ABSTRACT

The purpose of the thesis is to illuminate nursing practice in a freestanding Swedish inpatient hospice as seen from the standpoint of guests and nurses. The data are based on: 1) interviews with all nurses working in the hospice, two and 14 month into their hospice experience; interviews with 12 hospice guests and; 3) non-participant observations of activities of nurses (3245 observations) and patients (5286 observations) in the hospice and a hospital oncological unit. The tape recorded interviews were analyzed using a phenomenological hermeneutic approach, and the observational data were coded and submitted to statistical analysis.

Findings show that nurses experienced in terminal care went to the hospice for professional reasons, in contrast to the inexperienced nurses, who took the job for more personal reasons. The tension between being able to endure and enjoy being a hospice nurse is an essential feature in all the nurses' narratives, and indicates the intertwining and difficulty in separating the nurses as people and as professionals. In the second study, this intertwining was synthesized into the two themes: 'pursuing meaningful hospice care' and 'pursuing spiritual integrity', illuminating the nurses' vitalizing and devitalizing experiences.

Findings reveal that the meanings of nursing care as experienced by the 12 guests, were inseparable from the hospice milieu and their existential situation, interpreted as a limit situation entailing the prospect of becoming homeless. The meanings of the hospice spirit (nursing care and milieu), are interpreted as the contrasting experiences of hindering or not hindering the prospect of becoming homeless. A consoling hospice spirit supports experiences of wholeness and communion, *i.e.* becoming 'at home' in the midst of dying, while a desolating hospice spirit sustains experiences of alienation and fragmentation *i.e.* experiences of being homeless.

What stands out from the three qualitative studies is the similarity of the guests' and the nurses' experiences of nursing care, and the importance and balance of the polarity in experiences of light and darkness, understood as togetherness in the midst of separation, reconciliation in the midst of guilt and meaningfulness in the midst of meaninglessness, *i.e.* the experiences of consolation.

Findings from non-participant observations of the activities of nurses and patients show that the content of nurses' work and a patient's day differed markedly between the two sites. Though, patients and nurses were together more in the hospice than in the oncological unit, the patients at both sites only spent a small part of their day with nurses. When with patients, the nurses were most often helping them with their daily needs in the hospice, and with needs in relation to investigations and treatment in the oncological unit. The oncological patients were alone 3/4 of the day, compared to 1/2 a day for the hospice patients, who spent much of their time with relatives. Patients and nurses at both sites had only a few encounters with other health care professionals

Reflections are based on the understanding gained from the five studies comprising the thesis, that the tension related to caring for and having a decaying body, the intertwining between the environment and oneself as a nurse or a guest, and nurses' doing and being, are the basis on which the meanings of nursing care are experienced and from which they surface.

Key words: Hospice; Nursing; Lived body; Lived experience; Work sampling; Phenomenological hermeneutics; Consolation; At-homeness.

ORIGINAL PAPERS

The dissertation is based on the following papers which will be referred to in the text by their roman numerals:

I Rasmussen BH, Norberg A and Sandman PO. 1995. Stories of becoming a hospice nurse: Reasons, expectations, hopes and concerns. *Cancer Nursing* 18 (5): 344-354.

II Rasmussen BH, Sandman PO and Norberg A. 1997. Stories of being a hospice nurse: A journey towards finding one's footing. *Cancer Nursing* 20 (4): 330-341.

III Rasmussen BH and Sandman PO. 1998. How patients spend their time in a hospice and in an oncological unit. *Journal of Advanced Nursing* 28 (4): 818-828.

IV Rasmussen BH and Sandman PO. 2000. Nurses' work in a hospice and in an oncological unit in Sweden. Accepted for publication in *The Hospice Journal.* 15. 53-75

V Rasmussen BH, Jansson L and Norberg A. 2000. Striving for becoming at-home in the midst of dying. Manuscript submitted for publication. *The American Journal of Hospice & Palliative Care*17. 31-43

The papers have been printed with the kind permission of the respective journals.

INTRODUCTION

Getting cancer or loving someone who gets cancer is an event which profoundly changes one's life, as for example Beauvoir (1965) and Lorde (1980) describe. Hoping for a cure, often enduring exhaustive treatments, becoming beyond cure and facing death is an ordeal likened to being thrown into the deepest dark waters, to which one may either succumb in despair or raise above and live (Davidsen-Nielsen 1995, Young and Cullen 1996, Kemp and Kemp 1998). Being a nurse and caring for dying people and their loved ones may be experienced as a job to be done or as a gift and privilege to be handled with care (Saunders 1983, Asplund 1991). To be a nurse or a dying person in a hospice, is to set out in pursuit of a meaningful living amidst dying, which our history, culture and the institutionalization of the dying, have stripped death of humanness, *i.e.* sharing, loving and consoling (Kübler-Ross 1969, 1997, Saunders 1981, Cassel 1982, Aakre 1996). The humble aim of this thesis is to contribute to this pursuit, by illuminating the phenomenon 'nursing practice ('omvårdnad' in Swedish) in a hospice'.

The Swedish word 'Omvårdnad' is, as described by Lützen and Tishelman (1991), used interchangeably to mean 'nursing care' as well as 'care', the latter defining the theoretical field of the caring sciences. Though it is believed, that an essential condition for care and caring activities is an awareness of the suffering individual and our ability, through love, to alleviate suffering and to show mercy (Eriksson 1992[a], 1997), the phenomena of 'care' and 'nursing' may resist being defined and generalized by traditional means. These phenomena and their meanings may more easily be understood in the light of Wittgenstein's solution to the problems of universals, namely the family resemblances model, which emphasizes that a phenomenon gains its meaning through use rather than through rigid definitions (Bambrough 1966, Asplund 1994). When setting out to investigate 'omvårdnad' as is done in the present thesis, it is not the phenomenon of 'care' but the rather broader phenomenon of 'nursing practice', which hopefully includes care, that is the focus of the exploration. Nursing practice, includes the domain of nursing and the roles of nurses, and may be understood and experienced in a variety of ways by different participants (*e.g.* nurses, patients, physicians and society at large), and through the interacting of the participants in an ongoing process (*cf.* Tishelman 1994). The pursuit of an understanding of the phenomenon of nursing practice is, in this thesis, limited to the perspectives of nurses and adult people dying from cancer in the Western World, and more specifically in Sweden.

Life and death

Life is to be born, to live and to die, and at present 50 million people die yearly, 39 million in developing and 11 million in developed countries (Stjernsward 1997). It is stated, that for us as humans, it is only possible to comprehend ourselves as 'already born' and 'still living' - it is impossible for us to imagine our own death, because when doing so we are 'still living' (Ricoeur 1966, pp. 456-63, Bauman 1992, pp. 12-14). As humans we may be born with both a life instinct *Eros* and a death instinct *Thanatos* (Freud 1991), and we are supposedly the only living species who are conscious of our own mortality. Though we may have knowledge of our own death, it is not experience, it is only knowledge (Ricoeur 1966, pp. 456-63), and it is argued that as far as we know, death is the end of the subject and with it, the end of all perception. As Husserl would say, "there is no *noesis*, the act of cognition, without *noema*, the objects to be known - and *vice versa*" (Bauman 1992, p. 2). According to Ricoeur (1966): "the most decisive encounter with death is the death of a being I love. Here death is really sensed as my end - irreparable" (p. 461). Death, apart from suicide perhaps, is not a matter of choice, it comes when it comes, and is the ultimate defeat of reason. We can never define and control death however hard we try. Our consciousness of death is thus bound to remain traumatic and translates into anxiety (Heidegger 1962, p. 226), and loss or fear of loss (Kastenbaum 1993). In the Western World (for exceptions see for example, Kübler-Ross 1997), death is often conceived of as a void, a nothingness (Tillich 1952, Ricouer 1966), and a non-existence which, paradoxically gives existence to all beings, *i.e.* without death or our awareness of mortality there would be no history, no culture and no humanity (Bauman 1992).

Throughout history, we as humans have tried to understand and mediate our relationship with mortality. By studying art, mortuary traditions, symbols, literature, dying and grieving experiences from ancient to present time, the perceptions and approaches to death of various cultures have been illuminated. What is apparent is that although death is universal for human beings, the 'proper' preparation for death, grief, bereavement, mourning practices, and what constitute a 'good' or 'meaningful' dying and death, are prescribed within historical, cultural and socio-economic contexts, and seem to have had and to still have infinite variations (Aries 1981, Elias 1985, Giddens 1991). However, it appears universal for people, to fight and ritualize death, to stave it off, give it meaning, and often refuse to accept it as inevitable (Walter 1994-95).

Being born into the twentieth century, in Sweden, as a part of the Western World, our death and dying are experienced through meanings shaped by history, culture, and life situations *i.e.* age, gender, ethnicity, sexuality and social class (Eriksen 1996, Field, Hockey and Small 1997). To make a broad generalization, the 'tame' dying and death of the earliest times, has been replaced by the 'invisible' (Aries 1981) or 'lonely' (Elias 1985) dying and death of the present day. The dying and death of older times are interpreted as having been 'tame', *i.e.* familiar, simple, public and ritualized, an event occurring in every age group and as a part of everyday life, giving in its very ubiquity meaning and guidance about how to die, console and grieve. Today dying and death are described as 'invisible' or 'lonely', because they have become privatized, institutionalized and medicalized. These attitudes indicate how changes in society and life situations influence our perception of death (Aries 1981, Elias 1985, Kastenbaum 1993, Bury 1997, Floersch and Longhofer 1997). Life expectancy has increased to the point where in Sweden, it is 75.6 years for males and 81 years for females (National Board of Health and Welfare 1998). We more seldom die from acute, than from chronic degenerative diseases, which has made dying and death unfamiliar phenomena. Unfortunately, some would say, the vacuum left by moving from the 'tame' collective home death to the 'invisible', private, institutional death, leaves us without the rituals and moral guidance to give meaning to our dying and grieving (Aries 1981, Qvarnström 1993, Floersch and

Longhofer 1997, Kagawa-Singer 1998). Today, we are living or at least have been living in a society that avoids death. Death and dying have not until recently, with the rise of the thanatological and hospice movement, been neither a part of public discourse (Kastenbaum 1993, 1997, Hansen 1997), nor medical and nursing education (Gyllenskjöld 1977[a], Benoliel 1987-88, Hedly 1993, Kastenbaum 1995, 1997). Thus, it is argued, the hospice is needed in society today because we have lost our way, we have become poor consolers and alleviators (Aakra 1992).

Cancer, death and the modern health care system

Of the about 90 000 people who die in Sweden every year, close to 90% died, in 1989, in hospitals or other institutions (SOU 1989). During the last decade the Swedish authorities have supported the development of home care services at the expense of institutional care, and it seems to be a trend for more people to be cared for and to die at home (Beck-Friis 1993). In a catchment area for one Medical Centre Hospital in Sweden, it was found that, in a 4-year period (1990-1994), cancer deaths accounted for 22% of all deaths and 75% of the patients with cancer died in the hospital and the remaining 25% either at home or in a nursing home (Andershed and Ternestedt 1997). In 1995, on the national level, 36 065 people were given a first-time cancer diagnosis, and cancer was responsible for 23% of all deaths that year. Only cardiovascular diseases constituted a more common cause of death. (National Board of Health and Welfare 1997, 1998). In 1930 one in every five people diagnosed with cancer survived. In the 1990s, about 40% of all cancer patients are still alive 5 years after the diagnosis. There is however, a wide variety in survival rates depending on the kind of cancer. Science has had remarkable success in treating and curing for example lymphoma, testicular cancer and child leukemia (Nuland 1994, Stenbeck and Rosén 1995). In the years 1960-1995, in Sweden, there was annual increase in cancer cases of 2.1 per cent for both men and women (National Board of Health and Welfare 1998).

Understanding the disease processes of cancer in terms of statistics provides only part of the picture and says nothing about the meaning of experiences of the illness of people living with cancer, and how these meanings - just like the meanings of dying and death - are being guided and shaped by our history, culture and life situations. Cancer and death have a lot in common, as cancer is seen as repellent, repugnant and as polluting as death. Cancer and its killing metaphors translate into concepts of decay, destruction and death (Sontag 1979, Feigenberg 1985, Nuland 1994), and cancer is one of our myths representing life's dark and evil side (Feigenberg 1985), just like for example, the Black Death of former times (Kastenbaum 1993). Cancer has been around for thousands of years and has caused its 'victims' inexorable suffering. According to Nuland (1994) cancer is ugly and antisocial, it attacks from within, and slowly and relentlessly eats away the victim's life. The invading cancer cells may stop up every orifice in the body, or eat through blood vessels causing extensive bleeding, they consume bones and make them break, or they eat away a vital organ causing it to stop functioning. The cancer cells pierce through the skin creating ulcerous, evil smelling and rotting cancer sores (Pålsson, Isovaara and Norberg 1995), and as if this was not enough they send out metastases to other parts of the body spreading the decay and destruction everywhere until death is inevitable (Nuland 1994).

It may be wise to clarify the point that the criticism of the modern health care systems and their treatment of the dying presented in the literature, should be understood in terms of the concerns of our time, and our perceptions of the futures of our health care systems. None, one would imagine, wants to returns to the old days, and die of cancer without the solace of painkillers and treatments of modern days. However, there are still 51 countries in the world where there is no legal available morphine or weak opioids (Stjernsward 1997).

With the advances within technology, the natural and medical sciences the treatment of people with cancer moved, in the late nineteenth century, out of the home and into the 'paternalistic', physician-dominated institution of hospital (Eriksen 1996). The rapid advances in science and treatments led physicians, and with them, one may argue, nurses, to gradually and subtly change their goals from palliative care to absolute cure.

The shift from care to cure was influential in a change in the perception of death, which was no longer seen as a natural part of life, but a medical defeat or a statistical embarrassment (Doyle, Hanks and McDonald 1993). This meant and in some places still means that patients are viewed as disease objects and not as people with a disease. Dying patients are given the lowest medical, and at times nursing, priority. Study after study in many different countries shows that dying patients, not only cancer patients, are given less than optimal care, *i.e.* communication is defective, they receive highly aggressive treatment, symptoms are left uneased, pain control is inadequate, fear and spiritual needs are left unadressed, they are isolated and often left to die alone (Sudnow 1967, Saunders 1981, Hermansson 1990, Addington-Hall *et al.* 1991, Doyle, Hanks and McDonald 1993, Andershed and Ternestedt 1994, Mills, Davies and Macrae 1994, Bernhard 1995, SUPPORT 1995, Kastenbaum 1997). Thus the fact that the dying are a neglected and disadvantaged group in modern health care systems, is one explanation for the development of the thanatological movement and the rapid increase in the number of hospices and palliative care units in nearly all Western countries.

The thanatological movement

Despite its Greek classical etymology, thanatology is a term that came in with the twentieth century, and gained enough acceptance to be labeled a movement in the aftermath of World War II. The book 'The Meaning of Death', edited by Feifel (1959) and the work of Glaser and Strauss (1965, 1968), Weisman (1966, 1972), Hinton (1967), and Kübler-Ross (1969) are considered to be seminal works within the new science of thanatology (Qvarnström 1993), with Herman Feifel seen as the father of the movement (Strack 1997). Thanatology is the study of death, or as Kastenbaum (1993) proposes the study of life with death left in, and is the investigating, systematizing and implementing of knowledge gained through studies within various disciplines about and of death, dying and related phenomena (Feigenberg 1977). It is the study of death systems, *i.e.* society's multi-level, multi-faceted attempts to mediate our relationship with mortality for example, in terms of particular death-related roles and involvements (nurses, physicians, funeral directors) places, symbols, objects, suicide, murder, grieving, mourning practices and death education (Kastenbaum 1993). Clinical thanatology, a branch of thanatology, is directed towards the development of knowledge pertinent to the practical work of caring for the dying, preventing suicide, grief and bereavement work (Feigenberg 1977). In Sweden, the latter has been the focus for such pioneers within the health care system as, for example, Feigenberg (1977, 1985) and Qvarnström (1978, 1979). Among important dissertations within this field in Sweden are for example Hermansson (1990), Beck-Friis (1993), Hedly (1993), Andræ (1994), Salander (1996[a]), and Andershed (1998).

Theoretical models of dying

Out of the thanatological movement have grown several theoretical models or approaches to dying, each of which stresses a specific range of experience and behavior, a dying person will encounter (Kastenbaum and Thuell 1995). For example, stage or crisis theories (Kubler-Ross 1969), awareness/trajectory models (Glaser and Strauss 1965, 1968), task-based models (Corr 1991-92), and coping and adaptation models (Weisman 1972). The works of the two Swedish thanatologists (Feigenberg 1977, Qvarnström 1978, 1979), have been classified, not by themselves but by Hermansson (1990), as fitting best into the frame of a coping and adaptation model. Dying people are living with a deteriorating body, and are confronted with fears about losing control, independence and integrity. Living in uncertainty of what the future may bring creates worries about pain and suffering connected with dying, fear of loneliness, of being abandoned, fear of how loved ones will manage the situation, and what will happen to one after death (Gyllenskjöld 1977[b], Qvarnström 1979, Lev 1991, Fisher 1995). Dying people experience a range of opposing emotions such as hope and despair, denial and awareness, security and insecurity, dignity and humiliation, protest and submission and experiences of anxiety, anger, grief, guilt, shame, and loss of meaning and faith (Verwoerdt 1966, Hinton 1967, Kübler-Ross 1969, Weissman 1972, Feigenberg 1977, Qvarnström 1979). The realization that one's life is threatened or nearly over, brings despair, but is also reported to stimulate search for meaning, *i.e.* existential issues increase in importance when one is confronted with dying. To contemplate the meanings of one's life has been described as crucial for spiritual and emotional growth and for moving toward health within illness, in the midst of dying (Kübler-Ross, 1976, Qvarnström 1993, Hall 1997, Mount and Cohen 1997).

Reflection on the thanatological movement

Although the thanatological movement has brought death out of the closet, criticism of the movement have been voiced. As Feifel (1991) states, contribution to the knowledge base within the field, has come mainly from the biological and behavioral sciences, rather than the arts and humanities, though some significant contributions exist (see for example Bertman 1991). Also, according to Kastenbaum (1993) the studies and ideas have been more *about* death than *of* death, and have de-emphasized both the physical evidence of mortality and the fundamental nature of death. For example, none of the current 'theoretical models' about dying take fully into account the dying person's body as a physical reality (Kastenbaum and Thuell 1995), and death education may be about death but not of death (Kastenbaum 1993). Dying is treated in an abstract manner, not as a concrete physical and existential experience of the individual people and their loved ones, except in the field of clinical thanatology, and in the best hospices which, according to Kastenbaum (1993), also represent the best-of-the thanatology movements.

For a comprehensive description in Swedish of the content of the thanatological movement related to care of the dying, see Feigenberg (1977), Hermansson (1990), and Qvarnström (1993).

The hospice movement

Since Dame Cecily Saunders founded the first modern hospice, St. Christopher's in London in 1967, the number of hospices or palliative care services has increased dramatically amounting, in 1996, to about 700 in the United Kingdom (Waller and Caroline 1996), 2000+ in the United States (Kastenbaum 1997), and scores of others in the rest of the world including the Scandinavian countries. European hospices were started from the early 1980s to the present, and the same holds true for hospices in the Far East and Southwest Asia. In Africa hospices were started in the mid-1980s or later (Wilson and Kastenbaum 1997). Hospices have developed primarily around the needs associated with people with incurable cancer (Kastenbaum 1995). Although the term hospice originally meant a resting place for pilgrims, the term today denotes a philosophy, a concept of care rather than a specific place. The hospice philosophy promotes an acceptance of death, and quality of life in contrast to quantity. The patient and her/his family are considered as the unit of care, and their autonomy is of primary concern. A hospice promises, via an interdisciplinary team approach, to help and alleviate the physical, spiritual and psychological pain and suffering of the dying patients and their families, and to be available to share the experience of preparing for death, so that no one will have to suffer or die alone, unless that is their wish (Saunders 1981, Kearl 1989, Hayslip and Leon 1992).

The hospice movement has developed along different paths in Europe and North America (Greer *et al.* 1986, Ahmedzai 1990, Corless 1994). In England the speedy proliferation of hospices has been seen as a response to the poverty of care for the dying (James and Field 1992), and in North America as an alternative, a social movement in opposition to a technological death (Greer *et al.* 1986, Corless 1994), and a reaction against the physicians' total control of the final rite of passage (Kearl 1989, p. 439). In the United States, more than in England, the early hospice movement represented a shift in power from doctors to nurses and volunteers (Greer *et al.* 1986, Mor 1987, Seale 1989).

Hospice models

Today 'hospice' has become an umbrella term for many different kinds of services, to a broader group of the dying than people with cancer (Seale 1989, Ahmedzai 1990, James and Field 1992). In Britain the most common hospice model was originally that of an inpatient unit, usually freestanding and not part of the National Health Services, in contrast to North America where hospice programs were more likely to be home-based with few inpatient units (Ahmedzai 1990, Hayslip and Leon 1992). Today home care teams, symptom control teams, day care facilities, palliative care units or inpatient hospices and bereavement services work increasingly within a hospital setting (Seale 1989, James and Field 1992).

In North America, five models of hospice care are described: Two kinds of home-based care, provided either by groups of community-based professionals and volunteers; or via home-health care agencies or Visiting Nurse Associations (VNA), representing 17% of all hospices; Freestanding, full-service, autonomous hospice facilities accounting for 34% of hospice services, and; two kinds of hospital-based palliative care units, either being separate; or subacute units, emphasizing a continuum of care, and providing 49% of all hospice care (Mor 1987, Hayslip and Leon 1992). In the UK, in 1996, there were 200 hospice and palliative care inpatient services, about 250 hospitals with support teams, 384 home care teams in UK and Ireland, and 220 day care services, of which two-thirds were attached to hospice inpatient units, the reminder being freestanding. About 18% of the 160 000 people dying of cancer each year in UK do so in a hospice or palliative unit (Jackson and Eve 1997). Home care is the type of service most often received by hospice clients in every world region (Wilson and Kastenbaum 1997).

Reflection on the hospice movement

Concern has been voiced that hospices are losing their original charisma and are becoming more like hospitals, *i.e.* bureaucratized, re-professionalized and re-medicalized as they are re-absorbed into the traditional health care system (Abel 1986, Mor 1987, Seale 1989, James and Field 1992, McNamara, Waddell and Colvin 1994). Indeed, in 1987 palliative medicine was recognized as a medical specialty in the UK, and several chairs in palliative medicine have since been created in other countries (Doyle 1993). Waller and Caroline (1996) state that since the term palliative care was first brought into the lexicon (in 1975 when Balfour Mount opened the Palliative Care Service in the Royal Victoria Hospital in Montreal, Canada) it has become synonymous with hospice or terminal care. However, the question is whether these terms are really synonyms, or whether the whole shift in emphasis from hospice or terminal care to palliative care reveals an underlying movement (once again) away from death.

Palliative care incorporates a much wider area than does hospice care and may shift the focus away from death, because talking about and focusing upon palliation, may lead people to stop talking about and confronting the fact that the individual is going to die (Biswas 1993).

Despite the ambiguity, hospice and palliative care are often used as synonyms in this study in order to facilitate understanding.

Hospices in Sweden

In Sweden in 1977, the first Hospital-Based Home Care (HBHC) in Motala was initiated, offering help, even to terminally ill people, on a 24-hour basis (Beck-Friis 1993). Despite the government's (SOU 1979) resistance to specialized hospice units (arguing that all dying patients in all care institutions should receive high quality care), the first inpatient hospices were opened in the early 1980s, *i.e.* 'Bräcke diakonigård' in Göteborg and 'Ersta hospice' at Ersta Hospital in Stockholm. In 1991 a first and in 1997 a second palliative care unit were established at Stockholms Nursing Home, in 1991 Vitsippan was opened at Örebro Hospital, in 1992 Axlagården in Umeå, and in 1993 Hospice Gabriel in Lidköping. Though no official documents have been located, an unofficial, unpublished investigation, making no clams to be exhaustive, found that in December 1997, about 100 institutions throughout Sweden, had either palliative care or hospice units, beds and/or home care services. Ten palliative care advisory teams were located.

As studies continue to show that the care dying patients receive is mediocre (Andersson-Segesten 1989, Hermansson 1990, Hylander, Rawal and Arnér 1993, Andershed and Ternestedt 1994), the Swedish government now considers palliative care a high priority area (SOU 1995, Government Proposition 1996/97:60). Swedish physicians however, have been reluctant to engage in the development of palliative care compared to their counterparts in England (Sjöberg 1996); the first professor in palliative medicine has only recently been appointed at Linköping University (Johnsson 1997).

Hospice patients

Those who seek hospice care are most likely to be in the final stage of their cancer experience with less than 6 month to live. The criterion used in the USA, of imminent death within 6 months, is thought to exclude a large group of patients with life-threatening conditions, but whose remaining life time is not as predictable as that of patients with cancer. Thus, according to Kastenbaum (1995), it remains to be seen whether hospices are a viable alternative for people whose terminal illness is not cancer related.

Most dying cancer patients experience a multitude of problems. Wachtel *et al.* (1988) reporting from the National Hospice Study in the USA on end stage cancer, described the following prevalence of symptoms reported by patients, for example, anorexia (90%), weight loss (84%), dyspnea (64%), pain (60%), constipation (52%), nausea/vomiting (44%), fever (35%) and diarrhea (27%). Other symptoms are problems with fatigue, skin and sores, insomnia and mental status deficits (Hays 1986), depression, anxiety and frustration (Vachon 1993). Activity limitation appears to be almost universal among dying cancer patients, but the proportion of patients who become bedbound and totally dependent does not begin to exceed 50% until the last weeks of life is reached (Mor 1987). Prevalence rates of physical symptoms as well as psychosocial distress vary extremely widely in the literature, and among other things are related to the occurrence of symptoms in relation to the trajectory of dying and measurement problems (for an overview of this area see Mor 1987, Bruera 1993, Twycross 1993, Vachon 1993).

It has been found, that severe pain, problems with emotional well-being, physical integrity and social relationships are closely related to high degrees of psychological distress (Vachon 1993). A qualitative study illuminating concerns defined by patients and families facing loss in a hospice, found that issues related to health of the patients were the most frequently verbalized concern, followed by communication with the physician, the meaning of life, the care setting, *i.e.* cost, quality and environmental factors such as the view, air and doors to the outside, and lastly concerns about continuing to work despite the illness (Lev 1991). Investigating the dying experience from the perspectives of 23 families (the dying person, spouse and children), Davies *et al.* (1995) found the transition from living with cancer to experiencing a death from cancer, could be comprehended under the themes: fading away, redefining, burdening, struggling with paradox, contending with change, living day-to-day and preparing for death. Interviewing 30 patients with malignant glioma and their spouses, Salander, Bergenheim and Henriksson (1996) found, that most patients, despite their awareness of the grave danger emanating from the brain tumor, were able to use a broad repertoire of cognitive maneuvers to create protection and hope originating from the body, helpful relations, cognitive schemes and the handling of information. The spouses in contrast, were not able to create protection and hope to the same extent as the patients, and experienced great pressure and turmoil from having responsibility for the practicalities of continuing everyday life and the unpredictability of the future (Salander 1996 [b]). In hospice home care, employing a longitudinal qualitative approach, Hull (1990) found that for the families, most concerns were related to dealing with the physical symptoms experienced by their loved ones, especially confusion and seizures. Interaction with others was another major area of stress, as were concerns for self. What is revealed in several studies, is that the concerns and needs of relatives are different from those of the dying person and most be recognized and acted upon as such by health care professionals (Hull 1990, 1991, Davies *et al.* 1995, Salander 1996 [b], Persson, Rasmusson and Hallberg 1998).

A survey, in 1994-1995, of 116 hospice programs in 31 nations (not including the UK and the USA) found that the greatest number of hospice patients had some form of cancer, and was within the 60-79 age group. The prevalence of this age category was mostly observed in Europe and least apparent in South America. Only about 11% of hospice patients were under the age of 40 (Wilson and Kastenbaum 1997). The result of compiling reports of 14 studies in the USA, from the period 1980-1985, representing 15.119 hospice patients showed that most had cancer, were about 65 years old, white, suffering from serious functional impairment, were close to death (approximately 35 days for hospice home care patients, and less than 22 days for nearly half the patients in hospital inpatient hospices), and they had strong informal family support (Mor 1987). These data are congruent with with these of a Swedish study (Beck-Friis, Strang and Eklund 1989, Beck-Friis and Strang 1993) of 179 palliative home care patients with cancer. Here the average age was 70 years, median length of stay was 36 days, and in general the presence of a primary caregiver (often the spouse) was considered to be a prerequisite for home care. These patients too, suffered serious functional impairment, and the dependence on help with daily activities, as measured with the Katz ADL, proved to be a predictor for survival.

In a study from one county in Sweden, Andershed and Ternestedt (1997), found that of the 315 patents who died during an inpatient hospice's first three years (1991 - 1994), 96% had advanced cancer; the median age was between 73 and 76 years (30% of patients were over 80 years of age); the median length of stay was between 12 and 16.5 days and 57% were women in contrast to 38% in a nearby hospital-based home care program and about 50% had been living alone, especially the women. In another study Andershed and Ternestedt (1998[a]) found that 44 out of 67 patients with cancer had a short-term illness trajectory, dying within a year or less from the diagnosis, and that few of those with an illness trajectory of a month or less died at the hospice.

In general, more symptoms and combinations of symptoms, and especially bowel and bladder dependency, the use of intravenous therapy and the availability of support at home (a primary caregiver) have been found to distinguish those who use inpatient and home hospice care in the USA (Hays 1986, *cf.* Mor 1987). Hospital inpatient hospices served the more functionally impaired and medically needy patients than did home care hospices (Mor 1987). Seale (1991) found that patients who received hospice care in the UK, had fewer conditions other than cancer mentioned on their death certificate and were said to be more likely to have a strong religious faith than those receiving conventional care. In Sweden too, it has been found that those dying in hospitals are in a poorer condition than those dying in a hospice (Andershed and Ternestedt 1998[a]).

Hospices in both the USA and the UK are regarded as fairly white institutions, both as concerns staff and patients. Poor provision for the dietary, religious and other needs of minority groups, may play a part in discouraging minority ethnic users from assessing palliative care services (Smaje and Field 1997). Another reason could be awareness context. The open awareness context, means that both the dying person and the relatives know that the person is dying, in contrast to the closed awareness context meaning that the knowledge of dying is hidden from the dying person (Glaser and Strauss 1965). The open awareness context is related to the dominant *ethos* of individualism, and is well established in terminal care settings in both the USA (Mor 1987, p. 73, Hayslip and Leon 1992) and the UK (Seale, Addington-Hall and McCarthy 1997). It is a white Western phenomenon, not necessarily accepted by for example, the Chinese in Canada (Tong and Spicer 1994), in Italy (Gordon 1994), or across ethnic groups within the USA (Blackhall *et al.* 1995), and may play a part in why people from these ethnic groups do not assess palliative services. In the UK people dying of cancer were more likely to have been in full open awareness, than those dying from other conditions. People dying of cancer who were from the higher social classes and home ownership were more likely to be fully aware that they were dying. People in full open awareness were more likely to die in hospices or at home than in the hospital (Seale, Addington-Hall and McCarthy 1997), as were patients in Canada, coming from families with a high educational level (Kristjanson 1986). These data suggest that receiving hospice care may be difficult for people from lower social classes and certain ethnic minorities, as well as for non-cancer patients, and those with a cancer type that has a quick dying trajectory and those with severe symptoms (Seale 1991, Kastenbaum 1995, Andershed and Ternestedt 1998[a]).

The interdisciplinary hospice team

Although, the interdisciplinary team is an essential component of hospices, hospice care is primarily a nursing intervention, provided by and frequently coordinated and managed by nurses, at least in the USA (Greer *et al*. 1986, Mor 1987, Seale 1989, Dobratz 1990). 'Hospice' is a philosophy of patient care designed to keep patients comfortable and able to participate as autonomously and fully as possible in the activities of daily living until death. Good nursing care with interventions of comfort and compassion rather than cure is the ultimate objective (Mor 1987, Dobratz 1990, Zerwekh 1997). In the USA, the Joint Commission for Accreditation of Hospitals (JCAH) requires that hospices provide at least the following services: nursing; a physician; psychological/social work; spiritual, bereavement, and volunteer services (Mor 1987). However, the extent and composition of teams in the USA vary from hospice to hospice and between hospice types. Apart from nurses, other well-represented positions in hospices, identified by surveys in the eighties, were physicians (58-72%), social workers (58-63%), chaplains (39-46%), physiotherapist (17-38%), and psychologist (21%). Only 47% of freestanding hospices paid their staff, which reflects their dependence on both health care professionals and lay volunteers. Of all medical directors only 4% worked full-time (*cf.* Mor 1987). A survey of all inpatients hospices in the UK and Republic of Ireland in 1990 found that 76% of the National Health Service (NHS) hospices had at least one full-time and 24% a part-time medical consultant. Among the independent hospices 43% had a full-time, and 42% a part-time medical consultant, 15% had none (Johnsson *et al*. 1990). In the survey referred to above of 116 hospice programs in 31 nations, it was found that nurses and physicians comprised most of the core personnel of hospice programs worldwide. Worldwide the ratio of nurses to physicians was 4.8:1 and the ratio of volunteers to nurses 2.3:1, European hospices having a slight majority of professional staff as compared with volunteers. Social workers are on the staff of 70.1% of hospices and chaplains are staff member in virtually all African and South American hospices (Wilson and Kastenbaum 1997).

Research into hospice nursing practice is either patient/family-centered or provider-centered (Benedict 1990). The latter concerns nurses and is the focus of what follows. Results from surveys in the eighties, found that nurses comprised the largest group of hospice staff in the USA, with registered nurses (RNs) being the predominant group, and that the large majority of hospice nurses were women and experienced professionals, of whom 75% were above 30 years of age (Mor 1987). Vachon (1995), one of the leaders in the field of staff stress in palliative care, suggests that in the first decade of the hospice movement in the USA, hospices attracted people with noble intentions, but without the skills and knowledge to carry out their intentions. Many came into the field with a sense of calling and commitment stemming from their own experiences with death, a religious commitment, a dissatisfaction with the dehumanization of the dying in the hospitals, and a wish to focus on quality of life as opposed to quantity of life (Vachon 1995). In general the staff (physicians, volunteers, nurses) who choose to work in hospices are considered to be a special group, in that they perceive the hospice not merely as a job, but rather as a commitment to a philosophy and a way of caring that permeates other areas of their life (*cf.* Mor 1987, McNamara, Wadell and Colvin, 1995). Hospice nurses have been found to be more often religious, assertive, free-thinking, imaginative, independent and wanting less traditional nursing roles than their nonhospice colleagues (Amenta 1984, Dobratz 1990, Vachon 1995).

Caring for dying people and their families is described as being more demanding personally and professionally than most other nursing situations (Pickett 1993), and avoidance and detachment are documented as having been the prevalent coping strategies of a majority of nurses and physicians *vis a vis* the dying in nonhospice settings (Mor 1987, Benoliel 1987-88, Mills, Davies and Macrae 1994). In hospice nursing, closeness and compassion are guiding ideals, and these complex issues and their impact on nurses of being close to the dying and suffering have been investigated in many studies (*cf.* Vachon 1993, 1995). One of the earliest studies found that hospice nurses experienced a degree of distress only slightly lower than that of new widows (Vachon, Lyall and Freeman 1978). Today, although there are conflicting results, hospice nurses in general experience equal or less burnout, than their colleagues working in various specialties at the hospital. This is largely credited to the fact that from the earliest days of hospices, staff support programs and team development have been seen as integral to good palliative care (Mor 1987, Vachon 1993, 1995). The stress experienced is due in large measure to organizational issues such as excessive work-load and communication problems with other team members. It takes time away from patients and families, and creates an imbalance between the nurses' doing and being, an imbalance to which hospice nurses are reported to be very sensitive, since it depletes the energy needed to be able to continue caring (James 1989, 1992, Davies and Oberle 1990, McWilliam, Burdock and Wamsley 1993, Vachon 1993, 1995). Actually, Bram and Katz (1989) found, in contrast to what might be expected, that the fewer the hours of direct care, *i.e.* patient contact, the higher the burnout scores for hospice nurses and *vice versa*.

However, there are difficulties in dealing with issues of death and dying. Caring for the young and people with horrible physical symptoms and pain under great emotional and spiritual suffering, creates a gap between the 'real' and 'ideal' dying and death, and imposes threats to the nurses' shared system of values (Vachon 1993, McNamara, Wadell and Colvin 1995). In-depth studies of the experiences of hospice or palliative care nurses, have found that the nurses' personal professional values and expectations constituted the professional practice base that continually shaped their experience of hospice nursing, and that preserving their own integrity is at the core of their caring. Nurses need to maintain their own wholeness if they are to provide support to others (Davies and Oberle 1990, McWilliam, Burdock and Wamsley 1993, Byrne and McMurray 1997). Caring spiritually and guiding let go, require the nurses being grounded in self-awareness and a clear personal philosophy (Zerwekh 1993). Their understanding of the importance of caring for themselves, in order to continue caring and thriving, is probably, according to Vachon (1995), the reason why many nurses work in palliative care for a limited period of time, or on a part-time basis. No figures have been found describing the latter aspect of hospice nursing.

The actual role and work of hospice nurses may differ depending upon whether they have a supportive and coordinative function, as in a hospice home care setting, or are engaged in the day to day practical tasks of nursing care in an inpatient hospice setting (Seale 1989, McNamara, Wadell and Colvin 1994). Hospice home care nurses' work has been described in relation to activities (Lack and Buckingham 1978), roles (Burns and Carney 1986, Dobratz 1990), elements (Stiles 1990), competencies (Zerwekh 1993), clinical components (Davies and Oberle 1990) and efforts (McWilliam, Burdock and Wamsley 1993). These studies reveal that a greater part of the nurses' work is related to coordinating and collaborating on patient care plans, sharing, consulting and facilitating the work of other health care professionals/agencies, as well as negotiating the system on behalf of the patients and families. Another important part of nurses' work is responding to patients and families in crisis (Dobratz 1990), being there, sitting with, listening to, fostering reconciliation, sharing the moment and secrets (Davies and Oberle 1990, Stiles 1990, Zerwehk 1993), and sharing nearing death mystical experiences (Zerwehk 1993). Nurses' work involves controlling pain and symptoms, teaching, helping and guiding patients and families in preparing for death, and letting go of the attachment to life as it has been (Davies and Oberle 1990, Dobratz 1990, Stiles 1990, McWilliam, Burdock and Wamsley 1993, Zerwehk 1993), and lending a helping hand (Davies and Oberle 1990). Lack and Buckingham (1978) found that about one third of nurses' direct care time was spent in some form of supportive care, another third in assessment, and about one fifth on direct physical care, treatment and medication. Investigating the role of the registered nurse (RN) in home hospice care through a retrospective review of 360 patient records, Burns and Carney (1986), found the following: a large proportion of care activities in a hospice was provided by RNs; an important element of care involved phone calls between the RN and the family unit; and the intensity of nursing care fluctuated, being greatest during the week of admission to the hospice and the week before death. Burns and Carney (1986) estimated that direct care activities consumed 25% of the RN's total working time and that the remaining 75% involved traveling to patients' homes, attending staff meetings, conducting clerical activities and being elsewhere.

Inpatient hospice nurses' work has been described in relation to role transition (Samarel 1989[a]), stress and coping behavior (McNamara, Waddell and Colvin 1994, 1995), care and work (Wright 1981, James 1989, 1992, Gates 1991[a], Samarel 1989 [b]), and shared meanings (Byrne and McMurray 1997). What is important here, is the similarity between descriptions of the work of home care and of inpatient hospice nurses, apart from there being less emphasis on the coordinating role and prominence of physical care in the work of inpatient hospice nurses. Some studies suggest that these nurses, largely, integrate their physical and emotional care (James 1989, Samarel 1989[a], Rittman, Rivera and Godown 1997). In addition, they also indicate that at busy times, physical care takes priority over emotional care (James 1989, 1992) or caring behaviors (Samarel 1989[a]), and that, under these circumstances, the nurses accept a common-sense understanding of 'work' as 'doing something', *i.e.* providing physical care (James 1989). Other studies show that nurses routinize or hurry through their physical care which can, either in itself or through sheer demand, interfere with the nurses' emotional care (Wright 1981, James 1989, McNamara, Waddell and Colvin 1995).

Studies also indicate that the hierarchical characteristics of hospitals may apply to some hospices in both the USA and the UK, especially those integrated into the conventional health care system (Abel 1986, Seale 1989). Such a hierarchy is described as manifesting itself in subtle distinctions between medical and nursing staff, and between levels of nursing staff with nursing auxiliaries providing most of patients' physical care (*cf.* Seale 1989). No studies have been located describing the amount and content of direct care activities carried out by inpatient hospice nurses.

Evaluation of hospice care

This part of the thesis reflects research into hospice nursing practice which is patient and/or family-centered. However, the major thrust in hospice research has been to examine bio-medical issues of pain and symptom control, and the impact of hospices as an intervention, which has been conceptualized as the totality of hospice care and its impact on a variety of outcomes, including satisfaction with care (Corless 1994, Corner 1996). This makes it rather difficult to distinguish between nursing and other professional practices, which are necessarily interwoven in what follows.

The reality is, that hospices and palliative care services, have to demonstrate that they are providing 'value for money' if they are to attract continued or increased financial support (Goddard 1993). Excluding bio-medical pain and symptom control studies, most of the remaining research conducted is designed to investigate either whether hospices meet the needs of the dying and the families, better, *i.e.* more effectively and efficiently than traditional health care, or whether each setting is living up to its own standards of care. Most research is based on surveys, retrospective assessments by bereaved family members, retrospective reviews of medical records and death certificates and outcome measurements (Mor 1987, Seale 1989, Ahmedzai 1990, Goddard 1993, Corless 1994, Corner 1996). Four major methodological problems have however been encountered, briefly: 1) randomized controlled trials are difficult; 2) in measuring outcome variables such as quality of life, psychological distress, bereavement outcomes and pain, no generally accepted instruments have been used; 3) the closer to death the more difficult it becomes to assess patients' own views, and using relatives or staff as 'proxy' or 'surrogate' informants is not unproblematic, and; 4) the variety of hospice types and palliative care services makes comparisons difficult (Mount and Scott 1983, Kane *et al.* 1984, Mor 1987, Seale 1989, Ahmedzai 1990, Cartwright and Seale 1990, Goddard 1993, Higginson, Priest and McCarthy 1994, Field *et al.* 1995, Donaldson and Field 1998).

Thus, the findings emerging from hospice research are often contradictory, some suggest that there are higher standards of care in hospices, whereas other studies have detected few differences between hospice and nonhospice care (*cf.* Seale and Kelly 1997[b]) (for an overview of the early studies see Mor 1987, Seale 1989, and in Swedish, Hermansson and Ternested 1994). Like studies from the UK (Parkes 1979, McIllmurray 1989) the largest hospice evaluation study today, the National Hospice Study from the

USA (Greer *et al.* 1986, *cf.* Mor 1987) found a small but significant decline in physical symptoms such as pain, nausea and vomiting for patients in a hospital-based hospice compared to patients in a conventional setting. There were no observational differences regarding the fundamental hospice objectives 'quality of life' and 'bereavement outcomes' between hospice and nonhospice patients/relatives. Hospice patients were less likely to receive diagnostic tests, X-rays, an aggressive anti-tumor therapy, but were more likely to receive social service support than conventional patients. Johnson *et al.* (1990) found that patients in the UK were more likely to undergo invasive procedures in hospices where there was a full-time physician or medical director. Awareness of and witnessing others dying has been found to be both distressing (Seale and Kelly 1997[b]) and comforting, but patients who had witnessed the deaths of fellow patients were found to be less depressed that those who had not done so (Payne *et al.* 1996). Studies concerning bereaved relatives' experience of care in the UK, also show that in several respects hospital provision has moved towards hospice practice by providing equally high standards of symptom control, and that spouses' visiting patterns and involvement in care have become similar in both settings (Parkes and Parkes 1984, Seale and Kelly 1997[a], 1997[b]).

What seems to distinguish hospice from conventional care in nearly all studies is the patients' and relatives' satisfaction with the care as regards involvement, the superiority of the psychosocial climate, communication with and interpersonal skills of the staff in hospices in the USA (Buckingham *et al.* 1976, Kane *et al.* 1985, 1985, Greer *et al.* 1986, Dawson 1991) and the UK (Parkes 1979, Parkes and Parkes 1984, Seale 1991, Seale and Kelly 1997[a], 1997[b]). Hospital staff are more likely to be seen as 'too busy to care', whereas the hospice atmosphere is more likely to be perceived as being 'like a family'. Shortcomings in the physical environment, communication with staff and shortness of staff or an overworked personnel have been described by relatives of dying patients in hospitals in the UK (Parkes and Parkes 1984, Higginson, Wade and McCarthy 1990, Seale and Kelly 1997[a], 1997[b]) and the USA (Buckingham *et al.* 1976, Hull 1991). Likewise, results indicate that hospice as compared to nonhospice staff are better at meeting the needs of patients as perceived by relatives, and that overall satisfaction is negatively related to unmet basic needs, and positively related to the psychosocial support received from nurses (Dawson 1991, *cf.* Kristjanson and Ashcroft 1994). Another variable which proved to favor hospice over conventional care is the satisfaction of relatives with the site of death (Mor 1987, Dawson 1991).

In a search of Medline from 1966 and CINAHL from 1982 to 1995, Corner (1996) found 384 palliative care studies published in 122 different professional journals, most concentrated on evaluations, quantifying the symptoms patients experience rather than the experiences of patients themselves, and were preoccupied with the 'self discovery' typical of a new field of work. Corner (1996) contemplates whether the research agenda for palliative care has too narrow a focus, in not addressing all patient, family, and service concerns, or broader societal and cultural issues. Instead it has allowed a focus on treatment and pharmacology to become dominant, *i.e.* bio-medical research. Hospice research related to patient and family, as described above, has mainly been founded on outcome and comparison studies based on quantitative data. Though important, and at times more powerful scientifically, they cannot stand alone. Quantitative studies do not reveal the processes and understandings of the strengths and weaknesses of care that are essential if care is to be improved, and quantitative data may even be contradicted by qualitative data. For example Seale and Kelly (1997[a]), found that in the UK, the involvement of relatives in care had become similar, quantitatively, in the hospice and hospital setting. However qualitative data revealed that hospital spouses became involved partly because they wanted to, but also because the nurses were too busy to care, whereas at the hospice the relatives became involved because they wanted to. In the same study no difference was found in the number of relatives present at the death at the two sites, but the hospital group spouses were significantly more likely to indicate bad feelings about not having been present (Seale and Kelly 1997 [a]).

Research evidence regarding the processes of patient care emerging from participant observation studies suggests that inpatient hospice care in some instances has become similar to hospital care (the physical aspects of care predominates over psychosocial) (James 1989, 1992), and that the hospice style of care (time to build a caring relationship, and provide personalized care) has become possible in some hospitals in the UK (Field 1984) and the USA (Samarel 1989[a], 1989[b], Gates 1991[a], 1991[b]). One most important aspect of hospices, according to Saunders (1983), is an atmosphere of such welcome and confidence that patients and families begin to feel safe again. In the few qualitative studies of patients' experiences of inpatient hospice care, the atmosphere of the place described as relaxed, 'like a home', having a 'happy spirit', and being permeated with caring, stands out as a very important feature, and embodies both the physical and psychosocial environment in the USA (Buckingham *et al.* 1976, Gates 1991[a]) and in the UK (McDonnell 1989). In the 'qualitative' hospice home care literature from the USA, the relationship with or behavior of the nurses as seen from the patients' (Raudonis 1993) or families' perspectives (Stiles 1990, Hull 1991, Raudonis and Kirschling 1996), is emphasized, more than the atmosphere. For example, Raudonis (1993) found that home hospice patients' experiences of empathic relationships with their hospice nurses, could be captured in the category 'affirmation as a person'. The nurses' willingness to spend time getting to know the patient as a person, and the nurses' and patients' reciprocal sharing of themselves, were described, by these patients as having an immense effect on their quality of life and emotional and physical well-being. Examining caring behaviors among hospice home care nurses as perceived by family caregivers, Hull (1991) found caring behaviors included around-the-clock-accessibility and availability, taking time to talk in a calm, sensitive and nonjudgmental manner and clinical competence. In a study to illuminate elements of the nurse-family relationship in a home hospice, Stiles (1990, 1994) found the metaphor a 'shining stranger' captured the meaning of the families' experience. The families described the nurses' physical availability, their sharing of themselves, telling the truth and their use of humor as being very important and highly valued. The skills of the nurses were also valued; their relieving of pain and distress, teaching and giving explanations and the dignity with which they helped the loved ones in the dying phase, and the family in preparing for the death. Much the same was found in a study by Raudonis and Kirschling (1996), where the family caregivers described hospice nurses as respectful, kind, caring and clinical experts whose presence and personal sharing made them 'part of the family'. The nurses made it possible for the families to continue living, feeling that their loved ones were in expert, caring hands.

In the inpatients setting in the USA, the kindness and individual attentions and care received from the staff, are described as very important, and seem to be part of a whole atmosphere rather than individual relationships. The following seem to be essential for patients' living while dying: being able to express and talk openly about feelings; receiving care firstly and primarily from the family and secondly from professionals, especially nurses and physicians; the free environment and participation in daily tasks; and the possibility of being able to take care of both the family and other patients (Buckingham *et al.* 1976, Gates 1991^{a}, 1991^{b}). In a participant observation study, Gates (1991^{b}) found that dying patients in an oncological unit valued expertise in physical care and were surprised to receive psychological care, whereas hospice patients were more appreciative of personal care acts and expected to receive psychological care. In the oncological unit care as doing was emphasized, while in the hospice, care as presence of family was more strongly emphasized. In a hermeneutical study of 52 relatives' experiences of involvement in patient care at an inpatient hospice and a surgical unit in Sweden, Andershed and Ternestedt (1998^{b}) found that the experience of care of all relatives at the hospice and 43% of relatives at the surgical unit, could be described as 'involvement in the light'. Here the attitudes of the staff were described as being based on respect, openness, sincerity, confirmation and connection. The experiences of the remaining relatives of patients at the surgical unit were described as 'involvement in the dark', and the attitudes of the staff as based on lack of respect, lack of communication, lack of sincerity, dishonesty, avoidance and disconnection.

RATIONALE FOR THE STUDY

In concluding a literature review of hospice nursing research, Petrosino (1988) remarked: "If we define the focus of nursing research strictly as direct patient care, then research in hospice is sadly lacking" (p. 40). In a literature review of symptom control within hospice care six years later, Corless (1994) found a small improvement in clinical hospice research, but that what Petrosino (1988) wrote was still holding true - namely, that prior to intervention studies there is a need for good descriptive studies and qualitative research. Corless (1994) further suggested, that the role of the hospice nurse be examined. When this doctoral study was started no studies were located describing, quantitatively, the activities of patients and nurses in an inpatient hospice, and how or if they differed from conventional care. Such knowledge was thought important for an understanding of the processes of care and the roles of nurses in a hospice. Just as important to an understanding of the processes of care, and the hospice contribution to living while dying, are the experiences of patients, relatives and nurses. At that time only the few studies mentioned above (Buckingham *et al.* 1976, Gates 1991[b]) existed. They threw light on the meanings of patients' experience of nursing practice at an inpatient hospice in the USA, but no studies were located which related to nurses in such a setting.

A freestanding, purpose-build hospice is a new addition to the Swedish health care system, and whether such a hospice provides a good alternative for the dying patients, their families and Swedish society at large remains to be seen. Knowledge of and insight into the situation of the nurses and dying patients and the experiences of nursing practice in an inpatient hospice, can provide an understanding useful for future health care practice, education, planning and administration concerning care for dying patients in Sweden. Yet another rationale for the study is the unique opportunity to describe nursing practice in a newly opened hospice, with which data from replication studies in the future can be compared, thereby providing an opportunity to follow the evolution of nursing practice in a hospice over time.

The purpose and aims of the study

The general purpose of the study is to illuminate nursing practice in a hospice as seen from the standpoint of nurses and guests, by the means of narrations and observations.

An oncological unit was included in parts of the study, for contextual relatedness and to enhance the possibilities of gaining an insight into nursing practice at a hospice. Data on relatives' experiences of nursing practice in a hospice, and patients' and relatives' experiences of nursing practice in an oncological unit, have been collected, but are not included in the present study. The thesis comprised five papers with the following specific aims:

Paper I	To illuminate meanings of the experiences of becoming a hospice nurse, especially the nurses' reasons for wanting to work in a hospice, and their expectations, hopes and concerns about their future job.
Paper II	To illuminate meanings of the experiences of being a hospice nurse.
Paper III	To explore and compare the activities of nurses in a hospice and in an oncological unit.
Paper IV	To explore and compare the activities of patients in a hospice and in an oncological unit.
Paper V	To illuminate meanings of nursing care in a hospice as experienced by the guests.

METHODOLOGICAL FRAMEWORK

Ricouer (1976) when reflecting upon what it means to understand a discourse - making sense of a written discourse - writes " that the text as a whole may be compared to an object, which may be viewed from several sides, but never from all sides at once" (p. 77). Accordingly, the reconstruction of the whole has perspective aspects similar to those of a perceived object, or one could say, to those of a phenomenon such as nursing practice in a hospice. This phenomenon is so complex that a multitude of perspectives is needed in order to comprehend just a part of it. The present study employs only a few perspectives, namely, a phenomenological hermeneutic approach illuminating the meanings of nurses' and patients' experiences of nursing practice, and a non-participant observational quantitative approach, describing the activities of nurses and patients in a hospice and in an oncological unit. It was thought that the different perspectives, *i.e.*

methods/participants/aims, would yield different understandings, but also that the dynamism between these understandings and research paradigms would be productive in enhancing comprehension of the phenomenon under exploration. This approach is also called methodological triangulation or complementarity design (Polit and Hungler 1999, p. 264)

The quantitative methods used in this thesis are grounded in the tradition or paradigm of the natural sciences and the qualitative approach is grounded in the traditions of phenomenological hermeneutics (Nerheim 1995). These two approaches reflect the reality of health care professionals, who daily have to rely on knowledge (which may be entirely impersonal) gained from the natural sciences concerning symptoms, treatments and interventions, and knowledge gained from communication and phenomenological hermeneutics when interacting with, treating and caring for a sick person, which must be completely personal. Each tradition has it own language and assumptions according to which the 'scientific' or 'scholarly' rigor and results of a study can be judged. In executing the research, the investigator has attempted to remain faithful to the traditions within each paradigm. Since criteria for judging quantitative measurements and designs are supposedly known for the scientist within the health care community, only the phenomenological hermeneutic framework will be described here.

During the process of the study, the ideas and beliefs behind the whole approach of this thesis have become more conscious and articulated - largely due to insights gained from the plenitude of literature into death and dying, nursing, existential, psychological and sociological philosophy and research, clinical experiences, and not least the people and cultural atmosphere at the Department of Nursing, Umeå University. The beliefs are that a fundamental fact of human existence is incarnation, *i.e.* the human self (personality, ego, consciousness) is not disembodied, but intimately united with a concrete, flesh and blood body. The essence of humans is to-be-in-a-situation which is to-be-incarnated and present in a specific place in time, history and culture. Culture is socially and historically constructed, and narrative is a primary mode of knowing, *i.e.* as human beings we are making sense of the world by telling stories about it - it is through the use of narratives that we construct our world. As humans we represent our lives, to ourselves as well as to others, in the form of narratives, and we act not directly on the world, but on beliefs we hold about the world. Meanings, values and beliefs are social productions and are present in the shared languages and everyday life into which a person is born and becomes a part of. Reality is rooted in the fact that meaning surfaces in a person-world interrelationship (Marcel 1965[a], 1982, Ricoeur 1966, 1976, 1982, 1992, Sarbin 1986, Polkinghorne 1988, Kristensson Uggla 1994, Bruner 1996).

Conversational research interviews (Mishler 1986, Riessman 1993, Kvale 1996), and a phenomenological hermeneutic approach were chosen, as the means to gain entry into the meanings of nursing practice in a hospice, as experienced by guests and nurses. The latter was inspired by the French philosopher Ricoeur, and the application of his philosophy to interview texts, which has been and still is, under development at the Department of Nursing, Umeå University in Sweden (Åström 1993, Söderberg *et al.* 1997, 1999, Nilsson, Jansson and Norberg 1997), and the University of Tromsø in Norway (Lindseth *et al.* 1994).

Phenomenological hermeneutics can be understood as a descriptive interpretive approach. The word phenomenology comes from the Greek words *phainomenon* (things that appear) and *logos* (reason, discourse) and means 'reasoning or discourse about that which appears' (Honderich 1995). Phenomenology is about 'going back to the things themselves', to our lived experience of being in the world. It is a study of phenomena, *i.e.* of the 'objects' of human experience (Grotty 1996). Though we can never understand another person's experience as experienced, it is possible to understand the meaning of an experience, *i.e.* the experience remains private, but its sense, its meaning becomes public (Ricoeur 1976, 16). Ricoeur's phenomenology is influenced by Husserl (1859 - 1938), a German philosopher, and the prime mover of the phenomenology movement (Grotty 1996). For Ricoeur, phenomenology is most importantly the principle of intentionality, meaning that our consciousness is always conscious of something, an object, a thought, another human being, *i.e.* all perception is intentional, it is an activity of the perceiving subject, it reaches beyond the subject, it grasps something beyond the subject, it simultaneously calls into being an 'object' that belongs to a world which in principle can be shared. Thus the world is neither held in the mind nor out there, but is constituted in the meeting between the two. It is in this meeting that Ricoeur departs from Husserl, and agree with Heidegger that our 'fore-understanding' is ontological' rather than epistemological, meaning that we cannot suspend our 'fore-understanding' and describe the pure essence, the meaning, of the phenomena constituted in the intentional act, but can only describe and understand it through our 'fore-understanding' evolved from our shared language, history and interaction with the physical world. Since most words are polysemic, they have more than one meaning, they call for interpretation, *i.e.* hermeneutics. The fundamental phenomenological presupposition of hermeneutics is that every question concerning being is a question about the meaning of being, and it becomes a hermeneutical problem only insofar as the meaning is concealed. Thus there is a mutual belonging between phenomenology and hermeneutics. Phenomenology remains the unsurpassable presupposition of hermeneutics, but phenomenology cannot constitute itself without a hermeneutical presupposition (Ricoeur 1982, pp. 101-128, Bauman 1992, Kristenson Uggla 1994).

The word hermeneutic derives from Hermes, the messenger of the Greek gods and gave rise to *hermèneuein* meaning 'to interpret', and *hermèneutike* (technè) is 'the art of interpretation' (Honderich 1995). Ricoeur (1982) uses the following working definition of hermeneutics: "Hermeneutics is the theory of the operations of understanding in their relation to the interpretation of the texts" (p. 43). According to Ricouer (1976 p 92) the hermeneutic task is not to realize or understand the utterer's meaning (the intention of guests and nurses) but the utterance's meaning (the meaning of the text itself) conceived in a dynamic way as the direction of thought opened up by the referential function of the text. In other words what has to be appropriated is not the inner life of another person, as in the Romantic tradition of hermeneutics, but the disclosure of possible ways of being in the world. To understand a text is to follow its movement from what it says (the manifest description) to what it speaks about (the existential bearing of human beings), beyond my situation as a reader, beyond the situation of the author. I open myself up to possible modes of being-in-the-world which the text discloses to me (Ricoeur 1982, p. 177). This is what Gadamer (1975, p. 358) called 'fusion of horizons' or what Ricoeur (1976) designates appropriation, *i.e.* "to 'make one's own' what was previously 'foreign', and remains the ultimate aim of all hermeneutics" (p 91). According to Ricoeur this displaces the hermeneutic circle or spiral from a subjectivistic level (understanding the author better than she understands herself) to an ontological plane. The circle now being between my mode of being and the mode of being in the world that the text opens up and discloses in front of itself by means of its non-ostentive references (Ricoeur 1976, p. 94 and 1982, p. 178).

Set above both research paradigms employed in this study are the characteristic of human beings to be-in-a-situation and the nature of human intentionality, and thus the non-existence of the subject-object dichotomy (Marcel 1982, 82-103).

MATERIAL AND METHODS

The study involves nurses and patients/guests in a freestanding, inpatient hospice, and an oncological unit at a university hospital, both located in northern Sweden in a town with a population of about 100 000. An overview of the content and status of the papers comprising the dissertation is shown in Table 1

Interviews with nurses were conducted by the author, while a co-worker, Lilian Jansson, RN, Assistant Professor at the Department of Nursing, interviewed the patients. The observational studies were supervised by the author and carried out by two experienced nurses from each site.

Table 1 Overview of the status of papers and studies comprising the doctoral thesis

Paper	Main content of the studies	Participants	Methods/years for data collection	Methods for analyses	Status
I	Experiences of becoming a hospice nurse	19 nurses (14 RNs[1], 5 LPNs[2])	Research interviews 1993	Phenomenological hermeneutics	Published
II	Experiences of being a hospice nurse	18[3] nurses (14 RNs, 4 LPNs)	Research interviews 1994	Phenomenological hermeneutics	Published
III	Activities of patients at the two sites	21 (36)[4] hospice guests and 29 oncological patients	Non-participant observation. Ratings of patient acuity 1994-1995	Content and statistical analyses	Published
IV	Activities of nurses at the two sites	96 work-shifts of nurses (38 at the hospice and 58 at the oncological unit)	Non-participant observation. Ratings of patient acuity 1994-1995	Content and statistical analyses	Accepted for publication
V	Guests' experiences of nursing care in a hospice	12 hospice guests	Research interviews 1993-1995	Phenomenological hermeneutics	Manuscript submitted

[1] RN= Registered nurse, [2] LPN= Licensed practical nurse, [3] 17 nurses participated in both interviews, [4] Here 21 patients participated, but since 15 patients participated on more than one observation period and these periods were considered independent of each other the total becomes 36 participating hospice patients.

Settings

The hospice was inaugurated in December of 1992, and is the first freestanding purpose-build hospice in Sweden. It is housed in a beautiful wooden building shaped like a butterfly which is also the logo of the hospice. The facility has 16 single homely guest rooms located in the wings of the butterfly, most of them facing a meadow and a river. Each room has a small kitchenette and a bed settee for relatives. The nurses' station, the kitchen, a room with a bubble bath, the memorial, living and dining rooms and a beautiful atrium are in the body of the butterfly, dividing the guest rooms into two clusters of eight. The hospice was made possible through the hard work and enthusiasm of individual health care professionals, the financial support of the Swedish Cancer Foundation, the municipality's disposal of a building site, and the contract of care agreements between the hospice and the municipalities and the County Council of Västerbotten. The private foundation 'Hospice Care' owns and is responsible for the overall operation of the hospice. A chief nurse is responsible for the daily operation and nursing care, and physicians at the oncological clinic at the university hospital for the medical care. A Quality Assurance Board answered for research, development and evaluation of the hospice, and an educational corporation 'Axlagården Utbildning AB' for education in and the advancement of hospice care.

During the period 1993-1996 the hospice received much attention in both the local and national media, and it has received more than 6000 visitors. In this period the hospice admitted terminally ill people, mainly with cancer, from 18 years of age and older. Most guests (80%) died at the hospice after an average stay of 35 days (range 12 hours - 312 days). The median age was 76 years (range 25 - 95 years). During the hospice's first year the bed occupancy rate was low, but increased steadily reaching a mean of 82.3 for 1996. From January 1993 to June 1996, the hospice had 421 guests. Compared to recommendation in the literature (Sykes 1994) the nurse-patient ratio was low, *i.e.* with full-bed occupancy 0.8:1. In 1996 the hospice had 18 people working as volunteers, four hours/week/person on average, which was more than in other hospices in Sweden. Volunteers did not participate in the physical care of guests. The huge rustic kitchen and food services to patients and relatives were managed by the kitchen personnel. Pastoral services were provided by the church at the University Hospital, social work services by the oncological clinic, physical and occupational therapy by the guests' local health centre. The hospice guests paid a little more per day (45 SEK) to stay in the hospice, than patients paid at the University Hospital. Since 1994 bereavement groups for relatives have been offered as an option.

The RN-LPN ratio was 3:1 and as a matter of policy, all nurses worked part-time initially ranging 50-80%, the latter figure has been raised in the last years to 96%, since some nurses could not live on a part-time salary. During the hospice's first 4 years the job turn-over was lower among the nurses (three nurses), than among the physicians. The one medical position has been held in turn by an oncologist, a geriatrician and a primary health care physician, and lately by the physicians at the oncological clinic. The philosophy of the hospice is in accordance with the general principles underlying the hospice movement as described in the introduction. During the years the staff has had access to various kinds of group supervision, staff meetings and continuing education.

The oncological clinic consisted of 5 units, where the one included in the dissertation (III, IV) had 23 beds and admitted patients from 18 years and up. The unit provided specialized care for people from all of northern Sweden for the diagnosis and treatment of cancer, especially brain and lung cancer. In the years 1994-1995 the average length of stay was 7.5 days, and the RN-LPN ratio was 1:1. The oncological clinic is one of the six Oncology Centres located at the regional hospitals in Sweden, responsible for the gathering and co-ordination of information, resources and research, and the development of treatment programs and psychosocial oncology within its particular geographical area. For a more detailed description of cancer nursing in Sweden see Tishelman (1993).

At both sites nursing care was organized on the basis of a team nursing system (with elements of primary nursing at the hospice) during the day and evening and as a total care system at night.

Participants

Nurses

All nurses at the hospice were interviewed, by the author, in 1993, two months (I) and in 1994, 14 months (II) after the opening of the hospice. Seventeen of the nurses participated in both interviews. The characteristics of the nurses are described in Table 2.

Table 2 Characteristics of the hospice nurses

Paper	Female/male n	Age in years m (range)	Years in nursing care m (range)	RN/LPN
I	19 - 15/4	36 (26-53)	14 (0.5-26)	14/5
II	18 - 14/4	37 (27-54)	15 (1.5-27)	14/4

The observational study (III), included all nurses at the hospice and at the oncological unit, working during the 4 days and 2 nights of observations. Since the nurses were promised anonymity only staff grades were recorded. Thus the number of individual nurses observed is not known, only the number of nurses' work-shifts which is 31/29 RN and 7/29 LPN shifts at the hospice/oncological unit. The observation took place during a 5-month period in the winter 1994/1995 at the hospice, and during a 4-week period in the autumn 1994 at the oncological unit. Unforeseen circumstances led to the prolongation of the study period at the hospice. All nurses invited by the author to participate in both the interview and observational studies agreed to do so.

Patients

The activities of 36 hospice and 29 oncological patients' days/nights were monitored for a day or a night (IV). The observations took place over 6 observation periods (4 days and 2 nights) at the hospice during a 6-week period in the late spring of 1995, and 5 observation periods (3 days, 1 night and one 24-hour period) at the oncological unit during a 5-month period in the winter of 1994/95. The lower number of oncological patients in Table 3 is explained by the fact that six patients were observed at each observation period. At the hospice all 6 admitted patients participated during the first observation period. At the next observation period 6 patients were randomly selected. Because the flow of patients at the hospice was low, and a couple of patients were discharged and re-admitted, 15 patients were observed during more than one observation period. Since the observations took place over a time span of 6 weeks and the patients' conditions changed markedly, all 6 periods of observations were seen as independent observations, amounting to a total of 36 participating patients (21 individuals). At the oncological unit six patients were randomly selected for each of the five observation periods. However, if a patient was judged by the observers to be suitable for admission to the hospice (four patients were) these patients were automatically included in the study. The patients were selected and invited to participate, verbally and by letter, by the two nurses from each site who performed the observations. Two oncological patients chose not to participate, and one patient was withdrawn, as the observers perceived that the observations were too stressful for an already disoriented person. At the hospice all the patients agreed to participate. Characteristics of the patients participating in the observational study (IV) are described in Table 3.

Table 3 Characteristics of the participants during the observation days at the two sites (IV).

	Hospice care		Oncological care		
	[1]Participants (n= 21)		[2] Participants (n=25)		[3]Participants (n=4)
Age: mean ± SD	73.4 ±11.0		61.4 ±13.7		67.7 ±5.5
Male/female (%)	29/71		52/48		75/25
Diagnoses (1st, 2nd)	Ca mammae, Ca prostate		Ca mammae, Ca CNS		4 different cancer diagnoses
	Day	**Night**	**Day**	**Night**	**Day**
	(n=24)	(n=12)	(n=19)	(n=9)	(n=4)
Psychological needs[4]: mean, ±SD	20.7 ±26.6	14.6 ±9.3	20.1 ±21.7	12 ±14.7	27 ±19.3
Physical needs [4]: mean, ±SD	36.0 ±33.2	32.4 ±26.3	19.8 ±21.6	31.1 ±29.6	62.2 ±13
Katz ADL-scores[5]: median (1st, 3rd quartiles)	F (C, F)	F (E, F)	A (A, B)	B (A, F)	F (C, F)

[1] Fifteen patients participated in more than one day/night study. [2]Three patients participating in a night study are included in a day study (24 -hour observations), two of the patients participating in the 24 -hour observation were discharged in the evening, since their blood counts were too low for them to receive chemotherapy [3]These four patients were judged suitable for hospice care, but were in the oncological unit. [4] Mean of the perceived psychological and physical needs in mm along a 100 mm VAS. [5] Katz ADL- scores indicate activities of daily living, and include six items; bathing, dressing, toileting, transferring, urinary continence and feeding. The score ranges from A (independent in all items) to G (completely dependent).

Interviews with patients (V) began in the winter of 1993 and ended in the winter of 1995. A purposeful sample of 12 hospice patients were invited, verbally and in writing via letter from the hospice director of nursing, to participate in the study Selection of guests was guided by the following criteria:

1 A minimum length of stay of a week
2 The guest was oriented as to time place and person
3 The guest had the physical and emotional endurance to participate in an interview
4 The guest wished to participate in the study
5 The guest had an available relative/friend, who visited her/him regularly (this criterion is related to a larger study of hospice care)

The letter stated that the purpose of the study was to learn and explore what seriously ill patients feel is helpful and good *versus* negative and unhelpful nursing care, that the interview would be like a conversation, and would be tape-recorded. If a patient agreed to participate the co-worker (Lilian Jansson) visited the guest, assessed the criteria for selection and made arrangement for the interview. All guests invited to participate accepted, and their characteristics are described in Table 4.

Table 4 Characteristics of the guests at the time of the interviews

Paper	Female/male n	Age in years m, median (range)	Length of stay in days m, median (range)
5	12 - 10/2	70, 74 (32-95)	47, 43 (8-101)

Methods for data collection

Research interviews

Papers I, II, and V were based on open-ended research interviews which were conversational in nature (Mishler 1986, Riessman 1993, Kvale 1996, Polit and Hungler 1999), the purpose of which was to obtain description of the lifeworld of the participants in order to interpret the meaning of the phenomenon 'nursing practice' (*cf.* Kvale 1996, p. 6). To obtain narrations and descriptions of nursing practice that were as rich as possible, the following considerations guided the interviews:

> Broad open-ended questions will encourage the participants to narrate more freely; interview probes must depend upon the individual responses and will be used to clarify statements and their meaning and to elaborate on the participants' ideas of nursing (*cf.* Kvale 1996). Use of aspects of the 'critical incidence' technique (*cf.* Flanagan 1954, Polit and Hungler 1999) will encourage the use of narratives. It is essential to establish rapport to create an open and safe atmosphere in which a meaningful discourse can take place (*cf.* Mishler 1986). This is furthered by a quiet, undisturbed and aesthetically pleasing room, an interviewer who is genuinely interested in the life world of the participants (*cf.* Tishelman 1993, p 48), and who is humble and relaxed. Thus no more than one interview a day was conducted, and the interviewers arranged to have plenty of time before and after each interview. The interviewers must be sensitive enough to turn off the tape-recorder if it hindered the participants from narrating freely. Though both researchers are experienced nurses and interviewers, they had not before interviewed dying people and their carers. Since interviewing about dying is emotionally demanding, it was believed that meeting and sharing the experiences of an interview with the research team would help understanding the emotions evoked and knowledge

gained during the interview. This in turn would make it possible to increase the proficiency of the interviewers and thus the value of the data collected.

The audio-taped interviews were transcribed by a secretary. The transcription was validated, *i.e.* text and word on the tape were compared, and changes in voice tone, laughter and silences were added to the transcripts.

Research interviews with nurses (I, II)

The 37 interviews with nurses occurred in a secluded room at the hospice and lasted 45-100 minutes. During the first round of interviews (I), when the interviewer was not known to the nurses, each interview was preceded by a dialogue and exchange of personal and professional information. The interview then evolved from the request: "Please narrate your reasons for applying for the hospice position, and the considerations that guided you". During the interviews, if not addressed spontaneously, the interviewer probed for any uneasy thoughts and concerns the nurses had or had had in relation to their hospice employment. By the time of the second interview (II) the interviewer was well known to the nurses, and the interview evolved from the request: "Please narrate how you have experienced the last year as a hospice nurse". In addition the nurses were asked to narrate a nursing situation with a guest they especially remembered either positively or negatively.

Research interviews with patients (V)

The 12 interviews with guests at the hospice took place in the guest's room, and the tape-recorded part of the meetings lasted 20-60 minutes. Since agreement for each interview was obtained in person, the interviewer was not foreign to the guests, because they had already spent up to an hour together when arranging the interview. The interviews evolved around the topic: "Please tell me about your hospice experience". In addition the guests were asked to narrate a situation where they had found the nursing care to be particularly good and helpful, and a situation where it had been the opposite.

Non-participant observations (III, IV)

The non-participant observational studies (III, IV) were based on the assumptions and methods underlying the work sampling technique (Sittig 1993, Mundel and Danner 1994). Two experienced nurses, from the hospice and the oncological unit, respectively, volunteered to make the observations at their own units. They attended a two-hour training session followed by four hours of practice (pilot study) at the two sites. During the main study the two observers at each site divided the observation time between them. Since it has been suggested that if the underlying activities are random *i.e.* lacking any prominent periodic component, as most health care activities do, then one can sample at fixed intervals (Sitting 1993). Thus the activities of nurses were recorded at approximately 15-minute intervals (a total of 3247 observations) and activities of patients at approximately 10-minute intervals (a total of 5286 observations) during the 4 days and 2 nights of observation for each group. The nurse observers wrote down in their own words the content of the activity occurring at the moment the observation began. If more than one activity was taking place simultaneously, the observers wrote what they judged to be the main activity first. They also assigned each activity a predetermined code indicating where it took place and with whom. The interval had to be 15 minutes, when observing the activities of nurses, otherwise the observers would not have had time to observe all the nurses working.

Ratings of patients' acuity (III, IV)

In order to obtain a description of the total patient population on the observation days, all patients at both sites were classified according to the Katz Index of Independence in the Activities of Daily Living (Index of ADL) (Kane and Kane 1981, Brorsson and Åsberg 1984). The Index of ADL summarizes overall performance in six activities; bathing, dressing, going to the toilet, transferring, continence, and feeding and has a hierarchical structure. For each of the six activities the patients are classified as independent, partly independent or dependent on assistance. The midpoint 'partly independent' indicates a score of the patient's ADL performance as 'independent' for the first three activities and 'dependent' for the last three. We did however, change - partly independent in bathing - to dependent in five cases at the hospice, because the patient was scored partly dependent in transferring, and thus could not bathe independently. The score ranges from A (independent in all items) to G (completely dependent). In addition to the ADL- scores, the observers noted the age, sex, diagnoses, and perceived physical and psychological nursing needs on a Visual Analogue Scale (VAS) ranging from minimal to maximal along a 100 mm line. Patients were rated by the observers, together with the nurse responsible for the particular patient. These descriptions are provided in Papers III and IV.

Methods for analyses

Phenomenological hermeneutic interpretation

Most of what belongs in this section has already been described under methodological considerations. In addition, Ricoeur (1976) describes the interpretation of a text as involving three phases: naive understanding, structural analyses and comprehensive understanding, constituting dialectic movements between the whole and the parts of the text; between understanding and explanation; between distanciation and appropriation, and between what the text is saying semantically and what it is pointing to hermeneutically, *i.e.* the referential function of the text.

Where interpretations in Paper I are mainly based on a thematic analysis, the interpretations in Paper II, in addition to a thematic analysis, are based on a semantic analysis (identifying metaphors), an analysis of what is not present in the text, and a systematic attempt to invalidate the understanding related to each sub-theme (*cf.* Ricoeur 1976, p. 79). Findings, in Paper V are based on content and thematic analysis, concept clarification, and an attempt to validate alternative interpretations. The understanding of the hermeneutic spiral as guesses and validation circularly related as subjective and objective approaches to the text has been executed as follows: New ideas (naive understanding) gained through listening to the tapes, reading and analyzing the text, were validated or invalidated in the text (structural analyses) which again provided new ideas, which were discussed with colleagues and connected to the literature, which again were validated or invalidated in the text. Circular, or more accurate spiraling movements continuing until a comprehensive understanding of what the text was speaking about evolved, or in other words until the interview text had become appropriated. A more thorough description of the processes of analyses are provided in Papers I, II and V.

Content analysis

The 3247 written observations of nurses' (III) activities, and 5286 observations of patients' activities (IV), were, together with the observations from an identical work sampling study, carried out at medical, surgical, neurological and psycho-geriatric clinics respectively, submitted to a content analysis (*cf.* Rasmussen *et al.* 1997). The content analysis of the 12 260 observations in total of nurses' activities resulted in a Nursing Activities Classification (NAC), and of the 16 500 observations in total of patients' activities in a Patient Activities Classification (PAC). Both classifications consist of three levels *i.e.* domains, categories and sub-categories. An overview of the NAC and PAC can be seen in Papers III and IV. Content analysis in these papers was used as a research technique for the objective and systematic classification of observations, into mutually exclusive and exhaustive categories to which a numerical value can be assigned for computerization (Berelson 1971). The focus in the analysis was on the manifest, substance content features of the written observational data, *i.e.* the focus on **what** is written (Baxter 1994).

Statistics

The observational data and ratings of patients' nursing needs (III, IV) were entered and analyzed using StatView® and SYSTAT® software packages. The statistics of choice were descriptive statistics, frequency distributions, Kappa statistic, chi-square test, correlation and multiple regression analysis. A p-value of .05 or less was considered statistically significant.

Ethical considerations

The code of ethics from the 'Belmont Report' as described by Polit and Hungler (1999) is: The principle of beneficence (freedom from harm and exploitation, and benefits from research, including the principle of altruism); the principle of respect for human dignity (the right to self-determination, full disclosure and respect); the principle of justice (right to fair treatment and privacy). These principles guided our ethical consideration and will be intertwined in what follows:

Permission to carry out the study was given by the two nurse directors at the hospice and the oncological clinic respectively, the chief physicians at the oncological clinic and unit, the hospice's Quality Assurance Board, and granted from the Ethics Committee at the Medical Faculty, Umeå University (§50/94). Only the nurses and patients who had given their informed consent participated in the study (the right to self-determination). Confidentiality was guaranteed in relation to the interviews, and anonymity in relation to the observational studies (the right to privacy). Nurses and patients participating in the interview and observational studies were informed about the study both verbally and by letter, and were told they could withdraw at any point both before and during the interview and observational studies (the right to self determination and full disclosure).

Both hospitalized and dying patients belong to a vulnerable population (Raudonis 1992, Polit and Hungler 1999), and any research conducted must therefore be mindful of the ethical issues. Because of the emotionally charged nature of dying, and the patient's often fragile physical and emotional state, there seems to be a natural reluctance to burden dying patients with research (Ahmedzai 1990). Some researchers feel that dying people should not participate in research (de Raeve 1994) and have refrained from conducting such studies (Stiles 1994). Others argue that it is paternalistic, devaluing and disrespectful not to provide dying patients with an opportunity to share their experience if they wish to (Mount *et al.* 1995).

In relation to this study it was found that the oncological and hospice patients should have the liberty to make up their own minds as to whether or not they wanted to participate (right to self-determination). We were concerned not to increase the burden or distress of patients (freedom from harm and exploitation). Only patients who the nurses considered had the capacity to endure an interview were approached. By meeting the patients personally and arranging for the interview, the interviewer was able to assess whether the patients had the endurance, and the desire to participate (freedom from harm, right to self-determination). The researchers were sensitive to signs of exhaustion and distress during the interview and observations, and the patients were promised that their participation would not influence the care they received (freedom from harm and exploitation). The patient determined the time, place and duration of the interviews (the right to privacy). In the observational study the observers made an effort to intrude as little as possible on patients' privacy, allowing their professional judgment to guide the observations. The benefits of participating in the interviews and observational studies were judged to be greater than the risks. Research indicates that both patients and nurses may benefit from participating in interviews, in being grateful for and empowered by being given the opportunity to share their experiences (Tishelman 1994, Hutchinson, Wilson and Wilson 1994, Payne *et al.* 1996), and/or being of help to others (Raudonis 1992), *i.e.* the principle of altruism. Nurse researchers may have a nurse-patient (in addition to a researcher-participant) relationship, and it was decided that if a conflict in roles developed during the interview and observational studies the researchers would take on the role of a nurse (advocacy) instead of a researcher (advancing knowledge), *i.e.* evoking the principle of beneficence (Raudonis 1992).

FINDINGS

The findings from the three qualitative studies (I, II, V) illuminate the polarities in the meaning of the experiences of being human which surface when people are confronted with the frailty of life and the inevitability of death and separation as are dying people and nurses in a hospice. Findings from the two quantitative studies (III, IV) provide the structure or frame around which the meanings of polarities surface.

Interviews with 19 nurses, two months after their hospice employment, about their experiences of becoming hospice nurses (**I**), revealed that their professional and personal realms stood out as the two broad domains which distinguished the majority of experienced from the few inexperienced nurses. These domains were expressed in the two themes 'meaningful nursing care' and 'nurses as people', respectively. The experienced nurses came to the hospice because they hoped and expected that they would be able to provide meaningful nursing care for the dying, which they perceived had been impossible in the hospital. Though all nurses emphasized personal qualities over technical skills, the experienced nurses hoped for and expected to be able to use their professional, and the inexperienced nurses their personal proficiency, in caring for the dying person and the family. However, the tension between being able to endure and enjoy being a hospice nurse was an essential feature in all the nurses' narratives, and was interpreted as the nurses being in the very center of forces of existential anxiety, requiring them to fight to maintain an experience of wholeness and meaning in the face of anticipation of death. Thus the hope and expectations of the nurses were, through nursing care, to maintain a focus on living, by *creating* a supportive environment, and good palliative care; by hoping for *togetherness* in the close relationships with guests, families, and colleagues; and by hoping to help the dying person and the family to *reconcile* themselves and *live* as fully as possible. In doing this, the nurses could counterbalance the anxieties of *annihilation, separation, guilt* and *meaninglessness* of life, and thereby experience *meaning* in being a hospice nurse.

Some important phenomena embedded in the nurses' struggle between enduring and enjoying were for example, time, presence, honesty, courage, safety, respect, reciprocity, closeness and giving of self. These phenomena indicate 'being' more than 'doing' and the intertwining between the nurse as a person and as a professional, making it difficult to distinguish between the two. The nurses described their work as treading a fine line, and experienced personal and professional difficulties, when they were not successful in alleviating symptoms and suffering, and living up to their own expectations of 'good' care and a 'peaceful' death. The nurses' personal qualities and security were therefore interpreted as important factors for their ability to endure and to continue caring. Thus the two themes identified 'meaningful nursing care' and 'nurses as people', or the professional and personal realm, are tightly interwoven as are the nurses' hope and expectation in relation to the reality encountered. This interweaving was synthesized into the two themes: 'pursuing meaningful hospice care' and 'pursuing spiritual integrity' in the next study (**II**). The findings from this second round of interviews, 14 months into the hospice experiences of 18 nurses (**II**), showed that in relation to the first theme, the nurses' values of the ideal, *i.e.* 'good' nursing care, 'good' dying, 'good' working environment and the 'good' hospice nurse, were the lens through which they experienced and interpreted their hospice work as either vitalizing or devitalizing. In their daily work, the nurses struggled to pursue the good, harmonious, noble and beautiful in life and in dying, and risked slipping, when they were confronted, particularly when it was unexpected, with the foul, dissonant and meaningless nature of that same life and dying. In narrating these experiences the nurses used metaphors pointing to the 'sacred' and a 'consciousness of fault', *i.e.* evil, understood as the possibility of life taking a wrong direction. The polarity in the situation of hospice nurses, of being there in the realm of the harmonious and the dissonant, the meaningful and meaningless, and the good and evil in life and death, was interpreted as being the source of the nurses’ need to continuously pursue spiritual integrity, *i.e.* a daily struggle to keep energy flowing, to be cleansed and to find/create meaning in the midst of suffering and seemingly meaningless situations.

As in the first study (**I**) the nurses' struggles were still taking place around the phenomena of time, presence, honesty, courage, safety, respect, reciprocity, closeness, enjoyment and giving of self. In this second study (**II**) it became more apparent that meaningful hospice care was based in the sacred aspects of care, *i.e.* in being and communion rather than in profane aspects, *i.e.* doing and caring for a sick and decaying body. Yet, in the quantitative study (**III**) of nurses' work doing or the physical labor, rather than being or the emotional labor, constituted most of nurses' activities. Jumping to the last study (**V**) and meanings of nursing care as experienced by 12 hospice guests, the same polarities between nurses' being and doing were obvious. These guests too, emphasized the nurses' way of being over doing, and the phenomena of time, availability, patience, trust, honesty, safety, respect, joy, reciprocity and kindness. When these guests described nurses' doing it was often intertwined with the way they did things. The quantitative study (**IV**) shows that when they were with nurses, the guests were also helped with a physical aspect of their care, rather than just being together. However, it was not necessarily the same guests who participated in both the interviews and in the observational study.

The notion of doing and being is also one of the major features in the quantitative studies, mentioned above, of nurses' work (**III**) and a patient's day (**IV**) in a hospice and an oncological unit. The 3247 written observations of nurses' activities in the two settings (**III**), showed that hospice nurses spent about one third of a working shift in direct care, *i.e.* face to face with patients and/or relatives compared to the one fifth spent by the oncological nurses. Almost half of the hospice nurses' direct care time was spent helping patients with their basic physical needs, whereas about the same proportion of the oncological nurses' time was spent helping patients with medication, investigations and treatment. Being with patients without performing a physical task, took up a quarter of the nurses' direct care time in the hospice compared to a fifth in the oncological unit. The nurses' involvement in direct care both in the hospice and the oncological unit was found to be structured by institutional routines such as shift exchanges, staff meetings and meals. When not together with patients, nurses at both sites spent their time in indirect care, unit related and personal activities, or by being 'on their way'. It was found, that nurses at both sites, spent a little time on interdisciplinary cooperation but, especially at the hospice, spent a considerable time talking to colleagues about patients.

The 5286 observations of patient activities (**IV**) showed that the 29 oncological patients - including four patients in the terminal stage of their cancer (OH patients) - spent a little less than 3/4 of the day alone, mainly staying in their room, sleeping, resting or watching TV. Most, of the oncological patients (74%) did not have any visitors, whereas three of the four OH patients had. Hospice patients, in contrast, were less alone (about 45% of the day) spending much of their time with their relatives. When alone and with relatives, the hospice patients mainly stayed in their rooms sleeping and resting.

Hospice patients spent about 15% of their day (7am-9.30pm) with the nurses, compared to 10% for the oncological and 12.3 % for the OH patients. Of this time with the nurses, 2% of the hospice and about 1.8 % of the oncological patients' time was spent just being together. In terms of real time as opposed to portion of time, the hospice guests spent longer time with the nurses than the oncological patients. About two third of hospice patients' and nurses' time together was related to patients being helped with their basic physical needs, whereas about half of the oncological patients' and nurses' time together was related to patients being helped with medication, investigations and treatments. The four OH patients' and nurses' encounters had a pattern similar to that in the hospice. The encounters between nurses and patients at the hospice more often lasted longer than at the oncological unit, and relatives were present in 25% of the hospice, 1.6% of the oncological and none of the OH patient and nurse encounters. Being with relatives was the major difference in the day of an 'average' hospice and oncological patient.

The ideal picture of nursing care as being governed by patients' needs was challenged in both of these studies. Entering the variables: nurse-patient ratio, VAS scores for perceived physical and psychological needs, Katz scores, age, sex, and clinic into a multiple regression model, 47% of the variance in the time nurses and patients spent together in the nursing study (**III**), and 35% in the patients study (**IV**) could be explained, mainly by patients' physical needs (**III**) or by Katz scores (**IV**).

The meanings of nursing care as experienced by 12 hospice guests (**V**) were found to be inseparable from the hospice milieu and the guests' existential situation, interpreted as a limit situation entailing the prospect of becoming homeless. Thus the meanings of the hospice spirit (nursing care and milieu) as experienced by these hospice guests were: to be embraced in hospitality and supported in living in the midst of physical, spiritual and emotional suffering, confirming one's experiences being a person in a limit situation, and of being interconnected with others, supporting experiences of wholeness and communion, *i.e.* experiences of becoming at home with oneself, others and the world. Nonetheless, the meanings of the hospice spirit also incorporated, especially for one participant, experiences of being displaced, unsafe and entrapped in silence, paving the way for experiences of being isolated in a limit situation, of being fragmented and alienated, supporting experiences of being homeless, *i.e.* being disconnected from oneself, others and the world. What the guests were talking about was either a consoling hospice spirit making it possible to transcend despair through experiences of communion, or in the experiences of a desolating hospice spirit making the transcendence of despair unattainable.

COMPREHENSIVE UNDERSTANDING AND REFLECTIONS

The comprehensive understanding is based on an interpretation of the findings of the five studies comprising the thesis. The meanings of nursing practice have gradually become discernible, through the dialectic interaction of the comprehension of each individual study, *i.e.* each study shed a new light on the former studies and *vice versa*, thus new insights open up for potential horizons of meanings, which could be actualized in various ways (*cf.* Ricoeur 1976, pp. 71-95). The insights we have today are actualized in the understanding that the tension embedded in caring for and having a decaying and dying body, the intertwining between the environment and oneself as a nurse or a guest and between the nurses' doing and being, are the grounds from which meanings of nursing practice are surfacing and being experienced. In trying to understand and reflect on the findings, it seems most important to invoke Marcel's (1982, pp. 11-37) distinction between problem and mystery. We can and should try to solve problems, but not mysteries. The incarnated body, death, suffering. communion and a hospice 'spirit', one could say, are not problems to be solved, but mysteries to be related to and lived through. They become an antimony as soon as discursive thoughts try to reduce them or problematize them. Mysteries, such as communion, spring out from the sacredness of life (*cf.* Marcel 1973, pp. 104-119). Thus, an attempt has been made to avoid problematizing the findings, but to humbly reflect on possible ways of understanding the meanings of nursing practice in a hospice as disclosed through the interpretation of the text/findings.

The two observational studies (III, IV), provide the arena for nursing practice, and showed that when nurses and guests are together, the nurses are most often doing something, and that this something is much related to the guests' body and physical needs. However, when narrating about nursing practice neither the guests nor the nurses talked much about doing and bodily care, but rather about phenomena such as availability, patience, kindness, honesty and safety which related more closely to being, relations and atmosphere. In the three qualitative studies (I, II, V) there were many 'contrasts' or 'polarities' between the lightness and darkness in living such as: living-dying; creation-annihilation; harmony-disharmony; enjoy-endure; vitalizing-devitalizing; meaningful-meaningless; togetherness-separation; communion-isolation; connected-disconnected; reconciliation-guilt; wholeness-fragmentation; at homeness-homelessness; hope-despair; being-doing; physical-emotional/spiritual care and body-mind. At first these polarities were viewed as paradoxes, but closer examination revealed that they did not qualify as paradoxes since there was neither an existential nor an intellectual contradiction (*cf.* Kemp and Kemp 1998). They are more likely complementary phenomena, *i.e.* they cannot exist without each other - they give meaning to each other. However, the absence of the body and at the same time the complete presence of the body in the studies may at least at first glance present itself as a paradox, if not the very mystery of incarnation.

In the studies of nurses (I, II) the body and bodily care were either absent or interpreted as related to the nurses' devitalizing experience. The nurses' emphasis on and struggle to move towards the light side of the polarities described above, *i.e.* the harmonious, noble and beautiful in life, taken together with the absence of the decaying and dying body, evoked feelings that the nurses were trying to create a heaven on earth, by excluding or de-emphasizing the earthly phenomena of fickleness, bodily decay, suffering and evil. This may however, be a premature interpretation. The findings of the meanings of the guests' experiences (V), may help to throw another light on the understanding of 'heaven'. Dying from cancer, suffering physical decay, pain and multiple losses, mean experiencing the dark side of the polarities described above. Being-in-a-situation of having to die soon, is being confronted with limit situations (*cf.* Jaspers 1994, pp. 96-104) entailing the prospect of becoming homeless. It is the sick and decaying body that is preventing one from living as before, and is forcing one to leave home and move into a hospice to die. Thus the background of a hospice is the darkness in the polarities, and the decaying body is a reminder of the inevitability of death and separation. It is this body that is absent in the stories of nursing practice, *i.e.* the body as an object or object body, not the lived body. Thus it may be possible to understand, at least some of the findings, within the framework of incarnation or embodiment described by Gadow (1980), Marcel (1982), Boughton (1997) and Lawler (1997). These authors serve as inspiration for what follows.

According to Marcel (1982, p. 20) to be incarnated is to appear to oneself as this particular body, without being identified or distinguished from it, (identification and distinction are correlative operations significant only in the realm of objects). The 'lived body' is the most fundamental body-self relation and is the experience of an unbroken immediacy, a wholeness and unity of self and body. The lived body is not the instrument with which I act, it is my acting. The lived body is the immediacy of being-in-the-world, of feeling able to affect one's world and be affected by it. The self-body unity distinguishes itself from the world and this is its principal focus. Though disincarnation is not practically possible, except perhaps in death (*cf.* Kübler-Ross 1997), it is possible to become alienated from one's physical body, as described by the guests. Sickness, disability or being related to and acted upon as a disease object and not as a person, disrupt and separate the immediacy of the lived body into self and body. As a result of disrupted immediacy, the body emerges as an object, and is the experience of being unable to act as one desires or to escape being acted upon in ways that are not desired. In disrupted immediacy, the lived immediacy is shattered by constraint, and as described by the guests (V), the self is now opposed to and controlled by the body and its illness, pain and unpredictability. Body and self are at odds with one another and their relationship is one of a struggle and conflict. The body is now out of harmony with the self or *vice versa*. The existential otherness of the self - is the object body. In disrupted immediacy, self and body are related in the same way as the lived body and the world were related in the lived immediacy, but now it is an internal and not external distinction, the body object is as much a part of the world and its objects as it is a part of the self. According to Gadow (1980) the restoration of the unity between self and object body can take two directions. The first leads to a new dichotomy and the second a new unity. In the first direction, we try to master the body by objectifying it and comprehending it scientifically, *i.e.* relegating it to the abstract world of pure objectness and categories. The body becomes merely a problem to be solved. In the second direction, a new unity is achieved by the self living more smoothly in and through the body (instead of abstracting from it), a possibility that exists only because the self has encountered its own objectness. Through the experience of the object body there thus appears, both the loss of the original unity, and the means of recovering it at a new level. This new level, Gadow (1980) calls 'cultivated immediacy', and it is the restoration of a harmony and the reuniting of self and body achieved by transcending the relationship of a struggle. At the new level, self and body are experienced as distinct (unlike the lived body) but no longer opposed.

Within the above framework, it is possible to understand the text of the guests and the nurses in an expanded way. The findings from our studies (I, II, V) revealed that the guests' and the nurses' narrated experiences of nursing care in the hospice were very similar, and that together they participated in the same 'drama of suffering' (*cf.* Lindholm and Eriksson 1993). What stood out from these three studies was the importance and the balance of the polarity in the experiences of lightness and darkness in living, understood as creation in the midst of annihilation, togetherness in the midst of separation, reconciliation in the midst of guilt and meaningfulness in the midst of meaninglessness all of which were interpreted in the last study (V) as experiences of consolation. The meaning of consolation was interpreted here as a shift of center from me as a suffering person to the in-between, to experiences of belonging, and feeling at home with others and the world, *i.e.* communion, whereas in desolation there was no shift of center, and no experience of communion, the center is me and the darkness, I stay isolated in my despair (*cf.* MacIntyre and Ricoeur 1970, Marcel 1982, pp. 82-103, Söderberg, Gilje and Norberg 1999). Thus communion is being with, sharing feelings, belonging and participating (*cf.* Stern 1985, p. 148, Ekman and Norberg 1993, Häggström, Jansson and Norberg 1999).

With the above understanding of incarnation in mind, the meaning of consolation can be interpreted as a shift of center, from me as a person experiencing a disrupted immediacy and fragmentation, to the in-between, and the experience of a new unity of cultivated immediacy of wholeness and communion. In desolation there is neither a shift of center nor alleviation of a disrupted immediacy, body and self remain alienated from one another, and are problems to be solved, not mysteries to be related to. In the experience of communion, as described by the guests and nurses, there is no disrupted immediacy, nor a guest whose self is controlled by a dying body, nor is there a physical and psychosocial environment, a loved one or a nurse who makes the guest feel like a disease object, there is simply the cultivated immediacy of being-in-the-world. Likewise, there is no dichotomy either between the nurses' doing and being or between the nurse as a professional and as a person, there is simply a human who is a nurse, and who is available as a whole person, body and self. The returning phenomena of availability, patience, closeness, kindness, honesty, safety and joy, are phenomena situated in the lived body immediacy of being-in-the-world, pointing to the transcendence of the subjective realm, to the realm of belonging and the in-between.

Thus it may not at all be a heaven on earth the nurses are trying to create, but rather a healing environment of joy, beauty, togetherness and meaningfulness, in which they themselves and the guests and the families have the possibility of transcending the struggle with disrupted immediacy, at least momentarily. Actually, the root of the word heal, as Quinn (1989) has described, is the Anglo-Saxon word haelan, which means to be or to become whole. When we are alienated from ourselves, others or the world, we are not whole. Wholeness is fundamentally about relationship, relatedness and connection, and healing occurs when relationship is reestablished - relationship to and within oneself and others (Quinn 1989), *i.e.* making whole a divided personality (Duclow 1979). Healing then has a connotation similar to the phenomenon of 'becoming at home' as described by the guests in the last study (V) and by Marcel (1982 pp. 82-103). Thus the pursuit of a meaningful living amidst dying, as interpreted from the narratives of the nurses and guests about nursing practice in a hospice, is the striving for becoming at home with oneself, others and the world, in the midst of suffering and with the knowledge of death and separation lurking just around the corner.

As described by both the nurses and the guests the experience of being 'at- home' in the midst of dying is fleeting, and has to be regained over and over again. The experience seems to be situated in a present rather than in a future oriented perspective (*cf.* Wennolsen 1991). It is the comfort, joy and sharing of the moment that make it possible for both the guests and the nurses to transcend the despair of disrupted immediacy, and the reminder of death in a decaying object body. The moment then becomes of the utmost importance, and is easily disturbed. Firstly, if a guest is experiencing excruciating symptoms of anxiety, pain, nausea and vomiting, or disorientation and a nurse is unable to alleviate the suffering, both the guest and the nurse become situated in a state of disrupted immediacy not easily overcome. This is described by the nurses as a devitalizing experience leading to a struggle to be able to endure being a hospice nurse (I, II). McNamara, Wadell and Colvin (1994) describe similar findings, in terms of how 'bad' dyings drain the resources of the nurses and cause emotional and physical exhaustion. There are hints in the literature, that some hospice nurses may resolve this struggle by being forceful in the application of a pain medication regime (Buckingham *et al.* 1976) or even use sedation to the point where unconsciousness occurs (*cf.* Seale 1989, p. 554), *i.e.* the nurses take action to create the 'good' or 'peaceful' death they all implicitly work towards (*cf.* McNamara, Wadell and Colvin 1994, 1995).

The guests too (V) described the importance for their well-being, of getting help in alleviating symptoms, and being able to rediscover the pleasures of, for example, eating.

Symptom control then remains an essential cornerstone of hospice care and for the possibility of an emerging cultivated immediacy. The guests described the importance of someone being there, understanding and sharing the experience of suffering, even if symptoms can not be alleviated. Thus, one root of general nursing, not only hospice nursing, is the ability of the nurses even when unable to alleviate symptoms to remain present in the midst of profound powerlessness and helplessness (*cf.* Wallace 1995). This may be one reason why both the hospice literature (Davies and Oberle 1990, McWilliam, Burdock and Wamsley 1993, Zerwekh 1993), and the nurses in this study (I, II), emphasize the importance of being experienced in caring for the dying patients and being a whole and mature person. Remaining focused on the guest, rather than on the horrifying symptoms or suffering in itself, is described as being more difficult when one is a young and/or inexperienced nurse (I, II), and may lead to relating to a guest as if he/she is an object to be handled or to avoid having contact with.

Secondly, if, when helping a guest with her/his morning care, the nurses know that three other guests are waiting for their help it is difficult for them to be patient, to respect the guest's personal rhythm and to 'catch the moment' when it occurs. Patience and personal rhythm are central issues in hope as described by Marcel (1965, pp. 35-42), and in a consoling hospice spirit as described by the guests (V). Thus, if the nurses feel impatient and not are fully present, they may substitute their own rhythm for the guest's rhythm, and thereby disturb the delicate state of lived cultivated immediacy for both themselves and the guest. The guest then necessarily becomes an object or a problem that should be helped in a hurry. It was precisely an available, calm, patient and unstressed nurse that the guests valued so highly in the hospice. Further, as revealed by the nurses (II) and the study by McWilliam, Burdock and Wamsley (1993), the measure of meaningful nursing care is what happens **now**, time to care is brief and tomorrow may never come, the guest may have died, leaving no space for the nurses to reconstitute the care from yesterday. This is a heartbreaking experience, leaving the nurses with feelings of insufficiency *i.e.* guilt at having violated something sacred, namely the healing moment. This may be the reason why nurses are so sensitive to an imbalance in their doing and being, as described in the introduction of this thesis and in the nurse studies (I, II). Situations of disrupted immediacy could be interpreted as being the basis for the nurses' needs to constantly pursue spiritual integrity, and situations of cultivated immediacy as being the basis for the nurses' enjoyment, thriving and love of their work (II).

It may be wise to note here, that the author is well aware of the ongoing discourse concerning nursing and the body. In our Western society, the body and its products are in general considered to be unclean, polluting, profane and like death belong to the private sphere of life, making it uncomfortable for people to talk about (Lawler 1997). This means, that caring for the body and its products is the hidden work of nurses, *i.e.* much nursing knowledge and practice has been silenced and rendered relatively invisible because of the privacy and unspeakable aspects of the body (Wolf 1986, 1989, Lawler 1997). Emotions, feelings and the body belong together with the subjective, closeness and lived experience. The intellect, the objective, precise, descriptive and distancing are prioritized in the scientific discourse (Lawler 1997). Thus, we talk about patients and nurses chatting together, implying that everybody can do it (I and the nurse observers in studies III and IV, used the words small talk). I suppose that neither I nor the observers had quite understood how devaluing it is for nursing to label such an important aspect of nurse-patient reciprocal sharing as 'small talk'. This is especially true today when we know that this reciprocal sharing is experienced by both the nurses and guests as helping them to endure or transcend suffering, uncertainty and disrupted immediacy (I, II, V). Interestingly, caring for the body and its products is women's work (James 1989, 1992), and it is those with the lowest level of education and pay, who are closest to the patients' body products (nurses' aids or LPN's). Myself the nurses and guests have grown up in this culture, and it may add to our understanding of why the bodily aspects of care (for example the relieving experience of a good bowel movement) were not mentioned in the interviews with guests and nurses. This is a pity, for as shown in the observational studies, nurses' work in a hospice is to help guests with their bodily needs and daily activities. These essential aspects of nursing care are thus silenced, and with them much of hospice nursing and the understanding that, as nurses, it is through and by the manner in which we provide bodily care, that we have the possibility of reaching a patient's soul and supporting the healing process, *i.e.* transcending disrupted immediacy.

What was a dim understanding of hospice nursing practice in the beginning, had become a fuller awareness by the end of this study, namely the understanding of the importance of an aesthetic physical environment and the congruence between one's outer and inner space, and their relation to the meanings of nursing care as a healing environment. Though nursing practice in a hospice includes interacting nurses, guests and families, it is so much more than that. It is, as described by both the nurses and the guests, an atmosphere - a spirit that includes the view from the windows, closeness to nature, family or colleagues, the color and design of the rooms, the fountain, the lit candle and a spirit of comradeship, hospitality, joy, sorrow, wonderful food and a beautifully set table. It seems that one has to return to the insights of Florence Nightingale (1974) to fully comprehend the meanings of the healing environment and the consoling hospice spirit both the nurses and the guests talk about. For Nightingale (1974, p. 75) the locus of healing is within the person who is healing, and the art of nursing is to provide an environment such that the patient is in the best condition for nature to act upon her or him.

When narrating nursing practice it is difficult to separate out the contribution of individual nurses to the spirit and the presence of family and friends. The guests spend on average 15% of the time from 7am to 9.30pm, with the nurse, and 34% with the family. Some guests may spend up to 30% of this time with nurses, whereas others may spend no time at all, it is the family that provides the care and interacts with the nurses (V). Yet the guests perceive that the nurses are there, totally available whenever they need them. It is an atmosphere of availability, not solely a physical availability, the guests spoke about. The meaning of hospice nursing practice then is likened to being contained by a comfortable armchair. It is difficult to put into words and convey the experience of what it is that makes the armchair comfortable. It is easier to describe, when the armchair is uncomfortable and for example not providing support for the neck or the back, *i.e.* the experience of having been misplaced, of not being in the right place and of being out of touch with loved ones, or insecure when certain nurses are working (V).

The nurses' emphasis on and struggle to create a supportive working environment now makes sense, and is paramount for a healing environment for both themselves and the guests. Being there in a hospice in the midst of suffering and the darkness in the polarities of living, requires a supportive, creative and non-hierarchic working environment, otherwise the nurses cannot be calm, secure, available, unstressed, joyful, caring and focused on the guests' and families' needs and wishes, they are intertwined beings as are the guests (I, II). What the nurses emphasize and work towards is what most guests so much appreciate and experience, namely that in the midst of sorrows and fears one is embraced by a spirit of respect, beauty, dignity, freedom, love and safety making one feel a worthwhile person, one who is not abandoned, but closely interconnected with others and the world. Visiting in such a room with loved ones, makes it possible for one to entrust oneself to the care of others and ultimately to death, that is becoming in hope.

METHODOLOGICAL CONSIDERATIONS

The use of two methodological approaches in the thesis requires that the trustworthiness of the thesis must be considered in relation to the quantitative and qualitative paradigms, *i.e.* whether there is an effort to understand the data behind the findings within the traditional scientific approach of the natural sciences (III, IV) or within the naturalistic approach of phenomenological hermeneutics (I, II, V) (Nerheim 1995, Polit and Hungler 1999).

Quantitative data

Since the aim of studies III and IV was to obtain descriptions of the kind and extent of nurses' and patients' activities in a hospice and oncological unit, a work-sampling study was judged an efficient design. It was believed that experienced nurses, familiar with the language and activities in the two settings, would be the most reliable and would be able to catch, in a snapshot observation, the content of an activity, and be less disturbing to the units' normal operations, than unfamiliar observers. Work-sampling studies do not provide any opportunity for determining the quality of activities, which demands different and more time-consuming observational methods. The latter may be rewarding, by providing a deeper insight into the nurses' work and a patient's day.

Sampling

The sample size was adequate for a more qualitative estimate of activities of nurses and patients at the two sites, *i.e.* the sample makes for 95/100 probability at p=±.5% of the correct amount of time spent in each domain (Mundel and Danner 1994). The two sampling sites were selected on purpose, but not the participants. Here the total population of nurses, working on the observation days, was included in the study (III). Patients were randomly selected (IV), except the four oncological 'hospice' patients, and the patients participating in first observation-period at the hospice, where all admitted patients were included. The fact, that the same patients in the hospice, happened to participate in more than one observation period, most often in a day and a night observation (five patients participated during two day observations) did not disturb the distribution of the sample, which was a normal distribution according to the plot of residuals (Munro 1997, pp. 270-273). The lack of randomized sample sites requires generalization of the findings to be done cautiously.

Validity and reliability of the PAC and NAC

One needs to keep in mind that this study was designed to describe the main activity of nurses and patients as judged by observers familiar with the activities in the two settings. Consequently, neither the PAC nor the NAC catches the complexity of nurse-patient interactions, and may skew the results towards 'doing' by not revealing the integration of the nurses' physical and emotional labor. Another problematic issue is that at times classifying an activity as emotional or physical labor is a matter of interpretation. For example, sitting at a dying patient's bedside and checking if a patient is doing all right, were categorized in this study as 'surveillance-monitoring'. In hindsight, knowing the importance of nurses' surveillance for the guests' emotional well-being (V) some of these observations could have been classified as 'psycho-social, spiritual care'. Nevertheless, the observations have been classified consistently, as shown in the reliability estimates described below, this may also skew the results towards doing, and indicates the difficulties of separating the nurses' physical and emotional labor. However, no interpretation is required to classify an observation at the domain level of the PAC and NAC, and they embrace all data from six quite different nursing practice fields. Thus, there can be no questions about the content validity of the domains of NAC and PAC, but at category and sub-category level, studies in other settings need to be conducted to assess the content validity and generality of the two classifications.

In relation to the pilot studies (see III, IV) the Kappa statistics (Altman 1991) showed a very high level of interobserver (k = .92) and intrarater reliability (k = .95) and interrater agreement (90%), for the NAC, and for the PAC, an interobserver (k = .90) and intrarater reliability (k = .96), and interrater agreement (95%).

Ratings of patient acuity

The patients were classified according to the Katz Index (Kane and Kane 1981) and their perceived psychological and physical nursing needs by the observers together with the nurses caring for the patients. The Katz Index of ADL was chosen, because it is easy to learn and utilize. It has been translated into Swedish, and it is widely used and well established (Kane and Kane 1981, Brorsson and Åsberg 1984, Beck-Friis 1993). Patients' perceived physical and psychological nursing needs were marked as a point on a Visual Analogue Scale (VAS) ranging from minimal to maximal along a 100 mm line. It measures the nurses' experience of patients' nursing needs meaning the nurses' perceptions of the needs, which may not at all coincide with the patients' perceptions of their own needs. However, the scores for the patients' perceived physical nursing needs correlated significantly with the Katz scores ($r = .73$, $p = .001$), in the patient study (IV) and ($r = .78$, $p = .001$) in the nursing study (III). No measures were undertaken to which the patients' perceived psychological needs could be correlated, and these perceptions and scores are thus based in the nursing culture at the two sites, and may not be in accordance with one another.

Qualitative data

Here the aim of studies I, II and V was to gain access to meanings of nurses' and guests' experience of nursing practice in a hospice, and conversational research interviews are thus a viable method (*cf.* Mishler 1986, Kvale 1996). The textual analyses of the interviews were based on a phenomenological hermeneutic approach which is but one approach of many. It was chosen as expert supervision in this method was available, but also because of the success of this approach in illuminating the meanings of experienced phenomena (*cf.* Jansson *et al.* 1993, Nilsson, Jansson, Norberg 1997, Söderberg, Gilje and Norberg 1997, 1999).

Sampling

In the interview studies, all staff at the hospice, *i.e.* nurses, physicians, kitchen and maintenance personnel participated, but only the total population of nurses at the hospice is included in studies I and II. In selecting guests at the hospice, apart from the inclusion criteria described earlier, a purposeful sampling procedure with a maximum variation strategy was employed (Sandelowsky 1995, Polit and Hungler 1999, p. 298). The latter means selecting participants who differ in age, gender and civil status and are at the same time representative of the distribution of guests at the hospice, thereby enhancing the possibility of capturing a varieties of meanings of hospice nursing care.

Research interviews

The discourse of a conversational research interview is a joint construction by the interviewer and interviewee. An interviewee narrates experiences in a way which is coherent with her/his self interpretations, meanings, and intentions, and with what she/he perceives as the intentions and meanings of the interviewer (Mishler 1986, Riessman 1993). Interviews in the present study were conversations, in which meanings of the phenomenon investigated were developed between the interviewer and interviewee, and in which a large measure of freedom was given to the interviewees to express their thoughts, being interrupted only for clarifications. Both interviewers in the present study were nurses, and this has probably influenced both nurses' and guests' narrations, though no analyses to test this have been conducted (*cf.* Tishelman 1994 for further reflections). The use of aspects of the 'critical incidence' technique, *i.e.* asking the guests for example, about episodes of helpful and unhelpful nursing care (V), was as in Tishelman's (1994) study not unproblematic, although rich descriptions of nursing care were given spontaneously during the interview. It was however, very successful in providing rich narratives, in the interview studies with the nurses (I, II). The guests were in a more vulnerable situation than the nurses, thus the asymmetry in power distribution (*cf.* Kvale 1996, p. 126), may be one reason for the difference between guests and nurses in relation to a critical incidence. This aspect needs further clarification. Another aspect which possibly influenced the content of the interviews was the use of a tape-recorder. At times, both in interviews with guests and nurses, the interviewer had to turn the tape recorder off, as was the case in a study by Lev (1991). Thus a few nurses and guests were very conscious of the tape-recorder, and were especially afraid of having negative feelings and statements about people and strong emotions recorded. This is another aspect of interviewing as a research method where we are in need of deeper understanding.

As Greipp (1996) also found recruitment of guests for the interview study proved difficult, mainly because the nurses judged that the guests were not eligible or did not have the endurance to participate. All the guests invited kindly participated. The guests' physical well-being fluctuated, a few times interviews were postponed because a guest was too sick or too tired to go through with it or was engaged with unexpected visitors. When the interviews actually took place, the nurses and guests were very generous in sharing their experiences, and several of them expressed their gratitude for the opportunity to narrate their experiences and courteously invited the interviewers to come back. It seems, as others too have found (Tishelman 1993, Hutchinson *et al.* 1994) that the positive aspects of participating in interviews outweigh the negative. The interviewing was very emotionally and ethically demanding. The guests and nurses were talking about painful events, and often had difficulties finding words to describe their experiences. Thus, meeting with members of the research team after each interview was consoling. Though no analysis has been conducted in order to discover whether these meetings improved the proficiency of the interviewers, they were experienced in this way by the interviewers, in that clarifications of meanings were made more concise during the interviews and a better understanding of the interconnectedness between nursing care and the lifeworld of the participants was gained. All in all, although the interview texts are rich and illuminating and thus of high quality (*cf.* Kvale 1996, p. 145), it would have strengthened this study had more than one interview with each participants been conducted, making is possible to gain a deeper understanding of the phenomenon under investigation, and how and if it changed in time.

Phenomenological hermeneutic interpretation

What distinguishes the analyses in studies I, II and V, is the timing and understanding of the researcher, *i.e.* myself in getting into the hermeneutic spiral, and the use and understanding of the 'forestructure of understanding' (Heidegger 1962, pp. 190-95). In the first study (I), the naive understanding takes on a more descriptive form, and getting into the hermeneutical spiral and understanding of what the text is talking about, are first accomplished in the comprehensive understanding. In the last study (V) the naive interpretation is an interpretation of the text as a whole, and is the starting point for the structural analysis. Thus here, a true dialectic between the parts and the whole of the text, and between what the text is saying semantically and what it is pointing to hermeneutically, is undertaken, *i.e.* getting into the hermeneutical spiral at the beginning and not at the end of the analyses. Likewise with the 'forestructure of understanding', in the first study (I) I tried to lay out (bracketing) preconception and biases, validating the findings with the co-researchers, and staying close to what the text was saying semantically. In the last study (III) the 'forestructure of understanding' was used in a more deliberate way, by bracketing aspects or perspectives of the texts, and not only the more 'illusive' preconceptions and biases, by trying out different alternative interpretations, and by making explicit which perspective was brought to bear on the text. The analyses and use of 'the forestructure of understanding' in the second study (II), are in between studies I and III, and point to the evolving understanding and skill of the researcher, in conducting phenomenological hermeneutic analyses. Another factor that distinguishes the analyses between the three studies, is that in the first two (I, II) I was the interviewer and thus a co-producer of the text, but not in study V, though I knew the guests who participated quite well, from having interviewed their relatives. It is difficult to know whether this made a difference in the process of the analyses. It felt easier, in some ways, conducting the analyses in study V, but then I had more experience in doing this kind of analysis.

To ensure that one is accurately representing the experience from the interviewee's point of view, member checking, *i.e.* taking the interpretation back to the interviewees, is one technique often used by qualitative researchers, to establish validity or increase the credibility of an interpretation (Riessman 1993, Sandelowski 1993). This practice is based on studies which have the utterer's (interviewee's) meaning in focus. The focus of the analyses in the studies (I, II, V) was not on the utterer's meaning, but the utterance meaning, which cannot be validated by the research participants or interviewees. However, by taking the interpretations back to the nurse participants, and by making them public through publication, it can at best provide a deeper and different understanding of nursing practice. This in turn can then hopefully influence the care of both dying people and the nurses caring for the dying. Likewise, no attempt has been made in the studies (I, II, V) to make co-researchers determine whether what I, as the principal analyst, did was right or wrong, or whether we could reach a high degree of interrater reliability on the themes, this being irrelevant in relation to the concept of appropriation (*cf.* Ricoeur 1976, 1982). Rather, what the co-researchers did was to ensure the trustworthiness of the analyses. By reading the interviews and following my thoughts at close range, they helped me avoid gaps, inconsistencies and blinders, to make explicit what I had done and why, and they helped me to open up my mind to possible and alternative interpretations of the findings, guided me to relevant literature, and made sure that my interpretations were grounded in the data, *i.e.* making sure that what I said was a re-saying which reactivates what was said by the text (*cf.* Ricoeur 1982, p. 164).

According to Ricoeur (1976, pp. 71-88) it is always possible to argue for or against an interpretation, to confront interpretations and to mediate between them. He describes validation as an argumentative endeavor, *i.e.* the author enters into and situates the findings, by publishing them, in an ongoing discourse. A study then gains its credibility to the extent that the results of the study come to be viewed as sufficiently trustworthy for other investigators to rely on in their own work (*cf.* Kvale 1996, pp. 244-248). Thus, one does not talk about whether the findings from these studies can be generalized and applied to other settings, but rather if an interpretation conveys such insights and meanings that it becomes possible for the readers to understand their own practice in a new and expanded way, and by that hopefully prepare the road for a change or a confirmation of the existing praxis.

REFLECTION ON THE FINDINGS

The two observational studies (III, IV) showed that a day in the life of a hospice guest is spent mainly by resting and sleeping and/or being with family or friends. A lesser part of the day is spent with the nurses and fellow guests. When with the guests, nurses most often help out with physical needs, *i.e.* they are 'doing' something. The interview studies (I, II) reveal that the hospice nurses focus on the relational aspects of their work, and 'being with' was the quality marker of this work. These two aspects 'doing' and 'being' at first appeared to be in stark contrast to each other. However, the interview study with the guests (V) led to the insights that it is the 'spirit' of the hospice which was healing, and that the nurses' 'doing' is their 'being', *i.e.* embodied nursing care, which in its nature is spiritual nursing care. In this context it seems arbitrary to separate 'doing' from 'being', since it appears to be analogous to Marcel's (1965[a]) statement of the non-representative musical expression that: "It is a sphere where the thing stated cannot be distinguished from the manner of stating it" (p. 64).

Situating the study in relation to the care literature, the hospice nurses in this study share the characteristics of hospice nurses in the USA, *i.e.* most are women, registered nurses, experienced professionals, and above 30 years of age (Mor 1987). The majority of nurses in this study entered the hospice with what can be interpreted as a sense of being 'called to care'. This phenomenon is described by Saunders (1983, 1997), Mount (1997), and is observed among staff in hospices in the USA (Vachon 1995). The phenomenon being 'called to care' is described as both a way of being and a response to the primacy of the person (*cf.* Berman 1994), and is seemingly analogous with the ability to hear the silent cry for help in the depths of a human heart described by Weil (1962, pp. 12-14), and the responsibility of not abandoning the other, a responsibility called forth by the face of the other person described by Levinas (1993, p. 44). The 'call to care' as interpreted from the nurses' narratives, originates from either professional experiences of caring for the dying in hospitals and/or personal experiences with dying and death. Being appalled by and faring ill, both personally and professionally, about the way nurses themselves and others treat the dying and their families in the hospital, spurred them to grasp the possibility to change, when a new hospice was opened in town. They seized the possibility of entering a setting and being co-creators in changing the structure of care for the dying from a problem solving response to reduce fear and pain, *i.e.* doing, to a feeling-staying response, *i.e.* being (*cf.* Hultgren, 1994). Evoking Marcel's (1982) line of thoughts, this is abandoning viewing and relating to the suffering and dying patient as a problem to be solved, and instead restoring and protecting the mystery of human suffering and dying by engaging in communion with the people living through these experiences.

Being 'called to care' means having a voice and entering into a relationship with the dying patient - sharing the joys, fears and darkness and recognizing one's responsibility for her/him. Responsibility is understood as the experience of 'being there' for the other (*cf.* Eriksson 1992 [b], Levinas 1993, Berman 1994). Following a 'call to care' then inevitably leads to encounters of uncertainty and vulnerability (Lasley 1994). By 'being there', *i.e.* making oneself available to the suffering other, one is laying bare one's own vulnerability, or as described by Söderberg, Gilje and Norberg (1999) sacrificing one's own protection to embrace the other's fragility. In sacrificing one's own protection and sharing the agony of the suffering other, one becomes more prone to injury from despair and alienation, *i.e.* to being homeless. However, becoming available for the other is a mode of being that helps us to come into contact with the sacred dimension within ourselves, *i.e.* the experience of being safe, whole and connected in such a way that our doing is integrated into a way of being with others. It is by entering into communion with the other, that one gains oneself, *i.e.* experiences cultivated immediacy - being at-home with oneself (*cf.* Marcel 1965[b], p. 49, Gadow 1980, Neal 1994, Zingmark, Norberg and Sandman 1995, Söderberg, Gilje and Norberg 1999). Becoming available to the dying guests presupposes at-homeness with oneself and indicates the vital connection between myself and what I do, *i.e.* between me as a person and what I do as a nurse (*cf.* Marcel 1982, Söderberg, Gilje and Norberg 1999).

This is one of the main findings of this study, and supports the understanding of the meanings of being a hospice nurse that emerge from other studies (*cf.* Davies and Oberle 1990, Stiles 1990, McWilliam, Burdock and Wamsley 1993, Zerwehk 1993, Byrne and McMurray 1997). The understanding that being a hospice nurse is not merely doing a job, but is rather a way of being in the world, has also been described in the USA (Mor 1987) and Australia (McNamara, Wadell and Colvin 1995). The phenomenon of hospice nursing as a way of being in the world is an interpretation applicable to nurses experienced in terminal care. Whether this phenomenon is embodied by inexperienced nurses, we do not know. At the time of the interviews most of the inexperienced nurses in our study still had to learn to care for people suffering terribly from cancer. Re-interviewing today, the then inexperienced nurses, would help us to understand whether this sense of being in the world had in fact come to permeate their personal and professional lives. Other kinds of studies will have to be conducted to show where and how this phenomenon discloses itself and whether it has to be gained through the experience of caring for dying people.

The hospice guests in both the observational and interview studies shared the characteristics of hospice patients throughout the world as well as in Sweden, *i.e.* the majority were within the 60-79 age group and had some kind of cancer (Andershed and Ternestedt 1997, Wilson and Kastenbaum 1997). In our study there was a large preponderance of women, which is also observed in a few other individual hospices in the world (*cf.* Wilson and Kastenbaum 1997). Although hospice admission, given the situation, may be the best choice, the guests were forced to seek admission, since they had to go to a place where they could get professional care. The guests arrived at the hospice exhausted physically and spiritually and often in despair and deep sorrow about having to die soon. The hospice however, proved to be a sanctuary for most of the guests, a place with a spirit of such welcome and confidence that the guests and their loved ones could begin to feel safe again. This was what Saunders (1983) envisioned as the goal of hospice care.

The discovery of this study is that the meanings of inpatient hospice nursing practice, as interpreted from the guests' narratives, comprise a whole experience of the spirit of the place and not just a nurse-patient relationship. The spirit, encompasses the presence of family and friends, fellow guests, the physical and psychosocial environment and the possibility of close nurse-patient relationships. What was essential for the guests, as is also described by Gates (1991 [a]), was the possibility of staying connected with family and friends and of continuing to participate in life. This was what the 'hospice spirit' (nursing care and milieu) made possible and this is the meaning of nursing care as narrated by the guests. Nursing care has no meaning in and of itself, only in relation to the individual who received it and, as described by Lindholm and Eriksson (1993), Fagerström, Eriksson and Engberg (1998), and Sundin *et al.* (1999) if the nurses do not meet the needs and desires for care as experienced by the patients, the patients may suffer even from the care they receive and experience an intensified suffering related to the illness and life.

As shown in the observational study, guests in the hospice were less alone that patients at the oncological unit. Though we do not know how the oncological patients experienced being alone, Buckingham *et al.* (1976) have described how devastating it is to experience the monotony and loneliness in a surgical ward. In contrast, and as observed by Buckingham *et al.* (1976), Gates (1991[a], 1991 [b]) and by some of the guests in this study, fellow patients and their relatives provide a most powerful kind of support. Just under half the hospice guests in our observational study interacted with fellow guests half a hour at day on the average. Sharing a room with fellow patients allows an interaction not possible in a single room as in the hospice. Fellow patients are reported to be both comforting and distressing for patients (Payne *et al.* 1996, Seale and Kelly 1997 [b]). If the meaning of nursing care is to be found in the spirit of a place, which includes fellow patients this needs further illumination. For one participant in our study in particular the disquieting experience of the death of fellow guests, symbolized by the lit candle, and the lack of fellow guests who were up and around, intensified the experience of being homeless, an experience the nurses could not relieve. As described by Seale and Kelly (1997[b]) a few patients would not accept hospice care because of its association with dying, implying that to feel comfortable in a hospice one has to be open in some way to the prospect that one is dying.

An important part of the healing hospice spirit, as described by both the guests and the nurses, was the physical environment and the proximity to nature. The possibility of viewing trees and green from the sick-room window has been shown to speed recovery from surgery (Ulrich 1984) and the forces of nature are described by patients as a great alleviator of suffering (Lindholm and Eriksson 1993). The architecture and design of a ward conveys the spirit of the place, and either facilitate or hinder intimacy in encounters and thus the quality of connections and relations between patients, nurses and families (Fridell 1998). Thus the physical environment and its relation to the healing process and the meanings of nursing care, for all parties involved, is an area long overdue for research.

Most of a guest's time in the hospice apart from being alone, is spent with family and friends. The guest can stay connected with loved ones and life, both by being provided the physical space, but also by being supported in the healing process, *i.e.* getting help to alleviate symptoms, in a way that made the guest experience her/himself as a unique and indispensable person interconnected with others. Linking the findings of this study to the literature, one phenomenon that appears over and again as distinguishing 'good' from 'indifferent' or 'distressing' nursing care, as seen from the perspectives of both patients and nurses, is that of 'time' (Brown 1986, Rieman 1986, McWilliam, Burdock and Wamsley 1993, Tishelman 1994, Halldòrsdòrttir and Hamrin 1997, Fagerström, Eriksson and Engberg 1998). Time in this context is not understood as the quantity of time the nurse and patient spend together, but as the quality of the time shared. As Eriksson (1992^{b}) describes, time has more to do with the experience of the availability of the other person. What the guests describe is how the nurses embodied way of being conveys an experience of availability, *i.e.* their unstressed way of moving, their gentle touch, their special way of looking at one, the dignity one experiences when they help with personal needs.

As described by van Manen (1998) a bath makes it possible to feel not only the comfort of the nurse's touch but also the comfort and solace of a refreshed body, feeling like a whole embodied being again. He suggests that the healing relation to the nurse consists in the ability to reunite the patient with his/her body or one could say transcend disrupted immediacy. The hospice spirit which can be described as a caring communion (*cf.* Eriksson 1992^{b}) is incarnated in the nurses' doing, it is the way they do what they do, with love and an acute sense of the threshold of pain, suffering and zones of the guest's lived body, that supports the healing process. Thus as seen in the observational studies, hospice nursing care is still about doing, helping guests with basic physical needs but, as the interview study discloses it is not 'doing' in an alienated but an incarnated way. This is related but not equal to the terms task- and relationship-oriented care described in the literature (*cf.* Athlin 1988, pp. 33-39).

The meaning of nursing is thus to be found outside the 'self'. It is the responsibility of 'being there', available body and mind for the other person, submitting oneself to respond to the call from the suffering other and providing a space in time and room for the guests to reveal the wound, *i.e.* to cry, be angry and to share the sorrow and pain. The nurse-patient relationship may thus be experienced as relational subjectivity that is penetrated by the other, *i.e.* entering the sphere of communion, the in-between, by transcending the self and getting in touch with love, joy, beauty and goodness in life, that is coming into contact with the sacred dimension of being, and is consolation (*cf.* Weil 1962, pp. 10-14, Marcel 1963, p. 128, Norberg *et al.* manuscript). Marcel writes in several of his works about the in-between, *i.e*. the sacred dimension of being, such as love (1965[a], pp. 180-182), the creative milieu, in which each finds possibilities of renewal (1967, p. 45), and the co-belonging to the same destiny (1967, p. 46). The meaning of the hospice spirit as interpreted in this study, harmonizes with Marcel (1973, p. 116) when he quotes Massignon (1969) and writes about how we in hospitality find the sacred, *i.e.* in sheltering and in caring for the soul by caring for the body, hospitality attests to the immortal value of the most humble human life. It is when one is suffering the most that one needs consolation (Marcel 1982, pp. 11-37), thus a genuine smile from a nurse, may help one to transcend the suffering and move to the in-between and the experience of communion. A genuine smile of a second may be healing, while a half hour encounter with a nurse who relates to one only as a problem and a job to be done may increase the suffering and despair of disrupted immediacy. Uncaring encounters have been shown to have devastating effects on patients, and Halldòrsdòrttir and Hamrin (1997) raise the question of whether uncaring as an ethical and a professional problem should be treated as malpractice in nursing and health care (*cf.* Kemp and Kemp 1998).

The vulnerability and the intertwining between the nurse as a person and a professional lie at the core of the nurses' struggle between being able to enjoy and endure being a hospice nurse and between vitalizing and devitalizing experiences. In this study, as in the study by McNamara, Waddell and Colvin (1994, 1995), such experiences, are found to be situated in the shared meanings of the nurses about what constitutes good nursing care, good dying, a good working environment and a good hospice nurse. One interpretation, suggested in the literature (McNamara, Waddell and Colvin 1994) is that nurses employ actions to create the 'good' or 'peaceful' dying they all implicitly work towards. This in turn establishes a degree of stability, in the midst of the uncertainty and vulnerability of 'being there' by the side of the suffering patient. However, it also potentially implies rigidity of perception and limitation to spontaneity, *i.e.* if a dying patient's experience and beliefs about good living and dying, differ from what the nurses believe, then it may lead the nurses to force their own meanings and beliefs on patients (*cf.* Seale 1989, McNamara, Waddell and Colvin 1994, 1995). The only means we have of avoiding this, is to create a healing working environment that supports the nurses in sustaining the call, *i.e.* supports the nurses in staying available and open to respond to the call from the suffering other (*cf.* Berman 1994, van Manen 1998, Söderberg, Gilje and Norberg 1999).

The implication for nursing practice, education and administration is the need to ask what kind of environment and what kind of education will help nurses to experience and sustain the 'call to care'. Furthermore, to understand the meaning of nursing care as experienced by patients in different settings, we need to expand our inquires to include not only the study of the nurse-patient relationship, but to understand and combine it with the existential situation of a patient, and the organizational, physical and psychosocial atmosphere of a setting.

At the end of this long voyage for me as a writer and for you as a reader, the conclusion which can be reached is that the accomplishment of this thesis is a rediscovery of ancient human wisdom recontextualized into the setting of our 'postmodern' health care system, *i.e.* Aristotle's (384-322 BC) concepts of *poiesis* and *praxis* (producing and practice) (Aristoteles 1967, *cf.* Asplund 1991, p. 29), and Boethius' (480-524 AD) 'Consolation of Philosophy' (Boethius 1962). There is no better way to bring this thesis to closure, or to illuminate the meaning of a consoling hospice spirit and the experience of becoming at-home in the midst of suffering, *i.e.* to transcend despair and suffering through the experience of communion with others and the world, than through the words of Mia, a former guest at the hospice:

> " ... Yes, there is security in their taking care of me, I know I'm not going to be suffocated here somehow - that sounds a bit silly ... *No I don't think so* ... like, here I'm rescued and

taken into a warm open embrace and they are so friendly and confident - and there isn't any stress or anything and it's as if there is only me in the whole world and they care - they're really so good to me and then I feel really safe - you know, I feel like a little child who climbs onto its mother's lap ... *Then you're not afraid*? ... No the fear disappears - like the security is in the walls themselves - I don't know ..."

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