiety comes from within; it “springs from Dasein itself.” But anxiety does not detach the person from the world; it can exist only in one who is “resolute,” and cannot co-exist with fear. Heidegger explains “resoluteness” as follows:

Resoluteness, as *authentic Being-one’s-Self* does not detach Dasein from its world, nor does it isolate it so that it becomes a free-floating “I”. And how should it, when resoluteness as authentic disclosedness, is *authentically* nothing else than *Being-in-the-world*? Resoluteness brings the Self right into its current concerned Being-alongside what is ready-to-hand, and pushes it into solicitous Being with Others (Heidegger, 1962, p. 344).

Resoluteness paves the way for anxiety, in which state communication with others (solicitude) becomes a possibility, and the conditions for care (in the sense of this thesis) are in place. While fear prevails, caring is not possible.

³ There is a noticeable resemblance between Heidegger’s existential description of fear and Frank’s concept of the “chaos narrative” (see pages 177, 195).

Thus overcoming fear (which as indicated above, can be understood as a major cause of suffering) is the primary objective of care, but how is this achieved? It would seem that in fear one's state of mind is literally paralysed, focused upon the imagined consequences of the present situation (a "*malum futurum*"), in the sense that there is no possibility of freeing oneself from the grasp of the present in order to look to an authentic future. Shifting from this state to one of anxiety through resoluteness means that once more one's entire Being (including the environmental Present) becomes accessible. From anxiety, a new mood, hope, arises.⁴ Hope, like fear, is an expectation of the future, but in this case it is a "*bonum futurum*." Of hope, Heidegger writes:

But what is decisive for the structure of hope as a phenomenon, is not so much the "futural" character of that *to which* it relates itself but rather the existential meaning of *hoping* itself. Even here its character as a mood lies primarily in hoping as *hoping for something for oneself* [*Fursich-erhoffen*]. He who hopes takes himself *with* him into his hope, as it were, and brings himself up against what he hopes for. But this presupposes that he has somehow arrived at himself. To say that hope *brings alleviation* [*erleichtert*] from depressing misgivings, means merely that even hope, as a state-of-mind, is still related to our burdens, and related in the mode of *Being-as-having been* (Heidegger, 1962, p. 396)).

Merleau-Ponty's analysis of hope is also couched in terms of temporality. He argues that the fact of our birth means that we are committed to time; somewhere in the future death awaits us, before which event we are incomplete beings. Within the boundaries of birth and death lies the totality of our being. Merleau-Ponty writes: "Time exists for me only because I am situated in it, that is, because I become aware of myself as already committed to it, because the whole of my being is not given to me incarnate..." (p. 423). In addition, "[a] former experience, a coming experience, in order that they may appear to me, need to be borne into being by a primary consciousness, which in this case is my inner perception of recollection or imagination" (p. 424). The world is in place, but for the individual (who must always have a certain perspective, although this, as shown, must change continually), there is a "possibility of situations" (p. 407). Anticipating the future (whether fearfully or not) means that we bring it forward, towards us as a "present" which will then pass on to the past. Prospection, the anticipation of the future, is then a

⁴ It is interesting to note here that C. S. Lewis likens grief to fear. Certainly the overwhelming impression from his account of grief is that of being trapped, or captured, by his grief; of being unable to move away from that state until somehow, with time, he becomes accustomed to the absence of his wife and peace returns slowly to his life (Lewis, 1961).

sort of retrospection (“anticipatory retrospection”) (p. 414). To Merleau-Ponty, suffering resembles a chaotic state, in which one is trapped in a dream-like, atemporal state (dreaming being eternal, or timeless), the links with the temporal world severed. Hope, which rescues us from suffering, is a particular type of projection, described as a transcendent state, rising from this atemporal state of suffering. Transcendence is explained thus:

The very experience of transcendent things is possible only provided their project is borne, and discovered, within myself. When I say that things are transcendent, this means that I do not possess them, that I do not circumambulate them; they are transcendent to the extent that I am ignorant of what they are, and blindly assert their very existence (Merleau-Ponty, 1962, p. 369).

Finally, when hope (or even thought, which is in the same way “ahead of itself”), has transcended fear, those things that contributed to it fall into place (“they are dispersed and distributed each to its due place” [p. 371]).

Suffering and loneliness

Although Heidegger refers to the notion that in overcoming fear we are receptive to solicitude in others, both he and Merleau-Ponty convey a sense of aloneness in their conceptualisations of fear, suffering and hope. The common understanding of suffering as a state induced by trauma from which hope emerges (posited, for example by Scheler [1974]), implies that the individual has a moral responsibility to search for a meaning in suffering. Through a process which integrates past experience with present suffering, hope is the catalyst for the synthesis of possibilities which are unimaginable without it. Frankl (1969) reassures us by saying that suffering is by no means a prerequisite for discovering meaning in life, and certainly if suffering can be avoided then it should be, because, he points out, “unnecessary suffering is masochism.” But, even if suffering cannot be avoided, the sufferer is still free to choose his or her attitude towards it. Suffering is at once a freedom and a burden:

When a man finds it his destiny to suffer, he will have to accept his suffering as his task; his single and unique task. He will have to acknowledge the fact that even in suffering he is unique and alone in the universe. No one can relieve him of his suffering or suffer in his place. His unique opportunity lies in the way in which he bears his burden (Frankl, 1969, p. 99).

The price of this freedom is isolation; suffering cannot be shared with others.

In his phenomenological study *Loneliness*, Clark Moustakas (1961) demonstrates the existential distinction between loneliness and solitude. He argues that loneliness is a condition which parallels, or is, perhaps, integral to suffering; while solitude is a state which is deliberately sought as a refuge from the stresses of life, which, he claims, “is as much an intrinsic desire in man as his gregariousness” (Moustakas, 1972, p. 41).⁵ Of loneliness itself, he writes:

There is a power in loneliness, a purity, self-immersion, and depth which is unlike any other experience. Being lonely is such a total, direct, vivid existence, so deeply felt, so startlingly different, that there is no room for any other perception, feeling, or awareness. Loneliness is an organic experience which points to nothing else, is for no other purpose and results in nothing but the realisation of itself (Moustakas, 1961, p. 8).

The retreat to solitude takes courage, and solitude is an existential state with intangible, unquantifiable qualities, which Moustakas calls “aesthetic and mystical.”

Frankl and Moustakas are referring to suffering and isolation in general, but illness creates a particular sort of loneliness in a person, a phenomenon referred to by Frank (1995) as “the monadic body” (Frank, 1995). Frank observes that patients (and particularly the cancer patients whom he studied) tend to exist in isolation, and do not communicate with other patients. Medicine encourages this behaviour; even in the hospitals where patients are in close proximity to each other, a physical distance is maintained that is just large enough to make meaningful contact difficult. Patients also tend to communicate individually with doctors, rather than *en masse*. There is, then, a curious paradox in that patients might share a disease, and might even share a doctor, but

⁵ In his semi-autobiographical novel *The House of the Dead*, based on his term of imprisonment in Siberia, Dostoyevsky, writes of the paradox of “forced communal existence” within the confinement of imprisonment:

...I could never have conceived how terrible and agonizing it would be not once, not even for one minute of all the ten years of my imprisonment, to be alone. At work to be constantly under guard, in the barracks to be with two hundred other convicts and not once, never once to be alone! (Dostoyevsky, 1985, p. 30).

Despite this unremitting surveillance, paradoxically, he gradually came to cherish the terrible isolation he experienced at first because, being “inwardly alone,” it presented him with a unique opportunity to review his entire life.

their experience of the disease is completely individual and isolated. Such a situation does not encourage patients to form a collectivity.

This situation is further compounded by what Kleinman calls the “euphemization of suffering,” which, he believes, undermines the value of suffering itself by recasting it as disease, thereby denying its moral and existential dimension. In this way, “...an existential experience of tragedy and loss is reconstructed as a professionally managed experience of major depressive disorder” (Kleinman, 1995, p. 35). He points out that in America nearly all of the existential experiences of people suffering from diseases like cancer can be made to fit into the American Psychiatric Association’s (APA) classification of “serious depressive disorder,” effectively denying the legitimacy of this experience of tragedy and loss as fundamentally human experiences.⁶ The medicalisation of suffering insulates doctors from the suffering of their patients and relieves them from the responsibility to alleviate it in a meaningful way. This is demonstrated by the APA’s *DSM-III-R* definition of post-traumatic stress disorder (PTSD), which is based on the assumption that suffering of any sort should be overcome; it should not be endured. If the “symptoms,” for example feelings of grief after the loss of a loved relative or friend, remain after several months, then the person is deemed to be suffering from a disease, PTSD, rather than experiencing a natural reaction to the event. Kleinman writes:

The idea in the DSM is that suffering can not and should not be endured. It should be brought to an end. This is central to the ideology of America: there is nothing that needs to be endured. Even memories can be “worked through.” It is sadly wrong (p. 180).

Such contrived mechanisms (whatever the reason for them) are counter to what is for many a natural desire to share their suffering with others. For example, upon learning the nature and seriousness of his illness, Herman Roth’s reaction was to recall the medical events in the family’s history:

⁶ Not only medicine is guilty of this; anthropology, which claims to place human suffering in a moral framework, is another culprit. Kleinman writes:

The interpretation of some person’s or group’s suffering as the reproduction of oppressive relationships of production, the symbolization of dynamic conflicts in the interior of the self, or as resistance to authority, is a transformation of everyday experience of the same order as those pathologizing restrictions within biomedicine (Kleinman, 1995, p. 96).

...on and on, remembering the illnesses, the operations, the fevers, the transfusions, the recoveries, the comas, the vigils, the deaths, the burials – his mind, in its habitual way, working to detach him from the agonizing isolation of a man at the edge of oblivion and to connect the brain tumor to a larger history, to place his suffering in a context where he was no longer someone alone with an affliction peculiarly and horribly his own but a member of a clan whose trials he knew and accepted and had no choice but to share (Roth, 1991, pp. 70-71).

Here Herman was desperately trying to soften the dread of being alone in his anguish by placing his experience in the wider suffering of his family. Such a community of suffering is evident on a larger scale in which the suffering of the individual can be subsumed in the vast suffering of a nation, for example, in the collective suffering of the Russian people, the Jewish holocaust, or the genocidal destruction of the Cambodians. People who suffer, as did Herman Roth when the terrible diagnosis was made known to him, may seek comfort in the company of others who have also suffered, despite the fact that ultimately suffering is a solitary, individual experience. C. S. Lewis captures this truth when he describes the last night of his wife's life:

It is incredible how much happiness, even how much gaiety, we sometimes had together after all hope was gone. How long, how tranquilly, how nourishingly, we talked together that last night!

And yet, not quite together. There's a limit to the "one flesh." You can't really share someone else's weakness, or fear or pain. What you feel may be bad. It might conceivably be as bad as what the other felt, though I should distrust anyone who claimed that it was. But it would still be quite different. When I speak of fear, I mean the merely animal fear, the recoil of the organism from its destruction; the smothery feeling; the sense of being a rat in a trap. It can't be transferred. The mind can sympathize; the body, less... We both knew this. I had my miseries, not hers; she had hers, not mine (Lewis, 1961, p. 13).

Morris (1997) suggests that the inability to share suffering, its "voicelessness," indicates that suffering is "ultimately unknowable." He observes that people write about their experiences of suffering in an attempt to share it with others, to enter into a community of sufferers. However, such narratives usually view suffering retrospectively, after it has been overcome.⁷ In this respect, Lewis' *A Grief Observed* differs, as it documents his

⁷ Books such as *Songs of Strength*, a collection of illness stories narrated by women who were cancer sufferers, illustrate this point. In the Foreword to the book, the stories are described as being "tales of anger, frustration and disappointment but equally of hope, courage, and for most, survival" (Allbrook, 1997).

voyage through the suffering of grief to recovery as hope returns and rescues him from despair.

The link between suffering and isolation also appears in the work of Gabriel Marcel (1962) who uses the metaphor of darkness to describe suffering (or “trial”) during which, he says, we long for a form of light to relieve us from the “captivity” of darkness. A special sort of endurance is involved during captivity, and certain conditions must prevail in order that endurance can become a part of this experience. Captivity means that freedom (to do almost anything) is restricted in many ways and, in addition, implies the impossibility of “rising to a certain fullness of life, which may be in the realms of sensation or even of thought in the strict sense of the word” (Marcel, 1962, p. 30). This is the type of experience writers, or any artists for that matter, might have when inspiration deserts them in the event known as “writer’s block.” It could also be seen as a type of exile, or isolation from captivity of suffering:

We can, therefore, say that all captivity partakes of the nature of alienation. It may be in reality that, in taking me out of myself, it gives me an opportunity of realising far more acutely than I should have done without it, the nature of that lost integrity which I now long to regain (pp. 30-31).

The case of a sick person who does not appreciate, or perhaps even understand, the meaning of health until it is lost is an illustration of this point. The experience of illness is framed always in negative terms (dis-ease, dis-ability), that is, in relation to the world of health and wholeness of body. (See, for example, Barnard, 1995; Gadamer, 1996).⁸

The independence of visceral functions from consciousness means that we rely utterly upon them to sustain us, and this is what makes their failure such a betrayal. We are in fact commanded by our bodies; our bodies control us. When illness strikes, the body

⁸ This paradox can be understood in terms of Heidegger’s concept of that which is “ready-to-hand.” He writes that

...when something ready-to-hand is found missing, though its everyday presence [Zugegensein] has been so obvious that we have never taken any notice of it, this makes a *break* in those referential contexts which circumspection discovers. Our circumspection comes up against emptiness, and now sees for the first time *what* the missing article was ready-to-hand *with*, and *what* it was ready-to-hand *for*. The environment announces itself afresh (Heidegger, 1993, p. 105; emphasis in original text).

immediately becomes enormously important, to the extent that we can become obsessed by it. The desire to explain illness in terms that are acceptable, and avoid this concept of betrayal and failure is common, and not confined to the layperson (see, for example, Kleinman, 1995; Willis, 1989). For the ill person, this represents an attempt to wrest back illness as a valid experience and restore its existential significance by reclaiming it from medicine. This is particularly important for those suffering from long-term or chronic illnesses, for example cancer. On the other hand, the practice of concealing the gravity or even the nature of a person's illness denies them the opportunity to make sense of their condition in a realistic way (McNamara, 2000).

Eric Cassell interprets despair arising from illness as a manifestation of loss of control, arguing that "[s]uffering occurs when an impending destruction of the person is perceived; it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner" (Cassell, 1991, p. 33). People in this situation devise strategies for reducing suffering, for example,

- to live entirely in the present because suffering requires anticipating a feared future;
- to develop an indifference to what is happening;
- to deny the reality of the situation; and
- to become flexible by adapting to changed circumstances, and adjusting aspirations for the future within these terms.⁹

Cassell is concerned with suffering in chronic illness, but this applies equally to other non-acute illnesses like cancer. He writes:

Suffering arises in chronic illness because of the conflicts within the person that are generated by the simultaneous need to respond to the demands and limitations of the body and to the forces of society and group life. These struggles to meet opposing needs become internalised, and suffering occurs as the integrity of the person is threatened by the dissension. The suffering is exacerbated by conflicts of the self with the body and by dissension within the various parts, or aspects, of the person (Cassell, 1991, p. 64).

⁹ Cassell's model bears similarities to that of Elizabeth Kubler-Ross, in which she identifies a staged model of grief and dying which identifies the processes through which people progress as denial, anger, rejection, bargaining and finally, acceptance (Kubler-Ross, 1969).

Thus suffering is entirely subjective and is a function of the way in which the ill person constructs his or her situation.

Suffering is not confined to the ill, but is also experienced by those who care for them. Carers, too, become segregated, gathering themselves into discrete communities according to the illness suffered by those for whom they care. As the carer of a person with cancer, for example, I felt, and to a certain extent still feel, excluded from the experiences of those who cared for those with Alzheimer's disease, or people who had suffered a stroke. Carers seem to belong to exclusive "clubs." People with Alzheimer's disease, for instance, are said to lose their original identities and in effect become other people, or worse, nonpersons, who occupy a different "space," and their caring relatives grieve continually for the person who is already irretrievably lost even before their death. A diagnosis of cancer has a different effect. So entrenched are the myths surrounding cancer that the cancer patient's relatives regard it as a death sentence, despite medical advances that have virtually transformed it into a chronic disease (Sontag, 1978). A disease thus confers a particular identity upon their carers as well as the sufferers themselves. Diagnosis, followed by acknowledgment, and finally the acceptance of a disease state creates a new dimension which excludes those who are not privy to it, and embraces those who are with the warmth and concern of familiarity. Fellow-travellers in the world of illness support each other through common experience and knowledge.

Suffering and the fear of death

*"Dying is simple," she said.
"What's worst is ... the separation."
When she no longer spoke,
they lay alone together, touching,
and she fixed on him
her beautiful enormous round brown eyes,
shining, unblinking,
and passionate with love and dread.
From Last Days (Hall, 1998, p. 42).
* * **

When caring for dying patients, the doctor has a certain degree of power. If the fear of the dying process itself, which is often related to the fear of losing control, can be removed,

the patient has the opportunity to die calmly. The role of the doctor, and of medicine, is in these cases not to take over the patient's control but to support him or her in controlling the situation. Cassell admits, however, that not all patients can accept the fact of their dying, and if denial is their way of coping, then this should also be supported if that is what they choose.

Should suffering not be overcome, it can transform the fear of death to the longing for death as a means of escape. For example, Scheler warns that it is futile to try to deny the causes of suffering. Reality, that is the cause of suffering, must be faced otherwise we can look only to annihilation to relieve suffering. Indeed, denial becomes in itself a form of even greater suffering because it offers no chance for acknowledgment, the precursor to hope. He concludes that "...this technique of fleeing from suffering *must* end in a longing for death" (Scheler, 1974, p. 155). Suffering can be met in a variety of ways, including "dulling of the suffering to the point of apathy, heroic struggle against suffering, and suppression of suffering to the point of finding evidence that it is our illusion" (p. 155). Of these, the third offers a path to hope and the dissolution of suffering.

Adrian Moulynn (1982) claims that as time can be experienced as a measurable entity (objectively) or as a lived experience (subjectively), we possess a "dualistic temporal structure" which is responsible for the "two major fractures" of existence: the fear of loneliness and the dread of death, and it is the "dread of death" that is the most terrible because as human beings we have some foreknowledge of it. "Being alone (which, as previously mentioned, and which Moustakas demonstrates so effectively), does not necessarily imply "loneliness". On the other hand, it is possible to experience a state of loneliness when one is in the presence of others who are strangers. Moulynn argues that loneliness and dread of death are very similar, both being expressions of the human need of association with other beings; loneliness foreshadows the absolute, eternal isolation of death. We live into the future in both objective and subjective time, and therefore the

knowledge of death which denies us a future of any kind is a cause for suffering.¹⁰ He writes:

We experience loneliness as existential dread since we are aware that something is lacking in our existence and this prompts a restless search for one's completion by the other. Fortunate are the few who find this interweaving and interpenetration of two human beings, which is the most basic and final conquest of loneliness (Moulyn, 1982, p.197).

Nevertheless, Moulyn's primary thesis is that "...suffering has intrinsic value and that it is a positive, constructive power in life. Suffering heals fissures, dichotomies, and fractures. In short, suffering has meaning" (Moulyn, 1982, p.6). Overcoming any problem, striving to reach any goal, involves suffering, but achievement is rewarded with pride and satisfaction: "Man strives to do ethical deeds, to create beautiful constructs, to formulate true propositions. Suffering is the *conditio sine qua non* and it is the hallmark of our striving for these values" (p. 10).

Hope

Might we not say that hope always implies the superlogical connection between a return (nostos) and something completely new (Kainon ti)? Following from this it is to be wondered whether preservation or restoration, on the one hand, and revolution and renewal, on the other, are not the two movements, the two abstractly dissociated aspects of one and the same unity, which dwells in hope and is beyond the reach of all our faculties of reasoning or conceptual analysis? (Marcel, 1962, p. 67).

* * *

The healing process referred to by Moulyn in the previous section is not linear (imperfection followed by suffering followed by healing) but rather involves understanding the interrelation between these "components of our existence" (Moulyn, 1982, pp. 244-5). Moulyn posits, however, that suffering is a prerequisite to hope, has a creative component, and cannot exist in isolation from suffering. Gabriel Marcel (1962)

¹⁰ Moulyn observes that cultural achievements counteract this denial of a future by existing after the death of the artist; artists continue to live through their achievements. They are created during moments of subjective time (in the artist's mind) and transformed into artifacts (painting, musical manuscript, novel, etc.) during objective time. "These long-lasting testimonies to man's creativity deny the fragility of our temporal existence. Hence, they are a counterbalance against the dread of death." Cultural artifacts link subjective and objective temporality. But the artist suffers during the creative process as he brings together "the two worlds of reality and ideality" (Moulyn, 1982, p. 8).

also conceptualises hope in a creative and regenerative capacity.¹¹ It is hope's "mission," he writes, to relieve us of the loss of integrity and freedom which suffering brings. Hope is directed towards a "light" that is not discernible; that is, it is directed towards an abstraction. Hope is, however, not the same as optimism, which is a confident imagining of a particular (favourable) outcome, nor is it to be confused with ambition; it is more than these things. Hope is a kind of mysterious "super-rational" process; "hope is a mystery and not a problem" (Marcel, 1962, p. 35).

Hope, writes Marcel, depends not upon what is already in me, but "arises independently of my possible action, and particularly of my action on myself...hope has the power of making things fluid" (p. 41). The future is unknown and unknowable, thus hope is grounded on the imaginary, anticipated future. Hope, in "making things fluid," in some mysterious way, creates resources to be called upon for the creation of such an imagined future. Marcel says that in hoping we are virtually being "credited" for something that is to come, and it does not matter if that thing eventuates or not; hope is a state through which a person can become free of the bonds of suffering. Hope is "not interested in the *how*": to hope is not to assume that we will (personally) discover a way out, or a solution to a situation. Hoping means that the person believes that a way out "will be found," but not necessarily by him alone. A solution is already in place; it merely has to be discovered.

Marcel illustrates his conception of hope with the case of a man suffering from an illness, from which he is hoping to recover by a certain time. If this outcome does not eventuate, he may very well descend into a state of despair, in which everything seems lost to him, "naively identifying recovery with salvation." In coming to realise "in the depths of his being" that cure cannot be equated with salvation, however, he will be able to assume a new attitude to his life, understanding that however flawed or endangered it now is, it

¹¹ Hope is not the same as wishing for something, although there are similarities. To wish is to imagine that something is actually going to happen, "the illusion which makes us take our wished for realities." (Marcel, 1962, p. 44). It is necessary to distinguish between the expressions "to hope" and "to hope that": "hoping that" is the same as wishing for something, but "to hope" "transcends imagination, so that I do not allow myself to imagine what I hope for" (p. 45).

always retains an intrinsic value. Thus hope is a sort of transcendent state reached only through the individual's own understanding, and realization of self. Marcel continues:

It really seems to be from this point of view that the distinction between believer and unbeliever stands in its true meaning. The believer is he who will meet with no insurmountable obstacle on his way towards transcendence...[but]...in so far as I make my hope conditional I myself put up limits to the process by which I could triumph over all successive disappointments. Still more, I give part of myself over to anguish; indeed, I own implicitly that if my expectations are not fulfilled in some particular point, I shall have no possibility of escaping from the despair into which I must inevitably sink. We can, on the other hand, conceive, at least theoretically, of the inner disposition of one who, setting no condition or limit and abandoning himself in absolute confidence, would thus transcend all possible disappointment and would experience a security of his being, or in his being, which is contrary to the radical insecurity of *Having* (pp. 46-7).

There are interesting similarities between Marcel's notion of hope rising from despair and Janice Morse's conceptualisation of suffering in a clinical setting, in which she describes a transition from "enduring" to suffering, and then to hope (see Appendix B, page 270).

Hope strengthens us, but despair weakens. Despair ("spiritual autophagy") results when the "flame" that consumes the imagined future, in seeking personal becoming, turns back upon itself. To accept a situation, no matter how bad it might be, does not represent capitulation, but it is rather to face the situation while maintaining the integrity of the Self. On the other hand, capitulation, that is, giving in to despair, is a sign of the destruction of the Self. Marcel observes that as hope appears to be able to survive or exist within the "almost total ruin of the organism," it therefore is not a physical phenomenon, but has a spiritual dimension. Denial of a situation will not lead to hope, only false hope. Doubt in future possibilities, which despair signifies, destroys the link between the Self and "the matter in question."

Marcel concludes that "hope does not derive only from what is already in place, our "established experience." He sees it as a creative process, an "adventure now going forward" (p. 52). Hence we cannot call entirely upon past experience to create an imagined future. Marcel concludes that hope contains a temporal element:

...[D]espair is in a certain sense the consciousness of time as closed or, more exactly still, of time as a prison – whilst hope appears as piercing through time; everything happens as though time, instead of hedging consciousness round,

allowed something to pass through it...[I]f time is in its essence a separation and as it were a perpetual splitting up of the self in relation to itself, hope on the contrary aims at reunion, at recollections, at reconciliation: in that way, and in that way alone, it might be called a memory of the future (p. 53).

But hope is not merely illusion. To have no hope means that we are not prepared to risk anything (having those hopes dashed) in an effort to avoid disappointment. Hope therefore involves a degree of risk-taking. Being devoid of hope has the effect of “chaining reality down in advance” (p. 55). Finally, Marcel emphasizes that hope always involves some sort of communion, even if it is within oneself.

A social psychological approach to the issues of suffering and hope focuses upon the importance of finding some sort of meaning or explanation for suffering before hope can emerge. Locating a cause of the illness confers on the patient a feeling of control over the situation and restores their integrity. Taylor and Brown (1988) conducted a review of research in which they investigated theories arguing that positive illusions of the future enhance mental health. In their study of breast cancer patients, however, it was discovered that those women who appeared to cope best were those who had found a reason for the disease, which gave them a belief that they controlled the situation. Whether this reasoning was justified or not was irrelevant (it is notoriously difficult to identify a causal factor in this type of cancer). The women’s hope was, in fact, sustained by illusion. Positive attitudes fostered hope; there was a significant benefit in maintaining the illusions rather than “facing the facts.” A further advantage was that the women appeared to experience an enhanced ability to move outside their own worlds of illness to care for others and engage in new activities. The authors conclude that:

These strategies may succeed, in large part, because both the social world and cognitive-processing mechanisms impose filters on incoming information that distort it in a positive direction; negative information may be isolated and represented in as unthreatening a way as possible. These positive illusions may be especially useful when an individual receives negative feedback or is otherwise threatened and may be especially adaptive under these circumstances (Taylor & Brown, 1988, p. 193).

Barnard writes: “Hoping is not merely an intrapsychic activity. It is the *interplay* of personal imaginative processes with the possibilities of one’s historical situation, as these are made available and communicated through potent cultural symbols and social

practices” (Barnard, 1995, p. 54). The illusions which inspire hope must nevertheless be realistic. A culture which celebrates autonomy and self-sufficiency does not lend itself to the creation of realistic illusion for the chronically ill; imagination must still be contained. Clearly, the illusions that sustain hope must be situated within a biographical account of illness which encompasses the past, present and imagined, or hoped for, future; they must contribute towards a credible totality of the narrative. Illusion differs from denial or repression in which there is an effort to block information; it represents the re-interpretation of information for the purpose of narrative construction. This corresponds with Frank’s description of the “quest narrative,” in which the goal towards which the ill person strives is always unclear but nevertheless sustains the integrity of the narrative (Frank, 1995; see also Kleinman, 1988).

Illusion is a feature of both the psychosocial and phenomenological interpretations of hope; for Marcel the mysterious quality of hope is directed towards an illusory (and elusive) “light,” whereas narrative construction and explanatory models of illness develop through the adaptation and assimilation of similar narratives and medical information.

Summary of theories

Frankl (1969), Scheler (1974), Moustakas (1961) and Moulyn (1982) invoke powerful metaphors of captivity, alienation and silence in their conceptualisations of suffering and hope. Suffering is envisaged as a type of static, or atemporal state, out of which hope can be synthesised once a state of acceptance or acknowledgment of the situation is reached. Both a social psychology conceptualisation, for example as described by Frank (1995), Cassell (1991), Kleinman and Kleinman (1997) and Kleinman (1988), and existential perspectives such as those of Marcel (1962) and Moulyn (1982), propound this notion of hope arising from suffering. Suffering is therefore not a meaningless state; it is an absolute necessity to the human condition:

Being between the worlds of causality and intentionality, man suffers. After he has been successful in making these two worlds interpenetrate, man is a different person. Through suffering he has created a new emergent. He has changed a small sector of reality by means of activating the mental triad in a precious

present,¹² and, since he has suffered, he has changed himself also. Suffering is the necessary condition for our mental and our personal growth and for our becoming (Moulyn, 1982, pp. 285-6).

From the above discussion emerges the notion that suffering appears to be induced by a fear of what the future might hold. Sick people may fear pain (although pain in itself is not to be equated with suffering), the loss of autonomy, and death; the latter, as mentioned previously, being “the major fracture in our existence” (Moulyn, 1982, p. 206).

In summary, it can be seen that the existential understandings of suffering and hope outlined here do in many ways parallel the social and psychological observations of these states. Heidegger in particular, in positing a state, or phase of the experience, in which a person becomes receptive to the intervention of others through care (“solicitude”) provides an existential explanation for the isolation, loneliness and untouchable state of the suffering person. In Merleau-Ponty’s conception of the “transcendence” of hope, we reach a point when it is possible to disentangle ourselves from the bonds of a chaotic, atemporal state of suffering, rooted in the present: in this new freedom we can call upon the layers of experience and look to a future built upon them. Parallels can be found here with such concepts as loneliness and solitude; loneliness closely resembles suffering, but it is in solitude, when order has been restored from the chaos of loneliness, that hope takes shape. In becoming once again responsive to others, and open to dialogue (even if it is internal dialogue), care can be offered and accepted. The therapeutic power of suffering, as an experiential stage through which the ill person must pass in order to assimilate the new set of circumstances that illness brings, is reflected in Merleau-Ponty’s conceptualisation of hope as transcending suffering, restoring order and consequently meaning to the events and facts that constitute suffering. The different types of illness narratives posited by Frank can also be interpreted within an existential framework. He envisages illness as a “journey” during which the ill person discovers a purpose or meaning in the condition. Echoes of Heidegger and Merleau-Ponty can be found in Frank’s description of the narrative categories:

¹² The “precious present” is described as “the lived-in ‘now’ in which we accomplish the triplicate synthesis of present with past with future” (Moulyn, 1982, p. 24).

Restitution stories attempt to outdistance mortality by rendering illness transitory. Chaos stories are sucked into the undertow of illness and the disasters that attend it. Quest stories meet suffering head on; they accept illness and seek to use it. Illness is the occasion of a journey that becomes a quest. What is quested for may never be wholly clear, but the quest is defined by the ill person's belief that something is to be gained through the experience [Frank, 1995 #41, p. 115].

“Restitution stories” are stories of denial, imagining an inauthentic future; in the “chaos story” suffering is never transcended, and the “quest story” is the story of the transcendence of suffering through hope and the prospect of a realistic future founded upon a true reading of past and present.

In a similar way, Cassell's observations on how people deal with suffering can be linked to the existential perspective (see page 188), while Morris' statement that “...[s]ilence and the loss of voice may eventually constitute or represent for some who suffer a complete shattering of the self” (Morris, 1997, p. 279) hints at the existential crisis of despair. In conclusion, in Marcel's words:

Hope is essentially the availability of a soul which has entered intimately enough into the experience of communion to accomplish in the teeth of will and knowledge the transcendent act – the act establishing the vital regeneration of which this experience affords both the pledge and the first-fruits (Marcel, 1962, p.67).

Stories of suffering and hope

To the participants in this study, suffering, despair and hope were familiar experiences, both for themselves and the people for whom they cared. The integration of suffering and hope with the caring process is explored in this section. Carers and the people for whom they were responsible sometimes shared a great need to understand the nature and reasons for the afflictions in order to find meaning in their experiences. For one person, the inability of her mother to accept her situation, or to discover any meaning in her situation has had lasting and tragic consequences.

Suffering without hope

Victor Frankl (1969), while imprisoned during the Second World War in the Nazi concentration camp at Auschwitz, used his observational skills as a psychiatrist to help him understand the processes of suffering, despair and hope which permeated the lives of

the inmates. He observed that when people who were consumed by despair sought immediate comfort (for example, in smoking a cigarette) it often signified that they had ceased searching for a meaning in their existence and were about to die – they had given up hope entirely.¹³ Hope rests in the finding of meaning in whatever situation confronts a person: “The prisoner who had lost faith in the future – his future – was doomed. With his loss of belief in the future, he also lost his spiritual hold; he let himself decline and became subject to mental and physical decay” (Frankl, 1969, p. 95).

Such a situation was faced by Alice, whose mother retreated behind a curtain of silence and helplessness as illness and frailty overtook her. Alice had always enjoyed a loving relationship with her mother:

Alice: [My mother had been] a very strong and resourceful and independent woman. She was a matriarch, but a nice one. Very supportive and loving, but a strong woman...Up until she became old and frail, she was a great source of strength, love and friendship. I always knew she was there. I could talk about any problem that I had. I would go up to the country, and I would be totally embraced and welcomed. She was so pleased to see me. The house was welcoming, she'd cook special things for me, there'd be a lovely clean bed, flowers in the room. (Conversation with Alice).

When it became impossible for her to live alone, however, and she moved to a local hostel (having refused the offer to live with her daughter), she immediately became introverted and non-communicative. Alice said it was then that she “downed tools”:

Alice: Once she was there she gave up. It was almost as if moving out of her home, she lost her persona. Her identity was all tied up with her home, her plants. So she just lay on the bed, and from then on her condition deteriorated. (Conversation with Alice).

Alice wrote in her journal that her mother's only pleasure seemed to be in eating lollies and biscuits, mimicking the withdrawal that Frankl had observed in the Auschwitz prisoners. An entry written after a difficult time getting her mother into bed reads: “My prevailing memory of Mum after this visit is of her in bed – almost in the foetal position, eating a ‘comfort biscuit’”; and: “Mostly Mum sat with her eyes closed – suffering.” (Alice's Journal, p. 8).

¹³ Frankl likens this phenomenon to the problem of drug abuse, where people do not see any hope for a worthwhile future and resort to instant comfort in an effort to cope with their situation.

Alice was devastated when her mother failed to respond to her care:

Alice: It was more that I could bear to see her so *unhappy*. I'd be doing things like, I'd be trying to buy little cakes, find special cakes, find things to do, think of things that might happen. I bought her gismo things – you know those sort of things with sand pictures, and things that she could watch. I put up pictures in her room, I bought her tapes, I was *continually* – for a while there I was reading her Georgette Heyer books. I'd take her out in the wheelchair around the block. She didn't really enjoy that...I don't know that it was I wanted to please her; I wanted to fix her up. I wanted to have it so that she wasn't so desperately unhappy. I was trying to find some way that the day would pass more pleasantly, that she wouldn't be *suffering* in this sort of silent, stoical way. (Conversation with Alice).

Alice despaired because she was unable to reach her mother and help her find some comfort in the care which was lavished upon her. The health professionals did not seem able to offer an explanation for her mother's physical or mental deterioration, merely saying she was "depressed." Alice said:

Alice: One of the things that bothers me about the whole experience is that nobody ever thought that what was happening was something that they needed to talk to me about, or explain the physical process. I don't even know if anybody knew. They just seemed to think that this was something that just happened to old people. (Conversation with Alice).

In contrast with the other participants, Alice found it virtually impossible to care for her mother, who seemed so consumed by her suffering that she was unable to communicate, denying Alice the opportunity to repay the love and care which she herself had once received. Alice also suffered:

Alice: Yes. Well when I thought about what you said, when we met the other day – when you said that almost everybody found [caring] rewarding and uplifting, well, I certainly couldn't say that. I would say that I would never not have done it. Well, actually there wasn't even a choice, but I would never not have put in the amount of time and effort that I did, and I'm pleased that I did. I did for her the best I could, but she was so dreadfully unhappy. I think – you'll see it in my notes – she might have smiled at me four times in three years. She was just so *miserable* that there was no way that you could sort of feel, as you say, uplifted by it. But on the other hand, it was certainly a very meaningful experience, and I learnt a lot, and I really resented the people that kept telling me not to do it. *Unbelievable!*

Alice faced a double dilemma. The breakdown of communication between the two women made caring impossible, while the mystery surrounding the nature of her mother's illness gave her no basis on which she could explain her uncharacteristic behaviour. Alice was suspended in a void of uncertainty, grasping at unlikely strategies to

distract and amuse her mother. On rare occasions her mother seemed to break through the barrier; for example, Alice wrote in her journal:

On Xmas Day she smiled and tried to speak to me. She also smiled at me on my birthday. This is the first time she has done this for many months and the transformation of her face was miraculous. On my birthday I said to her that her smile was the best present I could ever have and she smiled at me again. (Alice's Journal, p. 24).

With encroaching age and frailty, Alice's mother lost the independence that she valued so highly, and as a result descended into a state of despair (Cassell, 1991). The sense of entrapment and isolation this story conveys is suggestive of Moulyn's (1982) conceptualisation of suffering as aloneness. The contingent inability to communicate with her daughter served not only to consolidate her isolation, but also, like some sort of contagion, to engulf her daughter as well. Alice, however, experienced her own particular form of suffering, one which stemmed from the impossibility of relieving her mother's anguish. Here the idea of reciprocity, which Mayeroff posits as an essential ingredient in caring, becomes clear. He refers to "the ability to be cared for," which implies a degree of participation or effort by the sick person is necessary before caring can occur. There must be a coincidence of concerns, which Merleau-Ponty calls an "interworld" (Merleau-Ponty, 1962), and which resembles Heidegger's (1962) state of "solicitous Being with Others," in which one becomes receptive to communication and, subsequently, care. Any imbalance in this shared environment (that is, relationship) means that whatever emotion, or process, that is poured into it cannot be nurtured and atrophies; the result is, in Marcel's words, "spiritual autophagy".

Hope: Discovering new purpose

Alice's experience is not replicated in any great extent, and certainly not with such relentless consistency, in the other stories of caring that contribute to the study. There are many instances where carers managed the alleviation of fear in their relatives, and even if they did not feel personally responsible for it, they were able to share and benefit from the process. It could be argued that the function of caring is to facilitate the overcoming of suffering or fear, which is achievable through the restoration of hope. Alice was denied the opportunity to care in this way because hope was seemingly unattainable for

her mother. From an existential perspective, as previously discussed, hope is envisaged as a state of mind which allows a person to break free of suffering (Heidegger, 1962; Marcel, 1962; Merleau-Ponty, 1962; Moulyn, 1982). Consequently, through hope the individual discovers a purpose to his or her existence, and this requires action of some kind, whether it be physical or mental.

Brad recalls an incident in which the palliative care nurse, Janet, has had a private conversation with his mother, who is near death:

Brad: [My father] was trying to make sure that she would eat [food that he had prepared for her], and of course she was losing her appetite anyway, and she got really crapped off, and she was really hard to be around, and really irritable, and really irritating. She was certainly a master at being irritating if she wanted to be! And I'll always be grateful for this woman, who is a palliative care nurse, who was her primary nurse from B- Home Hospice Care. I said to her: "Nurse Janet, this is the situation, and I don't know if it's the medication, or what." And she said: "Oh, well, your Mum's not able to do what she could, so she's angry about that"...Anyway, she spent about an hour with Mum, fixing up her syringe drive and various other things. She said, "No, don't you come in, we want some girl time here, girls together, don't we!" And Mum was sitting there grinning away. Janet had done her makeup a bit, washed her hair, so she felt pretty. And she was right as rain after that, and I was curious about that.

LP: Yes, I am too!

Brad: And I asked [them both what had transpired during their conversation] and they told me the same thing. Basically, Janet had said to her, "Well, look, you've done a job in this family, you've had a lot of jobs, a lot of work in this family, and you've done it very well. Now you've had a job description change. You have a different job now". All Mum was focusing on was her loss. She was no longer able to get up and cook, or clean, or care for the home, or the family, she couldn't go out and do her garden, and she loved that...

What happened was: Janet said; "You've got a different job now. Your job is to breathe in, and then out again. That's your job now. You've got to do that now." Of course at this stage Mum was no longer able to breathe in voluntarily. When she was asleep she would have long periods of apnoea. Really from late January she could have died in her sleep, but we had her sitting up at a particular angle which kept the fluid level down and she could sleep. But when she was conscious, it required most of her energy and her conscious attention to make sure her breathing was kept going. She suddenly realised she still had work to do, she still had a job, and therefore she still had a purpose. It was her purpose to do that. And it was OK, because she had a job. Janet rightly saw that my mother was somebody who saw duty as being very important. The thing in life is you do the *right thing*, you do what you're supposed to do. (Conversation with Brad).

What Janet had achieved was to help Mrs Morris accept the fact that her customary role which had developed around her life as a mother and wife was no longer possible. The

new role was focused on the present in which every moment of life left to her was precious, and depended upon her conscious effort to breathe. While Brad, as the informal carer, was not directly responsible for this transformation in his mother, the incident does illustrate the subtleties of hope and purpose. Although Mrs Morris could not hope to live for much longer, she could narrow her focus to concentrate not on her next day, or hour, but on the next breath.

Hope: Overcoming fear

In his medical practice, Cassell (1985) frequently noticed the paradox that hope can be maintained in a dying person even when there is no hope for a cure, and freedom from the fear of death is essential in this process. Moulyn (1982) stresses the significance of the fear of death by proposing that it constitutes the “parent-suffering” to which all suffering can be related. He writes:

Physical pain, anxiety, loneliness, and the dread of dying are four constituents of human existence which belong together. Physical pain can be a warning signal of impending death, as in a coronary attack. Anxiety, always a concomitant of physical pain, is a derivative of the dread of dying, which is the “parent-suffering” of all other modes of suffering. Loneliness and the process of dying are inseparable but they can also accompany the various modes of dying in a metaphorical sense. Dying is the ultimate fracture in our terrestrial existence, and it is the fundament of our suffering (Moulyn, 1982, p. 219).

It is of extreme importance to the carer that the ill person can succeed in overcoming this fear; this is graphically demonstrated in an incident related by Susan. She was very concerned about her father’s actual experience of death, and his “well-being” after he died. She was afraid that he would be “left alone,” not knowing what to do. She said: “One thing that frightened me, the whole way through, and even after he died a little bit, was that he’s going to get lost.” In the end she was satisfied that this was not the case (although she did have a dream later in which her father “came back” and said, “I don’t want this! I’m coming back!”). What convinced her that his death was a good one was the fact that just before his death, in his conscious moments, he appeared to be with a crowd of people, and clearly “saw someone” among these people whom he recognised. Having been relieved of the practical side of caring, Susan was able to participate in this release, and death was anticipated by both of them almost with excitement, rather than with dread.

Susan: He just made it, but he got there! Which was pretty important, because he died nicely, and I think that if he had not come to that realisation he would have fought like hell and it would have been an awful experience...Not that he was out of pain. I'd gotten to the point by the time he died – and he was so frightened, he was really, really scared of death. The night before, he'd just come to terms with it the night before he died, and had this big shift in personality, and become this really loose, relaxed, funny guy. He actually said to me: "You know, I'm a funny man!" Yes, you're just about to die! Why did you have to realise that *now*! The man he was the night before he died, he was just fantastic! It was the best I'd ever seen him!

LP: What caused that, do you think?

Susan: He'd lost his fear. He'd let go, and realised that OK, it's *not* going to be so bad. He wouldn't let us talk to him about it, and that was joyous, I was with him the day he – he was mostly unconscious the day he died. He died late in the afternoon. But, he was – he'd wake up, but only briefly, but he was yacketty yak! What I was seeing really went with my beliefs, or what I would like to believe happens. He was yacketty yacking to *someone*, and I'd told him: "Someone will be there. You *won't* be alone, there *will* be someone there!" Yes, I'm sure there was someone there. He was looking around like there was a room full of people, looking around and talking, talking. And then he found whatever or whoever it was he was looking for, he found them, and the – just *ecstasy* on his face!...

It was just – joyful is the only way I can describe it. So when – and even that day we thought he's got weeks, perhaps, because we hadn't come to terms with this idea that "it's not six months any more" business. It happened very quickly. His lung collapsed, that was it, you've got weeks. The nurse was saying, "Have you called your brothers?" They were all – two overseas, one interstate. So it started to dawn on me, "Oh, oh." So although I was shocked when he died, because it was, "Not *yet*!" It was also, "Oh, yes, he's up there, he's having fun now!" Because I knew that he would be *realising* something that he hadn't allowed himself to think about. I wanted to grab him back: "It's good isn't it!" (Conversation with Susan).

There are several ways of interpreting this episode, one being that perhaps Mr Reid's "vision" could be accounted for as an hallucination brought about by brain damage, or as a consequence of the drugs he no doubt was taking at the time. Alternatively, it could be described as a "near-death experience" whose origins are unknown, but which are often manifested in several well-defined forms. Included in these are "the meeting of deceased acquaintances/relatives; and strong emotions of ecstasy" (Kellehear, 1996, p. 44), which certainly is suggested by Susan's account of her father's experience. Kellehear also observes that a familiar effect of such experiences on those who recover from their trauma is that they subsequently lose any fear of death, perhaps because they now have privileged foreknowledge of a life beyond death. Whatever the nature of his visions, the effect of the experience was to resolve Mr Reid's suffering by indicating that in death he would not be alone, and his value as a person would be appreciated. The fact that Susan

herself could not see these spirit-like people in no way undermined her respect for her father's belief in their reality, and she shared his elation at this discovery. This incident in particular influenced her caring experience. Throughout her father's illness he was hampered by low self esteem, and was afraid of death, but here, in his last days, this suffering was resolved by a spiritual experience.

Deception

Shielding the dying from the realisation that death is imminent is an aspect of caring that presents a powerful moral dilemma to the carer. The assumption that their parents will be devastated by and desperately fearful of the truth so brutally revealed by technology leads them to attempt to protect them from the suffering that they presume this will incur. Deception by lying about their parents' condition or withholding information is then seen as a means of shielding their parents from further suffering, but at the same time they cannot enter into simultaneous self-deception.

Carers are acutely aware of the need for the sick person to be able to situate their experience within a meaningful narrative. The carer is often (but not always) privy to more detailed information about the sick person's condition than they are themselves, and might seek to protect the patient from the truth in an effort to inspire hope. This practice is common in some cultures; for example, Daniel (1997) describes how Tamils in Sri Lanka will hide unpleasant truths, including the knowledge of impending death, from their relatives in the belief that this tactic will spare them from suffering.

The assumption that the sick person will be devastated by the news of their imminent death motivates some carers to resort to subterfuge. De Beauvoir and her sister, for example, colluded in keeping the truth from their mother. They decided that at all costs she must not know that she had cancer of the small intestine, and when she awoke from surgery that had revealed "a huge cancerous tumour" in that region, she was told only a half-truth, that she had peritonitis which the surgeon had treated successfully. The sisters were torn between maintaining the deception that her condition was not desperate, and allowing her to talk about her fears that she was dying: "We forced her to say nothing

about her anxieties and to suppress her doubts: as had happened so often in her life, she felt both guilty and misunderstood. But we had no choice: hope was her most urgent need” (de Beauvoir, 1966, p. 59). Later, when her kidneys began to fail:

...[W]ater dripped from the pores of her skin; the sheet was soaked. She hardly urinated any more and her flesh was puffing up in an oedema. She looked at her hands, and in a puzzled way she moved her swollen fingers. “It is because you have to keep so still,” I told her....She had not asked for a mirror again: her dying face did not exist for her. She rested and dreamed, infinitely far removed from her rotting flesh, her ears filled with the sound of our lies; her whole person was concentrated upon one passionate hope – getting well (pp. 67 & 68).

De Beauvoir recognised the importance of fostering hope in her mother, but the deception wrought by her daughters merely intensified her suffering because she could not understand the meaning of her symptoms in relation to the story she had been told, while de Beauvoir herself suffered because she knew her lies had created hope for something that was ultimately unattainable.

Roth’s deception was not on such a grand scale as de Beauvoir’s; it was prompted more by his own revulsion at the morphology of his father’s brain tumour than by its presence. He assumed that his father would find the truth just as difficult to deal with as he did himself. The eye specialist suspected that a brain tumour was responsible for Herman’s paralysis and was probably contributing to his failing sight but was unwilling to operate on the cataracts until an MRI scan had been obtained. Philip knew about the tumour before Herman saw the neurosurgeon, but did not reveal this to his father at that time. Roth had decided to be “candid” like Dr Meyerson had been and tell Herman that the tumour was large, but he said nothing about its configuration. He also said that it was “pressing on the facial nerve, and that’s what’s causing the paralysis.” He did not have the courage to tell his father the truth, that it was “wrapped around” the nerve, a concept he found particularly distressing. He compromised by revealing a minimal amount of information to his father when he told Herman that his facial paralysis was due to a tumour, not Bell’s Palsy:

“Meyerson says that it’s a routine operation.”
“Will my face get better if he operates?”
“No. There just won’t be any more deterioration.”
“So, this is the way I am going to be.”

“I’m afraid so.” Two minutes and I had learned to talk like a surgeon (Roth, 1991, p. 15, p. 67).

Explaining illness

As previously discussed, Marcel (1962) proposes that hope arises from a person’s ability to realistically envision the future from within the constraints of his or her current situation. Thus if an explanation of illness can be found, a pragmatic view of the future is more likely than if its origins remain mysterious. As shown in the following examples, in some cases this need for explanation applies to carers as well as those who are ill or dying”. Thus the construction of an illness narrative is an important mechanism by which people make sense of, or find meaning in, their condition (Kleinman, 1988). Projection of this narrative into the future, which signifies hope, means that the inevitability of death has been acknowledged and it can be approached without fear. Nevertheless, many people also attempt to accommodate the onset of illness within this narrative by seeking a reason for its appearance. Both self-deception and deception by others can play a part in this search for explanation. This is a prominent theme in Susan Sontag’s work, *Illness as Metaphor*, in which she writes:

As once TB was thought to come from too much passion, afflicting the reckless and sensual, today many people believe that cancer is a disease of insufficient passion, afflicting those who are sexually repressed, inhibited, unspontaneous, incapable of expressing anger (Sontag, 1978, p. 21).

The notion that cancer strikes indiscriminately and without warning demands that we find a reason for it: the “Why me?” question. Sontag (1978) observes that nobody asks that question when stricken by typhus or cholera, whose causes are well known. She believes that the scientific understanding of disease causality finally removes it from the mythological and metaphorical repertoire. For example, once TB was understood to be a bacterial infection which could be easily cured with antibiotics it disappeared as a popular metaphorical device, and she imagines that the same fate awaits cancer once its mysteries have been unravelled. In the meantime, however, many people are captives of the notion that the cancer patient bears a moral responsibility for contracting the disease. I myself was not particularly concerned to find an explanation for my mother’s illnesses, perhaps in part because, as de Beauvoir said of her mother, “she was of an age to die”.

When I wrote that her osteoporosis was iatrogenically induced, I was clearly convinced by the medical literature which indicates that the breast cancer drug tamoxifen hastens osteoporosis. I did not wish to believe that she had succumbed to a disease that was largely avoidable. However, I was reminded of my own father's death when Susan told me how desperately her father wanted to believe he was not responsible for his lung cancer

Not long after my mother died, my brother and I fossicked through her collection of photographs, tiny Box Brownie remnants of her past. There was my father (who had died of some sort of lung cancer thirty-five years earlier), captured sixty years earlier standing in front of a truck near the little town of Hawker in the Flinders Ranges, where he had been born. It was a large truck, and stacked up like dominoes on the tray were dozens of slabs of some material that resembled slate. The caption read: "Here I am ready to leave with a load of asbestos." I was immensely relieved. My father had not been killed by the "roll-your-own" cigarettes that he favoured after all. He was a victim of circumstance. He had died of mesothelioma, which is always someone else's fault. (Extract from author's notes).

Susan's father had already suffered throat cancer ten years before the lung cancer from which he finally died was diagnosed. He had not smoked during those ten years. When he was admitted to the hospice, however, he was greeted with an unwelcome accusation from a palliative care doctor, who clearly held him responsible for his illness because he had at one time been a heavy smoker.

Susan: Well, he was actually exposed to asbestos [in his workplace], and he liked to believe, for his own conscience – he liked to believe that the asbestos – but you know he had smoked for forty years, very heavily.

LP: Probably the combination didn't exactly help.

Susan: He always made a point of saying, "It's the asbestos, it's the asbestos!" Because it helped ease his conscience a bit. The man's going to be dead in a month, *let* him ease his conscience. But [the doctor] went on at him – it was *awful*. It was so awful. (Conversation with Susan).

Susan's father knew that the disease they were dealing with was undeniably some sort of cancer; she merely encouraged her father to avoid being held responsible for his illness. She was not herself at all concerned with explaining the illness. Her concern was with her father's state of mind.

There was no doubt about the nature of Brad's mother's illness either. Brad's response to the news that his mother was dying of breast cancer was to seek a psychosomatic link

which would explain not only the fact of her particular illness, but also the site in which it appeared:

Brad: I sent her a couple of books about, you know – one of them was connected with – because I believed and I still believe that the body-mind connection is overwhelmingly important in the development of auto-immune disorders which is what cancer essentially is. For instance I don't believe it's an accident that my mother got breast cancer, as opposed to bone cancer, or stomach cancer, or something, given how she felt about her breasts, and how she felt about her sexuality, her whole life, how she'd been abused as a little child. She was not ambivalent; she was fundamentally negative towards it.

LP: And you think there's some sort of connection?

Brad: That's my belief.

LP: That's very interesting. I guess you've got other examples that lead you to believe that.

Brad: Yes, you'll probably find other people talking about this, and there's a lot of literature around it. At the same time I'm not at the simplistic level of: "Because she was sexually abused she therefore got breast cancer." It's more like: she was sexually abused, she was emotionally closed down, she was not able to accept positive praise about herself with any ease. She certainly wasn't somebody who gave out any positive – if you see what I mean. She was a fairly prickly person on an intimate level. Socially superficial, socially very pleasant indeed, and people liked her. And all those things together cohered upon the personality of somebody who's more predisposed to get cancer than they would be to get heart attacks, or heart disease...

Well, the other thing is, um...it could easily be argued that that kind of interpretation of why this particular cancer for this particular person is fanciful, because so many women *do* get breast cancer, and I could imagine you could say, surely you are not suggesting that all these women have problems with their sexuality. Well, the answer is that surely I am, actually! Anyway, that's really part of my thinking about what went on.

LP: So you did look for some sort of explanation?

Brad: Yes, I think everybody asks questions like: "Why me," or: "Why them?" if it's somebody who's close to you. And certainly my thinking about: "Why Mum. Why this?" – I didn't have to look too far. The answer to me was very salient, compared to other hypotheses, other than, she's a very intelligent woman. Very intelligent. (Conversation with Brad).

Throughout this interchange Brad's behaviour vindicates Sontag's observation that there is a widespread belief in such a thing as a "cancer personality," and that there must be some explanation, either somatic or psychic, for becoming a "victim" of cancer. The notion that disease, and particularly cancer, should occur randomly does not appear in Brad's reasoning. It is not clear whether his mother shared these sentiments, but certainly Brad himself believed that she was more or less doomed from an early age. Brad does not elaborate the purpose of the literature he sent her, but evidently neither it, nor her "intelligence," could save her from her fate.

Alice's mother did not suffer from cancer, but, for entirely different reasons, the lack of information about her condition was extremely stressful. She desperately needed the certainty of a diagnosis which would explain the symptoms of her mother's disease, to help her overcome her distress at being unable to understand her uncharacteristic behaviour:

Alice: I think I would have been better if I'd known how much Mum had dementia. The nursing home thought she had dementia, and I think she probably did a little bit, but it seemed more to me that there were times when she went into unreality, and times when she wasn't, and I also – The brain scans never really showed anything much. She had two brain scans while all this was happening... They do pick up Alzheimer's, anyway, but there are so many different types of dementia. I feel as though if you had known what was really wrong with her it would have helped. It's not the be-all and end-all, but we do need some sort of explanation for behaviours that are different...

The professionals, the nurses and the doctors that I dealt with seemed to think that this was reasonably common, that she was just getting old and stiff, she couldn't move, and because she didn't talk, they assumed she had, I think, a much higher level of dementia than in fact she had. So it was more that to me, that at times she entered unreality because if you're sitting in a room, and you're not actually having any contact with the world, and nobody's talking to you because you can't actually speak to them, you're not getting any of the external influences that allow you to keep yourself aware of and abreast of what's going on. There were certainly times, one time maybe eighteen months before she died, she said, "Tell me, am I getting cuckoo?" which was her way of saying – I said, "Well, sometimes you seem very confused, and this is just what happens when you get old". It was then she said, "Before I get too cuckoo I want to thank you for what you've done". And then she said that, so we're looking at about four or five months she made this tremendous effort, and said "you come every day!" So at times she certainly knew what she was doing and she made a tremendous effort to speak and to say it, and other times she'd be just lying there, or sitting there, and she'd be in a bit of a daze. I never knew whether she was right off with the fairies or not. And everybody seemed to think that this was what just happened, and that there were all these other people – and there *were*, there were all these other people there who couldn't speak or were babbling. (Conversation with Alice).

When no diagnosis was forthcoming, Alice tried to explain and even justify her mother's behaviour in terms of her lifelong principles of independence and self-reliance:

Alice: I think that – look, she'd had a hard life, and so she thought that the way you dealt with things was by yourself. She wasn't used to anybody helping her, so she couldn't *take* help, so she didn't want to be in this position that I was doing things for her. When I try to analyse it I don't even think *particularly* that she thought – in some ways she thought families should look after their own, there were sometimes these comments about the paid people, being paid to look after you, that this was never the same as if it was your family, but then on the

other hand, I don't think she would have ever wanted to have disrupted my life to the extent that she obviously did. So it's all very complicated. (Conversation with Alice).

This strategy was unsuccessful, however; Alice could not find a place for her mother's condition in the context of her past life.

Summary and Conclusion

Existential theories of suffering, fear and hope, explaining their highly individual and complex characters, have been outlined in this chapter. In view of this complexity, and its expression in the carers' stories used to illustrate suffering in their particular circumstances, it could be argued that the alleviation of the sick person's suffering, whatever its cause may be, is the carer's ultimate objective. This calls for a deep understanding of the nature and experience of suffering undergone by the sick person. The remarkably contagious nature of suffering, illustrated by the observation that the carer and sick person suffer in parallel, is seen as a consequence of the sharing of their worlds in the context of caring. Alice, unable to penetrate her mother's world, was effectively denied the opportunity to help her to overcome her suffering because she could not determine either its nature or its cause. This did not, however, resolve her own suffering, which, even after her mother's death, remained unrelieved.

The next chapter is concerned with what initially appears a more tangible aspect of caring: the various ways in which the sick person's body is understood and experienced. The advancing effects that disease and old age have on the body are constant and distressing reminders of approaching death, bringing with them a particular suffering that is not, however, entirely consistent with their overt appearances.

* * *

Chapter Seven. Ways of knowing the body

The preceding chapter demonstrates the possibility of a powerful involvement between carer and ill, through the vicarious and personal experiences of suffering and hope. This chapter is also concerned with a vicarious experience, although of an entirely different nature. Its focus is the understanding of the body in illness; the embodiment of illness. The primary and secondary materials used in the study indicate that the embodiment of their parent's disease and the visible bodily evidence of approaching death are highly evocative not only to the dying themselves, but also to the carers. This is an important and continuous aspect of caring, a constant reminder of unavoidable nature of the role.

The chapter is in three sections. The first is concerned with encounters with medical technology, which are frequent and seemingly unavoidable aspects of modern medicine, having the potential to evoke powerful emotional responses in both the carer and the ill person. The participants in this study experienced both positive and negative reactions to the revelation of those parts of their parents' bodies which are normally inaccessible. The virtual deconstruction of the body made possible particularly through imaging technologies interests many writers, and both theoretical and literary accounts of these experiences are offered here to support those related by the participants. This section is not intended as a critique of medical technology, but rather its aim is to explore the effects that the disclosure of visible, or at least quantifiable evidence of disease, and its progression or regression, can have on carers.

The concern of the next section is medical specialisation, the current rapid development and refinement of which is having unexpected effects on patients and carers. This phenomenon is related to the increasing sophistication of technologies which make possible the minute focus (both physical and intellectual) on highly specific parts of the body. The tension between the opposing understandings of the body, between the carer's

holistic view of their parent's bodies and the specialists focus on individual organs or even cells, is examined in this section.

The necessity for the carers to see and touch their parent's naked bodies raises issues of embarrassment, shame, and dependency for many of the carers, and the final section of this chapter deals with this aspect of caring. Throughout the chapter, the experiences of the carers and literary examples are supported by theoretical treatment of these topics.

The hidden body: Encounters with technology

...[C]linical experience sees a new space opening up before it: the tangible space of the body, which at the same time is that opaque mass in which secrets, invisible lesions, and the very mystery of origins lie hidden. The medicine of symptoms will gradually recede, until it finally disappears before the medicine of organs, sites, causes, before a clinic wholly ordered in accordance with pathological anatomy (Foucault, 1973, p. 122).

* * *

TB makes the body transparent. The X-rays which are the standard diagnostic tool permit one, often for the first time, to see one's insides – to become transparent to oneself (Sontag, 1978, p. 12).

* * *

In his phenomenology of what he terms “the absent body,” Drew Leder (1990) is concerned with those inner structures of one's own body, particularly the viscera, over which we have no active control in normal circumstances. There is no conscious awareness of the internal organs unless they are identified as the site of disease, in which case they immediately come to the attention of the patient, the physician and anyone else who is concerned with the patient's well-being and care. X-rays and other medical imaging technologies bring into view these phenomenologically obscure body parts, lifting them out of the protective body and exposing them to scrutiny. This technology is not intended to be an aesthetic medium for the enhancement of the lived experience of the body through the unveiling of its hidden structures, nor is it intended to give the carer a privileged view of another's most private zone; it is primarily an instrument designed to reveal the body's pathology. Other technologies explore the even more remote cellular structures of the body, and still others examine the biochemical processes that occur

within those living cells. Nevertheless, the impact that this information has upon the layperson, particularly one who is emotionally connected to the sick person whose interior is exposed to view, can be remarkable. The interplay between the doctors' objective, scientific reading of the images, the patient's lived experience of illness, and the carer's understanding of the images as bringing to the surface the hidden parts of another's body, is a thread which runs through many of the narratives of care cited in this study. This is a powerful illustration of the discursive chasm between the objective science of disease and the lived experience of illness, and in the following discussion I examine the tension between these perspectives as they appear in the narratives.

The preceding chapter demonstrates the possibility of a powerful involvement between carer and ill, through the vicarious and personal experiences of suffering and hope. This chapter is also concerned with a vicarious experience, although of an entirely different nature. Its focus is the understanding of the body in illness; the embodiment of illness. The primary and secondary materials used in the study indicate that the embodiment of their parent's disease and the visible bodily evidence of approaching death are highly evocative not only to the dying themselves, but also to the carers. This is an important and continuous aspect of caring, a constant reminder of unavoidable nature of the role.

The chapter is in three sections. The first is concerned with encounters with medical technology, which are frequent and seemingly unavoidable aspects of modern medicine, having the potential to evoke powerful emotional responses in both the carer and the ill person. The participants in this study experienced both positive and negative reactions to the revelation of those parts of their parents' bodies which are normally inaccessible. The virtual deconstruction of the body made possible particularly through imaging technologies interests many writers, and both theoretical and literary accounts of these experiences are offered here to support those related by the participants. This section is not intended as a critique of medical technology, but rather its aim is to explore the effects that the disclosure of visible, or at least quantifiable evidence of disease, and its progression or regression, can have on carers.

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The necessity for the carers to see and touch their parent's naked bodies raises issues of embarrassment, shame, and dependency for many of the carers, and the final section of this chapter deals with this aspect of caring. Throughout the chapter, the experiences of the carers and literary examples are supported by theoretical treatment of these topics.

Images of the interior

Bone Scan

*In the twinkling of an eye,
in a moment, all is changed:
on a small radiant screen
(honeydew melon green)
are my scintillating bones.
Still in my flesh I see
The God who goes with me
Glowing with radioactive
isotopes. This is what he
At last allows a mortal
eye to behold: the grand
supporting frame complete
(but for the wisdom teeth),
the friend who lives beneath
appearances, alive
with light. Each glittering bone
assures me: you are known.*

(Harwood, 2001, p. 183).

* * *

*The screen comes alight with images of my interior. My abdominal cavity is a TV star
(Brett, 2001, p. 20).*

* * *

X-rays, scans and other diagnostic images are windows to the body's hidden interior.

They are representations of the invisible cellular composition of the body's interior, but they are not at all like photographic images of structures that are visible, or even potentially visible. Familiarity with these images does not seem to have dulled the sense of wonder that many of us experience at being able to virtually look inside a living human body, whether our own or that of another person.

The aesthetics of imaging technology

Seeing my mother's X-rays had an unexpected and curious effect on me. Although many scans and X-rays had been taken during the course of her illness, these particular images of her bones were the only ones I ever saw. They were taken about six months before she died, and were meant to assess the progress of the secondary cancer which now affected her bones. Osteoporosis was already well established and it had been the cause of a fractured femur about a year previously. It is likely that in her case osteoporosis was an iatrogenic condition resulting from the drug therapy she underwent when the primary breast cancer had been diagnosed a few years earlier. Brain scans and other tests had shown no other traces of soft-tissue cancer, and it had not reappeared in her breast. The X-ray, as well as revealing the extent to which osteoporosis had progressed, confirmed the oncologist's suspicions that the cancer had spread to her ribs. (Extract from author's notes).

My mother did not see the pictures of her shadowy bones with the bright metal pin in the femur. She didn't ask to see them; she was not at all curious about them. It is possible that she was afraid to look at them, but she did not tell me that. (She was of a generation that thought that letters written by the GP to the specialist were private and not to be read by the subject. These days we steam them open; more intelligent doctors are careful to tell you exactly what they have written). I looked at the negatives secretly, guiltily, before I took them to the specialist. The delicately outlined bones of the skull, the twisted spine, and defenceless feet; it was like peering into a forbidden room, because even though they were my mother's bones, they were not my property. Then when I came home from the specialist's office, after the shadings had been explained to me, I took the films out of the envelope again, and scrutinised them, this time carefully inspecting every part of the skeleton, seeing the difference between the shadows that meant cancer and those that meant osteoporosis, trying desperately to understand, to see, what was happening to these structures, and to fit the pictures to the outside manifestations of the diseases. All I felt,

however, for some inexplicable reason, was an overwhelming sadness. I replaced them carefully in the yellow envelope. I kept the pictures until she had died, then I threw them out without looking at them again. They meant nothing to me then; they had told me nothing that I did not already know about her. I think that I was hoping at the time, even expecting, that the X-rays would give me an advantage over my mother, that I could get to understand and know her illness better than she herself did, that I could somehow be a step ahead of her in the experience we appeared to share, but all I felt was the distance between my experience and hers.

Philip Roth's emotional response upon seeing the irrefutable evidence of the tumour that was destroying his father's life was more powerful than mine had been in the episode just described. Herman Roth was eighty-six years old when he became ill. His facial paralysis was initially diagnosed incorrectly as Bell's palsy which is generally a temporary condition. Herman's paralysis did not disappear, however, and soon his hearing and sight began to fail. A massive brain tumour was discovered through magnetic resonance imaging; the brain was "photographed from every angle." Roth writes:

Being by myself also allowed me to be as emotional as I felt, without having to put up a manly or mature or philosophical front. Alone, when I felt like crying I cried, and I never felt more like it than when I removed from the envelope the series of pictures of his brain – and not because I could readily identify the tumour invading the brain but simply because it *was* his brain, my father's brain, what prompted him to think the blunt way he thought, speak the emphatic way he spoke, reason the emotional way he reasoned, decide the impulsive way he decided. This was the tissue that had manufactured his endless worries and sustained for more than eight decades his stubborn self-discipline, the source of everything that had so frustrated me as his adolescent son, the thing that had ruled our fate back when he was all-powerful and determining our purpose, and now it was being compressed and displaced and destroyed because of "a large mass predominantly located within the region of the right cerebellopontine angles and prepontine cisterns. There is extension of the mass into the right cavernous sinus with encasement of the carotid artery..." I had seen my father's brain, and everything and nothing was revealed (Roth, 1991, pp. 16-17).

Both Roth and I had found the experience of seeing into the deepest recesses of our parents' bodies profoundly moving. For a time we were able to secretly peer into the depths of our parents' bodies, instinctively trying to discover a link between what we saw in the films and what was evident in the people themselves. My mother was a small person, and being able to see her skeleton somehow heightened the impression of

vulnerability that surrounded this tiny, white-haired woman; it seemed as though death itself was represented by the images of her bones, and had been brought closer through this means. Looking at his father's brain, Roth felt that he was seeing the very source of his father's individuality; he was on the brink of connecting the body to the soul. Later, after his father knew of the tumour, and the problem of what treatment should be followed overshadowed everything, and he was trying (unsuccessfully) to understand his father and the relationship he had with him, Roth writes:

I slept fitfully until four in the morning, then I turned on the light, got out of bed, and looked at the pictures of his brain again, understanding nothing about that either. Had it been the MRI of Yorick's brain that Hamlet had been looking at, even he might have been speechless (pp. 120-130).

The significance that Roth read into the films was immediately and irrevocably altered by the doctor's intervention, which restored their proper scientific value and reduced them to mere representations of disease. The physician's technical description of the image claimed Herman's brain as a pathological specimen, rather than depicting it as a living, functioning organ; the diagnostic interpretation of the images of the bones destroyed their existential significance. Indeed, Cartwright's claim that "[t]he X-ray is a major technique of twentieth-century medical knowledge and power" (Cartwright, 1995, p. 107) is borne out by the imposition of the objective medical paradigm which effectively undermines the subjective understanding of the images.

Although X-ray plates and scans are remote from the reality of lived experience described by Harrison,¹ they have the capacity to evoke surprising responses. But what is

¹ Harrison literally touched, and tasted, her grandmother's bones after the body had been cremated, but despite their tangible quality the bones were still mysteriously sacred:

Ashes aren't so much ashes as fragments of burned bone, some large enough that I could observe the elegant tracery of the marrow's canals. These looked like lace, some white, others the colour of rust; the rest was a fine grey dust that adhered to my fingers as I sifted through the remains. I withdrew my hand from the bag, sucked one finger, and felt the grit between my teeth. I licked the other fingers and my palm as well. Tasting what was left of my grandmother – a woman made holy to me by love and by blood – was something I did alone, behind the closed door to my study. The privacy of the act was not born of shame but of its being sacred: a last intimacy between two women who, in turn, had diapered each other (Harrison, 1997, p. 123).

it like to observe moving images of the living body? Arthur Frank² describes two episodes in which technology uncovered the secrets of his own body. The first experience had a happy outcome: the angiogram revealed that he had recovered completely from a recent heart attack and the interruption to his life was only temporary. He was at first “mildly terrified” at the prospect of undergoing an angiogram, but in the event found it exciting:

The injection of the dye produced a flush throughout my body that was almost pleasant enough to make up for the pinch of the initial incision. But the real excitement was on the television screen, where I watched my own heart beat and saw the dye spread through the arteries...The next morning I had the thrill of remembering – as I remember it today – what my own heart looked like, beating on those television monitors. After months of staring at the abstract cardiograms of my heartbeat, here at last was a chance to see the real thing in action (Frank, 1991, p. 18).

He experienced the thrill of “seeing” his living, functioning (and healthy) heart, its unobstructed arteries flushed with blood, the very essence of health, promising a vigorous and fulfilling life ahead. This was “the real thing,” unlike the somewhat impersonal cardiograms he had previously undergone. Through the technician’s skills, he had become closer to his own body, *inside* his own body, watching it working in real time. X-rays capture the organ in an instant in time, and cardiograms in a sequence of discreet moments, but the angiogram virtually shows us life itself.

² Strictly speaking Frank is an intruder here because his account is autobiographical, but the passages are included because they illustrate so well the conflicting responses that such images both engender and legitimise; relief, wonder and excitement at the confirmation of health, and despair at the visual evidence of disease.

Brett imagines her body as being stolen from its interior organs, which, portrayed on films, have acquired their own personal identity when she writes in her poem *Taking the X-rays to the Hospital*:

...It wants to know. It wants to know
everything. What happened in the room
with the white walls, where the men hid
and the camera moved
and spoke and knew its name.
It wants to go back
it wants to reclaim the body
the flash lit and took from it forever.
It wants to –
It wants to go home.

(Brett, 2001, p. 161).

The medical view of the body's interior

From the outset physiology is condemned to understand nothing of life since it conceives life simply as a particular modality of death, since it sees the infinite divisibility of the corpse as primary, and since it does not know the synthetic unity of the "surpassing towards" for which infinite divisibility is the pure and simple past (Sartre, 1969, p. 34).

* * *

The stories related in the previous section suggest that modern technology overcomes traditional barriers to the body's interior, but there still remains an element of wonder and excitement at this privileged viewing. The medical interpretation of the images shatters this mystique, which in some ways is a reminder of earlier times when the medical understanding of the hidden body endowed it with sacred properties. There are echoes here too, of empirical medicine, which originated with the flowering of anatomy. At this time the use of instruments such as the microscope to examine the structures of the body was seen as challenging God's purpose, which was concerned with the outer manifestations of a person's condition rather than the interior which should remain properly hidden. Traditional practitioners thus questioned the morality of comparative anatomy, associating it with "theoretical medicine and mere book learning, claiming that anatomy should be subordinated to clinical practice" (Turner, 1992, p. 203).

While Augustinian thought held that the soul was responsible for the animation of the body, Descartes argued that the secret to the animation of the body lay in the body itself, which, without the soul, was merely a corpse. In many respects, medical technology substantiates the Cartesian view that the living body is a mechanical device which functions independently of the mind or soul. Baron (1992) argues that there is a tendency for modern doctors to be unaware of the value of the lived experience of the sick person in the diagnostic process, still regarding the human body as a virtual corpse. Even during the medical examination, for example, the patient is usually requested to assume the supine position of a corpse and any movements or participation requested by the doctor is in a totally silent and “unalive” mode. This is reminiscent of the Eighteenth Century attitude that the dead body would reveal everything about the disease that killed it, but while still alive this information was unavailable. Baron writes:

In that sense, the living body of the patient presents an obstruction that hides a deeper truth. It is a translucent screen on which the silhouette of disease is projected; the physician's task is to render the patient's body (and the patient) transparent so that the true disease can be directly apprehended (Baron, 1992, p. 38).

The living body is thus regarded as “a conundrum to be solved” (p. 38), and, “[d]iagnosis becomes an act of struggle with the body, the art of comprehending bodily characteristics so that they can be subtracted from the ‘clinical presentation’ leaving one the clearest view of the disease” (p. 39). This depiction evokes the thoroughly Cartesian notion of physical confrontation between the experience of illness, the lived experience of the sick person and the biomedical concept of disease as a molecular disturbance. Technology seeks to bring the invisible organs into view, to reveal the hidden body and expose the internal ravages of disease. Before the advent of such non-invasive techniques as the X-ray and the ultrasound scan, the physician was compelled to wait until the patient's death before the interior of the body could be inspected and the diagnosis completed. Visible, external signs are notoriously ambiguous, and thus conclusive identification of the disease was possible only if the patient succumbed, and the body's anatomy, “the final, most decisive authority,” would then relinquish its secrets (Foucault, 1973, p. 112).

The discursive gap: Undermining lived experience

Leder (1990) also comments on the reluctance of medicine to acknowledge a subjective understanding of illness. He writes that the lived experience of disease became “epiphenomenal” when the notion that the “real disease” in the Eighteenth Century was represented by signs on the dead body rather than in the experience of the sick person. The subsequent advance of technology, and the investing of medical faith in such devices as X-rays, stethoscopes (which Foucault [1973, p. 164] aptly calls “solidified distance”), physiological tests and so on, served to undermine the “lived experience” of the patient, revealing the truth and producing an accurate diagnosis. Preoccupation with the mechanics of the body and technological interventions that seem to justify this conceptualisation of the body deny the existential dimension of the person; a machine cannot exist in an “existential world.”

Foucault writes that the exclusive focus on the pathological entity, and disregard for the contextual circumstances, which he terms a shift from the clinical “gaze” to the “glance,” is a consequence of new and rapid developments in medical science:

The technical armature of the medical gaze is transformed into advice about prudence, taste, skill: what is required is “great sagacity,” “great attention,” “great precision,” “great skill,” “great patience.” At this level, all structures are dissolved, or, rather, those that constitute the essence of the clinical gaze are gradually, and in apparent disorder, replaced by those that are to constitute the glance. In fact, the gaze implies an open field....The glance, on the other hand, does not scan a field: it strikes at one point, which is central or decisive; the gaze is endlessly modulated, the glance goes straight to its object. The glance chooses a line that instantly distinguishes the essential; it therefore goes beyond what it sees; it is not misled by the immediate forms of the sensible, for it knows how to traverse them; it is essentially demystifying...The glance is silent, like a finger pointing, denouncing (Foucault, 1973, p. 121).

The X-ray, the MRI and ultrasound scan, by going straight to the source of the disease, render the patient’s experience of the disease irrelevant and justify the physician’s lack of humanity. The implicit faith in the accuracy of these technologies that many people have is often misplaced, as ultimately their reliability rests with the skills of the technician and the interpreter, the human mediators. Both patient and physician are nevertheless trapped by the medical model of disease. Baron writes: “Sick persons are the first casualties of a dualistic paradigm because they are immediately confronted with their own inability to

separate their minds from their bodies, and vice versa” (Baron, 1992, p. 45). Technology has in effect circumvented life by looking beyond the living body. The value of the patient’s lived experience of the illness disappears in the diagnostic process, and

...in that sense, the living body of the patient presents an obstruction that hides a deeper truth. It is a translucent screen on which the silhouette of disease is projected; the physician’s task is to render the patient’s body (and the patient) transparent so that the true disease can be directly apprehended (p. 38).

Frank’s account of the discovery of massive secondary tumours arising from his testicular cancer describes vividly the role adopted by some physicians as impartial scientific observers of the inner organs. He comments: “Ultrasound is exciting for the patient because the physician can tell you what he is finding as he sees the X-ray images on a TV monitor next to you. In my case, however, the diagnosis was a little too exciting” (Frank, 1991, p. 26). It was at this point, when the true nature of Frank’s illness had been discovered, that the interests of doctor and patient diverged:

Looking back, I respect what the physician was able to discover. But at the time in that basement laboratory, all I could think about was being told I had massive tumours. The physician added nothing to this abrupt statement. He would send a report to my family physician; that was it, not even a goodbye or good luck, just over and out. It was a triumph of science and a lapse of humanity....What was it like to be told I had cancer? The future disappeared (p. 27).

Frank did not have the luxury of a private viewing of his X-rays: in the presence of the technicians, diagnosis was instant. Frank was (naturally enough) devastated at learning this news, but the physician’s response was true to the biomedical tradition. The existential gap between the two perspectives is clear.

An aberration: Interpreting illness through medical data

X-rays and other images that depict the body’s internal structures provide images that are, in a general way, recognisable to the lay person. Cytology, however, deconstructs the human body further, revealing its cellular structure, while biochemistry reaches further again into the entirely invisible components of the body as it scans and identifies the molecular processes which occur in these cells. Health or disease, through these sophisticated technologies, are detached further from lived experience, discernable only in the laboratories of medical scientists. Some people, however, rely entirely upon the medical data to inform their understanding of their condition. Alsop, for example,

provides an account of his experience of becoming a leukaemia patient (the exact type of leukaemia is uncertain and puzzles the specialists), which is remarkable because it is written almost entirely in terms of technology. Throughout his book he rarely mentions his physical or mental state. His experience is dominated by blood cell counts; the time between collecting blood and bone marrow samples is most stressful because his attention is focused upon the anticipated call from the doctor (with whom he has struck an excellent relationship) during which the result, couched in technical terms, is revealed:

“What are the counts?” Or: “Your platelets are holding up okay, but your granulocytes are in the cellar, I’m sorry to say.” Or: “Your hemoglobin is around nine point five. But don’t worry – if it goes below we’ll transfuse you and bring you back over eleven.” Or: “There’s an increase in the megakaryocytes in your marrow, but I’ve got to say I couldn’t find many granulocytic precursors.” Or: “Now don’t get excited. But the percentage of blasts in your marrow is down from around forty percent to around twenty-eight percent. Probably just a blip on the screen – but it sure isn’t bad news.”

Before I got sick, all this would have been gobbledygook to me, but after the first week or so at the NIH [Hospital] I spoke this new language like a native. After I understood the meaning of the blood counts and the less frequent marrow tests, I would wait for the results – as all leukemics do – with a fast-beating heart. For they can spell life, or death (Alsop, 1973, p. 39).

The medical fraternity had even invented a new verb for taking bone marrow samples. They called it “marrowing.”

The oncologist with whom Alsop became so friendly was very young and inexperienced, and was eager to share his excitement or disappointment in the test results with his patient. He was also initially of the firm belief that it was incumbent upon the physician to be entirely honest with the patient, but this view changed as he realised that diagnosis, and hence prognosis (which of course Alsop was desperate to learn) was difficult in Alsop’s case. In the end, Alsop realised that the stress which anticipation of test results created was too great, and asked that he be told only what was necessary:

I told John Glick [the oncologist] that I wanted to know only two things: if there had been a real turn for the better, or if there had been such a turn for the worse that some action had to be taken – a transfusion, for example, or chemotherapy of some sort. John readily agreed. I think his lengthening experience as an oncologist is beginning to give him doubts about whether it is really a good idea to tell a cancer patient everything (p. 234).

So accustomed had Alsop become to experiencing his illness through the objective truth the tests revealed (i.e. how the doctors understood his leukaemia), however, that he did not believe in his own body's reaction to the disease, and soon begged to be told the exact numbers of cells the tests revealed, as before.

The implications of technology for carers

Alsop had implicit faith in the medical technology that translated his illness into a scientific format, and was supported by his oncologist who, at least in the beginning, still seemed to connect the cytological tests with his patient. Frank, also relying upon technology to reveal his medical condition, encountered a physician who had completely eliminated the person from his understanding of the disease. These narratives are concerned with the experiences of the patients themselves, but what can be said about the relationship between the hidden body of the sick person and caring? And do the tests and images of these hidden organs affect the process of caring?

Being a carer places a person in a privileged position of being able to examine and discuss the meaning of X-rays and other images of another person's body. Ambivalence toward X-ray and other images often results from confusion between existential and objective understanding of X-ray and other images. Carers are torn between believing in the human evidence before them, the visible manifestations of illness, and faith in the ability of technology to reveal the truth about the patient's condition.

Frank's experience as a recipient of care provides a unique perspective of the caregiver's role. He writes that: "Caregivers are the other halves of the conversations I encourage the ill to engage in. They are also the other halves of the illness experiences. The care they give begins by doing things for the ill persons, but it turns into sharing the life they lead" (Frank, 1991, p. 6). Because carers are concerned principally with sustaining relationships, and not with treatment regimes, and with the manifestations of illness rather than of disease, communication between physicians and carers is often severely compromised. They are engaged in different dialogues with the patient, as Frank suggests

when he writes that “[m]edicine assumes that the person who has the disease is the only one who is ill” (p. 105).

Similarly, Kleinman’s concept of the subjective understanding of illness as a narrative experience also places the carer in a privileged position in the world of the ill person, that is, as an integral component of the illness narrative (Kleinman, 1988). This theme is developed by Morris (1998), who views the situation from a postmodern perspective. He writes:

Like much postmodern art, contemporary medicine situates us in a world where visual images reproducing fragments of the body (X-rays, CT scans, MRIs) connect with implicit narrative contexts. The question is how far medicine can recognise a role for narrative beyond continuous retellings of the authorized biomedical story about tissue damage and organic dysfunction (Morris, 1998, p. 34).

He believes it to be crucial that we should be able to construct our personal narratives as a way of making sense of our world and what is happening to us, and so the denial, or trivialisation, of such narratives by medicine is a display of arrogance which, by undermining our belief in ourselves, restores control to medicine.

Images as texts: Reading the results

It is the expert’s task, not ours, to interpret the images in this scientific manner, but, as Simone de Beauvoir discovered, experts are not infallible. The history of her mother’s X-rays is important in de Beauvoir’s account of her mother’s illness (de Beauvoir, 1966). Some time before her femur fractured, Mme de Beauvoir had experienced an episode of severe abdominal pain, at which time an X-ray examination was ordered by her physician. Although unsuspected at the time, this provided the first warning of the cancer that was to eventually kill Mme de Beauvoir. The expert’s interpretation of the images, however, was reassuring, and the condition was immediately dismissed as being of little significance. De Beauvoir wrote: “When he had looked at the plates the doctor stated categorically, ‘There is nothing for you to worry about. A kind of pocket has formed in the intestine, a faecal pocket that makes the movement of the bowels difficult...’ He advised Maman to feed herself better and prescribed new and stronger acting medicines” (p. 12).

When in hospital recovering from the fractured femur, the abdominal symptoms returned in a much more serious fashion:

“We will have your stomach X-rayed tomorrow,” said Dr T, finally.

Maman was distressed. “So you are going to make me swallow that horrible stuff.”

“It’s not as bad as all that!”

“Oh, but it is.”

The next day they told me that the X-rays – stomach and lungs – had gone off very well, and that there was nothing out of order. Maman, looking calm, was wearing one of the pink nightgowns with white spots and the bed-jacket that Olga had lent her, and with her hair in a big plait, no longer had the look of a sick woman (pp. 20-21).

Later, “fresh intestinal X-rays” were ordered, and this time the result was not at all reassuring. De Beauvoir wrote: “What was the result of the X-rays? ‘We can’t understand them,’ the nurses replied in frightened voices. I managed to see Dr T. The information the plates gave was still obscure: according to him there was no ‘pocket’, but the bowel was contorted by spasms, nervous in origin...” (p. 23). Professor B, however, read the plates differently, and “In the end he told me that there was a tumour blocking the small intestine: Maman had cancer.” De Beauvoir immediately realised that her mother’s true condition had been “patently obvious – those ringed eyes, that thinness.” When the surgeon operated on Mme de Beauvoir the truth was revealed in all its horror: “They had wheeled her into the operating theatre and Dr N had come out a moment later: four pints of pus in the abdomen, the peritoneum burst, a huge tumour, a cancer of the worst kind” (p. 27).

Objective scientific probes such as X-rays are reliable only so far as the interpretation of the tests can be regarded as being reliable.³ In this respect they can be regarded as a form of text, the interpretation of which depends upon the perspective of the “reader.” Thus the initial understanding that Roth and I experienced of our parent’s X-rays was primarily aesthetic. However, the physician’s professional preoccupation with disease ensures that he or she will search for indications of pathologies. The data, in other words, are virtually meaningless until interpreted in the context of the viewer’s knowledge and concerns, a

³ Even the identification of a condition as disease or illness is not fixed; for example, alcohol and other substance abuses can be interpreted as social problems, as medical problems, or as crimes.

situation somewhat analogous to Ricoeur's concept of "distanciation" in texts (Ricoeur, 1981).

In the early stages, before Mme de Beauvoir had embarked upon the serious business of dying, the hopes, emotions and behaviour of everyone, including the medical and nursing staff, who were involved in the episode, depended upon the meaning invested by the physicians in the X-rays. Even Mme de Beauvoir herself relied upon the expertise of the doctors to inform her experience of illness, or at least how she would present herself as a patient. The evidence that Mme de Beauvoir was seriously ill was clear from her suffering and physical appearance, but reliance on the reading of the X-rays for diagnosis gave false hope, which was finally shattered when the tumour was surgically exposed. Conversely, some doctors seem to have complete faith in their own interpretation of the patient's symptoms without recourse to either the evidence of the X-rays or the patient's own knowledge of his condition. One of the study participants, Susan, related this story about her father's experience:

Susan: [My father] was a heavy smoker. He quit with the throat cancer. He didn't smoke for the last ten years, so it was just sort of in there waiting to grab him. That was the real bonus. It was shadowing him, I mean we all knew, without being told, that this was it, he's not going to survive this one. I wasn't as distraught as I probably would have been, because I felt that, well, we've had our bonus, and now we've got to give him up. It was only two months. He got flu, a nasty sort of flu thing, and his doctor just – as was his doctor's way - he kept putting him off, and putting him off. He always did it. He did that with the throat cancer, until Dad just demanded to see a specialist, because he knew he had throat cancer, and this guy wasn't sending him anywhere. By the time they got him, they had a week to get him fit for surgery, so he just made it. So he was saying to his doctor: "I've got lung cancer!" "No, you've got the flu." "I've got lung cancer!" Finally, he went off on his own, he went off to see his oncologist...and had the tests and he was due to see a respiratory specialist because they said they'd found "something," and then he had a seizure, and got taken off to hospital in the middle of the night, and got admitted to M- Hospital, and that's when they found out everything, and got the works. It takes something - it takes a "big bang" to get things rolling. It was just sort of: "Oh well, he can see a specialist in three weeks!" His body said: "No, stuff this! Let's have a fit and get this over and done with!" So off he went, and then they – he was in hospital for three weeks, which seems like forever. [By this time] it was at a stage where it was quite advanced, and because of the position it was in, they couldn't treat it. They did consider radiotherapy, but because of where it was it was going to affect his breathing, so it just wasn't worth it. There was no saving him. (Conversation with Susan).

In this story of clashing beliefs, the one person who understood his own body's signs, and the significance of its past medical history, was ignored.

The hidden body: Discussion

Everywhere we remain unfree and chained to technology, whether we passionately affirm or deny it. But we are delivered over to it in the worst possible way when we regard it as something neutral; for this conception of it, to which today we particularly like to pay homage, makes us utterly blind to the essence of technology (Heidegger, 1993b, pp. 311-312).

* * *

Heidegger proposes that the essence of technology is “ultimately a way of revealing the totality of human beings” (Krell, 1993, p. 309). The pervasiveness of technology in modern life is such that there is a danger of regarding it as the only way of revealing beings, and so we must not become subordinate to technology. Heidegger says that technology is both a means to an end, and a human activity, and that technology is the servant of man in that it provides the means of attaining man-made ends. He warns however, that “[t]he will to mastery becomes all the more urgent the more technology threatens to slip from human control” (Heidegger, 1993b, p. 313).

Heidegger looks at the “means” and the “end” in the instrumental definition. “A means is that whereby something is effected and thus attained,” and this must have a cause. The cause is also connected to the end, though, and “wherever ends are pursued and means are employed, wherever instrumentality reigns, there reigns causality” (p. 313). How can imaging technology be analysed within this framework? The images are requested and produced according to the needs and intentions of medicine. The fact that they might incidentally be appropriated for some other end, that is, to view the interior of a person's body in order to connect with the person's soul, or to attain some obscure position of power because of this unexpected knowledge, challenges their technical, objective purpose. It is a matter of misappropriating the images.

Despite Heidegger's interpretation, it would appear that X-rays and other medical images evoke different responses according to the perspective of the viewer. They have multiple

meanings: they are first and foremost representations of internal structures of a body. But to whose body do these structures belong? Carers understand them as belonging to someone they have known possibly at an intimate level, and certainly over a lifetime. They are familiar with the external appearance of this person, and even with the ravages that disease is inflicting upon this visible body. It is a source of wonder, however, to be able to see inside that body and to see the beauty of the internal structure without its pathological connotations. If we are free to examine the images alone, away from the medical environment of the hospital or the doctor's office, for some the instinctive reaction is to see them as representing the body as a form of art, like a painting which opens up understanding of the mysterious inner body. They are then interpreted aesthetically, somewhat as we would regard a photograph, showing the delicacy and beauty of the bones, the intricacy of the brain, the genius of nature. But they are more than mere depictions of some part of the body because they show us the hidden parts that we cannot see, and we immediately connect them with something mysterious and magical. They are, even today, potential windows to the soul (Cartwright, 1995). The connection with the hidden-ness of the inner body means that there is something forbidden about looking at them, exciting because it is forbidden and not normally accessible. Suddenly and unexpectedly we are presented with the opportunity to see a part of a person which they themselves have not seen, and we feel that this places us in a position of advantage.

But this is an illusion; images of the body's interior are works of art only insofar as they are examples of technical expertise of their creator. Their aesthetic value lies in the fact that they represent something that evinces an emotional response, a link with the soul of another person. That is a misinterpretation, however, and we must return to the real reason for the images, which is means to an end. The concern of the technician who produces the images is to achieve the most accurate and explicitly revealing picture of the body's interior for the benefit of the legitimate interpreter, the physician. Without the physician, the instigator of the process, there would be no image of the brain, no X-ray of the skeleton. The technician does not now (as in the past) produce X-rays purely for the edification of the lay population and is not at all concerned with a layperson's

understanding of his handiwork which is entirely incidental to the aim of the project.⁴ The intention then, is not to demonstrate the beauty of the body's interior, or to extend our knowledge of another person, but to hasten the diagnostic process by accurately locating the site and extent of the lesion.

The image, having been produced and perfected, then becomes instrumental to medicine's purpose, even if accidentally viewed by an outsider. Although the technician who produced the images might be able to accurately interpret the X-rays or scans, this goes beyond the technician's legitimate role as the producer of images. The doctor, equipped now with extended vision made possible by technology, draws upon his or her knowledge and particular expertise to interpret the images as indicators of pathology inside the body, beyond the clinical environment. The patient and the layperson rely absolutely upon the doctor's interpretive skills to reveal the truth as it is shown in the images, to the extent that medical opinion overrides what is self-evident to the patient and the carer. This new scientific focus, faithful to the technical purpose of the images, immediately destroys their fleeting aesthetic value and existential significance; they can now only be seen as indicators of disease. As soon as the nuances of the images are explained as indicators of pathologies, as something unwanted and dreaded, they take on a sinister meaning and the brief illusion of beauty vanishes irretrievably.

Once produced, the images no longer belong to the technician, they are artefacts designed for use through interpretation. Should they fall into the unskilled hands of the carer, they can have brief but illusionary careers as works of art, promising to reveal something previously inaccessible and to give a fresh understanding about a person. Thus from the carer's perspective, it would appear that in some ways we have not strayed far from the time when Röntgen first discovered X-rays, when they were understood as signifying "...the ultimate violation of the boundaries that define subjectivity and identity, exposing the private interior to the gaze of medicine and the public at large...[and]...the X-ray photograph was in fact viewed by some spiritualists as an image of the soul" (Cartwright,

⁴ The current enthusiasm for providing expectant parents with ultrasound images of their babies at the foetal stage *in utero* can be compared with the early profligate use of X-rays for similarly non-medical ends before their danger became apparent (Cartwright, 1995).

1995, p. 121). We are unexpectedly offered the chance to see something that only exists in imagination. For carers, the images portray the inner Being of the sick person, connecting body with soul.

For medicine, X-rays and scans enable the doctor to preserve professional distance while delving into the deepest interior of the patient, lifting out the organs from the body for inspection and depersonalising the body; they are facilitators of Foucault's "clinical glance." By transforming the "uncanny and alien" (Leder, 1990 p. 54) into ordinary and recognisable pictures, they demystify the body and invest power in the observer.

The dismembered body: Medical specialisation

Consultation of specialists. My sister at my side while a physician and a surgeon, Dr P, palpate the swollen abdomen. Maman groans under their fingers: she cries out. Morphine injection. She still groans. "Another injection," we beg. They are against it: too much morphine would paralyse the intestine. What are they hoping for then? (de Beauvoir, 1966, p. 25).

* * *

Specialisation is a feature of contemporary medical practice; it is one consequence of technological advances which enable the doctor to focus exclusively upon particular parts of the body. The shift from gaze to glance, as Foucault (1973) writes, dissociates the physical ramifications of disease from the person with whom it resides; it decontextualises illness.⁵ The parts of the deconstructed patient's body now become the property of different specialists who follow their own unique interests to the exclusion of all others, including those of the patient and the carer. Even cancer, in all its diversity, has its own "generic" characteristics which to a certain extent define the roles and identities of the carers, medical or otherwise. Because of advances in medical treatments, and the extension of life-expectancy, cancer is now essentially a chronic disease. Nevertheless, once diagnosed, cancer is the overarching and pervasive concern; symptoms and signs,

⁵ Turner claims that the effects of specialisation extend far beyond the world of the patient. He writes that "...specialization has undermined, or at last threatened, the professional coherence and solidarity of medicine as a whole" (Turner, 1995, p. 186).

vague or otherwise, which may appear from time to time, are regarded within this particular context. It can be quite shocking when these symptoms are recognised as indications of another, unrelated, condition. Such is the pre-occupation with cancer, that the possibility that there can actually exist any other coincident condition is easily overlooked, and the patient and the carer will look to cancer to explain even the slightest deviation in the physical or mental state of the patient. Doctors too are constrained by the existence of cancer. Sometimes, as my mother and I discovered, the consequences can be bizarre.

About half way through my mother's career as a cancer patient, suddenly, without any warning, her right femur fractured. The immediate effects, such as severe pain, the massive swelling of her ankle, the dramatic and total loss of mobility, confounded the oncologist. After several days of futile and half-hearted investigation (or so it seemed to us), an X-ray finally revealed the truth; the bone which had supported her everyday activities for eight decades had weakened and finally failed. It was assumed immediately that the spread of cancer was responsible for the broken femur. Metastases had been detected in the rib, and it was a natural assumption that the brittleness of the femur could be accounted for in this way. But it was not so; the fracture was the result of osteoporosis, a common, though insidious, condition.

In fact, as is to be expected in an elderly woman (or so we are told), osteoporosis as well as cancer was consuming her skeleton. The bones which had resisted the advance of cancer had betrayed her and fallen victim to a much more ordinary condition. The fractured femur, its repair and the rehabilitation which followed, were not part of the narrative of cancer. These events evolved separately; osteoporosis appeared as a discrete illness which was coincidental with, but unconnected with the cancer. Even the treatment was separate; medical responsibility for these unrelated conditions meant that there was no overlap between the treatment of the femur and the treatment of the cancer. The medical deconstruction of the patient into a collection of pathological events enabled the isolation of the two conditions, and, after a brief intervention, the hasty reconstruction of the primary status of the cancer patient. Indeed, the existence of the person herself was rendered irrelevant in this strange manoeuvring of medical expertise.

The orthopaedic surgeon was optimistic. I was told that he had recently operated (I assumed successfully) on a ninety year old woman. The only alternative, not operating, would mean death from pneumonia, or pulmonary oedema, because of unavoidable inactivity. There was no hope that the bone would knit. And indeed, in the end, the new metallic bone acclimatised remarkably well and within a few months my mother was again mobile, although only the synthetic femur was safe from the threat of cancer. Her recovery, however, exposed the ridiculous lengths to which specialisation has progressed.

After a few days, when it was clear that her recovery from the surgery was progressing well, and could be expected to follow the recommended course, she was moved back to the oncology ward, once again to the care of the oncologist. Residence in the oncology ward re-established her exclusive status as a cancer patient. The orthopaedic surgeon was no longer concerned with her, and did not, or perhaps could not, venture into that special world. Even the period of rehabilitation was of no concern to him, and we did not see him again until the obligatory six-week check-up. (I was ignored during this interview; only the recently restored and now permanent, although permanently altered, femur was of interest to this man). The oncologist, too, was somewhat disadvantaged during the post-operative stage of the incident. It was left to him to discharge my mother from the hospital (since she was only briefly an orthopaedic patient), although his expertise in this speciality was clearly limited. He decided to discharge her after she had been in the hospital for what I assume he considered long enough (about five weeks, I recall). By that time, she would presumably be expected to be able to walk, and he rang me one morning with the good news that I could take her home that afternoon. Panic stricken (I knew she could not stand unaided, let alone walk), I rang one of the nurses, who somehow arranged for her admission to a rehabilitation hospital. The oncologist visited her there a couple of times, but there was no sign of the orthopaedic surgeon. His role was enacted exclusively within the enclave of the theatre, with brief, secondary excursions into the orthopaedic ward and, more frequently, his consulting rooms.

What had been gained? A few more months of life, perhaps. After this brief interlude our existences resumed as before. The incident of the broken femur had merely diverted attention from the cancer, and afterwards we returned to it, bending our attention back to it when the repercussions of the fracture, and the unfamiliar world of rehabilitation, had retreated. What remained was the mere memory of a temporary nuisance, a diversion from the business of dying.⁶ (Extract from author's notes).

The two specialists' foci of interest were so refined that they failed to recognise what should have been their primary concern; the woman who lay before them. This episode floats surreally outside the cancer experience, an interruption never to be integrated into the half-finished narrative of illness or of care.

Mme de Beauvoir's situation was the reverse of my mother's; in her case it was the fractured femur which occupied the exclusive attention of the physician, and the possibility of malignancy was not considered by the orthopaedic specialist. De Beauvoir writes: "[Professor B] seemed disconcerted when I told him that her bowels had been giving her trouble. The Boucicaut [Hospital] had reported a broken neck of the femur and

⁶ Two years after my mother's death, a questionnaire from her health insurance company was sent to her at her old address, requesting an assessment of her prosthesis.

he had confined himself to that: he would have her examined by a physician” (de Beauvoir, 1966, p. 14).

Even palliative care is not immune from the separation of interests. Kellehear writes that the aims of palliative care are “...to relieve distress and alleviate the symptoms of a progressive illness that is no longer responsive to medical curative treatment” (Kellehear, 1999, p. 4). The holistic, multi-disciplined nature of palliative care expressed here appears to be incompatible with the notion of specialisation, but these aims are so remote from those of mainstream medicine that it is often regarded as a medical specialty in its own right. An important inclusion in the World Health Organization’s concept of “good palliative care” is that it “provides appropriate support for the dying person and his or her family” (p. 4). It was with this expectation that I approached our first encounter with a palliative care specialist.

The palliative care specialist, Dr W, was very tall; a big, robust looking man who wore brown tinted spectacles, and had cultivated a luxuriant, bristly moustache. At this particular time my mother was anorectic, a result of radiotherapy. The oncologist was on leave, and in his absence Dr W was caring for his patients. I took Mum to the hospital because I thought (and so did she) that she was dying. I had no notion at that stage of the resilience and persistence of the human body.

The ward had four beds, and my mother was in the one nearest the door. The curtains were drawn around it, so the ordinary activities of hospital life were excluded, creating another more fragile, temporary world. My mother was a tiny person, and was further diminished by the disease. She was now almost indiscernible on the unwelcoming hospital bed.

There was no examination. Dr W stood on one side of the bed, I on the other, only further away so as not to interfere with the consultation. His eyes were invisible behind his glasses; the light reflected back at me from the lenses, although he did not look directly at me, or address me personally. He said, after learning from the nurse that my mother’s immediate problem was nausea so severe that even swallowing tablets was out of the question: “We’ll give you a little injection to stop you feeling sick.” The consultation was over. The specialist had barely acknowledged the presence of the patient, and certainly not the existence of the patient’s daughter, or the legitimacy of my presence there. (Extract from author’s notes).

It is frightening to be with a person who cannot eat but needs food in order to survive the terrible weakness brought about by some therapies. This assault seemed, at the time, utterly unreasonable. Radiotherapy was offered as the only available palliative measure,

but its effects were devastating and uncontrollable at the time. The promised palliative effect was so remote from the treatment that the connection between the two defied belief. At this time I could do nothing to alleviate my mother's distress, and therefore suffered along with her. I needed to be included in this consultation, but in reality neither of us took part in it. It was essentially a farcical encounter which for us served no purpose whatever, and merely reinforced my sense of exclusion from the business of cancer.

One of the more difficult and distressing consequences of the disparity between the medical and lay understandings of illness emerges when choices about treatment and end of life decisions need to be made. Philip Roth, for example, when confronted with two specialists who confidently recommend quite different approaches to the treatment of his father's brain tumour, is tortured by the terrible choice he faces in whether to advise his father to submit to either type of brain surgery, with all their uncertainties and dangers, or to let the tumour take its course. In an exchange with his friend, Joanna, he says:

"He's facing a very bleak prospect...They tell me he's going to be in desperate shape in a very short time. They're going to have to try to get it out. It's a terrible operation."

"Does he want it?"

"Want? No. But the alternative is to let it grow and take the consequences, and that could be grotesque. The problem is that for an eighty-six-year-old man, even if he survives – and the doctor claims they survive three times out of four – the recovery will be a nightmare. He'll never be himself again, though maybe he can be something close to himself."

"So much closer," Joanna said, "than with that thing in his head."

"With that thing he's doomed. It's a helluva choice, but there is no choice."

"With the end of life it always gets that way" (Roth, 1991, pp. 122-3).

Later he says: "The choice isn't real, however. The alternative is unacceptable. The choice would be to jump out of the window."

Decision making is one of the most taxing aspects of Roth's experience; each new piece of information which technology presents to Roth and his father requires another decision to be made about treatment. The time between tests, before new information becomes available, when decisions do not have to be made, represents a "reprieve." At one such time, Herman suddenly decided that he should return to normal life, and accept his friends' advice to become involved with the Jewish social activities again. Roth said to

himself: “‘A reprieve,’ I thought, ‘and let him enjoy it. Enjoy it yourself,’ I thought, ‘if only until the next decision has to be made tomorrow’” (p. 136). The reprieve was brief, however; after twenty-four hours they could no longer ignore the illness, and “the brain tumour took charge again” (p. 142). Eventually, Roth’s cousin, a doctor who had more than simply professional concern for Herman, told them that as the tumour had probably existed for ten years, that there was no way of knowing what the consequences of leaving it there would be, and there was no point in embarking on surgery that would almost certainly have terrible consequences. They then decided to go ahead with the cataract removal, which had been planned before the tumour had been discovered, so that at least Herman would be able to see for however long he had left.

Here the specialist’s and patient’s priorities are quite different. At eighty-six, Herman Roth is more interested in regaining his sight than the removal of the tumour, a sentiment clearly understood by Roth’s cousin who is, in this instance, acting in the capacity of a relative rather than as a doctor. Roth found the draft of a letter that Herman was writing to the ophthalmologist, which read: “‘Dear Dr. Krohn, I want my sight back. I want my eye fixed. That’s what I want. Herman Roth.’” (p. 144). Later he said to his son: “‘Phil, I want my eyesight back. I want Dr. Krohn to fix my eye. Enough farting around with this other thing’” (p. 148).

The dismembered body: Discussion

Description, in clinical medicine, does not mean placing the hidden or the invisible within reach of those who have no direct access to them; what it means is to give speech to that which everyone sees without seeing – a speech that can be understood only by those initiated into true speech (Foucault, 1973, p. 115).

* * *

Foucault is referring here to the development, through language, of what he describes as a “new esotericism” by which means medicine lays claim to illness. As “disease,” described in technical terms which have no meaning to the lay person, the patient’s illness can be observed and treated, in virtual isolation from the patient as person. Medical terminology appropriates the illness, removing it from the complications of social and, it would seem, other medical contingencies.

Good (1994) writes that he is always astonished at the unique world that medicine occupies; when he moves from one environment to the other when lecturing he is struck by the different view that medicine has of the body and of disease. This is reflected also in the language used in these areas. The discipline of medicine can be understood not only as a unique way of understanding, but also as a way of conceptualising, or thinking:

Entry into the world of medicine is accomplished not only by learning the language and knowledge base of medicine, but by learning quite fundamental practices through which medical practitioners engage and formulate reality in a specifically “medical” way. These include specialized ways of “seeing,” “writing,” and “speaking” (Good, 1994, p. 71).

He describes medical education as following a hierarchical pattern, in which students are confronted first with epidemiological information about a disease, then an example of a person suffering from the disease, and finally with the diseases’ physiological manifestations. The next step is perhaps cytological, and then the focus narrows to the molecular, through electron microscopy. The ultimate goal then is not the broad sociological repercussions, that is, the effects of the disease on real people, but it is to separate and distance the disease from the person by this focus on the absolutely objective microstructure of the body’s components. Good’s interviews with medical students demonstrate that they are encouraged to disregard the personal aspects or effects on individual patients, and their social world. The purpose of the clinical encounter is to sever this bond with their normal context and place them in a medical context in which they have no power; control here rests with the physician. Good observes: “Medical education begins by entry into the human body. Viewed through the microscope, entered physically in the gross anatomy lab., seen with astonishing clarity via contemporary radiologic imaging, or presented by master scientists, the body is revealed in infinite, hierarchical detail” (p. 72). Once the body is regarded in this manner, dissociated from normal reality, the doctor enters “another world.” But the students sometimes found themselves instinctively trying to enter this world, with its medical gaze, even when not in the clinical situation, imagining what the person they were talking to would look like if he or she were dissected as in the anatomy laboratory. The body is “reconstructed” in a way that is appropriate to the medical gaze.

Specialisation, the ultimate refinement of the medical “glance” (Foucault, 1973), mirrors this hierarchical structure as each specialist discipline focuses exclusively upon its own territory. The “clinical gaze,” which took in the entire world of the patient, has been swept aside by a burgeoning scientific knowledge which confuses the medical landscape with detail. The illness experience of the patient, and the concerns of the carer, are lost as specialists shift in and out of the situation, oblivious to the reality of illness itself. This lapse in humanity is illustrated in de Beauvoir’s account of an exchange with her mother’s doctor:

Maman had just been taken up to her room, N told us. He was triumphant: she had been half dead that morning and yet had withstood a long and serious operation excellently. Thanks to the very latest methods of anaesthesia her heart, lungs, the whole organism had continued to function normally. There was no sort of doubt that he entirely washed his hands of the consequences of that feat (de Beauvoir, 1966, p. 28).

Later, she writes: “Dr N was smart, athletic, energetic, infatuated with technique, and he had resuscitated Maman with great zeal; but for him she was the subject of an interesting experiment and not a person. He frightened us” (p. 46).

“Dr N” understood that his function as a surgeon was to prolong life at all costs, in much the same way that Herman Roth’s surgeons were concerned only with the problem of excising his tumour, without regard for the consequences for Herman (and, of course, for his son Philip). Herman’s main concern was his failing eyesight, which was creating enormous difficulties for him in his everyday life; the tumour itself was not the cause of this but the specialists, in their enthusiasm for operating on the tumour, forgot that he was in any case nearing the end of his life, and removing the tumour (an exceedingly dangerous procedure), was not really in Herman’s interests.

The minute deconstruction of the patient’s body, which medical specialisation oversees, severs the connection between the illness experience and the body itself. The alienation of the carer’s experience, which is mediated through the body of the sick person, is hastened by the intervention of the specialist who overrides (or at least, circumvents) the concerns of the ordinary doctor. Carers and patients who might struggle to find common

ground with the medical profession find their understanding of illness, and the construction of their illness narrative, threatened further by the intervention of the specialist.

The Naked Body

I was not worried by her nakedness any more: it was no longer my mother, but a poor tormented body. Yet I was frightened by the horrible mystery that I sensed, without in any way visualizing anything, under the dressings, and I was afraid of hurting her...I took hold of that skeleton clothed in damp blue skin... (de Beauvoir, 1966, p. 47).

* * *

This section is concerned with the vulnerability of the ill which is associated with dependence upon others for bodily care. Both shame and embarrassment affect the carer as well as the sick person, but being able to observe the naked body of our parents also offers an unexpected opportunity for us to satisfy our curiosity about something that is traditionally regarded as taboo. The relationship between carer and parent can then be re-examined from a fresh perspective.

Sartre (1969) tells us that in its unclothed, defenceless state, the body is deprived of its subjectivity, and is distanced from its inhabitant. When clothed, personhood is restored, and sexuality and the physical state of the body become secondary unless the naked person retains control through other devices. Inga Clendinnen encountered such a situation during an incident that occurred when she was a young woman. Her sick mother was feeling well enough to take a bath, and while she was “relaxing blissfully in the warmth,” Clendinnen put fresh sheets on the bed, and cleaned the room. She had just arranged her mother’s favourite roses in a vase when her mother called for her:

Somehow she had levered herself out of the bath alone, and was sitting on the stool drying herself, with a second towel draped across her. I thought she wanted me to help dry her, but she didn’t. As I came in she stood up and dropped the towel. This most modest of women wanted me to see her body, to count the cost of being a woman: the veined legs, the pouched belly, the flaccid breasts, the stained nipples. She looked at me with a glance which was at once an appeal and an apology: She was confessing the real sin of the flesh: that it aged, that it betrayed you. The display was also an invitation, and a threat. You are a woman now. Join us (Clendinnen, 2000, pp. 137-8).

By deliberately displaying her ravaged body, her mother pre-empts any voyeuristic tendencies which Clendinnen might entertain either then or in the future. The mystery of her body is literally uncovered and the balance or the relationship (in which her mother dominated) is retained.

Although age and illness undermine or diminish the body's sexuality, as Clendinnen was shown so harshly, this realisation can lead also to the nostalgic speculation about the sick person's sexual life. Kerry relates what she described as a "profound experience," in which she suddenly saw her mother's body not only as the vessel that nurtured and carried her until her birth, but as the embodiment of love within which she had been conceived:

Kerry: But prior to her dying there was one very profound experience for me and actually I do think about that a lot, and I like it better than the gasping breath scene [when she was dying]. It was one time – it was fairly close towards the end, and she was actually lying in the bed. And the nursing staff had come to sponge Mum down (you don't need to go away), and when they lifted up - well, she didn't have many clothes on - just a little top on – and the rest of her – she was just so painfully thin, and I remember looking at her around where the womb area was. It occurred to me how I'd been inside her, and I looked at that little area that was so tiny, thinking that I'd been in there, and how I'd come out, and how I'd been conceived of love, and actually carrying that baby and giving birth to that baby, and looking after that baby –. Even talking about it now, you can see how it's affecting me. I found it extremely profound. The thing about it is, I know they talk about this Mother-Daughter bond. I know that sort of exists, but it wasn't as though that was sort of a real thing for me. Look, I loved my parents dearly, but it's not like it was one of my hobby-horse things. I have felt it quite a lot since Mum has gone. Now, I haven't quite worked out whether it's because mother and child, or mother and daughter – that's probably part of the component - I think that the other component is that now both my parents are gone, those two people who we disagree with sometimes...(Conversation with Kerry).

Modesty is meaningless in this context; and that barrier having been removed, Kerry was free to explore thoughts and emotions that would have been impossible while her mother was healthy and independent. Similarly, while helping his father in the bath, Roth deliberately studied his father's penis, fixing it in his memory:

"Ah, it feels good," he said, pushing water over his chest with his two hands. Weakly at first, then more vigorously, he began to flex his knees and I could see the muscles working in his thin shanks. I looked at his penis. I don't believe I'd seen it since I was a small boy, and back then I used to think it was quite big. It turned out that I had been right. It was thick and substantial and the one bodily part that didn't look at all old. It looked pretty serviceable. Stouter around, I

noticed, than my own. "Good for him," I thought. "If it gave some pleasure to him and my mother, all the better." I looked at it intently, as though for the very first time, and waited on the thoughts. But there weren't any more, except my reminding myself to fix it in my memory for when he was dead. It might prevent him from becoming ethereally attenuated as the years went by. "I must remember accurately," I told myself, "remember everything accurately so that when he is gone I can re-create my father who created me." *You must not forget anything* (Roth, 1991, p. 177; emphasis in original text).

These anecdotes, despite their clear sexual connotations, demonstrate that sexuality is not necessarily instrumental in evincing feelings of shame, nor is it the only important factor in the equation of power. The integrity of the body, for example, is an indication of strength and control; illness, old age, or anything else that might undermine its integrity, also challenges the autonomy of the person concerned. The clothed body confers autonomy through illusion, but the naked body, being "defenceless," yields to control by others. Kerry's mother and Roth's father have relinquished their independence because of their frailty and in so doing have moved to a different state of bodily awareness which avoids the "object-state" to which Sartre refers. They have reclaimed their subjectivity, but it is one in which their nakedness, and their sexuality, are relevant only as signifiers of their selfhood.

Clearly, illness affects the way in which the body of the sick person is apprehended. Frank (1991) writes that illness is experienced fundamentally as a loss of autonomy, and therefore the patient will deliberate with himself or herself to what extent the illness will be revealed in an attempt to retain a degree of control. Toombs (1987) also argues that the primary experience of illness is as loss of control over the body; and, she writes: "Illness disrupts the fundamental unity between the body and self" (p. 229). Even if a person recovers from the illness, he or she is always aware of the body's potential to fail or be beyond their control. As the person's physical status changes, the perception of the body is irrevocably altered and understood from a new perspective, and "[t]he patient needs support in his efforts to establish the integrity of a newly defined self" (p. 230). Toombs observes that loss of control of the body, "...the perception of loss of wholeness and bodily integrity," and uncertainty about the future, are among certain fundamental, or eidetic, characteristics which are common to all illness experiences, and in these eidetic factors the reality of illness is revealed (Toombs, 1987, p. 234; see also Charmaz, 1991).

The experiences of Kerry and Roth show that the parents' frailty and dependence confer upon others a new freedom to scrutinise their bodies, presenting an opportunity to observe them in terms of their sexuality. Curiosity about our parents' bodies is not necessarily always associated with sexuality. This unexpected opportunity also allows us to indulge our fascination with the physical degradation of the body. This can be understood in terms of a "power relationship," in which power is envisaged as resting with the person who views the Other as an object (Sartre, 1969). However, this possibility does not always present itself unequivocally to a carer who has a unique and lifelong knowledge of the Other.

Most of us are not invited so blatantly as Clendinnen was to observe the Other's body; curiosity must usually be satisfied in a more covert fashion. Nancy Miller (whose mother had always been rather vain), studied her mother's dead body:

Except for the effects of the chemotherapy, my mother's cancer was almost invisible. When she died, I found myself alone with her corpse. Unembarrassed by her dead-eyed stare, I carefully examined the body that had fascinated me all my life and that now lay open to my inspection...Despite its obvious frailty, her newly slim body, thoroughly exercised over a lifetime of fitness *avant le lettre*...was unnervingly youthful. And her face revealed the bone structure she had always maintained was the true source of beauty (Miller, 1996, pp. 41-42).

Miller's dead mother is now utterly defenceless but is immune from shame, while Miller herself is able to dissociate the body from her mother's person sufficiently to regard the body merely as object.

In death my mother's body meant nothing to me; there had been ample opportunity to observe its deterioration over the years that I cared for her and it held no mysteries for me. The manifestations of the disease, however, I found curiously fascinating. Like Miller, I was struck by the invisibility of cancer, even during the last stages of her illness:

Bathing my mother should have given me the chance to observe the deterioration of her body, the encroachment of the disease, but in fact this was wholly internal, and to my relief, invisible. Virtually the only outward sign of the cancer was the small pale scar on her breast, and when she was undergoing radiotherapy, the targets drawn on her hip by the therapist. Over time she just became smaller, until the skin lost its underlying support, revealing at last the enduring skeletal structure. (But this was an illusion; the X-rays told me that the bones were in

reality mere shadowy vestiges of what they had once been). The skin on her back was white, unchallenged by the sun, as the skin on her hands was after years of gardening. On her back it was like the skin of a baby, white and pure and fine. Clothed, and with her hair neatly combed, she looked frail, but not particularly unwell... (Extract from author's notes).

It was extremely important to my mother that for as long as possible she would always dress carefully, despite the difficulties this presented for both of us. She did not abandon this illusory device until a few days after she entered the Hospice, when she was surrounded by dying people, and hope had vanished. Clothing for her was not a denial of sexuality; it was a denial of illness.

It is of crucial importance for the sick person to maintain the illusion of health, to conceal the evidence of decline, as this is an indication of the loss of autonomy and admission of defeat. Dependence upon others for bodily care renders the sick or disabled person particularly vulnerable because inhibitions must be cast aside and embarrassment overcome. This is true also for the carer who now cannot avoid seeing that which has previously been taboo; the naked body of a parent. Modesty, the reluctance to bare our naked body to others, soon disappears as illness claims the body. Mme de Beauvoir abandoned her customary modesty as her illness progressed. She was no longer ashamed of the appearance of her emaciated body, showing no self-consciousness at exposing it to her daughter. De Beauvoir, however, was at first embarrassed at the sight of the body which had had different meanings to her during her life:

Maman had an open hospital nightdress on and she did not mind that her wrinkled belly, criss-crossed with tiny lines, and her bald pubis showed. "I no longer have any sort of shame," she observed in a surprised voice... The sight of my mother's nakedness had jarred me. No body existed less for me: none existed any more. As a child I had loved it dearly; as an adolescent it had filled me with an uneasy repulsion: all this was perfectly in the ordinary course of things and it seemed reasonable to me that her body should retain its dual nature, that it should be both repugnant and holy - a taboo (de Beauvoir, 1966, p.18).

Her mother had rid herself of all the "exigencies and prohibitions" which had ruled her life, and although de Beauvoir thoroughly approved of such an attitude, she was nevertheless shocked at discovering that it compelled her to regard her mother's body in a new and frightening way. She writes that "...this body, suddenly reduced by her capitulation to being a body and nothing more, hardly differed at all from a corpse - a

poor defenceless carcass turned and manipulated by professional hands, one in which life seemed to carry on only because of its own stupid momentum” (p. 18). Illness had reduced, or rather transformed, the status of her mother’s body; no longer was it the familiar body that she had known all her life. Now, de Beauvoir writes: “For the first time I saw her as a dead body under suspended sentence” (p.18). Later, de Beauvoir was afraid not of the nakedness of her mother’s body, but of the terrible destruction wrought by the disease. She writes:

I was not worried by her nakedness any more: it was no longer my mother, but a poor tormented body. Yet I was frightened by the horrible mystery that I sensed, without in any way visualizing anything, under the dressings....I took hold of that skeleton clothed in damp blue skin...(p. 47).

When the Other’s body is in fact a dead body, how do we see it then? It is now merely an object, but it is the body of someone who is nevertheless still meaningful to us as a person. The body itself is not meaningful, however; only the memories of the person who once inhabited it are significant. Sartre (1969) agrees when he writes:

I never apprehend the Other as body without at the same time in a non-explicit manner apprehending my body as the center of reference indicated by the Other. But all the same we cannot perceive the Other’s body as *flesh* as if it were an isolated object having purely external relations with other thises. That is true only for a *corpse* (Satre, 1969, p. 344).

Sartre argues that the body of the Other must always be regarded as being contextually situated, as a “synthetic totality.” He continues,

As a *corpse* – i.e., as the *pure past of a life*, as simply the *remains*- it is still truly understandable in terms of the surpassing which no longer surpasses it; it is *that which has been surpassed toward situations perpetually renewed*...the corpse is *no longer in situation* (p. 348; emphasis in original text).

Unlike Miller (see page 243), most people see only the face of the dead person, which has been carefully prepared by the nursing staff for viewing. Kerry, for example, who was not present when her mother died, arrived at the hospice to find that she looked unfamiliar in death:

Kerry: I can remember looking at Mum and thinking, “Well, that doesn’t really look like Mum.” They’d pulled her hair back, and she was never a very big lady, and she’d got really thin. It reminded me a bit of those ballerinas, you know, when they get older and they have their hair pulled back, and it shows their cheekbones. And really thin. (Conversation with Kerry).

De Beauvoir's curiously emotionless account of the events that took place when Sartre died belies her distress:

He was asleep and breathing quite strongly; he was obviously in a coma, and had been since the evening before. I stayed there for hours, watching him. At about six I made way for Arlette, asking her to telephone if anything happened. At nine the telephone rang. She said, "It's over." I came with Sylvie. He looked just the same, but he no longer breathed (de Beauvoir, 1985, p. 124).

Later, when he was dressed and lying in his coffin, she remarks: "He was calm, like all dead people, and like most of them, expressionless" (p. 125).

What, then, does the body really represent to the carer? When a person is alive (even if unaware of our scrutiny) the person and the body are seen as one; the body represents the person. In an argument similar to that of Sartre mentioned above, Heidegger writes:

But as soon as Dasein "exists" in such a way that absolutely nothing more is still outstanding in it, then it has for this very reason become "no-longer-Being-there" [Nicht-mehr-da-sein]. Its being is annihilated when what is still outstanding in its Being is liquidated (Heidegger, 1962, p. 280).

Death "delimits" Dasein, but it does not eliminate the dead person's Being for those who remain; even Being-no-longer-in-the-world is still, Heidegger says, a way of Being.

In the dying of the Other we can experience that remarkable phenomenon of Being which may be defined as the change-over of entity from Dasein's kind of Being (or life) to no-longer-Dasein. The *end* of the entity *qua* Dasein is the *beginning* of the same entity *qua* something present-at-hand (p. 281).

Heidegger distinguishes between the dead body as "corpse," that is, as being of significance as, say, an anatomical specimen, and as the "deceased," which still has meanings beyond that of a corpse for those left behind. This can be seen also in the way in which post-mortem care is administered by nurses (see, for example, Wolf, 1988). One of the participants, Zoe, describes how her sister (who, as well as caring for their dying mother in an informal capacity, is also a nurse) continued her caring activities after her mother died:

Zoe: ...and they just rang and said that Mum had passed away. So she had waited – that would be her! – she waited until we went! So we went back, and [my sister] fixed her up, made her comfortable until the doctor came. I'd just felt that it was lovely, and I think that's what Mum would have wanted too. (Conversation with Zoe).

Here, perhaps calling upon her professional objectivity, Zoe's sister Anne is able to attend the body of their dead mother.⁷ The exact nature of how she "fixed her up" is not revealed, but in the words "made her comfortable," it appears that Zoe understood her mother to be still in some way aware of this attention; that is, the body was not yet regarded objectively as a mere corpse.

The naked body: Discussion

Modesty and in particular the fear of being surprised in a state of nakedness are only a symbolic specification of original shame; the body symbolizes here our defenceless state as objects. To put on clothes is to hide one's object-state; it is to claim the right of seeing without being seen; that is, to be pure subject. This is why the Biblical symbol of the fall after the original sin is the fact that Adam and Eve "know that they are naked." The reaction to shame will consist exactly in apprehending as an object the one who apprehended my own object-state (Sartre, 1969, p. 289).

* * *

As far as the body is concerned, even the body of another, we must learn to distinguish it from the objective body as set forth in works on physiology. This is not the body which is capable of being inhabited by a consciousness (Merleau-Ponty, 1962, p. 351).

* * *

Although the narratives used in the study indicate shame is not necessarily concerned with sexuality, it is in this context that its existential character is usually framed. Parvis (1972) writes that Scheler concludes from his phenomenological examination of shame (which incidentally Parvis declares is "highly rewarding" because it is distinct from psychological description), that the feeling of shame is unique because it is "an independent emotion which cannot be empathically felt in the way sorrow and sadness can" (Parvis, 1972, p. 363). It is a feeling "through which we can feel our own selves," and it derives from an "oscillation" of intentionality between the general (i.e., those things that can be shared by all), and the individual. It arises from a heightened sense of self, a turning back on oneself. Scheler deduces from this understanding of the process that shame exists in both spiritual and bodily senses, and these are not reducible to each other. Shame is related to (or rather contains qualities of) pride and humility, and is also close to repentance and honour: "In repenting, one is also ashamed of oneself. A sense of

⁷ Wolf (1988) provides a detailed account of post-mortem care in nursing.

shame is ordinarily paralleled by a sense of honor, while shamelessness is accompanied by the absence of a feeling of honor” (p. 364). The relationship of shame to nausea and aversion are seen through their similar physiological manifestation as a “vital inhibitory effect on absorption of food and sexual drive.”

Scheler’s analysis of shame links it with general categories of feelings, but he does associate shame primarily with sexuality. For example, in considering the bodily and spiritual feelings of shame:

Both of [the forms of shame] represent the index of tension (Spannung) which exists between love and drive. With body, love appears as vital love (vitale Liebe) whose concentration is reached in sexual love. With spirit, love appears as spiritual love (geistige Liebe) which is directed toward spiritual personality. With body, drive appears as drive-impulse (Triebimpuls) which in its sexual form is condensed as an erotic sensation of tingling desire (Kitzel der Wollust). With spirit, drive appears as vital drive (vitaler Grundtrieb), involved merely in increasing the power of life (Liebensmacht) (Parvis, 1972, p. 364).

Similarly, Merleau-Ponty, discusses shame as an adjunct of sexuality and its repression through ecclesiastical agencies. Sexuality can either be deliberately flaunted or unwillingly exposed when the body is unclothed, and this means that nakedness itself is a source of shame, although the naked body is ambiguous:

Usually man does not show his body, and when he does, it is either nervously or with an intention to fascinate. He has the impression that the alien gaze which runs over his body is stealing it from him, or else, on the other hand, that the display of his body will deliver the other person up to him, defenceless, and that in this case the other will be reduced to servitude. Shame and immodesty, then take their place in a dialectic of the self and the other which is that of master and slave: in so far as I have a body, I may be reduced to the status of an object beneath the gaze of another person, and no longer count as a person for him, or else I may become his master and, in my turn, look at him. Saying that I have a body is thus a way of saying that I can be seen as an object and that I try to be seen as a subject, that another can be my master or my slave, so that shame and shamelessness express the dialectic of plurality of consciousnesses, and have a metaphysical significance (Merleau-Ponty, 1962, pp. 166-7).

The narratives examined in this section are concerned with how illness influences the way in which the body of the sick person is apprehended by the carer. Professional carers are able to retreat behind the veil of objectivity when confronted with the naked body of their patients, while the patients themselves can also avail themselves of this shield by their understanding of the principles of professionalism within which they consult health

professionals. Informal carers, however, are not afforded this device. Both carer and sick person must, instead, deal with the everyday issues of shame and embarrassment, although they are tempered by the unique circumstances which illness imparts to their situation.

Scheler suggests that shame is associated with notions of honour and pride (Parvis, 1972). These sentiments are unsustainable in their familiar forms when illness has devastated the body and rendered it dependent upon others. Access to the naked body of the sick person is a contingency of caring to which both carer and patient must become accustomed. Thus the shame that Herman Roth felt at having “beshat” himself is of a different kind than bodily shame, being linked to the relinquishment of independence, and acknowledgment of helplessness. Roth “felt awful” about the terrible sense of shame he knew his father felt, understanding that this episode represented a symbolic shift in the power balance in their relationship. His father was no longer in control of his bodily care, but this gave Roth an opportunity to show strength by hiding his revulsion and comforting Herman.

Sartre writes that in feeling shame at our own nakedness,

...shame supposes a me-as-object for the Other but also a selfness which is ashamed and which is imperfectly expressed by the “I” of the formula. Thus shame is a unitary apprehension with three dimensions: *I am ashamed of myself* before the *Other*...[and] ...if any one of these dimensions disappears, the shame disappears as well (Sartre, 1969, pp. 289-90).

The shift in the balance in the relationship can be viewed as a release from customary constraints, bringing with it a new freedom, offering the chance to observe the sick person’s body in the most intimate way. The ill must acknowledge their new, objective, status and relinquish inhibitions to subjection of themselves to the gaze of the Other in order to correct the imbalance in the relationship. Illness, and the proximity of death, undermine the customary balance of the relationship and gradually we must concede that the body we see is no longer so closely associated with the person we have known for a lifetime. The body is transformed; it is now, as de Beauvoir writes, “a dead body under suspended sentence,” soon to take up a new identity as a corpse. Thus seeing our parents’ bodies in a state of nakedness, stripped of the mantle through which their subjectivity was

expressed, tempts us to see them objectively, almost as being detached from the person. Suddenly they become vulnerable to our gaze and there is now the opportunity to see them not as parents (which bear a special relationship and hold a unique meaning to our own subjectivity) but as objects to be observed and considered dispassionately. At the same time, however, they are not like any other person's body, and their sexuality has a special significance because we cannot ignore the fact that that is what gave us our existence.

Summary and Conclusion

This chapter is concerned with the embodiment of illness and disease. The diagnosis of illness enforces the exposure of the body to the scrutiny of strangers as well as familiar people, and this exposure can be distressing for a number of reasons. The chapter begins by considering the chasm that exists between the discourses of disease and illness, with particular reference to the impact of technological advances in medicine which uncover even the most private and secret parts of the body. Medicine's scientific, objective interpretation of the information produced by these techniques is not generally shared with the layperson, especially the carer, who might understand X-ray and other images as representations of a familiar human being rather than as mere pathological evidence.

The scientific deconstruction of the body made possible with these techniques is expressed in medical practice by the exponential blossoming of medical specialisation now being witnessed. A generalist medical approach that apprehends the human body as an integrated organism, rather than as a sum of many discrete parts, is rare in the modern Western world. The carer, however, cannot dissociate body parts from each other, or from the person who inhabits that body.

In the final section of this chapter, the sick person's body, although retrieved from the medical gaze (or "glance"), presents issues of a different kind. Illness and frailty precipitate both carer and ill person into a situation of unfamiliar intimacy, in which shame and embarrassment can present many difficulties. These difficulties can, however, be balanced by the unexpected opportunity, which this intimacy makes possible, to reflect

upon their parents' past lives and sexuality, and even upon their own conception, gestation and birth.

This is the final of the three chapters in which the principal themes emerging from the research material have been examined in detail. The next chapter brings these discussions together in a concise phenomenological description of caring under these particular circumstances.

Chapter Eight. Being there

But when you enter that caring role, it sort of becomes a very clear focus, as distinct from all the other baggage. So you do go into a role. I mean, you don't intellectualise it. That's the mystery. (Conversation with Anne).

* * *

A mystery is a problem which encroaches upon its own data, invading them, as it were, and thereby transcending itself as a simple problem (Marcel, 1948, p. 8).

* * *

In the previous three chapters the phenomenological analysis of the primary and secondary sources used in this study has revealed a number of elements which, although they do not in themselves define caring¹, emerge as being of considerable significance in clarifying the phenomenon. They have been explored within theoretical frameworks that reflect the existential orientation of the study with the intention of extending and enriching the understanding of these factors.

In Chapter Five the ways in which caring is conceptualised in theory and practice was examined. The review of features of caring experienced by the carers, and which also appear in the literature, began with a brief account of how caring is perceived by those receiving care. The carer's experience itself was explored according to a number of themes: a comparison between nursing and informal care, upholding the truth, nourishing body and soul, ways of communicating, the issue of self-deception as denial, simple and difficult tasks, and temporality. Finally, the carers reflections upon their caring experience were considered.

Chapter Six *Hope and Suffering*, began with an overview of the existential view of suffering, including the ideas put forward by Kleinman, Scheler, Frank and Frankl. This was followed by a review of existential theories of suffering and hope, in particular those of Heidegger and Merleau-Ponty. Morse's bio-psycho-social theory of transitions between states of suffering and endurance is briefly discussed in comparison with existential theories of suffering. Examples of hope and suffering which appear in the

¹ Throughout this chapter, the term "caring" refers in particular to informal caring.

research material were grouped under the following themes: suffering without hope, finding a new purpose through hope, overcoming fear through hope, and explaining illness as a means of coping with fear and despair.

The focus of Chapter Seven, *Ways of Knowing the Body*, was an issue that affects the carer, health professionals and the ill person in different ways; the way in which the ill person's body is experienced. The first section of the chapter (*The Hidden Body*) dealt with the ways in which medical technology reveals the body's interior by means of X-rays and other procedures, and how these images are interpreted by medicine, the sick person, and the carer. In the second section, (*The Naked Body*), shame and embarrassment, and ways of overcoming them were examined. The final section was concerned with medical specialisation, which has so narrowed the focus of interest that the body has become metaphorically deconstructed, its parts excised from its totality.

The objective of this final chapter is to review these elements in a process which, in terms of Heidegger's concept of authentic Being-in-the-world, captures and describes the fundamental existential aspects of the carers' experiences. The context of the study is highly specific, being concerned with the impending death of the carer's parent, and the elements, once selected, have been situated within the corresponding existential framework. A discussion of the elements of caring that have emerged from the study is therefore preceded by an account of Heidegger's understanding of Being-towards-death. The chapter concludes with the proposal that caring can be understood within an existential framework as an authentic way of being.

Elements of caring

The phenomenological analysis of caring undertaken in this study is underpinned to a large extent by the work of Heidegger, and his conceptualisation of death is briefly restated here in order to emphasise the existential factors that distinguish caring for the dying from caring in other contexts. It also provides a preliminary framework for the summary of the elements of caring identified in this study which follows.

Being-towards-death

Heidegger states that the totality of *Dasein* is defined by death, but upon achieving its totality, *Dasein* ceases to exist as an entity. He writes that “[Dasein’s] Being is annihilated when what is still outstanding in its Being has been liquidated. As long as *Dasein* is an entity, it has never reached its ‘wholeness.’ But if it gains its ‘wholeness,’ this gain becomes the utter loss of Being-in-the-world” (Heidegger, 1962, p. 280; emphasis in original text). The statement that “death is the possibility of the impossibility of *Dasein*” (p. 294) clearly expresses the extraordinary existential significance of this paradoxical situation. In addition, Heidegger argues that to deny the facticity of death is an inauthentic way of being. In other words, we must accept the prospect of being unable to know our own *Dasein* in its totality as we cannot experience a state of death, or as Heidegger writes: “Our everyday falling² evasion *in the face of* death is an *inauthentic Being-towards-death*” (p. 303; emphasis in original text). What then is an authentic way of Being-towards-death? How is it possible to accept the prospect of the impossibility of Being? Heidegger declares that we *must* face it as a possibility, to “*put up with it as a possibility*” (p. 306; emphasis in original text), but in an authentic attitude, death must be “anticipated” as the possibility for the potentiality for Being that is *Dasein*.³ Only when the existential significance of death as completion of *Dasein* is properly understood can death be apprehended authentically.

Although death is always “impending,” it does not generally occupy one’s everyday thoughts, and hence the diagnosis of a terminal illness, or simply the recognition that death is now something to be addressed with immediacy rather than postponed to some indefinite time in the future, in effect casts people into a different existential world. For these reasons it can be seen that the contributors to this study embarked upon a journey which began with the realisation that their parents were dying, and that as carers they were to be deeply involved in their experiences as they neared the end of their lives. It was a journey that took them from their familiar everyday existence into an untested

² The “falling” of *Dasein* refers to “a basic kind of Being which belongs to everydayness” (Heidegger, 1962, p. 219).

³ See page 24 for an account of the meaning of “anticipation” in Heidegger’s philosophy.

world in which they were required to call upon inner resources to cope with its challenges. It was, as the following summary shows, a world in which the carers' experiences were often characterised by such factors as freedom, responsibility and creativity.

Major elements of caring for dying parents

Temporality and parallel worlds

The existence of a distinct world of informal caring is suggested by the experience of one carer who has acted as both an informal carer and a nurse; it is also evident in the accounts of patients who receive both modes of caring. It is possible to interpret the fundamental differences between informal and professional caring as being derived from the fact that the objectives of these two modalities are defined by the paradigms of illness and disease respectively. Despite its epistemological ambivalence discussed in Chapter Two, nursing as a profession is primarily informed by the biomedical paradigm which is the distinguishing feature of Foucault's "medical gaze", and by the spiritual concerns of the patient in only a secondary manner. The situation is reversed for the informal carer, and although these primary objectives and their inherent responsibilities are interchangeable, it is difficult, if not impossible, to satisfy them concurrently.

The notion of a discrete world of informal caring is further enhanced by the fracture between the biomedical and lay perceptions of the human body discussed in Chapter Seven. Informal caring entails interaction with medical and other health professionals, who may at times demonstrate little understanding of the experiences that patients and their informal carers are undergoing. This is an observation found in virtually all of the sources used in this study. An indication of the existential gulf between the two worlds of caring is highlighted by carers' accounts of viewing images of their parents' internal organs. Access to such images, despite representing an infringement upon the biomedical domain, can offer the carers the unexpected freedom to inspect the normally invisible parts of their parents' bodies. What superficially appears to be a relatively simple aspect of caring emerges, through a different interpretation, as one of great significance. It links

the visible evidence of the body's vulnerability and impermanence with the existential elements experienced at the end of life.

The separation of the world of informal caring from the biomedical world only partially describes its exclusivity; in many ways it is also isolated from the everyday world. The overwhelming preoccupation with the dying persons' situation effectively removes them as well as their carers to a parallel world in which they observe the activities of others but are remote from them. This situation (or perhaps "perception" is a better term) is in some respects beneficial for the carers because the shift in focus enables them to retreat from everyday concerns and focus more fully upon the task at hand.

The relief of suffering

A major responsibility encountered by the informal carers is to recognise the nature of their parents' suffering, for without this understanding they cannot take steps to address it. Suffering is experienced in ways which reflect individual sensibilities; for example, factors such as loss of autonomy, bodily shame and the fear of death are potential sources of fear and suffering. Identifying the sources of suffering requires an intimate knowledge and understanding of the sick person. Upon identifying the cause, carers then undertake the subsequent responsibility of devising means of alleviating these forms of suffering and fostering hope through the acceptance of reality, a process which also demands great sensitivity and empathy. The carers use differing approaches, each drawing upon their own particular talents and skills. The stories related by the carers show that there is no single definitive approach to caring; its crucial element appears to be simply an ability to care in a compassionate manner that creates or strengthens the bond between the two actors.

Responsibility and the "power relationship"

The parents' loss of autonomy means that it is now becomes incumbent upon their carers to make decision on their behalf. The magnitude of these decisions, and the context in which they must be made, contributes to the stress experienced by the carers. It falls upon most of the carers interviewed to assume responsibility at some stage for decisions

concerning their parents' end-of-life treatment, relocation to nursing homes, or the move from their home to another location. Conversely, this responsibility can be interpreted as gaining control over the sick person's life. The vulnerability of the sick places the carer in a position of power, but at the same time this imbalance is (or at least should be, if caring is to be carried out in an authentic manner) tempered by the moral implications of responsibility.

Freedom and creativity

The responsibilities identified above are eased to some extent by the release from everyday social inhibitions that characterise the world of caring. Some carers discover in their role a licence to abandon prevailing conventions which forbid such things as viewing their parents' naked bodies, discussing such confronting issues as their own funeral arrangements, or even their approaching death. In this way caring can be accomplished in unfamiliar and innovative ways. Thus caring opens up opportunities by extending the boundaries of normal conventions of behaviour, and it grants a certain freedom through the privilege of intimacy. Caring is conceptualised in a number of different ways. For the carers, the most satisfying experience appears to be on those occasions when they are able to abandon inhibitions imposed by social and peer expectations, whether real or imaginary, and find the ways of caring most suited to the situation and their individual personalities and capabilities. In this way caring both offers and invites a degree of freedom not normally encountered in the everyday world. Conversely, the absorption in the world of caring that preoccupation with the concerns of the sick person demanded at times had the effect of distancing the carer from everyday affairs. The worlds of caring and of everyday life appear to exist in different time frames.

Reciprocity

The notion that caring is a mutually beneficial endeavour is found in most theories of caring, and it is certainly an aspect which appears in the stories used in this study. In recounting their stories, with one exception, the participants appear to have benefited in a number of ways from their experience. The stories also indicate that their parents benefited in an existential way from the attentions of their children. The importance of

openly discussing their own death and funeral arrangements, the sharing of memories, and simply silent companionship cannot be underestimated. All of these things require a certain understanding and openness between the two people, and it also requires a realistic apprehension of what the future might hold. In biomedical parlance, both diagnosis and prognosis need to be fully understood and anticipated. Should this knowledge be inaccessible then it becomes impossible to establish a relationship that fosters caring in the sense that has been described in the phenomenological discussion.

Deception.

Relief of suffering, however, cannot be achieved by entertaining or fostering false hopes. When carers attempt to deceive their parents by fostering illusions that recovery is possible, or by concealing the truth about their condition, they suffer guilt because they are aware that it is probably in their parents' best interests ultimately to know and accept the truth. Carers also at times practise a form of self-deception⁴ in which they imagine they can effect their parents' recovery by providing superlative care. Deception and self-deception appear to be practised in an experimental or exploratory manner which could almost be described as hopeful in a child-like way, but are usually abandoned when it is realised that they have only a negative effect on the construction of a credible narrative of illness. These narratives emerge as an important aspect of caring because their trajectories do not avoid the reality of death. Deception that remains unresolved before death persists as a source of anguish for the carer.

Death and the totality of Dasein

Caring does not necessarily cease upon the parent's death. Its continuation is reflected in a number of ways; for example concern for the spiritual wellbeing after death, meticulous attention to funeral arrangements and the disposal of possessions. Sometimes these matters had already been discussed with the parent and raising such matters is in itself regarded as an aspect of caring. The fact that the carers continue to remember and reflect upon their experiences and, in the case of de Beauvoir and Roth, to perpetuate these

⁴ Sartre applies the term "self-deception" to indicate a way of Being which bears similarities to Heidegger's "inauthenticity"(Sartre, 1969).

reflections in writing, is a further indication that caring does not cease with the death of their parent.

Summary of elements of caring

The above review of the research findings, expressed within the framework of Heidegger's view of authentic Being-towards-death, suggests that it is possible to conceptualise caring for a dying parent as a number of elements which are characterised by three major interconnected entities; freedom, responsibility and creativity. These entities appear to be governed by the unique relationship that develops between carer and parent, a relationship to which Frank alludes when he writes that "the carer is the other half of the ill person" (Frank, 1991, p.6). As this relationship develops, the actors move away from their everyday familiar worlds and become immersed in a new shared world. The dominant feature of this world is the vulnerability of the dying person, which ushers them into a state of dependence upon their son or daughter, while challenging the carer to find ways of alleviating their suffering and supporting them emotionally and physically. This task is in some ways facilitated by the possibility of freedom inherent in a world in which social conventions can be overlooked, allowing them to act as they see fit, in a way that aspires to authenticity. Caring therefore fundamentally involves a move away from inauthentic behaviour, which is governed by everyday social conventions, towards authentic existence, which is governed by reality of Being. This is not an easy transition: the abandonment of social pretexts, conventions and norms of behaviour that stand in the way of authentic behaviour is difficult and there are bound to be lapses. If caring is to occur, it is essential to move beyond the constraints imposed by society, and it is the carer's role to abandon these inhibitions and enter entirely into the world of caring, to immerse themselves in this world which is the dying person's world. In this regard, caring consists of a fusion of interests. A number of features emerge from this discussion:

First, it appears that caring brings into sharp definition the difference between authentic and inauthentic behaviour. The intimacy that caring necessitates adds to the richness of life because it helps the carer discover the other person's past through shared memories.

It also makes the carer more receptive to the deep feelings of the Other and to reject conventions that hamper the expression of these feelings.

The second observation is that caring is a creative enterprise which can flourish in this atmosphere of freedom. Caring can therefore be understood as an art which is a concrete expression of a deep emotional feeling. It is the tangible expression of a relationship. It is the individual's own way of expressing the relationship. If it cannot be experienced authentically, then it fails as an artistic project. The discovery of the other person means that their suffering can be understood and therefore freedom is accompanied by the responsibility to alleviate their suffering in an appropriate fashion.

Third, the need to care is fundamental and if this is denied the carer feels deep distress and suffering. Caring cannot happen unless it is reciprocated in some way. Even when the other person has died he or she responds in an abstract way, living still in the carer's memory.

Finally, caring is an exploration of that person's worth in our life, and ours in theirs. It offers an opportunity to memorialise them. While we are caring for them the opportunities are put in place, through the things we experience together, to revisit them at our leisure, as it were, at a later date when we are distant from the experience.

The more significant features of caring as expressed by the contributors to this study have now been summarised, but this does not reveal or explain the precise nature or object of their engagement. We can now return to the question: "What is it that these people were doing, and what is the nature of caring?" Once again, Heidegger, in his concept of authentic Being-in-the-world, provides a mechanism by which this problem can be addressed.

* * *

Caring: An authentic way of Being

A Being-with-one-another which arises [entspringt] from one's doing the same thing as someone else, not only keeps for the most part within the outer limits, but enters the mode of distance and reserve. The Being-with-one-another of those who are hired for the same affair often thrives only on mistrust. On the other hand, when they devote themselves to the same affair in common, their doing so is determined by the manner in which their Dasein, each in its own way, has been taken hold of. They thus become authentically bound together, and this makes possible the right kind of objectivity [die rechte Sachlichkeit], which frees the Other in his freedom for himself (Heidegger, 1962, p. 159).

* * *

It appears that the carers are confronted with a pervasive existential concern; that is, to support their parents as they confront the proximity of death. At the same time they face a crisis of their own in the impending loss of their parent. The phenomenological exploration of the material used in this study, which has been recapitulated in the previous section, indicates that above all caring represents an authentic way of Being. Heidegger identifies two ways of Being-in-the-world: Being alongside the world signifies concern, while Being-with signifies solicitude, and, as described in Chapter One (page 17), authenticity is characterised by “leaping ahead” in a way that assists the Other

...in his existentiell potentiality-for-Being, not in order to take away his ‘care’ but rather to give it back to him authentically as such for the first time. This kind of solicitude pertains essentially to authentic care—that is, to the existence of the Other, not to a ‘what’ with which he is concerned; it helps the Other to become transparent to himself *in* his care and to become *free for* it (Heidegger, 1962, pp. 158-9).

Put simply, the outcome of authentic Being-in-the-world for the carer is the facilitation of authenticity in the Other. To be denied the realisation of this facilitation for any reason (as was the case for one of the participants), is to be denied the possibility of one's own authenticity. The outcome of such a situation is that the carer, being unable to anticipate the future (in the Heideggerian sense) experiences a form of suffering, or an existential crisis.

But what directs or motivates the carers to seek an authentic way of Being? What prompts the move from mere concern (an inauthentic mode of Being grounded in “everydayness”) to a state of solicitude in which they are engaged in encouraging their

parents to accept their situation (and even the prospect of their death) authentically? Heidegger posits that Being-in-the-world is disclosed by two “equiprimordial” (i.e., inseparable) factors that constitute Being-there: by our “state-of-mind” (or “having a mood”), and by “understanding”. A state-of-mind (or “mood”) is not to be equated with that which can be reflected upon, or a “psychical condition.” Heidegger writes:

“A mood assails us. It comes from neither ‘outside’ nor from ‘inside’, but arises out of Being-in-the-world, as a way of such Being...*The mood has already disclosed, in every case, Being-in-the-world as a whole, and makes it possible first of all to direct oneself towards something*” (p. 176, emphasis in original text).

Thus state-of-mind also reveals to us those things that matter to us: “*Existentially, a state-of-mind implies a disclosive submission to the world, out of which we can encounter something that matters to us*” (Heidegger, 1962, p. 177; emphasis in original text).

State-of-mind has three characteristics: the disclosing of Being-in-the-world; making possible to direct oneself towards something (through this disclosedness), and to reveal to us that which matters to us. Clearly this reasoning can be applied to the experience of the “parallel worlds” discussed above; the manner of Being-in-the-world both discloses that which “matters” (the concerns of the sick person) and directs the carer’s action to this end. This is what motivates the carer and at the same time isolates the carer from the everyday world.

The second ingredient of Being-there is “understanding” which is “conceived primarily as Dasein’s potentiality-for-Being”, and this rests with state-of-mind.

Only because the Being of the ‘there’ receives its Constitution through understanding and through the character of understanding as projection, only because it *is* what it becomes (or alternatively, does not become), can it say to itself ‘Become what you are,’ and say this with understanding (p. 186).

Understanding can be informed by several factors which are responsible for an inauthentic way of Being, which as Heidegger explains, is

...the kind which is completely fascinated by the ‘world’ and by the Dasein-with of Others in the ‘they’...Idle talk discloses to Dasein a Being towards its world, towards Others, and towards itself—a Being in which these are understood, but in a mode of groundless floating. Curiosity discloses everything and anything, yet in such a way that Being-in is everywhere and nowhere. Ambiguity hides

nothing from Dasein's understanding, but only in order that Being-in-the-world should be suppressed in this uprooted 'everywhere and nowhere' (Heidegger, 1962, p. 221).

These factors can be classified as:

- "idle talk" which perverts the act of disclosing because it is groundless, or at least grounded only in public perceptions which do not necessarily coincide with those relevant to one's own Self;
- curiosity, which is concerned with knowing simply for the sake of knowing and not with knowledge as the foundation of authentic action; and
- ambiguity, which refers to the multiplicity of understandings possible in a particular situation.

These factors are responsible for an inauthentic way of Being,

Clearly understanding, and the consequent disclosure of the potentiality for Being-in-the-world, depends upon the terms upon which it is based; understanding itself has possibilities, and can be authentic ("arising out of one's Self"), or inauthentic (arising from everyday, public perceptions, or "idle talk"). The separation of authentic from inauthentic understanding described here is illustrated in the experience of those who attempt to care according to what they believe are publicly accepted ideas of caring, rather than to care according to their own (authentic) knowledge of their parent.

Summary and Conclusion

The objective of this thesis is to investigate the nature of caring as experienced by adults who have cared for their dying parents, the point of departure for the project being the adoption of an existential phenomenological position. The issues that characterise the topic cross a number of disciplinary boundaries, and the phenomenological approach was chosen primarily because of its facility to accommodate a diversity of disciplines. Three major modes of discourse (oral accounts, autobiographical material and theoretical discussion), are linked in an endeavour to explicate some of the existential features that characterise the phenomenon of caring in the context selected for the study. Verbal accounts of caring, provided principally by five people who had undertaken the care of their dying parents, serve to supplement my personal writing, in which I have explored

my own experience as a carer at some length. These primary sources are supported by several literary accounts of caring, particularly those of Simone de Beauvoir and Philip Roth. From these accounts a number of common features are identified and explored in conjunction with appropriate existential theories. These theories provide the means to develop a rational interpretation of the various factors that form a unified thread throughout the examples.

The journey of discovery represented by this research has then, through the theoretical foundations of the ordinary activities and experiences of caring, revealed an existential expression of caring in the face of death. The individual anecdotes and episodes described by the carers cannot themselves be described as “caring”; they are merely constituents of caring which have a particular meaning only within that context. Taken in isolation they are of little significance, but together, when facing the prospect of a parent’s imminent death, they lead the carer to an understanding of their experience that reaches far beyond that which the biomedical perspective, or the “clinical gaze” would admit. But this does not in itself signify complexity; on the contrary, caring is (at least in this example) unidirectional. It is focused at all times upon the understanding of the parent’s death, the preparation for their death, to the seeking of an authentic apprehension of death which acknowledges its facticity, and through this authentic attitude is able to facilitate a similar authentic apprehension of death in the dying person. Caring, then, cannot be dissembled permanently and conclusively into its constituents, for those constituents are guided and informed by the single overarching concern that is caring itself, and their particular conformation is defined by the same parameters. This study, in the words of Michael Crotty, “... pursues, not the sense people make of things, but what they are making sense of” (Crotty, 1996, p. 3; see also Chapter One of this thesis, page 2). It has been an hermeneutic undertaking in which a number of existential elements of caring have been identified and explored, but this having been achieved, returns to that base with a deeper understanding of human experience in the face of the greatest of all mysteries. In revisiting and summarising the major themes arising from the stories of caring, being always mindful of Heidegger’s concept of Being-in-the-world, it is thus

possible to interpret caring as representing a particular way of Being. What, then, is caring but an authentic way of Being?

If caring is a “mystery,” as one of the participants in this study suggests, and if Marcel’s notion of a mystery as being something that transcends the familiar and comes instead from within a person’s Being is accepted, then this phenomenological study offers a means of at least partially explicating the phenomenon. From an existential perspective the possibilities and opportunities that caring generates, in addition to the immediate and intended benefits to the sick person, are disclosed in the description contained in the above section. This indicates that caring has the potential to open new vistas in the individual’s life-world, and through continual introspection in the phenomenological tradition, this process can be unending. Once a person’s attention has been consumed by a concern for the spiritual and physical wellbeing of another so completely as it had been for those who contributed to this study, this preoccupation need not be relinquished in the future. The carer can choose to preserve that person in their consciousness for as long as they please, within the framework has been set in place (established) during the caring process. There arises from this discussion the possibility for future research aimed at investigating the effects of reflectivity which, although pre-existing in the carers who took part in this study, had been actively encouraged and enhanced through their participation in the phenomenological process. A study focused on the effects after a number of years would possibly reveal the extent to which caring does or does not continue to influence their way of Being.

This thesis is a serious inquiry into the existential aspects of a phenomenon which is familiar to many. It is also intended to address the imbalance, revealed in the literature search, that currently exists between the wealth of phenomenological research into caring as an aspect of nursing, and the paucity of similar research in the area of informal caring. By focusing upon this particular phenomenon, the outcome, revealed through a thorough exploration of its components, is a vision of the possibility that caring holds for the enrichment of human consciousness. There is no reason, however, why this approach

should be reserved exclusively for caring. It is the phenomenological approach, not the phenomenon itself, that enhances the appreciation of the life-world.

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Appendix A: Informed Consent Form

**SCHOOL OF PUBLIC HEALTH, LA TROBE UNIVERSITY,
BUNDOORA 3083**

Project Title: THE PHENOMENOLOGY OF INFORMAL CARE

Senior Investigators: DR JOHN WILTSHIRE, SCHOOL OF ENGLISH, LA
TROBE UNIVERSITY

MR MICHAEL MCGARTLAND, SCHOOL OF
PUBLIC HEALTH, LA TROBE UNIVERSITY

Researcher: MRS LINDSAY PAUL, SCHOOL OF PUBLIC
HEALTH, LA TROBE UNIVERSITY

The aim of this study is to investigate the experience of informal caring, in particular that of adults who have been the primary carers of their aged parents. The main focus of the study is how these people reflect upon this experience since the death of their parents, and whether this has subsequently affected their attitudes and values.

The research is a requirement for the degree of Doctor of Philosophy. The project is being jointly supervised by Dr John Wiltshire and Mr Michael McGartland.

If you agree to participate in the project, you will be required to take part in an informal interview, during which you will be asked to talk about your experience as a carer, and how you think it may have affected your thoughts and feelings in the period since your parent died. The interview may take one or two hours, and one or more follow-up interviews may be necessary. Interviews can take place in your home or at La Trobe University, whichever you prefer. You are free to withdraw from the project at any time up to one month after the first interview.

The interviews will be tape-recorded and transcripts made from the recordings. These transcripts will be made available to you should you wish. Recordings and transcripts will be treated as confidential. It will not be possible for anyone except the researcher to identify you, as your name will not be attached to the interview material. During the research and after the project has been completed, the tape recordings and transcripts, as well as any computer data, will be stored in a locked filing cabinet or on a secure computer in the office of one of the senior investigators.

It is not anticipated that the interviews will cause any distress. The intention is to understand how people learn from significant experiences. The information will be used to construct a picture of how caring affects people's lives, and what it means to them.

The results of the project will appear in a thesis written by Mrs Paul, and possibly in journal publications and in presentations at conferences, but at no time will you be identified in any of these reports.

Any questions regarding the project may be directed to Dr John Wiltshire, School of English, La Trobe University, Bundoora 3083; Phone: (03) 9479 2397, or Mr Michael McGartland, School of Public Health, La Trobe University, Bundoora 3083; Phone: (03) 9479 1739.

Should there be any complaints or queries that the senior investigators are unable to answer, you may contact the Secretary of the Faculty Human Ethics Committee, Faculty of Health Sciences, La Trobe University, Bundoora 3083; Phone: (03) 9479 3574.

* * *

I,have read and understood the above information, and any questions I have asked have been answered to my satisfaction. I agree to participate in this project, realising that I may withdraw at any time. I agree that research data collected during the project may be included in a thesis, presented at conferences and published in journals, on condition that my name is not used.

NAME OF PARTICIPANT (in block letters):.....

SIGNATURE:.....DATE:.....

NAME OF SENIOR INVESTIGATOR:.....

SIGNATURE:.....DATE:.....

NAME OF RESEARCHER:.....

SIGNATURE:.....DATE:.....

* * *

Appendix B

A note on Morse: Suffering and enduring

Employing the technique of concept analysis, Janice Morse and her co-workers have explored hope and suffering in order to bridge what they consider a perceived lack of understanding of these experiences within the nursing profession. Morse and Doberneck (Morse & Doberneck, 1995) identified in hope a number of “abstract and universal components” which appear to arise from a person’s realistic appraisal of their situation and the establishment of an approach to the future based on this understanding. Hope also incorporates a continual evaluation process as the person moves away from the prior state of suffering. The related concepts, suffering and enduring, were explored by Morse and Carter (1996) by examining biographical illness narratives. The authors concluded that enduring is an emotionless state which exists as three types: enduring to survive, to live, and to die. Suffering itself they defined as “an emotional response to that which is endured, to the changed present, or to an anticipated future” (p. 43). There exists a dynamic relationship between suffering and enduring, which is explained by these authors as follows:

Individuals move from enduring to suffering when they are able to acknowledge that which is being endured, and when they are emotionally strong enough to experience the emotional onslaught of suffering. If the latter is overwhelming, individuals may retreat to enduring. Once they have suffered enough and are able to accept the changed reality, individuals gain new insight and appreciation for life as a *reformulated self* (Morse & Carter, 1996. p. 43).

In this schema, enduring is no longer seen as a *way* of suffering (for example, stoically, or patiently), but is virtually reconstituted as an entity in its own right. This construction of a discrete, emotionless state called “enduring” has implications for nursing, because the emotionless state of those who are enduring places them beyond the reach of others, and they need to return to suffering when they are “ready.” Enduring is a conscious effort to maintain control of the situation: “When enduring, individuals intuitively recognize – and fear – that to give in to emotion, to ‘break down,’ will result in an emotional release so powerful that they will lose control, disintegrate, and not be able to regain control.” (p.

48). There is an intense and deliberate focus on the present and the physical manifestations are that the patient shows “an expressionless, mask-like face, may move perfunctorily in a robot-like manner, and their voices may lack spontaneity and assume a slow monotone” (p. 48). From suffering, hope arises as the reality of the situation is acknowledged. However, the person should not be moved prematurely into suffering from enduring, as “suffering requires energy, and if one is moved prematurely into suffering, the patient may fear that s/he may be overwhelmed with suffering and disintegrate” (p. 57). Morse and Carter argue that because only the patients themselves can know when they are ready to move from enduring to suffering it is “foolhardy” to break into the protection of what appears to be a state of withdrawal from reality.

In what could be construed as further deconstruction of suffering, later research by Morse and Penrod (1999) identified a further state of “uncertainty” in which a goal is recognized by the patient but the path of action to it is unclear. This is an emotional state but one in which the individual is without hope (“uncertainty paralyses hope”). Two further states are then noted: “undecidedness,” in which alternative goals are identified but the individual is uncertain which to choose (this is again a state without hope), and optimism, which is an attribute of the individual which may contribute towards the state of hopefulness.

Morse’s theory of suffering and enduring is not without criticism. Marilyn Rawnsley (1996) for example, although “comfortable postulating suffering as theoretical abstraction of a multidimensional human experience that incorporates all actual and anticipated threats of meaninglessness and dissolution of self,” questions the necessity to claim the existence of a separate state of “enduring.” Rawnsley’s concept of suffering as “a multidimensional phenomenon that incorporates endurance as well as expressive symptoms of distress” (Rawnsley, 1996, p. 65) is more in keeping with Heidegger’s existential conceptualisations of hope and fear (discussed on pages 178-180) than is Morse’s idea of a range of experiences which, although related to suffering, are individually identifiable. Whether it is possible (or even desirable) to identify such an orderly progression of emotional states in another person is debatable; it could lead to an

expectation that there is a “correct” way of suffering, in much the same way that Kubler-Ross’ concept of the five stages of dying can be at times misapplied as proscriptive rather than descriptive (see, for example, Charmaz, 1980)

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