Caring for Dying and Meeting Death

The Views of Iranian and Swedish Nurses and Student Nurses

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To my family and
all nurses working with dying persons
It is sad that our society hides from the reality of death, the natural law of nature, and in doing so diminishes the opportunity to learn, to share the experience in an atmosphere of unconditional love; the opportunity that, so many times, only emerge as the final bell in life is about to be rung.

Abstract

Nurses play a principal role in the caring for dying persons and their families. Increasing diversity and globalisation demand culturally sensitive and competent health personnel who have scientifically based knowledge about the universal phenomenon of death and dying. A mixed method of research was conducted to describe student nurses' and nurses’ views of caring for dying people in the cultural contexts of Iran and Sweden. In the first part, a quantitative method with two questionnaires (FATCOD and DAP-R) was used to examine the student nurses’ and registered nurses’ attitudes towards death and caring for dying persons in Iran. In the second part, a phenomenological hermeneutic approach was used to illuminate the meaning of nurses’ experiences with the caring for dying persons in the cultural contexts of Iran and Sweden.

According to the results (I, II), student nurses’ and nurses’ attitudes towards caring for dying people were influenced by their attitudes towards death, education, previous experience with death, and previous experience of caring for a dying relative. Iranian nurses were unlikely to talk about death with dying persons and their families. The findings of the qualitative part indicate that professional care for dying people is a lifelong learning process that takes place in a socio-cultural context (III, IV). The Iranian and Swedish registered nurses’ experiences showed similarities that crossed cultures. The existential context for their care was almost identical. The nurses met people and their families at the end of their lives. Being invited to share the understanding of this unique experience raised an ethical demand to care within close relationships. It called for a personal and professional response in all aspects. Swedish nurses preserved patients’ dignity by meeting personal caring needs according to each person’s preferences as well as providing each person with appropriate information. Iranian nurses were also concerned about each person’s dignity, although they were not allowed to inform persons and family members about a person’s real condition. They believed that such information could hasten the patient’s death. Swedish nurses regularly used teamwork. Team reflective practices were important in the support of their professional development. The study revealed that Iranian nurses lacked collaboration between nurses and other professionals, including social workers.

The results suggest that student nurses and nurses should be offered the opportunity to reflect on their experiences, feelings, actions, and reactions to death, as well as caring for dying people and their families. This could be accomplished at work or in professionally guided individual or group sessions. Such supervision could transform their personal experiences into positive and constructive learning. Recognition of the common foundation behind different cultures, religions, and nurses’ own caring behaviours could support the universal phenomenon of care as a human mode of being, in order to be able to provide culturally sensitive and competent and supportive care to patients with various cultural backgrounds. General educational programmes and programmes dealing with end of life care must focus on to the fact that patients’ and family members are unique beings with unique backgrounds and preferences. Specific training programmes should aim at increasing an understanding among professional carers about what shape patients’ world views in order to support their dignity and well-being at the end of life.

Keywords: Attitude towards death, Attitude towards caring for dying people, Caring for dying people, Lived experience, Transcultural study, Iranian registered nurses, Swedish registered nurses, Student nurses.
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Original papers

This dissertation is based on the following papers, which will be referred to in the text by their Roman numerals.


III. Iranmanesh, S., Axelsson, K., Sävenstedt, S., & Häggström, T. (In press) A caring relationship with persons who have cancer. Accepted for publication in *Journal of Advanced Nursing*.

IV. Iranmanesh, S., Häggström, T., Axelsson, K., & Sävenstedt, S. Caring for dying people: Nurses’ experiences in the contexts of private homes and a special unit in hospital settings in Sweden. To be submitted for publication.

Paper not included

Inspired by questions

My choice of a subject for this thesis was influenced by personal experience. I experienced my older sister’s death at 25 years of age, and I’ve cared for dying people. A great number of Iranian people live with chronic and incurable disease like cancer. I also lived near a town named Bam, where a huge number of people died in an earthquake in December 2003. During this event, I witnessed the sudden, unexpected end of many lives. Because of this experience, I understand that it is challenging for the Iranian healthcare system to make progress in the area of death and care for dying people. As a nurse educator, I was involved in both theoretical education and practical training. I often felt frustrated because of my own lack of knowledge and the lack of palliative care education in the Iranian general nursing curriculum. Regardless, nurses who were involved in caring for dying persons had to carry out care at their level best.

In Sweden, palliative care is a well-established part of the curriculum for registered nurse education and practice. Coming to Sweden inspired me to reflect on what I could learn. In doing so, I created two questions: (1) “What attitudes do student nurses and nurses from different subcultures in Iran have towards the death and caring for dying people?” and (2) “What experiences do nurses in Iran and Sweden have when caring for dying people?” These questions motivated me to conduct studies in both Iran and Sweden. Caring for dying persons involves many perspectives. These perspectives include understanding the dying person, family members and the staff providing care. All these perspectives are equally important in a comprehensive understanding of caring for dying persons. My choice to study nurses’ perspectives was based on my background as a registered nurse and as a nurse tutor. I was further inspired by my belief that the education of nurses in palliative care can be further developed within different cultures as well as trans-culturally.
Introduction

Human lives include a steady existential questioning and search for meaning. Death is an inevitable and natural phenomenon. The steady increase in organ transplantation requires physicians to define death and to determine when a patient is considered a dead body. Previously, brain death was considered the death of a brain in a living patient. Today, brain death is considered as the death of the patient (Wackers, 1994). Death causes an existential crisis for many people, especially those who are facing a life-threatening disease. According to Sand and Strang (2006), the inevitability of death triggers an existential crisis that involves patients’ and families’ emotions and perceptions. This leads them to experience existential isolation. A life-threatening disease such as cancer involves patients and their families. Thus, the family members who have a supportive role often become caregivers, exhausting themselves. Even if people today prefer to die at home and to be cared for by their family members, they still need professional services and support (Proot, Abu-Saad, Crebolder, Luker, & Widdershoven, 2003). This need has been approached with palliative care since the 1960s.

Palliative care is a globally progressive subject in healthcare. Palliative care affirms life and regards dying as a normal process. It intends neither to hasten nor postpone death. It offers a support system to help patients live as actively as possible until death. Palliative care uses a team approach to address the needs of patients and their families. It offers a support system to help the family cope during the patient’s illness and in their own bereavement (WHO, 2003). The support and counsel of patients and families are important aspects of palliative care. Therefore, they require nurses and other health professionals to have good interpersonal and caring relationships with both the person who is dying and with her or his family members. Creating a good caring relationship becomes the most important focus of care giving when treatment of a person’s body has reached the limit and a cure is no longer expected (Sabatino, 1999). Several studies (Rasmussen, Sandman, & Norberg, 1997; Rittman, Paige, Rivera, Sutphin, & Godown, 1997; Byrne & McMurray, 1997; Berterö, 1999; Berterö, 2002) reveal the importance of the relationships between nurses and the persons who are dying. The nurses in these relationships should be able to develop trust, provide counselling to patients and families,
relieve pain, assist patients in living their remaining life as meaningfully as possible, facilitate
death acceptance and stay with the dying persons until the end.

The relationships between nurses and dying persons are extremely valuable, as valuable, and
even more valuable, than other clinical interventions (Richardson, 2002; Liu, Mok, & Wong,
2006). The perception of caring for dying persons involves nurses having professional attitudes
and skills in order to provide good care. This includes emotional and practical support (Liu et
al., 2006). According to Keegan et al. (2001) the dying persons’ relatives consider all aspects of
care important towards the end of life. However, they pay special attention to the attitudes with
which care is given and how it preserves the patient’s dignity. Studies exploring the experience
of being a family member of a dying person (Eriksson & Lauri, 2000, Wong & Chan, 2007)
have revealed the family members’ grieve with feelings of sadness and helplessness. They need
active informational and emotional support from nurses.

Palliative care requires nurses to have certain qualities in order to work in such a challenging
environment. Some of these qualities were explored by Wright (2002), Gaydos, (2004),
George, Grypdonck, and De Casterle (2002), and Olthuis, Leget, and Dekkers (2007). They
suggest that the context of palliative care requires effective teamwork, self-confidence,
development of insight into the philosophy of palliative care and a willingness to apply this
confidence. The philosophy of palliative care is to alleviate suffering and to improve the quality
of life of patients who are facing death. Therefore, the values and beliefs of the nurses towards
death and dying should be directed towards that philosophy. Personal motivation, which is a
reflection of a nurse’s attitudes towards giving care to people who are dying (Olthuis et al.,
2007), might be affected by the his or her beliefs and values about death (Holloway, 2006). It
might also be affected by his or her personal and professional experiences related to death and
dying (Dunn, Otten, & Stephens, 2005).

Professional identity is constructed within the work context, and these identities are
continuously constructed and altered (Bleakley, 2006). Related to nursing care, the context of
palliative care with its special activities does influence the formation of nurses’ professional
identity. Palliative care facilitates nurses’ personal and professional development (Mok & Chiu
Being with a patient is a way of relating to dying people. It has the potential to allow nurses to conceive a new way of relating to dying persons and thereby develop their way of caring (Krisman & McCorkle, 2002). This can be described as a transformation (Endo, 2004).

The nurses’ working organisation and social context also influence the formation of their caring identity. This occurs through the acquisition of caring attitudes and the development of caring behaviour (Gastman, 1998). Caring identity is learned in both the institutional and social context. These can be transferred by narratives about people who embody ideal care. The concrete content of care depends on a person’s capacities and on the prevailing cultural traditions in the community from which that person comes. Thus, the understanding of care from a single nurse’s point of view and its content depends on the life story of that nurse (Gastman, 1999). The nurses’ understanding of care as well as his or her attitudes and behaviour become more important in the context of palliative care, where a variety of feelings and experiences are evoked in the face of death. Different views on death are based on the differences in various cultures. The prospect of mortality could be both the foundation on which culture is built (Bauman, 1992) and the primary challenge in the search for meaning (Seale, 1998).

Our world is rapidly becoming a global community. This creates a need for us to further understand the universal phenomena of death and professional caring for dying persons. It is also essential to know more about prevailing views on death and dying. This is most important among future and presently working registered nurses in different cultures. Therefore, a transcultural study has to focus on differences and similarities between people living in different cultures. This must consider human care, based upon the people's cultural values, beliefs, and practices. This knowledge should be used to provide culturally specific or culturally congruent nursing care to people (Leininger, 1991).
Conceptual framework

The four papers in this thesis are based on a conceptual framework of key concepts that are linked together. These concepts present my conceptual framework for investigating the nursing students’ and nurses’ views of caring for dying people in the cultural contexts of Iran and Sweden. The concepts include caring, learning and developing professional identity, attitude, and culture.

Caring

The concept of “care” in this thesis was used both generally and phenomenologically. From a general point of view, caring is seen as the human mode of being (Roach, 1997) and is not related to culture or to gender (Schoenhofer & Boykin, 1993). It does not belong to any specific discipline or society (Roach, 1998). Caring implies alleviating suffering through charity, love, faith, and hope (Eriksson, 2002). This corresponds with Lögstrup’s (1971) view that an ethical, radical and unconditional demand calls for love and care. A person responds to another person’s trust by performing caring actions and protection for another person and his or her life. This occurs whether it is pleasant or unpleasant “the well being of those I meet is in my open hands” (p. 46).

Phenomenologically, caring is defined within a particular context. According to Dunlop (1994), the science of caring is possible if one diverges from the method of natural science to the universal principles that articulate what caring means in a cultural context. Care means that persons, events, projects, and things matter to people (Benner & Wrubel, 1989). Furthermore, live bodies open persons to particular life-worlds and make care necessary and possible (Benner, 2001). Care and cultural traditions of caring are typically provided in private homes, schools, and hospital settings. It must be related to the person’s concerns that shape his or her being-in-the-world (Spichiger, Wallhagen, & Benner, 2005).

The concept of “palliative care” is used in this thesis in correspondence with the World Health Organization’s (WHO, 2003) definition. It is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness. This occurs through the prevention and relief of suffering by means of treatment of physical and spiritual
pain. The final aim of palliative care is to provide a dignified death. The understanding of palliative care in this thesis includes the expressions “caring for dying people” and “caring for people at the end of their lives”. This understanding is almost incorporated into the concept “holistic care”. Holistic care is understood as a response to all the needs of a person, regardless of whether these needs have physical, psychological, social, or spiritual roots (Strang, Strang, & Ternestedt, 2002). Spiritual care is regarded as an essential feature of palliative care.

“Spiritual care” is a required concept in palliative care since dying persons often experience spiritual pain. The loss of their future and the approach of death make it difficult for dying persons to establish the meaning of life and being. These issues force terminally ill persons to experience spiritual pain as a loss of identity and meaninglessness of life (Murata, 2003). To alleviate the spiritual pain, a dying patient must be viewed as a person in a relationship. Spiritual care requires nurses to be with patients and listen to their anxieties. “Being with” is in contrast to “doing to” patients (Krisman & Mccorkle, 2002). It is the appropriate approach to meet the patients’ need to be valued (Mok & Chiu, 2004). It can be assumed to be more important when a person knows that her or his life is about to end soon. Spiritual care is about listening to the patient’s life-review and paying attention to events and persons who are mentioned as being important for each patient (Murata, 2003).

**Learning and developing professional identity**

Care givers develop a range of beliefs and attitudes about the professions for which they are preparing themselves (Mc Kimm, 2008). Thus professional identity is a set of beliefs, attitudes and understanding about the caring role, within the context of work (Lingard, Reznick, DeVito, & Espin, 2002). The formation of professional identity does not occur just during professional training. It can be framed within the context of social identity. Professional caregivers gain their identity as a result of their experience with care throughout their lives. Forming a professional identity is a process whereby individuals acquire and integrate into their lives knowledge, attitudes and values deemed appropriate and acceptable by their chosen profession (Pilhammar Andersson, 1993). Öhlén and Segesten (1998) describe professional identity from the perspective of a nurse as ‘having the feeling of being a person who can practice nursing with skill and responsibility’ (p. 721). Professional identity formation takes place on a
structural level as formal educational and entrance requirements into the profession. It also occurs on an attitudinal level. This includes the individual's sense of “a calling” to the field (Brott & Kajs, 2001). Thus, professional identity is a subjective effort of lifelong learning and identification. Individuals, with their life history and gender, become able to perform an already existing task by acquiring knowledge, developing an attitude and creating their own professional practice (Salling Olesen, 2001).

Learning is a conscious activity guided by intentions and reflections, including reciprocal intention-action-reflection activities (Jonassen & Land, 2000). Storytelling is one way to reflect. Storytelling discovers the meanings of one’s experiences. Life history is both an expression of experience and an interpretation of that experience (Dominice, 2000). It can be a rich source of learning (Knowles, 1980). Franz (2005) believes that communicative learning emerges from working effectively with each other across different perspectives, personalities and worldviews. This type of learning can be transformative. It can change one’s frame of reference or way of seeing the world (Tosey, Matison, & Michelli, 2005). It implies a heightened consciousness and development of thinking processes (Wade, 1998).

Professional learning has two aspects. First, learning for a profession is learning the necessary knowledge and skills for the profession. Second, there is learning that takes place within the profession when facing practical, everyday tasks. The latter has the potential to increase professionals’ individual capacities to behave professionally. It also strengthens their personal insights (Salling Olesen, 2006).

**Attitude**

Attitude is a multifaceted concept with a broad meaning. In this thesis, I used a definition by Eagly and Chaiken (1993, p. 1): “Attitude is a psychological tendency expressed by evaluating a particular entity with some degree of favour or disfavour”. It is in line with Fishbein and Ajzen’s (1975) definition of attitude as the degree of positive or negative affect consistently associated with a person's response to a well defined class of psychological objects. Fazio (1995, p. 214) also claimed that “attitude is essentially an association between a given
object and a given evaluation, which may range in nature from very hot to a cold cognitively, based judgment of the favourability of the attitude object”.

Although death is a common existential matter, people’s attitudes, beliefs and practices related to death are diverse in different societies because they are based on the individual. Attitudes are thus influenced and shaped by the social and cultural context, including religious belief systems (Holloway, 2006). Attitude towards death is a belief system composed of cognitive, affective, and behavioural components that reflect individuals' attitudes related to death, dying, and bereavement (Kastenbaum & Aisenberg, 1972). An attitude towards death, dying, and bereavement represents a personal enduring readiness to respond to these phenomena. It is shaped by a person's view of the world, the person's place in that world and the person’s perceived control of it (Morgan, 2004). Attitudes towards death may vary in different cultural contexts, and the care that nurses provide to terminal or dying patients may be affected by their attitudes toward death (Kemp, 2005).

**Culture**

Culture has been characterised as “the set of distinctive spiritual, material, intellectual and emotional features of a society or a social group that encompasses art, literature, lifestyles, ways of living together, value systems, traditions and beliefs” (UNESCO, 2002). Giger and Davidhizar (2004, p. 3) define culture as a patterned behavioural response that develops over time. It is a result of imprinting the mind through social and religious structures and intellectual and artistic manifestations. Culture significantly contributes to creating the context within which people understand their worlds and live and make decisions about their own significance. Bauman (2000) refers to culture as a continuously and unending structural activity that constitutes the core of human praxis and the human mode of being in the world.

Religion is a part of culture and can be seen as a means to unite people in a shared experience. It provides an explanation of life and a unified way of looking at the world (Davies, 1994). Signifiers such as “religious”, “secular”, or even “God” have dramatically different meanings and connotations in different cultures (Beyer, 2003). They are laden with historical, political, social, and theological implications that are unique to each country and the subcultures therein.
Religion and spirituality are often used interchangeably. Spirituality is the main part of religion and lies at the heart of religion for many people. Wright (1999) suggests that spirituality is the summation of people’s values and determines how people interact with the world. In contrast, religion is seen as a pathway to follow the practices and thoughts that are appropriate to the God or Gods of a particular faith. Moreover, spirituality is about how people construct knowledge through images and symbols. These often emanate from the deepest core of our being and can be accessed and manifested through art, music, or other creative work within the culture (Tisdell, 1999, p. 93).

The concept of trans-culture refers to the beliefs and definitions of universal concepts that transcend cultural boundaries (Brink, 1999). Trans-culture is a form of culture created not in separate spheres but in holistic, diverse cultures. It is based on the principle that a single culture is incomplete and requires interaction and dialogue with other cultures (Milhouse, Asante, & Nwosu, 2001). Based on these notions, trans-cultural perspectives can be understood as a collective and joint experience. These are complex communications capable of transcending cultural boundaries and enriching existing aesthetic and cultural practices (Germaine, 1997).


**Contexts of the studies**

Sweden is a part of European culture, whereas Iran is a part of Middle Eastern culture. The respective cultures in Iran and Sweden differ with regards to the dominating religion and also with regards to how influential the religion is in the everyday life of the people. Many religions are represented in both countries, but the majority of the people in Iran follow Islam, and the majority in Sweden follow Christianity.

Iran is ruled by an authority of theocrats. It is regarded as a religious country, and the majority (99.4%) of the people in Iran consider themselves to be religious. However, there is low attendance (27%) in religious service (European Values Study Group, 2000). Iranian people are perceived as religious, but their world views include a combination of magic, religion, mysticism and theology, as reflected in their poetry and arts (Tabari, 1970). Religious beliefs among Iranian people strongly and explicitly deal with the fact of death (Ghavamzadeh & Bahar, 1997). For a Muslim, death is the transition from the earthly form of existence to the next (Sheikh, 1998). It is just a part of the journey in anticipation of meeting God (Athar, 1999).

Sweden is regarded as a secular country (Hagevi, 2002). Among Swedish people, 46% claim that they believe in a personal God (Norris & Inglehart, 2004, p. 18), and less than 10% attend religious services at least several times a month (Gregory & Baltimore, 2005). For most Christians, Christ was God’s son, who gained power over sin and death with his resurrection. He is believed to unite all the living and the dead and the spirit can be seen as a personal agent of God (Marshall, 1994, pp. 357-361). Spirituality and the matter of life after death are central to Christianity (Walter, 1996). However, many people in Western countries (mainly non-religious ones) believe that religion is a narrow expression of spirituality. Strang et al. (2002) showed that the health care system in Sweden generally tended to have a view of spirituality that treated spirituality as broader than religion.

The results of the study of Iranmanesh, Häggström, Axelsson, and Sävenstedt (In press) indicated that there are differences among Iranian and Swedish nursing students’ religiosity. All the Iranian participants (N= 110) stated that they believed in God and took part in religious
activities every day or sometimes weekly. In contrast, 56.6% (N=113) of their Swedish counterparts claimed that they were Christians. However, only 10% indicated that they took part in religious activities several times a week.

Iran is a country where the nuclear family, based on marriage, prevails. In contrast, Swedes often practice non-family living in young adulthood. Young adults often leave their parental home before entering into a co-residential partnership through cohabitation or marriage (Bernhardt, Goldscheider, Goldscheider, & Bjerén, 2005, p. 15).

Cheraghi, Payne and Salsali (2005) point out that there are no hospice-care units in Iran like those in Western countries. Palliative care, including hospice care, is well established in Sweden. Universities provide special training courses in palliative nursing and support the quality and development of palliative care through teaching and research (Fürst, 2000). The differences in palliative care education in both countries was indicated in a study by Iranmanesh et al. (In press) where Swedish nursing students had about 40 hours education and reflective supervision during their practical education. In contrast, their peers in Iran had two to four hours of theoretical education about death and care for a dead body. They had no special education or training in the care for dying persons, although the topic was included in other courses.

The two countries have different demographic indicators (Table 1). It can be assumed that the average Iranian, compared to the average Swede, is more familiar with death in everyday life as the adult mortality rate in Iran is higher than that of Sweden (WHO, 2004). The people of Iran have experienced major wars and extensive natural disasters, such as the Bam earthquakes (year 2003), which resulted in the death of a huge number of people in the last thirty years. Presumably, there is a difference in the experience of sudden death. Still, the people in Sweden have experienced considerable collective death, such as the Estonia ferry accident (year 1994) and the Asian tsunami (year 1995). There are also some residents of Sweden who have escaped wars and natural disasters in other countries.
Table 1: Health and welfare indicators in Iran and Sweden (WHO, 2004)

<table>
<thead>
<tr>
<th>Country</th>
<th>Total population (millions)</th>
<th>Life expectancy in years for Males/Females</th>
<th>Child mortality rate among Males/Females*</th>
<th>Adult mortality rate among Males/Females**</th>
<th>Total health expenditure as % of GDP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Iran</td>
<td>69</td>
<td>56.1 / 59.1</td>
<td>39 / 36</td>
<td>190 / 118</td>
<td>6.5</td>
</tr>
<tr>
<td>Sweden</td>
<td>9</td>
<td>71.9 / 74.8</td>
<td>4 / 3</td>
<td>82 / 51</td>
<td>9.4</td>
</tr>
</tbody>
</table>

* Under 5 years, (per 1000 population)

** between 15 and 60 years, (per 1000 population)
Rationale

Diversity and globalisation in the world demands culturally sensitive and competent health professionals. The phenomenon of death and dying is universal. How death and dying are experienced by caregivers is an urgent research topic. Internationally and cross-culturally conducted nursing research should be a powerful tool for improving scientifically based clinical nursing practice, education and management. A growing number of researchers have studied the experience of caring for dying people in different contexts. However, a literature review reveals a lack of knowledge about trans-cultural topics. In a review of the literature, only one study, conducted in Greece and Hong Kong, was found on the topic of trans-cultural care for dying persons (Papadatou, Martinson, & Chung, 2001). My questions could not be answered through the scientific reports that I found. There was a lack of international comparative studies concerning attitudes of registered nurses and student nurses towards death and caring for dying people. There were also few studies describing how registered nurses experience caring for dying people and their relatives within different cultural contexts.
**Overall aim**

The overall aim of this thesis was to describe nursing students’ and nurses’ views of caring for dying people in the cultural contexts of Iran and Sweden.

**Specific aims**

In paper **I**, the aim was to compare the attitudes towards death and caring for people who are dying among two different groups of student nurses in the south east of Iran- Bam (BNS) and Kerman (KNS).

In paper **II**, the aim was to examine the attitude towards death and caring for people at the end of life among Iranian nurses (oncology and non-oncology) in the capital of Iran (Tehran).

In paper **III**, the aim was to elucidate the meaning of a caring relationship with people with cancer.

In paper **IV**, the aim was to elucidate the meaning of nurses’ experiences of caring for dying persons at home and in a special unite in a hospital.
Methods

Research design is a framework of how a researcher intends to conduct the research process in order to answer the research question (Brink, 1996). A parallel approach of mixed methods was used in this thesis. A mixed method research includes quantitative and qualitative research methods. The choice of combining qualitative and quantitative studies in this thesis was based on research questions that could not be answered by a single method. The field of mixed methods developed as a pragmatic approach focusing on research questions. It developed in order to utilise the strengths of qualitative and quantitative methods (Creswell & Plano Clark, 2007). Both the qualitative and the quantitative methods were equally valued (cf. Holloway & Wheeler, 1996). There is a philosophical argument against using a mixed-method design. This argument is that the phenomenological philosophy in research is difficult to mix with the philosophy of positivism (Creswell & Plano Clark, 2007). In this thesis, the risks of combining methods were handled by not mixing methods in the individual studies. Furthermore, the data were analysed and presented separately. By using this approach, I found suitable ways of answering the different research questions, providing an opportunity to present a greater diversity of divergent views (cf. Tashakkori & Teddlie, 2003).

A quantitative descriptive method was used in study I and II in order to measure the participants’ attitudes. The statistical analysis focused on the causal relationships between attitudes and a set of variables. Quantitative researchers state that an individual’s attitudes, perceptions and preferences can be quantified by assigning a number to the perceived qualities of these concepts (Babbie & Mouton, 2002). The study utilised surveys to measure and describe the attitude towards death and caring for dying people (cf. Burns & Grove, 2005). A phenomenological hermeneutic approach was used in studies III and IV to illuminate the meaning of caring for dying persons. Its emphasis involved experiences and meanings (cf. Dahlberg & Drew, 1997). The researchers tried to find and present the meaning of phenomena, and they considered the registered nurses’ experience with caring for dying people via transcribed interview texts. In the analysis, the researchers moved between what the text said and what it talked about (cf. Lindseth & Norberg, 2004).
The quantitative design

Quantitative design is based on the assumption of quantification of constructs. It is characterised by the assumption that human behaviour can be explained by what may be termed social facts. These facts can be investigated by methodologies that utilise the deductive logic of the natural sciences (Horna, 1994). Quantitative investigations look for distinguishing characteristics, elemental properties and empirical boundaries and tend to measure how much or how often (Nau, 1995). According to Polit and Beck (2004), a quantitative descriptive design focuses on prevalence, incidence, size and quantification. Burns and Grove (2005) state that a descriptive design may be used for the purpose of developing a theory, identifying problems with current practice, making judgments or determining what others in similar situations are doing. It is critically important for acquiring knowledge in an area in which little research has been done.

The strengths of quantitative methodologies, according to Easterby-Smith (1991), are numerous. They allow comparison and replication, independence of the observer from the subject being observed, and measurement of the subject through objective variables. Furthermore, quantitative methodologies help in the search for causal explanations and fundamental laws. Generally, they reduce the whole to the simplest possible elements in order to facilitate the analysis. The weaknesses of quantitative methods are that the methods do not provide information on the context of the situation where the studied phenomenon occurs, not do they provide the ability to control the environment of the respondents when answering questions in a survey (Matveev, 2002). There are limited outcomes due to closed type questions. Finally, it does not consider the evolving and continuous investigation of a research phenomenon.

The qualitative design

Phenomenology is one way of studying phenomena within a culture. The methodology seeks to focus on a person’s experience. It is based on that person’s previous understanding and knowledge, which are embedded in culture and history. Husserl (1977) described phenomenology as a turn unto the things themselves. It was described as a view of the world
based on experience. He viewed phenomenology as a radically genuine science of ontology and developed phenomenology as a means of describing the human experience as it presents itself to the researcher (Husserl, 1977). Phenomenology was further developed by several followers, including Merleau-Ponty (1996). This study describes phenomenology of the body in accordance with the fact that individuals live in and through their bodies, which are constantly perceived (cf. Merleau-Ponty, 1996). A central principle of Husserlian phenomenology is the notion of intentionality. The life-world, which is a phenomenological concept, is used in phenomenology based on life experience (Dahlberg & Drew, 1997). The life-world is lived and experienced. It appears meaningful to our consciousness and is not an objective world, but a humanly relational world (Todres, 2007). The overall aim of life-world research, according to Dahlberg, Dahlberg, and Nystrom (2008, p. 37), is to describe and elucidate the lived world in a way that expands our understanding of human being and human experience. In this sense, phenomenology and hermeneutics are each other’s prerequisites (Ricoeur, 1976). Hermeneutics is the art and science of interpretation. It occurs through the use of language, which is a shared aspect of understanding (Heidegger, 1962). According to Gadamer (1976), we understand others through interpretation of language, the fundamental mode of operation of our being-in-the-world and the all-embracing form of communication in the world. Thus, the phenomenological-hermeneutic approach is essentially the interpretation of the phenomena as it appears in a text. Phenomenological hermeneutics helps us to develop the critical understanding of a studied discourse. In other words, it helps us to obtain knowledge of the essential meaning of a lived experience (Lindseth & Norberg, 2004). We have to assume that these essential meanings exist when communication refers to a common world. These essential meanings are not ready to be grasped by our thinking. Instead, they must be studied and revealed in the interpretation of the text (Lindseth & Norberg, 2004).

**Setting**

Study I was carried out at nursing faculties in two cities located in southeast Iran, including Kerman and Bam (Table 2). In study II, a sample was selected from two hospitals in Tehran, the capital of Iran. In study III, interviewees were selected among nurses who worked in an oncology unit in the capital of Iran (Tehran). The sample in study IV was selected from
Swedish nurses working in Northern Sweden with dying persons. These nurses worked in a hospital, where there was a ward with a special unit for palliative care, or in a hospice care unit, where registered nurses cared for people in their home.

Table 2: Overview of the participants, data collection and data analysis

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<td>I</td>
<td>Attitudes towards death and caring for dying people in two different groups of nurse students in southeast Iran, Bam and Kerman.</td>
<td>Nursing faculties in southeast Iran (Bam and Kerman)</td>
<td>110 student nurses, of whom 50 were from Bam and 60 were from Kerman.</td>
<td>DAP-R and FATCOD questionnaires</td>
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Participants

Homogeneous and criterion-based samples were used in the four studies and participation was voluntary (cf. Holloway & Wheeler, 2002). The two groups of students in paper I and nurses in paper II were homogeneous in the sense that they lived in the same culture, although their background differed. The student nurses also studied the same subject. The nurses in paper III and IV, and oncology nurses in paper II, were homogenous in the sense that they care for dying people. In paper III, nurses were selected through the chain sampling approach, where key informants recommended one person, who in their turn recommended another (cf. Patton,
2002). In paper IV the head nurses of a hospital ward and a home care team were asked to give an information letter to the nurses, asking them to participate. For both papers (III, IV) the criteria set were that the interviewees should be registered nurses with experience of caring for dying people. In addition, the sample used in the four studies is a part of a population that was conveniently accessible to the researcher.

In study I, the sample consisted of 110 fifth- and sixth-semester student nurses at the faculties of nursing in Bam and Razi (Kerman) (Table 2). Of these students, 50 were born in Bam (the city that was stricken by an earthquake), and 60 were from the city of Kerman. Almost 80% in both groups were females. All of them belonged to the age group of 20 to 29 years of age (mean= 25).

In study II, the sample consisted of 120 registered nurses working in a hospital setting, and 64% were nurses working in oncology settings (Table 2). Among the 120 nurses, 12.2% claimed that they were educated in caring for people who are dying. Nearly 58% had less than two years of experience caring for people at the end of their lives. About 40% had experienced the death of a close relative, 39.4% had experience with caring for a dying member in their family, and 62.3% had experienced a life-threatening situation within last six months. The majority of the participants claimed that they had experienced God’s existence in their daily life and regularly attended religious activities.

In study III, eight registered nurses who were working in oncology units in Tehran, Iran were interviewed (Table 2). The interviewees’ ages were between 25 and 50 years. Four of them were men. All of them were registered nurses with BSc degrees in nursing. Their mean oncology experience was seven years.

In study IV, the four registered nurses working in the hospital setting had between seven and 36 years of nursing experience. The four home-care nurses had between 14 and 37 years of experience. Those who worked in the hospital setting had a mean of about nine years of experience. The home care nurses had a mean of 12 years of experience working with palliative care. The ages of the hospital nurses ranged from 35 to 58 years. The home care nurses’ ages ranged from 37 to 56 years.
Data collection

In the studies I and II the degree to which participants considered themselves as likely or unlikely to care for people at the end of life was measured using Frommelt’s Attitude towards Caring of the Dying (FATCOD) (Frommelt, 1991) (Table 2). This scale consisted of 30 items designed to measure participants’ attitudes towards providing care for dying persons. The questions were graded from 1 to 5 (1= strongly disagree to 5= strongly agree). Fifteen of the items were worded positively, and fifteen were worded negatively.

The extent to which participants favoured or disfavoured statements about death was measured with an instrument called the “Death Attitude Profile Revised” (DAP-R) (Wong, Reker, & Gesser, 1994). This was a multidimensional measurement using a 7-point Likert-type scale. It was composed of 32 questions that described attitudes towards death. The questions were grouped into five components, including fear of death (7 questions), death avoidance (5 questions), neutral acceptance (5 questions), approach acceptance; viewing death as a gate way to the after life (10 questions) and escape acceptance; viewing death as an escape from dreadful life (5 questions). The answers to these questions were graded from 1 to 7 (1= strongly disagree to 7= strongly agree).

In study II, both questionnaires were translated from English into Farsi. A standard forward-backward procedure was applied for translation. Translation of the items and the response categories was independently performed by two professional translators, and then a temporary version was provided. Afterwards they were back translated into English. After a careful cultural adaptation, the final versions were provided. Translated questionnaires were then tested in a pilot-testing procedure. Suggestions by nurses were combined into the final questionnaire.

In the qualitative studies (III, IV) an open-structured interviews were conducted with a narrative methodology (cf. Sandelowski, 1991) (Table 2). The participants were asked to narrate their experience of caring for dying people. Clarifying and encouraging questions were used, such as “Please, explain more about…”? or “Can you give an example”? The interviews in study III were conducted by me in Farsi. In study IV, Swedish language was used by experienced Swedish researchers (T. H., and S. S). During the interviews, the researchers tried
to strike a balance between listening to the stories told by the participants and keeping the focus of the stories on the aim. The interviews lasted between 45 and 65 minutes.

**Analysis**

Data from the questionnaires (I and II) were analysed using the Statistical Package for Social Scientists (SPSS). A Kolmogorov-Smirnov test indicated that the data was sampled from a population with a normal distribution. To examine the relationship among all measured variables (including demographic factors and variables in the DAP-R and FATCOD questionnaires), a descriptive analysis comparing means and correlations was used. Comparisons were considered significant when p < 0.05.

The interviews (papers III, IV) were analysed using the principles of phenomenological hermeneutics, influenced by Ricoeur (1976) (Table 2) and described by Lindseth and Norberg (2004). In order to facilitate the analysis process among the four authors, the text was translated from Farsi and Swedish into English. In paper III, the transcribed text was translated from Farsi into English. Afterwards, meaning units were identified. In paper IV, the procedure was different. Meaning units corresponding to the aim of the study were first identified in the Swedish transcripts. These meaning units were thereafter condensed and translated into English.

The meaning of the translated text was thoroughly checked using several steps. This included going back to the original transcriptions and recordings during the analysis. In the first phase of the analysis, the interviews were read with an open mind in order to gain a naive understanding of the meaning of the subject’s relation with persons who have cancer. Also in this first phase, there was an attempt to identify an approach for further structural analysis. Next, a structural analysis was done. Parts and the whole structure of the text were de-contextualised and systematically analysed to invalidate or validate the naive understanding. Finally, a comprehensive understanding was formulated. This step was a sophisticated mode of understanding. The understanding emanated from and was supported by a critical dialectic between the first two phases (cf. Ricoeur, 1976) of understanding and explanation, as well as between the whole and the parts of the text. (cf. Lindseth & Norberg, 2004).
Ethics

In the quantitative studies (I, II), the researcher orally informed the participants in their own language that their participation was voluntary and about the purpose of the study. The researcher also talked about the procedures. This was conveyed in a written form to each participant. Confidentiality was secured, and no personal information appeared on the questionnaires. In study I, since many of the students had experienced the earthquake in Bam, the participants were offered counselling. This discussion addressed the reason for the study and issues related to caring for dying people.

In the two qualitative studies (III, IV), one ethical consideration was the assurance of confidentiality for the participants. These participants were informed about the purpose of the study and assured that their participation was voluntary. Terminally ill persons and the experiences related to them are an emotionally charged topic and may be a painful reminder of previous experiences. This risk was handled by the researchers’ attentive and sensitive attitude towards the interviewees’ emotional reactions. The researchers also gave the participants sufficient time to consider their participation in the study.
Results from quantitative studies

The results from quantitative studies (I, II) answered the following research question: “What attitudes do nursing students and nurses from different subcultures in Iran have towards death and caring for dying people?” The results were summarised under the heading “attitudes towards caring for dying people”.

Attitudes towards caring for dying people

The results in papers I and II revealed that the nurses’ and student nurses’ attitudes were influenced by their personal characteristics. This included their attitude towards death and their level of education. They were also influenced by their past experience; including previous death experiences and their experience in caring for a dying relative (Figures 1 and 2).

![Diagram](image.png)

Figure 1: Factors influencing student nurses’ and nurses’ attitudes towards caring for dying people

One influential factor in their attitudes towards caring for dying people was the student nurses’ and the nurses’ attitudes towards death. In both papers I and II, the student nurses and nurses reported that they were likely to view death as a gateway to the afterlife. Those who felt this way were more likely to give care to dying persons than those who did not hold this view. There seems to be a contradiction in the results. The fear of death was found to have both a positive and a negative correlation with attitudes towards caring for dying people. In paper I, there was a positive correlation, while in paper II, there was a negative correlation. In paper II, the nurses who viewed death as a natural part of life were more likely to give care to dying people than those who did not share these views. Education was another influential factor that
was related to personal character. The results of paper I indicated that student nurses who were educated about death and dying were more likely to give care to people at the end of life than those who were without any education (Figure 2).

A third factor that was related was past experience. In paper I, previous experience with death decreased the positive feeling about caring for dying people. The student nurses who had more previous experience with death (such as a near-death experience or the death of someone close) stated that they were less likely to give care to dying people compared to those who had less such experiences. In paper II, the experience of caring for a family member who was dying was found to be positively correlated with attitudes towards giving care to the people at the end of life (Figure 2).

Figure 2: Overview of the correlation of some influential factors on the student nurses’ and the nurses’ attitudes towards caring for dying people in paper I (white colour) and paper II (grey colour). A “+” symbol indicates a positive correlation and a “−” indicates a negative correlation.

In paper I, student nurses from the city of Kerman (KSN) were more likely to view death as a gateway to an afterlife than those from Bam (Bam student nurses, BSN). The BSNs were less
fearful of death and had more previous experience with death than the Kerman student nurses (KSN). Both groups were the same age and same level of education. BSN were less likely to give care to dying patients than their counterparts in Kerman.

In paper II, the majority of Iranian nurses were likely to provide care and emotional support to the dying people and their families. However, they did not have a positive attitude toward most aspects of the care for dying people. For instance, they were unlikely to talk with them or even educate them about death. The only demographic factor that positively affected nurses’ attitudes towards caring for dying persons was their previous experience in caring for a dying member of their own family (Figure 2).
Findings of the qualitative studies

The findings of the qualitative studies (III, IV) are presented according to the second question: “How do nurses in Iran and Sweden experience meaning of caring for dying people?” The findings from these papers (III, IV) included: (1) “Sharing space and time to be lost”, (2) “Caring is a learning process” and (3) “Performing care within a cultural context”.

Sharing space and time to be lost

Professional care for people at the end of their lives means sharing time with the people who are dying and their relatives, which all occurs within a limited time. This was a part of the comprehensive understanding presented in paper III, expressed as “a demand to create a close relationship with the patients and their relatives”. In the comprehensive understanding of paper IV, it was expressed as “being invited to the last and private waiting room”. In paper IV, the main theme was to meet patients as unique persons, meaning a demanding, trustful and close relationship. Since the patient and his or her family members were seen as united, the nurses’ relationships included the family. They talked with the family about care at the end of life. The relationship with dying persons and their family members in both groups involved addressing the family members’ personal needs and making efforts to meet their concerns with counselling and support.

Spending time with dying people, listening to their concerns, using touch, and talking with them supported the nurses’ interactions with the persons and even went so far as to have a healing effect (III, IV). Physical care often was combined with emotional care. In paper IV, Swedish nurses listened to the patients and became aware of their wishes. They also comforted the dying persons. Overall, this approach constituted a means to become aware of a person’s needs and preferences when facing death. It also allowed nurses to become aware of what the people perceived through their senses to be tasteful and beautiful. Iranian nurses (III) often used touch in situations characterised by anxiety and physical pain. This was a means of comforting children and young people with cancer.

In both countries (III, IV), meeting the spiritual needs of dying people was seen as an important part of nurses’ daily care. It meant searching for the meaning together with dying
persons and their families. This was the best way to assist them in coping with the difficult situation they faced. Sharing discussion about existential matters, values and beliefs served as a means to alleviate dying persons’ spiritual pains and anxieties. When nurses in both countries became involved in such matters, they attempted to respect the dying persons’ beliefs and faiths even if their own views were different.

**Caring is a learning process**

One meaning of caring for dying people was that caring was considered to be a learning process. In paper III there was a theme, “being close and then becoming compassionate”, and in paper IV there was sub-theme, “learning in a challenging environment”. This theme and the sub-theme deal with caring as a learning process. Nurses in both countries stated that caring for terminally ill persons required them to develop their own personal ways of caring. Both papers showed that participants regarded this as a development, which was integrated within a learning process. Caring as a learning process meant developing consciousness. In paper III, nurses’ learned to be compassionate in a process that took several years. In paper IV, they expanded consciousness through an ongoing learning process, as expressed by meeting each person as a unique being. The learning process of caring was also interpreted as expanding self-consciousness. Paper IV revealed that Swedish nurses became confident and self-reliant with few uncertainties about their ability to care. They learned to keep a balance between being professionals and being close to the people who were dying and their families. Therefore, they were able to handle the anxieties caused by work. Nurses in both Iran and Sweden (papers III, IV) experienced relations with dying persons that made them change the way they looked at their own lives. They discovered that they had changed their views on many things. There was also a feeling of frustration among Iranian (III) nurses that was combined with sadness. This was especially true in situations when they were emotionally touched by a patient.

**Performing care within a cultural context**

According to papers III and IV, nurses in both countries were aware of available resources for optimal caring for terminally ill persons in their cultural context or organisation. Existing
culture, resources and organisation of care could be regarded as supportive. In contrast, lack of these things resulted in frustration among the nurses.

Swedish nurses’ (IV) care for dying people and their family members were based on trust. They focused on honesty and providing clear information about the person’s real condition. This was seen as essential in assisting family members in the face of the death of their loved one. It also helped the dying people face the end of their lives according to their will. In contrast, paper III showed that some Iranian nurses were frustrated because they were not permitted to tell the truth about the diagnosis. There were also some Iranian nurses who felt that dying people were not prepared to hear that they had an incurable disease. In fact, such a disclosure could hasten their death.

Paper III revealed that Iranian nurses’ religious beliefs gave them insight into their care for dying persons. Values and religious beliefs as well as religious practices were used by nurses as a strategy to cope with the stress and difficulties that they faced in their work. Paper IV indicated that Swedish nurses’ personal philosophical foundations assisted them. These beliefs gave them meaning in caring for dying people. Nurses in studies III and IV expressed that their closeness to dying people was supported by their personal experience of having cared for a dying relative. Nurses’ personal experiences of death and caring for a dying relative also assisted them to give meaning to caring for terminally-ill people (papers III, and IV). They described how their own experience of having a dying family member had affected their approach to these patients.

Swedish nurses (IV) expressed that team work and sharing responsibilities within a group was important. This practice supported their professional development. In contrast, Iranian nurses (III) indicated a lack of collaboration between nurses and other professionals such as social workers. It led nurses to experience a heavy workload in the assistance of patients and their families. They found that necessary economic resources were limited and that they had to support some patients personally. According to paper IV, professionally led group discussions in a team setting contributed to the Swedish nurses’ professional development. Such discussions helped them face their problems and develop their professional care individually.
(and as a team). In the context of home care, team reflection occurred in special counselling sessions. This mainly occurred when nurses faced difficult situations. In contrast, hospital nurses felt frustrated because of the lack of such counselling in their work.

Swedish nurses (IV) working in home care and those who worked in hospital settings stated that they had an appreciation for life because of their previous care experience. For the home care nurses, this appreciation meant that they were given fewer tracks or routines. The job required more independence than hospital jobs. The text showed that these nurses found it stimulating to help people who were dying and their relatives, even going so far as to allow patients to remain at home, even when people needed advanced and technical care. In people’s homes, nurses performed their care independently and competently. One nurse said that during home care she was a person while in the hospital she was one of the sisters. In other words, in the hospital she was one entity among a flock of white coats with name tags. The nurses working in the special unit in the hospital appreciated the opportunity to focus on a holistic care approach. They preferred this to their previous experience of being forced to focus on physical care. In the interpretation of the influence of different contexts, the dying person was seen as a guest in the hospital while the nurse was seen as a guest in the home care setting.
Discussion

The overall aim of this study was to describe nursing students’ and nurses’ views of caring for dying people in the cultural contexts of Iran and Sweden. The results of the quantitative studies (I, II) were integrated and presented together. This analysis included nurses’ and student nurses’ attitudes towards caring for dying people. The findings of the qualitative studies (III, IV) were also integrated and presented. Findings from these studies included (1) sharing space and time to be lost, (2) caring is a learning process and (3) performing care within a cultural context. In the discussion below, the results from the quantitative studies I and II will be discussed under the same heading as before. The findings from the qualitative studies (III and IV) will be further integrated under the heading “Performing care in an existential, organisational and cultural context”.

Attitudes towards caring for dying people

One of the main results of the two quantitative papers (I, II) was the correlation between attitudes towards death and caring for dying people. Negative attitudes towards death resulted in more negative attitudes towards caring for dying people. This result was in correspondence with Holloway’s (2006) statement that nurses’ beliefs and values surrounding death can influence their relationship with people who are at the end of their lives. The results in paper II showed that the Iranian nurses’ views of death as a natural part of life were positively correlated with their attitudes towards giving care to dying people (II). This finding was in line with Rooda, Clements and Jordan’s (1999) results showing that caregivers who are comfortable with death are more likely to interact positively with patients. They are also more likely to speak directly and honestly about death and to be emotionally comforting.

Papers I and II also indicated that a religious view of death (death as a gateway to the afterlife) positively affected Iranian student nurses’ and nurses’ attitudes towards caring for dying people. This corresponds with Lundmark’s (2006) results. That study found a positive correlation between religiosity and spiritual care to people who are dying. Schoenrade (1989) suggested that a belief in the afterlife permits an individual to reconcile the positive and
negative aspects of death. By enhancing the perspective of death, such beliefs allow individuals to accept the negative aspects of death (Schoenrade, 1989).

There was a correlation between previous personal experiences with death and attitudes towards death and caring for dying people (I, II). In paper I, Bam student nurses with more experience of death had less fear of death than their Kermanian peers. This result was supported by Franke and Durlak’s (1990) study, which reported that caregivers who had experienced a close family member’s death or a near death experience had less anxiety about death than people who did not have such experiences. In paper II, the Iranian nurses who had experience in caring for the dying were more likely to give care to dying persons than those who did not have such experience. According to Dunn et al. (2005), nurses’ personal motivation to care for dying people is affected by their personal and professional experiences related to death and dying. Therefore, reflective practice together with individual or group supervision may help nurses and student nurses to manage painful experiences that may hinder close contact with dying people. Professionals working with end-of-life care should be offered professional and regular supervision in order to develop their profession (Teasdale, Brocklehurst, & Thom, 2001).

The correlation between fear of death and attitudes towards caring for dying people among participants in papers I and II seems to indicate a contradiction. This contradiction could be explained by the limitation of the scale. Fear of death is a broad and complicated term and includes several items, such as fear of one’s own death, death of others, and the process of dying. These items are related, even if each has a different effect on people’s attitudes. For instance in paper I, Bam student nurses with extensive experience with death due to the huge earthquake were less fearful of death but also less likely to care for a dying person. This is inconsistent with the finding in paper II and with some earlier studies, which found that nurses and student nurses who had less fear of death (Rooda et al, 1999; Wessel and Rutledge, 2005; Iranmanesh et al, In press) were more likely to give care for dying persons. The studies referred to, used the same instruments (FATCOD and DAP-R) and it could be that the instruments are not specific enough to measure the different aspects of fear of death.
The results indicate that the Iranian nurses did not have positive attitudes towards caring for dying people (II). They had no inclination to talk with patients about death or to educate them on the topic. One possible reason could be their lack of education on the topic of death and dying. The results of paper I demonstrate a positive correlation between education concerning death and dying and attitudes towards caring for dying people. Iranmanesh et al. (In press) reported that Swedish student nurses who had been taught about caring for dying persons were more likely to give care to dying people than their Iranian peers. It was concluded that the reason behind this was a lack of palliative care education, and lack of specific training among Iranian student nurses. Kwekkeboom, Vahl, and Eland, (2005) as well as Mallory, (2003) report that nursing education, including courses dealing with death and dying, has a positive effect on nurses’ and student nurses’ attitudes towards death and caring for dying people. The importance of education is further elaborated on by Miyashita et al. (2007), who state that palliative care education affects nurses’ attitudes towards care and helps them develop strategies to alleviate the communication difficulties between nurses and patients.

**Performing care in an existential, organisational and cultural context**

Caring for a dying person is specific in that a dying person’s lifetime is running out. The space that her or his body is occupying will soon be left empty. The nurses’ care was described in paper IV as an invitation to “a private and final waiting room”. The reality of death is present like the air in a room. The alleviation of existential pain requires nurses to be closed and compassionate (III) and view patients as unique people (IV). Facing death or an incurable disease means living with existential pains, feelings of meaninglessness, loneliness, reduced self-respect, and loss of the sense of control (Murata, 2003). Being a professional, caring nurse in the last waiting room is a unique experience. It is different from most of the nursing care in the other wards. Rasmussen (1999) suggests that being a hospice nurse has more to do with being than with doing. It is difficult to distinguish between the nurse as a person and the nurse as a professional.

The existential context demanded nurses to create a close and trusting relationship with dying person and the whole family. These relationships facilitated a sharing of the meaning about human existence with each unique person and her or his family members (III, IV). Sand and
Strang (2006) emphasise that respect, empathy and provisional care with mutual togetherness and belonging may decrease the perception of existential loneliness for dying persons and their families. These authors explain that nurses do not provide physical and psychological perspectives in separate steps. Instead, they provide them together. This was the means of providing care to the dying people that Swedish nurses used (IV). Iranian nurses (III) often used touch in situations characterised by anxiety and physical pain. This was a means of comforting children and young people with cancer. Sand and Strang (2006) recommend an intentionally sensible use of the hands. This use could have the greatest impact on bodily discomfort, especially in severe illness. It may reduce bodily suffering since symptoms affect both the mind and soul (Sand & Strang, 2006).

Nurses’ close relationships with dying people in both Iran and Sweden were ethical, unconditional (III, IV) and compassionate (III). Love and honesty are examples of morality, a common virtue among all nurses in the world (Armstrong, 2006). Care is a part of the core of being human, regardless of the culture or context. It is a response to people’s experience of connectedness (Roach, 1997, p. 16). The existential context of caring for dying people demands that nurses (III, IV) have a holistic view of care, including spiritual care. This corresponds with Piles (1990) and Carroll (2001), who state that there is a connection between spiritual care and holistic philosophy. According to Strang et al., (2002) if personnel have a common care philosophy that presumes humanistic values and respect for patients and their values, the potential for patients to be seen and met as the people they are, will be promoted (p. 56). The nurses in papers III and IV experienced relieving persons’ anxieties and supported them in their search for meaning. Spirituality is a personal search for meaning and purpose in life. It entails the connection to self-chosen and or religious beliefs, values, and practices that give meaning to life. They inspire and motivate individuals to achieve their optimal being (Tanyi, 2002, p. 506). Swedish nurses (IV) expressed spirituality as a search for existential meaning. Iranian nurses (III) interchangeably connected spiritual care and religiosity. Swedish nurses’ (IV) concerns about patients’ spiritual and existential needs were seen as a part of holistic care. This finding reflects the results of Strang et al. (2002) and Lundmark (2006). They conclude that holistic care is desirable in Swedish health care. Furthermore, holistic care includes spiritual needs of patients. However, this has not yet been realised in Swedish health care.
Papers III and IV identified a professional development among nurses that took place in a learning process. This finding corresponds with the findings in the study of Iranmanesh et al. (In press). In this study, both Iranian and Swedish student nurses viewed caring for dying people in a positive way. Furthermore, they viewed it as a worthwhile learning experience. Caring as a learning process among Iranian and Swedish nurses (III, IV) meant developing consciousness. The nurses’ development could be interpreted as part of the mutuality or reciprocity that existed in the caring relationships with dying persons. Maturity and growth are important elements in relationships between patients and nurses during end-of-life care (Berterö, 1999; Mok & Chiu, 2004, Gaydos, 2004). An asymmetry in caring relationships could potentially be unethical if it is not balanced with reciprocity (Fredriksson & Eriksson, 2003). Personal and professional development can be the main strategy that nurses use to cope with the challenging work that they do. Wengström and Ekedahl (2006) claimed that professional development is a coping process that nurses use when caring for persons with cancer.

Nurses in both countries (papers III, IV) viewed caring for dying persons as an opportunity to re-examine their values about life and death. During their work, nurses faced their own mortality which forced them to reflect and to become aware about the importance of enjoying the ongoing life. According to Byrne and McMurray (1997), nurses who work with dying people develop a personal philosophy of death and dying. They also develop a realistic perspective of death and dying. They view it as an inevitable, natural and real phenomenon of life. Nurses’ personal development can be viewed as a prerequisite for professional development. In hospice care, the personal dimension of professional identity is important. Personal identity should be considered a prerequisite for the development of a professional identity (Olthuis et al., 2007).

Most Swedish nurses mentioned their philosophical foundations. These foundations facilitated their caring relationships with dying persons and their family members (IV). Their colleagues in Iran (III) considered religion and religiosity as factors that supported their caring relations with patients and their family members. This reflects the finding of Iranmanesh et al. (In press). This study showed that Iranian student nurses considered themselves more religious and they
tended to view death from a more religious perspective than their Swedish peers. This agrees with Tomás-Sábado and Gómez-Benito’s (2004) statement that what happens after death often is linked to religious issues.

Professional development among Iranian nurses was mainly about developing closeness and compassionate (III). This closeness among Iranian nurses (III) rendered not only satisfaction and enrichment but also frustration. The frustration was due to the tension between their desire to do the best for the patient and their feelings of powerlessness. Often they felt that they were not able to meet all needs sufficiently. This is inline with Blomberg’s and Sahlberg-Blom’s (2007) statement that if nurses handle difficult situations by developing excessively close relationships with patients, these approaches would not be favourable for patients, relatives, or nurses.

In this study it was revealed that Swedish nurses (IV) had high self-esteem and were able to balance closeness and distance. They saw themselves as able to keep a balance between being professionals and being close to the patients and their family members. One possible explanation for Swedish nurses’ self-esteem could be that they worked in teams, not individually. Blomberg and Sahlberg-Blom (2007) explain that team work is complementing, helping and strengthening one another in a support for facilitating closeness and its balance with distance. Wengström and Ekedahl (2006) report the supportive role of teamwork when providing effective care in oncology units. Sengin (2003) reports that the relationships with co-workers and supervisors in team work, as well as collaboration with physicians in decision-making contribute to the nurses’ job satisfaction. In contrast to Swedish nurses (IV), the Iranian nurses worked individually. They lacked support from other healthcare professionals, so they had to manage all of the patient’s needs by themselves, even the patient’s economic problems. There are some possibilities that may have caused the lack of professional or inter-professional team work in the Iranian health care system. Headrick, Wilcock, and Batladen (1998, p. 773) list a number of barriers to inter-professional collaboration such as: differences in schedules and professional routines, varying levels of preparation, qualifications and status, differences in requirements, regulations and norms of professional education, fears of diluted professional
identity, differences in accountability, payment and rewards as well as concerns regarding clinical responsibility.

The practice of reflection in teams was an effective strategy for Swedish nurses to manage difficult situations and to develop their caring identity (IV). In the context of home care, team reflective practices were made in special counselling sessions. These sessions were mainly used when nurses faced difficult situations. This contributed to their professional as well as their personal growth, which is in line with Teasdale, Brocklehurst, & Thom’s (2001) view on clinical supervision. The nurses working in the special unit in the hospital (IV) felt frustrated due to the lack of such counselling, which they used to have. They missed the clinical supervision that could support and stimulate reflection. Ghaye (2005) stated that reflective practices in groups are empowering. Such practices help caregivers make decisions, share views and support ideas. It can also support the creation of a group identity, which strengthens the team. Bleakley (2006) further adds that power processes in team-based work are processes of meaning and identity formation.

The other factors that may contribute to self confidence and professional maturity are age and years of experience. The mean age of participant Swedish nurses (paper IV) was about 10 years more than that of Iranian nurses (III). The Swedish nurses had been working in special palliative care and they had more experience of caring for dying people than their colleagues in Iran. According to Dunn et al., (2005) by gaining psychological maturity and experience novices in the context of palliative care can move along a continuum toward acquiring practical knowledge that is needed to become expert nurses.

Swedish nurses (IV) appreciated their organisational support. Both home care and hospital nurses were satisfied with their work, enjoying it more than their experiences from working in other units. Nurses (IV) working in private homes experienced more autonomy, providing a better foundation for person-to-person relationships and leading to more satisfaction than previous work in regular hospitals. The private home has very significant meaning for most people a concept that is clear in the nurses’ understanding of homes. According to Zingmark, Norberg, and Sandman (1993), home is where one psychologically begins and where one needs
to return, even if only rarely and in memory. These authors state that at home, patients experience being present, being a part of and being related (p. 16). Environmental creations based on the idea of a home bring human values with them. Home care providers view people as valuable human beings throughout the progression of diseases (Zingmark, 2000). Despite being guests, the home care nurses had control over patients’ care. They felt that they had the ability to provide good one-on-one patient care (IV). Nurses’ reported similar experiences when caring for people in private homes (Williamson, 2007). Hospital nurses (IV) described a lack of control over their practice and practice environment. This agrees with results reported by Tullai-McGuiness, Madigan, and Anthony (2005) in their study comparing nurses’ experiences in private homes and hospitals.

The results in paper II showed that Iranian nurses were not likely to talk with patients about death. Furthermore, Iranian nurses in paper III were frustrated with the lack of organisational support and that they were not allowed to tell the truth to the persons and their families. Miyashita et al. (2007) concluded that autonomy has a positive impact on nurses’ attitudes towards caring for dying people. The lack of autonomy among Iranian nurses could be related to public healthcare views on the nurses’ profession. According to Emami and Nasrabadi (2007), the Iranian public views the nursing profession as less than professional. In Sweden, the favourable public opinion could be reflected in the nurses’ high self-esteem, autonomy and job satisfaction (IV). Emami and Nasrabadi (2007) stated that nurses working in Iran described their profession as socially undesirable.

Iranian nurses (III) felt that even if they would be allowed to tell the truth, the cultural context, expressed in kinship relationship, would not be accepted. They found that patients and their families were not prepared to hear about incurable diseases. A disclosure could hasten their death. This finding should be considered in the cultural context prevailing in Iran. The individual is viewed as a part of the family. The society values people’s mutual dependency and harmony within the family rather than the individual’s autonomy (Ghavamzadeh & Bahar, 1997; Omeri, 1997). This view of family ties is different in Sweden where young adults often leave the parental home before entering into a co-residential partnership through cohabitation or marriage (Bernhardt et al., 2005, p. 15). Iranian family ties become more obvious when a
person becomes sick. Professionals in the health care system may hesitate to tell the patients and families grave news. They believe that it could strike the whole family and temporarily paralyse their lives.

**Methodological consideration**

As with any methodological approach to research, there are limitations to the use of a mixed-method design. One risk could be that the findings from two or more different data collection methods will not corroborate (Creswell & Plano Clark, 2007). This risk has been handled by separate quantitative and qualitative methods. The methods were viewed as enriching each other. The choice of method was based on the two different research questions.

Fear of death was found to be both positively and negatively correlated with attitudes towards caring for dying people. There is often a limitation in the specificity of different instruments to a context. The psychological rating scales are influenced by the context and its influential factors can not be removed (Adams, 1998). In order to determine the effects of each parameter, each item should be investigated separately. In addition, the factors assumed to be influential need to be further investigated according to the culture and social circumstances.

The instruments used in studies I and II were developed in an American context, which is different from an Iranian context. Thus, there is a risk of problems with both the validity and reliability of the results. These problems were handled by doing a factor analysis (Rotated Component Matrix) on the results. The loading of the items was similar to the American results. The validity of both scales was assessed through a content-validity discussion. Scholars of nursing care at the College of Nursing, University of Tehran and Kerman have reviewed the content of the scales. They have agreed upon a reasonable representation on the questions in the scales of the universe of religious and cultural aspects of death and dying in Iran. To reassess the reliability of both scales, alpha coefficients of internal consistency and three-week test-retest coefficients of stability were computed. The scales presented an acceptable reliability.
In paper I, the questionnaires were in English, and the students had limitations in their fluency in foreign languages. There was a risk of the students not fully understanding the questions. The participants were encouraged to ask about the content if they did not understand a question. There was a high rate of completed questions in the questionnaires. Ten questionnaires dropped out. This indicates that the participants comprehended the questions.

The qualitative studies were based on narrative interviews that were performed in Farsi and Swedish. In order to involve all members of the research team in the analysis, the interviews were translated into English. Translation is one threat to the accuracy of a cross-cultural, cross-language qualitative approach. Concepts do not always cross cultures and languages (Tsai et al., 2004). A way of compensating for language problems is to involve members of the target language in the analysis process, including data collection, translation and analysis. The analysis should be integral to minimise threats to the accuracy of the cross-cultural qualitative research findings (Tsai et al., 2004). The translation of interviews in this research project was done by the research members. In order to decrease the risk of losing important aspects of the text during analysis, the authors worked as a team and thoroughly analysed the text. The translations and interpretations were checked and discussed in a review of the original text. Though the problem of translation was thoroughly dealt with, it remains a major challenge in the research project and should be viewed as a possible limitation.

Rigor in trans-cultural studies
According to Im, Page, Lin, Tsai, and Cheng (2004), evaluation of the rigor of a cross-cultural nursing study includes an analysis of cultural relevance, contextuality, appropriateness, mutual respect, and flexibility.

Cultural relevance: Death and dying has been described by social scientists as the foundation upon which culture is built. Beliefs as well as practices surrounding death are of key cultural significance in all societies. In both studied cultural contexts, the subject seems to be culturally relevant.

Contextuality and appropriateness: One of the authors of these studies has Iranian background and three have Swedish backgrounds. The interviews were completed in the
informants’ mother tongues to enhance the possibility of sharing through common and familiar verbal expressions. Research should be headed by a researcher who shares the ethnic and linguistic background of the researched (an “insider”). This allows the researcher to make culturally relevant and appropriate decisions (Bhopal, 2001). It is also important to include members of the studied ethnic group who do not share the background of the researched. These people should be a part of the research team in order to assist with developing culturally competent knowledge (Sawyer et al., 1995). In this research project, the Swedish and Iranian researchers functioned as cultural agents to ensure that concepts were understood and properly linked to their cultural context. It was obvious during the analysis that the insider’s knowledge made her or him overlook behaviours or concepts that were culturally unique. It was sometimes easier to recognise and interpret cultural aspects in data by using an unfamiliar cultural context. The phenomenological hermeneutic approach implies an awareness of pre-understanding. This awareness contributes to the data and allows researchers to elucidate phenomenon. The authors were familiar with caring for dying persons and the environment in which care is performed. However, reflections were necessary to determine how this influenced interpretation in the research process.

Mutual respect: The interviewers (III, IV) were aware of the need to establish a trusting relationship. This was accomplished through general questions about the interviewees’ background, working conditions and the context of care.

Flexibility: The interviews were conducted at times and in places that the interviewees had chosen. The questions were open–ended, and the interviewees were not interrupted or corrected in any way. The conversation was seen as a new view of the phenomenon under investigation. This approach allowed for new follow-up questions related to the phenomenon.

The participation in all studies was voluntary. It is reasonable to assume that the registered nurses who volunteered to be interviewed had a positive view of caring for dying people. There may have been registered nurses who had other views. These nurses could have provided other aspects and nuances to the findings. This is a challenge that could be addressed in the future.
Implications for practice

The results in this thesis suggests that education about caring for persons at the end of life should be included in the education of registered nurses as being of utmost importance for the attitudes towards death and care at the end of life. Student nurses and nurses should be offered opportunities to reflect on their experiences, feelings, actions and reactions to death and caring for dying people in their families in order to enhance the possibilities to utilise personal experiences as a part of positive and constructive learning. This requires access to professional supervision for re-interpreting their personal and professional experiences.

The results showed that being with dying people raise an ethical demand that calls for personal and professional response, regardless of sex, culture or context. The physical and organisational context must be supportive and enable nurses to stand up to the demands of close relationships. Specific units and teamwork across various personnel seem to be a solution that is missing in Iran.

Professional caregivers must be sensitive and pay attention to the preferences of each unique person’s perceptions through her or his senses. This includes views, tastes, sounds, smells and bodily contact. The ability of a dying person to see a sunset (IV) may seem petty, but is important in providing good care for people at the end of their lives. The same goes for the other senses. These circumstances deserve attention in all educational programmes and especially in programmes dealing with end of life care. In order to implement holistic care, caregivers must pay attention to patients' spiritual needs.

The results also suggests that in the search for good care at the end of life, it is possible and important to learn from nurses of different cultures, since a single culture is incomplete and requires dialogue with other cultures. This is important for a multicultural society like Sweden, which has a large number of immigrants, including Iranians. Swedish nurses should be aware of other cultures and their nurses’ views. Nurses can provide culturally sensitive and competent care in order to relieve the suffering of patients from other cultures. This enables overall improvement of well-being and health.
Conclusions

Finally, the conclusion is that I have found some answers to my two questions: (1) “What attitudes do student nurses and nurses from different subcultures in Iran have towards the death and caring for dying people?” and (2) “What experiences do nurses in Iran and Sweden have when caring for dying people?” Anyhow, these answers are in no way complete, they rather demand further research.

The student nurses’ and nurses’ from different subcultures in Iran had different attitudes towards death and caring for dying people. The difference seems to be related to their attitudes towards death, level of their education and their past experiences of death and dying. The majority of Iranian nurses were likely to provide emotional support to the dying people and their families, but they were unlikely to talk with them or even educate them about death. Assumingly, proper education and professionally led supervision with reflection on past and recent experiences with death and dying may develop student nurses’ and nurses’ attitudes towards caring for dying persons. It may assist student nurses to achieve a realistic view of the profession.

The Iranian and Swedish nurses shared an experience of the foundation of caring for dying people since it was performed in the existential context of a person’s end of life. This constituted an ethical demand to care in close relationships. The nurses were supported by their own personal and professional experiences as well as their own philosophical foundation, but they also needed support from the socio-cultural and organizational context. Both groups considered holistic care as the appropriate approach. Professional care for dying people was potentially a learning process that developed the nurses’ personal and professional life when supported by teamwork, reflective practice and counselling based on nurses’ personal and professional histories.
پرستاران در امر مراقبت از بیماران و خانواده آنها نقش اصلی را ایفا می‌کنند. امروزه افزایش تعاملات و پیده‌گیری جهانی شدن موضوع از این رو تعداد بیماران و خانواده آنها زیاد شده است. در عرصه مراقبت بهبود وکارکنی باشیم که دارای دانش و آگاهی لازم در خصوص پیدایش هرگونه مرتبط و مردن باشد. از اینجا که مطالعات کمی در زمینه مطالعه این موضوع در کشورها مختلف صورت گرفته است، این مطالعه به منظور توصیف دیدگاه‌های پرستاران و دانشجویان پرستاری در زمینه مراقبت از اشخاص در حال مرگ با روش چندگانه در ایران و سودان انجام شده است. در این مطالعه به‌نام بررسی و نگرش پرستاران و دانشجویان پرستاری ایرانی و سودی در خصوص مرگ و مراقبت از اشخاص در حال مرگ استفاده شد. در قسمت دوم از روش پیدایش شناسی برای توضیح معنا تجربی مراقبت از بیماران مراحل انتها زندگی در زمینه‌های مختلف فرهنگی استفاده شد.

نتایج این بررسی نشان می‌دهد که پرستاران و دانشجویان پرستاری در دو فرهنگ مختلف، هم دارای دیدگاه‌های مشترک و هم دیدگاه‌های متفاوت نسبت به مرگ و مراقبت انتهازندگی می‌باشند. یکی از دیدگاه‌های مشترک این است که مراقبت از بیمار در حال مرگ به صورت فرنگی برای یادگیری تصویر می‌شود که می‌تواند موجب تعلیم هویت فردی و حرکاتی پرستاران بیشتر مواجه به انسان‌ها در پایان زندگی‌هایمان از مراقبت‌ها و فراهم می‌کند که لازمه آن مراقبت معنی‌دار است. ارتباط نزدیکی و همبستگی است. یکی از عواملی که بر دیدگاه پرستاران و دانشجویان پرستاری در زمینه مراقبت انتهازندگی تاثیر زیادی دارد، نگرش آن نسبت به موضوع مرگ و تجارب شخصی آن به‌اش. مشارکت کنندگان در این پژوهش دیدگاه‌های متفاوتی نسبت به مرگ و مراقبت انتهازندگی داشتند که می‌تواند ناشی از تعلق آنها به جوامع مختلف باشد که در آن زندگی کرده‌اند. بعلاوه این اختلاف می‌تواند به دلیل تفاوت زمینه‌ای باشد که مراقبت در آن صورت گرفته است. پرستاران سودای شرط بیمارستان را از طریق توجه به آنها به عنوان انسان‌هایی با نیاز‌های اطلاعاتی خاص حفظ می‌کردنند. این تمامی تفاوت‌ها و این احساس‌های مختلف در حالت پرستاران ایرانی تجربه خودر از این جهت اطلاع مهمی را به بیمار و خانواده و در خصوص تجربیاتی که باین روبرو شده‌انداز می‌کردند، چون همان معتقد بودند این کار باعث سرعت و تسریع پیدا می‌شود. پرستاران و دانشجویان پرستاری ایرانی تماشایی به صحبت با بیماران در حالت مرگ و خانواده آنها در
خصوص موضوع مرجعی نداشتند. پرستاران سوداده تجربه کار گروهی را به عنوان عامل مهم در تعیین هرفا های خود می دانستند در حالیکه پرستاران ایرانی بر فقران چنین همکاری گروهی محسوسی بین خود و سایر حرفا ها از قیل مددکاران اجتماعی اشاره می کردند.

دیدگاه‌های عمومی حاصل از این پژوهش با تازگی است از فلسفه راک (Roach) در مراقبت که این را بر آن داد. در حالی که وجود انسان و صرفه‌جویی از عوامل اجتماعی و فرهنگی و با تازگی از تجربه ارتباط با دیگران می دانند.

نتایج این پژوهش می تواند به استادی پرستاری این دانکه ارزشمند را یادآوری کند که چگونه فرهنگ و تجربه ها در افزایش دیدگاه‌های فردی و نیز زیمنهای که در این مراقبت صورت می‌گیرد می‌تواند بر دیدگاه‌های پرستاران و دانشجویان پرستاری در پرداختن به مراقبت از مراحل انتهای زندگی موثر باشد. این مطالعه توصیه می‌کند که آموزش دانشجویان پرستاری و آموزش‌های مداوم پرستاران باید شامل کارگویی و آموزش‌های عملی به نظارت به افراد و گروه‌ها به عوامل یک راهبرد به منظور ارائه سطح مراقبت از انسانها در مراحل انتهای زندگی، منظور قرار گیرد.

توانایی دوک مبتنی زیرینی تجربه متفاوت مراقبت می تواند متقاضیان مراقبت سلامتی را نسبت به موضوعات متقاوت فرهنگ حساس کرده و صلاحیت مراقبت برای بیماران متعلق به سایر فرهنگ‌ها و در نهایت ارائه مراقبت سلامتی را به همراه اورده. برنامه‌های آموزش‌های عمومی و به ویژه برنامه‌های اختصاصی در زمینه مراقبت انتهای زندگی که در ارتباط با درگذشت‌های بیمار و منطقه با وضعیت اطرافی شده باند، می تواند شان بیمار را حفظ کرده و موجب گذراندن بهتر مرحله انتهای زندگی شود.
ATT VÅRDA DÖENDE OCH MÖTA DÖDEN
Iranska och Svenska sjuksköterskor och sjuksköterskestuderandes perspektiv

Sjuksköterskor har en betydelsefull roll i omvårdnaden av personer som befinner sig i livets slutskede och deras närstående. I de flesta länder ökar mångfalden av personer från olika kulturer med ökande globalisering. Detta ställer krav på att personal inom hälso- och sjukvård är medvetna och lyhörda för olika kulturers likheter och olikheter, samtidigt som det krävs att behandling och vård baseras på vetenskaplig kunskap. Kravet på kunskap omfattar också kunskap om det universella i mötet med döende personer och döden.

I Sverige är palliative vård väl etablerad och ämnet är inkluderat både i den teoretiska och den praktiska utbildningen av legitimerade sjuksköterskor. När jag kom till Sverige från Iran fick detta mig att reflektera över brister inom dessa områden i den Iranska hälso- och sjukvården och dess utbildning av personal. Reflektionerna gjorde att jag formulerade två forskningsfrågor: Vilka attityder har sjuksköterskestuderande och sjuksköterskor från olika subkulter i Iran till död och till omvårdnad av döende? och Vilka erfarenheter har sjuksköterskor i Iran och i Sverige av att vårda personer som är döende?

Det övergripande syftet med avhandlingen var att beskriva sjuksköterskor och sjuksköterskestuderandes syn på omvårdnad av personer som är döende och på död i iranska och svenska kontext. Studierna genomfördes med olika metoder (mixed method). I de två första delarbetena användes två frågeformulär (FATCOD och DAP-R) för att undersöka sjuksköterskor och sjuksköterskestuderandes attityder till död och till omvårdnad av personer som är döende. De två sista delarbetena genomfördes med en fenomenologisk hermeneutisk ansats för att belysa innebörden av sjuksköterskers erfarenheter av att vårda personer som är döende.

I artikel I var syftet att jämföra attityder till död och till omvårdnad av personer som är döende mellan två grupper av sjuksköterskestuderande i sydvästra Iran, från staden Bam och staden Kerman. I studien deltog 110 studenter i termin fem och sex. Av dessa var 50 studenter ifrån staden Bam, där en omfattande jordbävning inträffade 2003. I artikel II, var syftet att undersöka attityder till död och omvårdnad av personer i slutet av livet bland iranska sjuksköterskor som arbetade på
onkologiavdelningar och allmänna vårdavdelningar i Irans huvudstad Teheran. I studien deltog 120 iranska, legitimerade sjuksköterskor. Av dessa arbetade 64 procent på onkologiavdelningar. Resultaten från dessa enkätundersökningar bearbetades med deskriptiv statistik och sambandsanalyser.


Resultaten visar (I, II) att sjuksköterskors och sjuksköterskestuderandes attityder till omvårdnad av personer som är döende var påverkade av informanternas utbildning och tidigare erfarenheter av död och av att ha vårdat en närstående som varit döende. Iranska sjuksköterskor var obenägna att tala om död med personer som var döende och deras närstående.

utveckling. Iranska sjuksköterskor hade inget samarbete sjuksköterskor emellan eller med andra professioner, inklusive socialarbetare.

Utifrån resultaten föreslås att sjuksköterskor och sjuksköterskestudenter bör få möjlighet att reflektera över sina erfarenheter, känslor, handlingar och reaktioner när det gäller död och omvårdnad av personer som är döende och deras närstående. Detta skulle kunna ske under arbetet och i professionellt ledd handledning individuellt eller i grupp. Sådan handledning kan vara konstruktiva inlärmningstillfällen och bidra till att erfarenheter blir positiva. Det tycks finnas en gemensam grund i omvårdnad av personer i slutskede som är kulturöverskridande. Om den grunden erkändes skulle det stödja professionell omvårdnad av personer som är döende över kulturgränser och religionsgränser. Det skulle också hjälpa sjuksköterskor att bli känsliga för olikheter i kulturer och därigenom utveckla kompetens till stödjande omvårdnad av patienter med varierande kulturell bakgrund. Utbildningar inom omvårdnad måste ge allmän grund i att alla är unika personer med olika bakgrund och olika preferenser. Specifika utbildningsinsatser inom palliative vård bör syfta till att öka professionella vårdares förståelse för vad det är som formar olika patienters och närståendes syn på världen och livet, så att de kan bli ännu bättre på att bevara värdigheten hos personer som befinner sig i slutet av sina liv.
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support they gave me during the last months of finalizing my dissertation. I also want to convey my gratitude to all participants in my studies, the nurses and student nurses both in Sweden and Iran who have given all the data as the basis in my thesis. You have taught me so much by kindly sharing your experiences through interviews and filling questionnaires. Thanks for your patience with performing the filling in of the questionnaires and sharing your experience in the interviews.

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Words fail to express my appreciation to my supportive and caring siblings. First in my memory comes my kind and heartedness sister: Monavareh! I know you are resting in peace
and I am sure that you are very proud of my success. My sisters Motahareh and Atahareh, and my brother Mohammad Javad! I would never forget your profound kindness and genuine support since I was a small child. You did the best for your youngest sister. I do wish to be able to compensate just a piece of your kindness. I also sincerely thank all my brothers and sisters in low for their help and assistance.

Finally, where would I be without my parents, Hossein and Shahrbanoo, My mother and father! You made me who I am today. I am sure you are with me, although death prevented you from seeing the completion of my thesis and degree. My mother! You are still motivating me to be strong and preserve stand firm in my personal, professional, and academic life. I wish to live my life as you did: full of happiness, empowerment and trust. Your voice is in my ears forever:”Sedi! Do not worry, stay positive, be strong, put your hand on your heart and just murmur:

والفصر ان الإنسان لفي خسر الا الذين أمنوا وعملو الصالحات وتواصوا بالحق وتواصوا بالصبر.

And I do, and I inspire. Thanks mom and God bless your soul.

I wish everyone health, peace, and happiness

Sedigheh,

Luleå Jan 2009
References


Paper I
Student nurses’ attitudes towards death and dying in south-east Iran

Sedigheh Iranmanesh, Stefan Savenstedt, Abbas Abbaszadeh

Abstract
In this study, the attitudes of student nurses from Kerman and Bam in Iran towards death and caring for dying patients were compared. Two types of questionnaire were used: the DAP-R (Death Attitude Profile Revised) and FATCOD (Frommelt Attitude Towards Caring for Dying patients). The Bam student nurses, who had more experience of death due to the Bam earthquake in December 2003, were found to be less afraid of death and also less likely to give care to people at the end of life compared to their counterparts in Kerman. In both groups, those who were educated about death and dying had more positive attitudes towards caring for people who are dying than non-educated participants. The study suggests that adding palliative care education, accompanied by a reflective narrative approach, to the nursing curriculum is necessary to improve quality of care at the end of life.

Every human being must eventually face the reality of death and dying, but nurses deal with the phenomenon frequently during the daily care of patients. Student nurses are also involved in the care of people at the end of life, and death is a significant and noticeably frequent event in the practice of nursing. Examining one’s attitude towards death and dying needs to begin in the student years, when attitudes towards working with dying patients are formed (Hurtig and Stewin, 1990). There are some studies that support the idea that the attitude towards death is an important factor influencing the behaviour of health care professionals when caring for people at the end of life (Rooda et al, 1999; Wessel and Rutledge, 2005).

Attitudes regarding death can be defined both in positive and negative terms, although the latter has been investigated in the majority of studies. In other words, while a few researchers examined the correlation between positive attitudes towards death and some psychological factors, there are several studies that examined the association between death anxiety and demographic or experiential factors (Neimeyer et al, 2004). For example, considerable literature supports the idea that educational programmes positively change student nurses’ negative attitudes towards death and caring for people at the end of life (Mok et al, 2002; Mallory, 2003; Kwekkeboom et al, 2005). Some related studies identified the impact of nurses’ religious views, such as a belief in a supreme being, or belief in an afterlife, on attitudes towards death and caring for people who are dying (Rooda et al, 2000; Lundmark, 2006). Others reported the impact of gender on attitudes towards death (Russac et al, 2007; Pierce et al, 2007). General anxieties, such as the death of a significant other, or near-death experience, were also found to be influential factors on students’ attitudes towards death (Franke and Durlak, 1990).

All the above factors which represent socio-cultural background, together with the individual characters of nurses, probably shape the different attitudes towards death and dying among student nurses. Hence, this descriptive study aimed to compare the attitudes towards death and caring for people who are dying among two different groups of student nurses in the south east of Iran – Bam (BNS) and Kerman (KNS) – areas where death and dying have not been studied previously.

Context
The samples of student nurses in this study were from Kerman and Bam, two cities of the same province in the south-east of Iran. Kerman is at the centre of the province, with an estimated population of 533,799 (World Health Organization (WHO), 2004). It is believed to have been founded as early as the third century. It is the most developed and largest city of the province and is prone to natural disasters. Significant health indicators for Kerman province are given in Table 1.

The city of Bam is located in a vast plain...
in the south-east of Kerman Province. The city is famous for its ancient architecture and the 2500 year-old Arg-e-Bam citadel. On 26 December 2003, the city of Bam, with a population of around 240,000, was devastated by a 7.7 magnitude earthquake, resulting in the death of >40,000 people, rendering 30,000 injured, and leaving some 75,000 people homeless (WHO, 2004). A total of 18,000 buildings (87% of all buildings), including 131 school buildings, and nearly every health care facility, were destroyed (WHO, 2004).

However, the tragedy of the loss of tens of thousands of people and virtually all of the city’s homes and infrastructure caused intense suffering. In the months and years that ensued, the huge grief associated with the horrible exposure to death was complemented by other disturbed reactions, on both a personal and societal level.

Although the city is starting to come back to life again, people are still dealing with great personal loss. Apart from natural disasters which lead to collective deaths, chronic diseases such as cancer are also a significant cause of death in Kerman. In Iran, 70% of all deaths are caused by chronic disease (WHO, 2002) and compared to other Iranian provinces, Kerman has the highest rate of the incidence cancers such as breast cancer (Fallah, 2007).

Despite this, end-of-life care is still a new concept in Iran, including at Kerman University, where the education for registered nurses is a four-year training programme at Bachelor level. The nursing education curriculum does not include any specific academic subject or clinical training in palliative care, even though the subjects of death and dying are included in other courses. In the whole of Iran, including Kerman Province, there is no specific hospice care like there is in western countries (Cheraghi et al, 2005); however, some hospitals do provide palliative care for people at the end of life.

### Method

#### Design

Approval was granted for the collection of data from the head of the faculties of nursing in Kerman and Bam. The study was carried out based on a descriptive comparative design at Razi (Kerman) and Bam faculties of nursing.

#### Background information

Initially, a questionnaire was designed to obtain background information which was assumed to have an influence on attitudes towards death and dying. It was developed based on the experiences of a pre-test among students and included questions about gender, age, previous education about death and dying, previous experience in dealing with people at the end of life and previous experiences of death, including experiencing the death of someone close and near-death experience.

#### The instruments

To measure student nurses’ attitudes towards caring for people at the end of life, Frommelt’s Attitude towards Caring of the Dying (FATCOD) scale (Frommelt, 1991) was used. This is a 30-item scale designed to measure participants’ attitudes towards providing care to people at the end of life. Fifteen of the items were worded positively and 15 were worded negatively. The questions are graded from 1 to 5 (1=strongly disagree to 5=strongly agree).

The student nurses’ attitude towards death was measured with the Death Attitude Profile Revised (DAP-R) (Wong et al, 1994). This is a multidimensional measurement using a seven-point Likert-type scale. It is composed of 32 questions that describe attitudes towards death. A factor analysis made by Wong et al (1994) on research from an American setting revealed that the questions could be divided into five components, including fear of death (7 items), death avoidance (5 items), neutral acceptance (5

### Table 1. Health indicators of Kerman Province (WHO, 2002)

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Kerman province</th>
<th>National</th>
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<tbody>
<tr>
<td>Population growth rate</td>
<td>2.36</td>
<td>1.23</td>
</tr>
<tr>
<td>Population above 65 years of age (%)</td>
<td>5.3</td>
<td>5.5</td>
</tr>
<tr>
<td>Gross death rate</td>
<td>4.3 (rural)</td>
<td>4.4 (rural)</td>
</tr>
<tr>
<td>Infant mortality rate per 1000 live births</td>
<td>17.9 (rural)</td>
<td>18.1 (rural)</td>
</tr>
<tr>
<td>Under 5 mortality rate per 1000 live births</td>
<td>35.4 (rural)</td>
<td>32.3 (rural)</td>
</tr>
<tr>
<td>Maternal mortality rate per 10000 live births</td>
<td>53 (rural)</td>
<td>35 (rural)</td>
</tr>
<tr>
<td>Prevalence of mental disorders in different forms in population over 15 years of age</td>
<td>23</td>
<td>21</td>
</tr>
<tr>
<td>Literacy rate for persons above 6 years of age (%)</td>
<td>79.9</td>
<td>81.4</td>
</tr>
</tbody>
</table>
items), approach acceptance (10 items) and escape acceptance (5 items). The questions are graded from 1 to 7 (1=strongly disagree to 7=strongly agree).

Reliability and validity
These two scales were originally developed and tested in an American cultural context, which is different from the research contexts, so the validity and reliability of both scales were re-checked. A factor analysis (Rotated Component Matrix) of the results was performed to examine the context validity of the five identified components of the DAP-R scale. The concession of the items was similar to the American results. The validity of both scales has been assessed through a content validity discussion. Scholars of statistics and nursing have reviewed the content of the scales from religious and cultural aspects of death and dying and agreed upon a reasonable content validity. To reassess the reliability of scales, alpha coefficients of internal consistency and three-week test-retest coefficients (n=62) of stability computed. The alpha coefficient for FATCOD was 0.77 and for DAP-R varied from a low of 0.63 in fear of death to a high of 0.87 in approach acceptance. The three-week test-retest coefficients of stability for FATCOD was 0.69 and for DAP-R varied from a low of 0.67 in fear of death to a high of 0.89 in escape acceptance. Both scales presented an acceptable reliability.

Data collection and analysis
During spring 2007, fifth and sixth semester nursing students at the faculties of nursing in Bam and Razi (Kerman) were
invited to participate. Participation was voluntary and they were briefed for the purpose of study and procedure in their own language, both verbally and with written information. To secure confidentiality there was no personal information on the questionnaires.

In both groups, 110 sets of questionnaires were distributed with a drop-out rate of ten. In all collected data, 98% of all questions were answered. Data from the questionnaires were analyzed using the Statistical Package for Social Scientists (SPSS). A Kolmogorov-Smirnov test indicated that the data were sampled from a population with normal distribution. The comparison between two groups in all measured factors was done using a descriptive analysis and an independent T-test. A Pearson correlation was also used to find out the correlation between attitudes towards caring for people at the end of life and all measured factors. Comparisons were considered significant at the p<0.05.

Ethical considerations
Issues related to death are often connected to strong emotions, and the students were offered counselling in connection to the filling in of the questionnaires. This was especially important since many of the students had experiences from the earthquake in Bam. As well as being informed that their participation was voluntary, there were also discussions with the group of students about the aims of the study and issues related to caring for dying people.

Results
Participants
Data from 110 student nurses were gathered; 50 were originally from Bam and 60 were originally from Kerman. A descriptive analysis of the background information revealed that about 80% of both groups were females. All of the participants belonged to the age group of 20 to 29 years of age (mean=25). The students differed in previous death experience and near-death experience. About 97% of the BNS claimed that they had experienced the death of someone close or a near-death experience but only 10% of the KNS indicated that they had such experiences. About 32% of participants in both groups claimed that they did not take a specific course on death and dying but material on the subjects was included in the other courses. Another (68%) stated that no information dealing with death and dying was previously presented to them. None of them had any specific clinical experience of caring for people who are dying.

Attitude towards caring for dying patients
According to the independent T-test analysis, there were both similarities and significant differences between the attitudes of the BNS and the KNS towards caring for people who are dying. The BNS were less likely to take part in caring for people at the end of life than the KNS (Table 2). The results also indicated that in both groups those who are educated about death and dying were more likely to provide care to people at the end of life than those without any education.

Attitude towards death
The results indicated that the BNS tended to have less fear of death than their Kermanian peers. The BNS were more likely to view death as an escape from a dreadful life than the KNS, while the KNS were more likely to view death as a gateway to the afterlife compared to the BNS (Table 2). In sub-scales of natural acceptance and death avoidance there were not any significant differences between the two groups.

Correlation between the scales
In both groups, Pearson correlation (Table 3) indicated that positive attitude towards caring for people at the end of life is positively correlated with fear of death (r=0.185) and approach acceptance (r=0.273). The students who reported that they are more likely to view death as a fearful event and as a gateway to the afterlife had a more positive attitude towards caring for people at the end of life than those with less fear of death and less approach acceptance. The
results also indicated that a positive attitude towards caring for people at the end of life was correlated negatively with escape acceptance ($r=-0.271$) and previous death experience ($r=-0.178$). This suggests that the students who had more previous death experience stated that they are more likely to view death as an escape from a dreadful life had less positive attitudes towards caring for people who are dying than those with less escape acceptance and less previous death experience.

**Discussion**

This study revealed that attitudes towards death and caring for people at the end of life are different among the Kerman and Bam nurse students, even if they are in the same province with similar cultures. They were different in positive attitudes towards death as well as in negative attitudes towards death. The results indicated that attitudes towards death among both groups of participants influenced how well they related to the people at the end of life. This result is correspondent with the findings of previous studies (Rooda et al, 1999; Wessel and Rutledge, 2005), which reported a significant correlation between attitudes towards death and attitudes towards caring for people who are dying.

The BNS were less afraid of death and they were more likely to view death as an escape from a dreadful life than their Kermanian peers. This could be explained by the fact that great exposure to death among the BNS made death more of a reality but at the same time as an attractive alternative to the life conditions that are felt to be unbearable (Neimeyer et al, 2004). According to the earlier study, the caregivers who had experienced a close family member’s death and near-death experience had less death anxiety than those who had not had such experiences (Franke and Durlak, 1990).

Despite having less fear of death and more death experiences compared to the KNS, the BNS were less likely to take part in caring for people at the end of life. This is inconsistent with earlier studies, which found that nurses and student nurses who had less fear of death (Rooda et al, 1999; Wessels and Rutledge, 2005) and more death-related experiences (Brent et al, 1991) were less averse to caring for people at the end of life. This could be explained by the fact that some people are not anxious about death but they are fearful of how they are going to die or of the process of dying.

According to Richardson (2002), the dying process is often a highly emotional area and the stress of watching someone die sometimes leaves them afraid of a similar type of death. Their reaction could be avoided by being with people who are dying. On the other hand, it is also possible that the KNS with a greater fear of death compared to the BNS tend to handle or compensate for their fear by having contact with people at the end of life and taking part in caring for them. The KNS in spite of having more fear of death were more likely to view death as a gateway to the afterlife compared to the BNS.

According to Schoenrade (1989), a belief in an afterlife permits an individual to reconcile the positive and negative aspects of death. So, while enhancing a positive death perspective, such a belief also allows the individual to accept the negative aspects of death (Schoenrade, 1989). This higher approach acceptance among KNS could also be another reason for their tendencies to give care to the people at the end of life compared to their counterparts in Bam. This can be supported by a previous study, which found a positive correlation between approach acceptance and positive attitude towards giving care to dying patients (Rooda et al, 1999). It seems that values and beliefs about death, together with previous experiences of death, contributed to the different attitude towards care of the people who are dying among two groups of participants.

In both groups ones who were educated about death and dying were more likely to give care to the dying than non-educated participants. This finding is consistent with previous studies (Mok et al, 2002; Mallory, 2003; Kwekkeboom et al, 2005). In those studies they concluded that within an educational, experiential programme and through sharing personal and work-related experiences, perceptions of student nurses towards death and caring for people at the end of life became more positive.

**Limitations**

This article has focused solely on the psychological aspects of attitudes towards death, while the attitude is a very complex term with broad meanings (Olthuis and Dekkers, 2005). Furthermore, all data in this study were collected by use of self-report questionnaires. The dependence on self-
report aspects in this study may have led to an overestimation of some of the findings due to variance, which is common in different methods. The study is based on a sample of all nursing students in the fifth and sixth semesters at the faculties of nursing in Bam and Razi (Kerman). There are limitations in generalizing the results from this sample to the situation of other nurse students. On the other hand the sample size is large and it likely that the results reflect attitudes among other students with similar educational experiences and experiences of collective death. The questionnaires were in English and the students had limitations in their fluency in foreign languages. There was a high rate of completed questions in the questionnaires and only ten drop outs, which indicate that the participants comprehended the questions well. The participants were also encouraged to ask about the content if they didn’t understand a question. It is still clear that the comprehension of the questions can be viewed as a confounding variable, which may have contributed to the results.

Conclusion

This study suggests that courses about death and palliative care education are essential and should be added to the nursing curriculum. According to the findings and bearing in mind the psychological definition of attitude which is ‘a learned tendency’ (Fishbein and Ajzen, 1975), the educational programme needs somehow to relate to the characteristics of the students. These characteristics may contribute to constructing the student nurses’ attitudes towards death and also to the quality of their interaction with people at the end of life. As such, incorporation of narrative reflection into palliative care education (Wessels and Garon, 2005) could be an effective teaching approach which will improve the student nurses’ awareness of their attitudes towards death and care of people who are dying. Of course, further study is needed to clarify all of these issues.

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Fishbein M, Ajzen I (1975) Belief, Attitude, Intention and Behavior: an Introduction to Theory and Research. Addison-Wesley, Massachusetts
Paper II
Attitudes of Iranian nurses toward caring for dying patients

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2Valiasr Hospital, Tehran University of Medical Science, Tehran, Iran
3Faculty of Nursing and Midwifery, Kerman University of Medical Sciences, Kerman, Iran
(RECEIVED November 15, 2007; ACCEPTED December 2, 2007)

ABSTRACT

Objective: To examine the attitudes of Iranian nurses toward caring for dying patients.

Methods: Nurses’ attitudes toward death and caring for dying patients were examined by using two types of questionnaires: the Death Attitude Profile–Revised (DAP-R) and Frommelt’s Attitude towards Caring for Dying Patients (FATCOD), both with a demographic survey.

Results: The results showed that most respondents are likely to view death as a natural part of life and also as a gateway to the afterlife. The majority reported that they are likely to provide care and emotional support for the people who are dying and their families, but they were unlikely to talk with them or even educate them about death. They had a tendency not to accept patients and their families as the authoritative decision makers or involve families in patient care. Nurses’ personal views on death, as well as personal experiences, affected their attitudes toward care of the dying.

Significance of results: Lack of education and experience, as well as cultural and professional limitations, may have contributed to the negative attitude toward some aspects of the care for people who are dying among the nurses surveyed. Creating a reflective narrative environment in which nurses can express their own feelings about death and dying seems to be a potentially effective approach to identify the factors influencing their interaction with the dying. Continuing education may be required for Iranian palliative care nurses in order to improve the patients quality of care at the end of life.

KEYWORDS: Attitude toward caring for dying patients, Attitude toward death, Palliative care, Palliative care education, Iranian nurses

INTRODUCTION

Palliative care nurses strive to provide an environment in which individuals at the end of life can experience a peaceful death (International Council of Nurses, 1997). Their personal attitudes toward death and end-of-life care should be consistent with that aim. In the personal interaction with the dying, a perception that a humanistic relationship exists with the nurses and is recognized and valued at a personal level is important (Richardson, 2002). The success of nurses in palliative care relies on their relationship with each patient and it is related to her/his interest and willingness to care for people at the end of life (Olthuis et al., 2006). This personal motivation, which is the reflection of nurses’ attitudes toward giving care to the people who are dying (Olthuis & Dekker, 2003), might be affected by not only their beliefs and practices (Holloway, 2006) but also by their personal and professional experiences related to death and dying (Dunn et al., 2005). For instance, there are some research studies that found the effect of death education on nurses’ attitudes toward care of people who are dying (Hainsworth, 1996; Wessel & Rutledge, 2005). Others revealed the relationships between professional nurses’
experiences and their attitude toward caring for persons at the end of life (Rooda et al., 1999; Dunn et al., 2005).

Some studies found a close relation between personal experiences related to death and dying with attitude toward care of people who are dying (Franke & Durlak, 1990; Waltman & Zimmerman, 1992). Besides personal/professional experiences, nurses' sociocultural heritage also may translate into different ways of interacting with people at the end of life (Kao & Lusk, 1997). Therefore, the American Association of Colleges of Nursing (AACN) asserted that one of the competencies necessary for nurses to provide high-quality care at the end of life is recognizing one's own attitudes, feelings, and values about death and dying (Ferrell, 2001). So, this descriptive study aimed to examine the attitude toward death and caring for people at the end of life among Iranian nurses (oncology and nononcology) in the capital of Iran, Tehran.

**Context**

The sample of nurses in this study was selected from the Cancer Institute and Valiasr Hospital, which are under the supervision of the Tehran University of Medical Science. Assuming both that the Iranian nursing profession is strongly influenced by sociocultural context (Adib Hajbaghery & Salsali, 2005) and death as a foundation on which culture is built (Bauman, 1992), it seems necessary to mention the context in this study. According to the Leininger (1985), sociocultural factors may influence attitudes toward death and dying, including values and beliefs, kinship relationship, political and economical factors, and educational and technological situations.

Iran, as one of the most ancient world civilizations, is part of Middle East culture. The population is about 67 million, and, of this, 51% are younger than 20 years and 6.5% constitute the older people (World Health Organization, 2005). The Health demographic indicators are indicated in Table 1. Most religions are represented in this country, but the preponderance is Islam. The country is ruled by theocrats. The majority (99.4%) of the people in Iran consider themselves to be religious (European Values Study Group and World Values Surveys Association, 2000), and religious beliefs are strong and explicit in dealing with the fact of death (Ghavamzadeh & Bahar, 1997).

Iranians are familiar with death. Besides the Iran—Iraq war and natural disasters, which led to the considerable collective death in recent years, the major causes (65%) of death among Iranian are heart disease, cancer, and accidents (Budget & Planning Organization, 1988). So apart from chronic disease, accidents seem to be a significant cause of death or at least life-threatening situations among Iranian people.

Iranian families are nuclear and in some areas extended. Familial relations and sentiments are so strong that, for instance, incurable disease strikes not only the patient but the family as well (Ghavamzadeh & Bahar, 1997). The eldest family members are regarded as a source of spiritual blessing, wisdom, and love, and they often prefer to die at home with their family members (Cheraghi et al., 2005). End-of-life care is still a new topic in Iran, and palliative care education is neither included as specific clinical education for nurses who are involved with end-of-life care nor as a specific academic course in the nurse educational curriculum. In addition, there is not any specific hospice care centers like in Western countries (Cheraghi et al., 2005), but the health care system has already started to provide palliative care for people at the end of life.

**METHODS**

**Design**

There was approval from the heads of the Cancer Institute and Valiasr Hospital prior to the collection of data. The study employed a descriptive design and was conducted in those two hospitals.

**Background Information**

First, a questionnaire was designed to obtain background information that was assumed to influence attitudes toward death and dying. It was developed based on the experiences of a pretest among nurses and included four categories: (1) personal characteristics like gender, age, and marital status, (2) professional characteristics like previous education about caring for dying patients, years of nursing

<table>
<thead>
<tr>
<th>Table 1. WHO Health and Welfare Indicators in Iran</th>
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<tbody>
<tr>
<td>Indicator</td>
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<tr>
<td>Total population</td>
</tr>
<tr>
<td>Healthy life expectancy (M/F) 2002</td>
</tr>
<tr>
<td>Gross national income per capita (PPP international $)</td>
</tr>
<tr>
<td>Total expenditure on health per capita (Intl $, 2004)</td>
</tr>
<tr>
<td>Probability of dying between 15 and 60 years M/F (per 1,000 population)</td>
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<tr>
<td>Probability of dying under age 5 (per 1,000 live births)</td>
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experience, and years of working with people who are dying, (3) previous experiences related to death within the last 6 months such as experience of caring for a dying member in the family, experience of death of someone close, and experience of life-threatening situations, and (4) religiosity index consisting of intrinsic (belief in God) and extrinsic (attendance at religious services and activities) religiosity.

The Instruments
To measure the nurses' attitudes toward caring for people at the end of life, a translated version of Frommelt's Attitude towards Care of the Dying (FATCOD; Frommelt, 1991) was used. This scale has 30 items designed to measure participants' attitude toward providing care to people at the end of life. Fifteen of the items were worded positively and 15 were worded negatively. The questions are scored from 1 to 5 (1 = strongly disagree to 5 = strongly agree).

The nurses' attitude toward death was measured with a translated version of the Death Attitude Profile—Revised (DAP-R; Wong et al., 1994). This is a multidimensional measure using a 7-point Likert-type scale. It is composed of 32 questions that describe attitude toward death. A factor analysis made by Wong et al. (1994) on research made in an American setting revealed that the questions could be divided into five components, including fear of death (7 items), death avoidance (5 items), neutral acceptance (5 items), approach acceptance (10 items), and escape acceptance (5 items). The questions are scored from 1 to 7 (1 = strongly disagree to 7 = strongly agree).

For translation of both questionnaires from English into Farsi, the standard forward–backward procedure was applied. Translation of the items and the response categories was independently performed by two professional translators and then temporary versions were provided. Afterward they were back-translated into English, and, after a careful cultural adaptation, the final versions were provided. Translated questionnaires went through pilot testing. Suggestions by nurses were combined into the final questionnaires versions.

Reliability and Validity
The two translated scales were originally developed and tested in an American cultural context, which is different from the research contexts, so the validity and reliability of both scales was rechecked. A factor analysis (Rotated Component Matrix) on the results was done in order to examine the context validity of the five identified components of the DAP-R scale. The load of the items was similar to the American results. The validity of both scales was assessed through a content validity discussion. Scholars of statistics and nursing care have reviewed the content of the scales from religious and cultural aspects of death and dying and agreed on a reasonable content validity. To reassess the reliability of both translated scales, alpha coefficients of internal consistency and three-week test–retest coefficients (n = 50) of stability were computed. The alpha coefficient for FATCOD was .68 and for DAP-R varied from a low of .59 in natural acceptance of death to a high of .77 in approach acceptance. The three-week test–retest coefficients of stability for FATCOD was .63 and for DAP-R varied from a low of .65 in fear of death to a high of .79 in approach acceptance. So both translated scales presented acceptable reliability.

Data Collection and Analysis
Accompanied by a letter including some information about the aim of the study, the questionnaires were handed out by the third author to 120 nurses who were introduced by the head of each ward at work during two months (May and June 2007) at the Cancer Institute and Valiasr Hospital in Tehran. Some oral information about the study was also given by the third author. Participation in the study was voluntary and anonymous. One hundred twenty sets of questionnaires were distributed, with a dropout of six. In all collected data, 98% of all questions were answered. Data from the questionnaires were analyzed using the Statistical Package for Social Scientists. A Kolmogorov–Smirnov test indicated that the data were sampled from a population with a normal distribution. Descriptive statistics of the sample and measures that were computed included frequencies, means, and reliability. A Pearson correlation was used to examine relationships among the measured factors (DAP-R scores and demographic variables) and scores on the FATCOD.

RESULTS
Participants
A descriptive analysis of the background information (Table 2) revealed that the participants belonged to the age group of 20–50 years with a mean age of 33 years and were mainly female (81%). About 68% were married and the majority had a Bachelor of Science degree in nursing (91%) with 1–10 years experience of working in hospitals (72%). Whereas 64% of participants were oncology nurses, only 12.2% claimed that they were educated in caring for people who are dying. Almost 58% of respondents stated that they had less than 2 years of experience of caring for people at the end of life. Regarding
previous experience of death and dying, 36.9% had the experience of death of someone close, 39.4% had the experience of care for a dying member in the family, and 62.3% had experienced a life-threatening situation within the last 6 months. Considering religiosity (Table 3), 81.6% of respondents reported that they always experience God’s existence in their daily life, and 19.3% claimed that they attended religious services daily. Of the participants, 79.9% stated that they performed religious activities like praying daily.

Descriptive Findings

Descriptive analysis (Table 4) indicated a neutral to a moderately positive attitude toward giving care to people who are dying among the participants (mean = 3.55). Most of the nurses in this study were likely to give care and emotional support to persons at the end of life and their families as well. They acknowledge care of people at the end of life as a worthwhile experience. But most of the participants did not tend to involve persons who are dying and their families in the care and accept them as in-charge decision makers. They also reported themselves unlikely to talk about death with persons at the end of life and even educate them about death and dying. Furthermore, they stated that they are not likely to give honest answers to the dying persons about their conditions. In DAP-R subscales, on average, nurses reported that they have a low fear of death and death avoidance, but most of them viewed death as a natural phenomenon in life and also as a gateway to the afterlife.

Correlation Analysis

Pearson correlation analysis (Table 5) indicated a significant correlation of natural (r = .257) and approach (r = .293) acceptance with attitude toward giving care to persons who are dying. It means that those who viewed death as a natural part of life or as a gateway to the afterlife were more likely to give care to persons who are dying than those who did not share these views. But fear of death was negatively (r = -.199) correlated with attitude toward giving care to persons who are dying. Among demographic characteristics, the experience of death of someone close (r = .331) and also care for a family member who is dying (r = .271) was positively correlated with attitude toward giving care to people at the end of life.

DISCUSSION

The results of this study indicated a significant relationship between nurses’ views on death and their attitudes toward giving care to people at the end of life.
According to the results, approach and natural acceptance of death was positively correlated to the attitudes toward giving care to people at the end of life, but fear of death was negatively correlated. This result supported other research that found nurses who had less fear of death and accepted death as a gateway to the afterlife (Wessel & Rutledge, 2005) or as a natural part of life (Rooda et al., 1999) tend to have a more positive attitude toward giving care to people who are dying than nurses who did not have these views. It could be explained by the fact that caregivers view death as a natural part of life are more likely to interact positively with the terminally ill and to talk honestly about death with them (Rooda et al., 1999). The other findings indicated that nurses who had previous experience of death of significant others or experience of care for a dying member in the family are more likely to give care to people at the end of life than those who did not have such experiences. According to Franke

<table>
<thead>
<tr>
<th>Scale</th>
<th>Scale items</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>FATCODa</td>
<td>Attitude toward caring for dying patients and their families.</td>
<td>3.55</td>
<td>0.36</td>
</tr>
<tr>
<td></td>
<td>Giving nursing care to the dying person is a worthwhile learning experience.</td>
<td>4.38</td>
<td>1.20</td>
</tr>
<tr>
<td></td>
<td>The family should be involved in physical care of the dying person.</td>
<td>2.50</td>
<td>1.24</td>
</tr>
<tr>
<td></td>
<td>Dying people should be given honest answers about their conditions.</td>
<td>2.94</td>
<td>1.25</td>
</tr>
<tr>
<td></td>
<td>The dying person and his or her family should be the in-charge decision makers.</td>
<td>2.87</td>
<td>1.11</td>
</tr>
<tr>
<td></td>
<td>Families need emotional support to accept the behavior changes of the dying person.</td>
<td>4.55</td>
<td>0.58</td>
</tr>
<tr>
<td></td>
<td>I would be uncomfortable talking about impending death with the dying person.</td>
<td>4.05</td>
<td>1.32</td>
</tr>
<tr>
<td></td>
<td>Educating families about death and dying is not a nursing responsibility.</td>
<td>4.35</td>
<td>1.25</td>
</tr>
<tr>
<td></td>
<td>I would be uncomfortable if I entered the room of a terminally ill person and found him or her crying.</td>
<td>4.15</td>
<td>0.97</td>
</tr>
</tbody>
</table>

| DAP-Rb | Fear of death.                                                              | 3.28 | 1.30|
|        | Death is no doubt a grim experience.                                         | 4.14 | 2.06|
|        | The uncertainty of not knowing what happens after death worries me.          | 3.92 | 2.06|
|        | Death avoidance.                                                            | 2.95 | 1.44|
|        | I avoid death thoughts at all costs.                                         | 2.49 | 1.72|
|        | I try to have nothing to do with the subject of death.                      | 2.81 | 1.68|
|        | Approach acceptance.                                                       | 5.40 | 0.98|
|        | Death brings a promise of a new and glorious life.                          | 5.42 | 1.61|
|        | Death is a union with God and eternal bliss.                                | 5.85 | 1.45|
|        | Escape acceptance.                                                         | 4.14 | 1.44|
|        | Death is deliverance from pain and suffering.                               | 4.01 | 1.85|
|        | Death provides an escape from this terrible world.                          | 4.13 | 1.97|
|        | Natural acceptance.                                                        | 5.81 | 0.85|
|        | Death is simply a part of the process of life.                              | 6.07 | 1.22|
|        | Death is a natural aspect of life.                                           | 6.14 | 1.29|

| aThe item range for FATCOD = 1–5. |
| bThe item range for DAP-R = 1–7. |

Table 4. Frommelt Attitude towards Care of the Dying Patients (FATCOD) and Death Attitude Profile–Revised (DAP-R) Scores

<table>
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<tr>
<th>Scales</th>
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<tbody>
<tr>
<td>FATCODa</td>
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<tr>
<td>DAP-Rb</td>
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<tr>
<td>Demographic factors</td>
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<tr>
<th>Subscales</th>
<th>FATCOD</th>
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<tr>
<td>Fear of death</td>
<td></td>
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<tr>
<td>Approach acceptance</td>
<td></td>
</tr>
<tr>
<td>Natural acceptance</td>
<td></td>
</tr>
<tr>
<td>Experience of caring for dying at home</td>
<td></td>
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<tr>
<td>Experience of death of someone close</td>
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<tr>
<th>Scales</th>
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<tr>
<td>DAP-Rb subscales</td>
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<tr>
<th>Subscales</th>
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<td>Natural acceptance</td>
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| aDAP-R: Death Attitude Profile-Revised. |
| bCorrelation is significant at the level of p < .05. |
| **Correlation is significant at the level of p < .001. |
and Durlak (1990), death of a significant other could be the highest life experience to decrease death anxiety. These findings can be supported by previous studies that found the experience of a close family member’s death to be a positive influential factor not only on the attitude toward giving care to people at the end of life among nurse students (Brent et al., 1991) but also on the attitude toward providing continuing care for bereaved family members among caregivers (Waltman & Zimmerman, 1992).

The majority of nurses in this study reported that they accepted death as a natural part of life and also as a gateway to the afterlife. An attitude of acceptance toward death seems to be associated with familiarity with death (Ghavamzadeh & Bahar, 1997) and stronger religious beliefs (Neimeyer et al., 2004). Apart from the reported mortality rate and religious beliefs among Iranian people, the demographic characteristics in this study also revealed that more than half (62.3%) of participants had experienced a life-threatening situation within the last 6 months, and the majority (51.6%) claimed that they always experience God’s existence in their daily life.

On average, the majority of nurses in this study claimed that they are likely to provide care and emotional support for people who are dying and their families and acknowledge it as a worthwhile experience. But they did not have a positive attitude toward most aspects of the care for them. It could be related to the lack of education and clinical experiences related to death and dying among the participants. More experience (Dunn et al., 2005) or more education (Wessel & Rutledge, 2005) leads to less anxiety about death and consequently a more positive attitude toward care of people who are dying. But in this study, more than half of the participants (about 58%) had less than 2 years of experience in working with people at the end of life, and the majority of them (87.8%) had not received any education on how to care for them and their families. In addition, Iranian nurses are overworked due to the nursing shortage in the health care system (Nikbakht & Emami, 2006). So they may have limited time to spend with patients and their families in order to talk with them or even educate them about death and dying. Another possibility, as was mentioned before, is related to cultural limitations. For instance, the relations and sentiments among Iranian families are so strong that, apart from the patient, the family members will be severely struck if they are informed that their loved one is near death (Ghavamzadeh & Bahar, 1997). These reactions, which make the patient worse or disrupt the family, may lead nurses to be likely, one hand, to give them care and support them emotionally, but be unlikely, on the other hand, to talk with them about death, to give them honest answers about the patient’s condition, and even to involve them in the care.

Limitations

The convenience sample of nurses, which is not representative of all Iranian nurses, including oncology or nononcology nurses, could limit the generalization of the findings. Furthermore, use of the self-report questionnaires may have led to an overestimation of some of the findings due to variance that is common in different methods. Another limitation is related to the article’s focus on the psychological aspects of attitude, as “attitude” is a very complex term with the broad meanings (Olthuis & Dekkers, 2003).

Implications

The findings of this study suggest that how nurses view death together with personal experiences affect on how they felt about care of people who are dying. Besides the findings, the lack of education and experience as well as some cultural and professional limitations may have contributed to the negative attitude toward some aspects of the care for people who are dying among most of the nurses. So creating a reflective narrative environment in which nurses can express their own feelings about death and dying (Wessel & Garon, 2005) seems to be as an effective approach to identifying the influential factors on their interaction with people at the end of life. Furthermore, continuing education may need to be added to the palliative care in order to improve the quality of care at the end of the life.

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Paper III
A caring relationship with people who have cancer

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Abstract

Aim: This paper is a report of a study conducted to elucidate the meaning of a caring relationship with people with cancer.

Background: A caring relationship becomes the most important focus of caregiving when treatment of the body has reached the limits where cure is no longer expected. Caring as perceived by people with cancer involves nurses having professional attitudes and skills in order to provide good care, including emotional and practical support.

Methods: A phenomenological hermeneutic approach influenced by Ricoeur was used. Eight nurses working in an oncology unit in Iran were interviewed in 2007 about their experiences of caring relationships with people who have cancer.

Findings: The findings were interpreted as getting involved in a mutual/demanding close relationship. Closeness demanded nurses to be present, to listen to patients, and to be compassionate. Closeness was also mutual and characterized both caregiving and receiving new insights into values in the nurses’ own lives. The close relationship was at times frustrating when they were faced with situations that they could not handle and were out of their control.

Conclusion: Closeness is an important foundation for caring, and acquires a special dimension in the care of people with cancer and their relatives. It derives from the personal and professional experiences of nurses in their own life stories. Nursing education should include a reflective approach in order to develop caring skills in oncology nursing that are not merely attuned to medical care.
What is already known about this topic?

- Caring relationship is the most important focus of caregiving for people who have cancer.

- Involvement and reciprocity are important elements of nurse–patient relationships in the end-of-life care.

- Sociocultural status and personal differences have effects on the meaning of cancer for both patients and nurses and ultimately on nurse–patient relationships.

What this paper adds

- A caring relationship with people who have cancer creates an ethical demand emanating from closeness in that relationship.

- The ethical demand is influenced by nurses’ sociocultural context and their embedded knowledge.

- Closeness in the caring relationship with people who have cancer is not only satisfying but also frustrating, due to the tension between nurses’ desires to do the best for patients and not being able to meet their needs sufficiently.

Implications for practice and/or policy

- Nursing education should include a reflective approach in order to develop caring skills in oncology nursing that are not merely attuned to medical care.

- Developing a close relationship with people with cancer and their families requires nurses to be assisted by a supportive organisation and provision of the resources necessary for their work.

Key words: Iran, nursing, cancer, caring, relationships, phenomenology, hermeneutics
INTRODUCTION
Humans have a natural tendency for relational connection (Buber 1958) which includes an ideal of care and responsiveness, in that there is a value for the power of human contact and connectedness (Hartrick 1997). Confrontation with people’s vulnerability and suffering generates specific moral reasons for helping those in need for establishing an interpersonal relationship with them (Nortvedt 2001). This attention includes presence in order to preserve human dignity in the face of pain and extreme breakdown. The attention applied in a nursing context includes provision of comfort and communication through touch, guiding patients in coping with the consequences of illnesses for their lifestyles, and interpretation of the illness by encouraging patients to express themselves so as to understand themselves better (Gastman 1999).

BACKGROUND
A caring relationship becomes the most important focus of caregiving when treatment of the body has reached the limits where cure is no longer expected (Sabatino 1999). Caring for people who are terminally ill requires that nurses “be with” patients in contrast to “doing” to them, which means connecting to them and being present, conveying to patients in an unhurried manner that they as individuals are the nurses’ priority, and that the nurses will not be distracted by other demands (Krisman-Scott & McCorkle 2002). Cancer as a life-threatening disease involves both the people affected and their families (Mystakidou et al. 2002). Culture and values, along with life experiences, socioeconomic status, and personal differences, have effects on the meaning of cancer, in addition to how people cope with the disease (Juarez et al. 1999). Hence, creating a therapeutic partnership with clients and their families during their crises with cancer is both a challenging and extremely rewarding experience for nurses (Jens et al. 2001). Researchers who have explored the phenomenon of caring for people who have cancer and their family members describe caring relationships based on reciprocity as a core element in the care (Berterö 1999, Liu et al. 2006, Kendall 2006a, Kendall 2007). Nurses encountering with people who have a cancer diagnosis experience feelings of frustration and sadness, but these encounters also provide opportunities for their personal and professional development (Berterö 1999, Kendall 2006a, Kendall 2007). Caring as perceived by people with cancer involves nurses having professional
attitudes and skills in order to provide good care, including emotional and practical support (Liu et al. 2006).

According to Roach (1997), caring is the human way of being, while Leininger (2002) claims that caring is the essence of nursing, even if the meanings and expressions of care vary transculturally. Studies in Iran have indicated that nursing profession is strongly influenced by the socio-cultural context (Adib Hajbaghery & Salsali 2005). A qualitative study with a narrative data collection was therefore conducted among Iranian oncology nurses to explore the meaning they give to caring relationship with people with cancer.

THE STUDY

Aim
The aim of the study was to elucidate the meaning of a caring relationship with people with cancer.

Design
A qualitative approach was used to understand the meaning of nurses’ lived experiences of caring relationships with people who have cancer (cf. Van Manen 1990). The meanings of phenomena cannot be understood if they are not considered through human experiences. When the experience is expressed it can be analyzed as text and considered as the knowledge informants have about that phenomenon (Dahlberg et al. 2001). Therefore, open narrative interviews with nurses working with people who have cancer were used to discover through the stories a world that is further exposed to new interpretations and understandings (Barton, 2004). The data were analyzed using a phenomenological hermeneutic approach influenced by Ricoeur (1976). This method provides an opportunity to combine the philosophy of the meaning of lived experiences with a hermeneutic interpretation of a transcribed interview text. The interpretation can create a deeper understanding of the phenomena, based on dialectical movement between understanding and explanation to a new understanding. In the new understanding, the text is interpreted, based on the researcher’s preunderstanding (Ricoeur 1976).

Study context
Iran is a part of a Middle East culture and has a population of 68 million. There are about 120 000 nurses working in the healthcare system (Adib Hajbaghery & Salsali 2005). The national
programme for educating nurses is perceived as highly biomedical and technically-oriented, although many nurses believe that a holistic essence in nursing is a motivating factor for carrying out their work as nurses (Nasrabadi et al. 2003). Like most Iranians, a majority of the nurses consider themselves religious (Iranmanesh et al. 2008), and religious beliefs are often, in an explicit way, integrated into their views on caregiving. Nurses are expected to pay attention to patients’ religious beliefs and activities, such as worship and praying, as an important coping strategy (Taleghani et al. 2005). Gaining support from significant others is an approach used by Iranian patients with cancer in order to cope with their disease (Taleghani et al. 2005). Therefore, kinship relationships are an important factor influencing the care, since the meaning of care among Iranian people is expressed as family respect, closeness and being together (Omeri, 1997). Cancer care is a developing area of the healthcare system in Iran due to a high incidence of the disease (Fallah & Kharazmi 2007).

**Participants**

A purposive sample of eight interviewees was selected among nurses working in a major cancer hospital in Iran. They were selected through the chain sampling approach, where key informants recommended one person, who in their turn recommended another (Patton 2002). Interviewees were selected on the basis of their experience of working in oncology wards for the purpose of providing information about the meaning of a caring relationship with people who have cancer. The interviewees were aged between 25–50 years, and 4 were women and 4 men. All were Registered Nurses with a Bachelor of Science degree in nursing. They had a mean of 7 years’ experience in cancer nursing.

**Data collection**

After informed consent was obtained, the nurses were scheduled for interviews at a time convenient to them. Tape-recorded interviews in the Farsi language were conducted using a narrative methodology (Sandelowsky 1991). Participants were asked to narrate their experiences of caring relationships with people who had cancer. During the interviews, the researcher (S.I) tried to strike a balance between the narratives and the aim of the research. The interviews lasted between 45 and 55 minutes, and all data were collected in 2007.
Ethical considerations

The study was approved by the appropriate ethics committee, and the hospital director, matron, and head nurses where informed about the aim of the study and the methods to be used. Head nurses informed staff members and invited nurses to participate. Informed consent was sought from participants both orally and in writing. All participants were informed about their rights to withdraw from participation at any time and that anonymity would be maintained. Participants were given time to consider their participation in the study. Speaking about patients who are terminally ill and experiences related to this has an emotionally charged nature and may be a painful reminder of the situation in relation to participants’ significant others. This risk was handled by the researcher by being attentive and sensitive to interviewees’ emotional reactions.

Data analysis

The interviews were analyzed using the principles of phenomenological hermeneutics influenced by Ricoeur and described by Lindseth and Norberg (2004). The method has been used, among others, by Sävenstedt and Häggström (2005) in a transcultural study and by Berterö (1999) in a study of caring for people who have cancer. The transcribed text was translated into English to facilitate the analysis process among the four authors. The meaning of the translated text was thoroughly checked by studying the original Farsi transcription during the whole process of analysis. The analysis and interpretation of the text involved a dialectic movement between understandings of the whole and of parts of the text through three methodological phases. In the first phase, the interviews were read with an open mind in order to gain a naive understanding of the meaning of caring relationship with people with cancer, as well as to initiate creation of an approach for further structural analysis. Next, a structural analysis was done, in which parts and structure of the text were decontextualized and systematically analyzed to validate or invalidate the naive understanding. Finally, a comprehensive understanding was formulated. This step was a sophisticated mode of understanding emanating from and supported by a critical dialectic between the first two phases (Ricoeur 1976). The comprehensive understanding was based on a dialectical movement between understanding and explanation, between the whole and the parts of the text, and was the final of several possible interpretations of the text upon which we unanimously agreed (Lindseth & Norberg 2004).
FINDINGS

Naive understanding
According to the interview text, a caring relationship with people with cancer seems to mean getting involved in a mutually-demanding close relationship. To create a close relationship with patients and their relatives, nurses need to be present, actively listen, and share their stories and beliefs, as well as respecting their faiths. It also demands nurses to be involved in patients’ personal and economic problems. The demands and personal involvement integrate nurses with their own spiritual lives and make them realize the value and satisfaction of caring for people with cancer. The demands also make nurses frustrated when they face inequalities in the healthcare system that affect the possibility of caring for people with cancer and their relatives according to their perceived needs.

Structural analysis
In the structural analysis, the text was divided into meaning units that were further condensed, compared across the interviews, grouped, and labelled. Finally, the labelled groups of the meaning units were abstracted into three themes, as described below.

Becoming close and then compassionate
According to the text, a caring relationship with people with cancer enabled nurses to come close to and as a consequence also be compassionate to patients and their family members — a compassionate relationship characterized by mutual trust was formed. They experienced that working with patients in the oncology wards required them to be closer and more compassionate to them compared to caregiving work in the other wards. This closeness with developed over time and its development was supported by their professional experiences, knowledge about caring for people with cancer, and by their personal experiences, values, and religious beliefs. Professional experiences had taught them that being close facilitated accessing the needs of people who had cancer:

*I learned from people that they need us to be there and spend time with them. Over time I realized that this is the most important thing in the care.*

Religious beliefs seemed to give insights into the need to be compassionate. Values and religious beliefs and practices gave new meaning to nurses’ professional lives. Their spiritual foundation
and religious beliefs assisted them in a positive way to cope with and provide meaning to the caregiving work on the oncology unit. They also referred to specific religious beliefs that guided their practice or their approach to patients. One of them talked about her belief in a life after death, a circular process of life and death as a divine order, and that such a belief facilitated forming caring relationship with people at the end of their lives:

_Really, I am not afraid to get close to a person who is near to the death, because I believe that death is just a bridge between this earthly life and the life after death._

The nurses’ personal experiences also contributed to the development of being compassionate. They described how their own experiences of having a family member with cancer had affected their approach to these patients. One experienced nurse who had children of her own claimed that insights gained as a mother made her understand the feelings of a mother of a baby with cancer:

_I am a mother and I am not able to see even a small sore or a little blood on my baby’s hand, so maybe that is why I am very kind with babies and their mothers._

In the text, the meaning of closeness included talking and listening in a way in which nurses allowed patients and their family members to express their feelings. The nurses experienced how being there and listening to patients could relieve anxiety and physical pain. They emphasized that talking with and listening to patients with cancer distracted them from thoughts about the disease and made them feel alive. Listening to concerns without biased judgments and with respect was experienced by nurses as an important part of their caring relationship. They were involved in patients’ and their family members’ search for the meaning of illness in their lives. Each person with cancer had an individual unique belief that was expressed in different ways, whether this was regarded as religious or superstitious:

_She told me that her daughter was bitten in the eye [by something evil] because she had very beautiful eyes. It was difficult to answer her. I talked with her and was able to convince her to go home and have a rest._

Closeness in the relationship was also expressed by using touch. Touch was often used in situations characterized by anxiety and physical pain, and was a way of comforting children and young people with cancer. This closeness also made it possible for nurses to preserve hope among their patients, and to build trust to a level where they could sometimes convince doubting
people with cancer to undergo difficult treatments with chemotherapy. Sometimes nurses facilitated relationships between patients cured of cancer and other patients doubting the chemotherapy in order to convince them:

*When we introduced him to that young man who was cured, he became persuaded that the side effects could be removed and then gradually he accepted to undergo the chemical therapy.*

Closeness also meant involvement with the personal problems of the whole family. Nurses witnessed patients’ and family members’ emotional, psychological, and economical distress caused by the cancer diagnosis and treatment costs. They described how such problems negatively affected the whole family’s psychological situation and well-being, and felt the need to support such patients and their families both socially and economically. The lack of a supporting system made nurses seek external resources to meet the needs of the family, and if they were not successful, they tried to solve the problems on their own:

*Some times we play a role as a mediator between the donors and the people. We collect the money from the volunteer donors or even from the staff for people to pay for their trips to their home cities.*

**Becoming inspired, satisfied, and gaining new personal insights**

Participating nurses narrated situations where they were touched by the relationship between the person with cancer and their family members, and they described such a relationship as inspiring. These were extraordinary situations where family members made efforts that were not expected of them according to the cultural tradition:

*It was really surprising to see how kind those two girls were towards their stepmother and how they took care of her.*

There could also be situations where people with cancer showed a strong tenacity to fight their illness, despite the consequences of the cancer diagnosis. Some patients experienced extremely distressing complications and yet they felt alive and did surprising things:

*Even if his hand was amputated and he had dyspnoea due to metastasis of his cancer, he was still interested in learning to use the computer. He asked me to teach him.*
The nurses experienced satisfaction when they were able to alleviate patients’ symptoms or minimize the side effects of the drugs they had to use. Being able to provide comfort and improved physical care, including paying attention to any side effects caused by chemotherapy, also contributed to their satisfaction. Even during moments of encountering suffering and tragic death, nurses could experience feelings of satisfaction, as they felt that they had done their best to promote patients’ well-being:

Even if they would be at the end, we try to help them to have a dignified death or pass through it more easily, and it makes us satisfied.

An important part of the nurses’ descriptions of rewarding experiences was the positive feedback and acknowledgment they received from many patients for whom they cared, and from their family members. This included caring relationships where they had been able to meet personal needs, share their life stories, and comfort them. Acknowledgment by family members often continued even after the death of loved ones, and nurses gained personal strength and a feeling of being valued from these appreciations:

When a patient acknowledges me, I feel good to be human because I can do something to save another person’s life.

Interviewees described how relationships with people with cancer made them change their outlook on their own lives, and they discovered that their views on many things had changed. Witnessing people’s suffering made them re-examine their own attitudes towards life and accept that incurable disease and death are parts of life. They expressed this as being rewarding, gaining an inner strength, and being more patient with their own personal problems:

Life has nothing to be worried about; even death which is a reality of life comes to me whenever God wants.

Being frustrated

The text revealed that nurses’ became frustrated when they were faced with inequalities related to the shortcomings of the health and social care system. Limitations in what the healthcare system could provide to save a life was discouraging. Caring for patients who would soon die and not being able to help them brought feelings of frustration:
Here we tried so much to take care of the people and to prolong their life but actually we do not get the result.

Some interviewees described how some patients’ rights to an equal chance to receive the best care and treatment were denied due to their socioeconomic situation. Not only patients, but also the nurses caring for them, suffered as a result of these inequalities:

It is really painful to see how the people are provided with care and treatment in a different way due their economical situation.

Nurses also complained about heavy workloads and that their salaries were low. They did not have enough time to spend with the people who had cancer. All interviewees revealed an ongoing tension between spending time with patients and being part of a busy ward, and they felt frustrated about their pay and about having to work more than one shift in different wards to earn more money in order to be able to manage their daily lives:

We have usually 40 people in the ward and most of us work here as the second or third working shift, so you can imagine how tired we are when we start to work.

The text also revealed frustration about the tension between telling the truth and the cultural code of always preserving hope. Some nurses were frustrated at not being allowed by physicians to tell the truth about diagnoses. On the other hand, there were also some who felt that patients would not be prepared to hear that they had an incurable disease, and that disclosure could hasten their death. One argument for being open and telling the truth was that the person with cancer could then accept the disease and fight it instead of denying it. Telling the truth could also provide an environment where nurses could educate clients and their families. Such openness could facilitate discussion about how to reduce or even stop the progression of cancer and help patients to overcome fear and sadness:

In the last moments he still was not able to accept that he was near to death, so he held my hand and appealed to me to do something for him.

There were also times when feelings of frustration among nurses were combined with sadness, especially in situations when they were emotionally touched by a patient. These situations could be demanding and nurses had to handle their own grief and sense of loss.
Comprehensive understanding

A comprehensive understanding of the phenomenon of a caring relationship with people with cancer and their family members as described by the Iranian oncology nurses has a foundation in the ethical demand that is developed by the caring relationship. The demand seems to emanate from a developed, close and mutual relationship that requires to be maintained. Closeness seems to be a means to assist patients and their families to find peace with the cancer illness, and ultimately with the prospect of death. The ethical demand seems to be rooted in nurses’ socio-cultural context. Embedded knowledge relates to nurses’ personal and professional experiences, kinship relationships, and beliefs about life and death are manifested in how they relate to their patients. The ethical demand to provide care to patients and their families offers not only satisfaction and enrichment, but also frustration due to the tension between their wishes to do the best for patients and the feelings of powerlessness and not being able to meet all their needs sufficiently.

DISCUSSION

Caring is a way of being (Roach 1997) and its meaning varies culturally (Leininger 2002). The meaning of Iranian nurses’ caring relationships with people with cancer can be related to both aspects. In our study, this meaning was understood as emanating from a radical ethical demand, which is consistent with Lögstrup’s (1971) view on human relationships. Lögstrup (1971) argues that the ethical and radical demand is unconditional, calls for love and care and responds to the other person’s trust by performing actions that will amount to care and protection of their life, whether these are pleasant or unpleasant: ”The well-being of those I meet is in my open hands” (p.46). In our study, compassion was created in relationships with people who had cancer and was closely linked to and a result of closeness in the relationship. Compassion is an expression of love and is characterized by mutual respect, attachment, affection and trust (Hatfield & Rapson 1993).

The nurses’ closeness in reciprocal relationships with people with cancer and their family members was pleasant and rewarding. Similar findings were reported by Kendall (2006a, 2007), who found that nurses described how experiences from caring encounters with patients with cancer gave them great insight into themselves and their practice. Ricoeur (1994) asserted that, although an ethical relationship is asymmetrical and the initiative comes from the compassionate
other, the one suffering is not solely receiving and the compassionate one is not only giving; the relationship is mutual. In fact, any asymmetry that exists in a caring relationship could potentially be unethical because it is not balanced by reciprocity (Fredriksson & Eriksson 2003).

Our interviewees’ closeness to patients and their families made them knowledgeable and understanding of their needs. Olthuis et al. (2006) describe how, in a relationship characterized by closeness, the nurse is listening and using task-oriented touch, and is present “as being there” for a patient who wants contact. In this way, nurses can support patients and assist them with preserving hope. Nurses recognize that being hopeful and finding meaning in life are powerful weapons against cancer (Benzein & Saveman 1998), and can have a positive impact on quality and even quantity of life (Lin et al. 2003).

In this study there were aspects of embodied knowledge related to nurses’ life histories in the Iranian context. Within the experience of closeness in relationships with patients and their family members there was an aspect of implicit trust. The manner in which nurses responded to patients’ trust was related to the embodied knowledge and beliefs that nurse, as human beings, gradually absorb in the course of their personal and professional life histories. In accordance with the philosophy of phenomenology, individuals live as subjects in and through their bodies (Merleau-Ponty 1995). Healthcare professionals practise their embodied knowledge when they treat and care for patients (Dahlberg et al. 2001). What determine the meaning of care for a nurse is inner beliefs and the experiences, as well as the outside professional context of nursing, and not theoretical arguments (Gastman 1999). In our study, personal beliefs supported nurses’ caregiving and they also developed their embodied knowledge.

The interviewed nurses live and work in Iran, which is a country that is ruled by the authority’s theocrats and is regarded as a religious country. Almost all Iranians (99.4%) consider themselves as religious, but there is a low attendance (27%) in religious service (European Values Study Group 2000) and their world views are a combination of magic, religion, mysticism and theology, reflected in their poetry and arts (Tabari 1970). Religious beliefs strongly and explicitly deal with the fact of death (Ghavamzadeh & Bahar 1997). According to Narayanasamy and Andrews (2000) since Muslims believe in the resurrection of the physical body as well as the spirit, a sensitive health-care approach aims to meet the spiritual needs of Muslim’s patients and helping them to achieve spiritual comfort during crisis such as illness.
Nurses in this study believed that caring for sick patients enabled them to strengthen their own faith, gave them energy, and brought rewards from God, which corresponds with findings in other Iranian studies (Nasrabadi et al. 2003). Moreover, it has been shown in other studies that nurses’ views on death, together with their personal experiences of death, influence how they feel about caring for people who are dying (Iranmanesh et al. 2008). Studies have shown that religious belief systems might infuse care-giving duties with sacred meaning, leading to greater satisfaction (Mickley et al. 1998, Pearce et al. 2006).

The unpleasant part of closeness was nurses’ feelings of frustration because of the tension between their wishes to do the best for their patients and their feelings of powerlessness and not being able to meet those wishes sufficiently. Heavy workloads and low socio-economical status created a difficult working situation and contributed to feelings of frustration. Similar Iranian experiences have been described by Emami and Nasrabadi (2007). In addition, nurses in this study, like those in Quinn’s (2003) and Berterö’s (1999) studies, claimed that the healthcare system did not allow them the necessary time to respond to the sensitivity of care.

Nurses were aware of their role as providers of appropriate information to the patients about cancer diagnoses, but preserving patients’ levels of hope throughout the disease course was a greater obligation for them. Some felt uneasy about meeting people who were not informed about their diagnosis and still believed in a cure of their condition, whereas others were convinced that disclosure of the diagnosis could destroy hope and hasten death in people who have cancer. Beliefs about non-disclosure in this study could be related to the Iranian culture of kinship relationships, which is so strong that a cancer diagnosis may affect the whole family (Ghamzadeh & Bahar 1997).

Cancer is often associated with death; thus, receiving a cancer diagnosis can lead patients to experience severe distress (Maguire 1995). Caring for people with cancer seems challenging, since nurses in different cultures have similar experiences of being faced the situation where the information given to patients is not clear and leads to feelings among families of being deceived (Berterö1999, Kendall 2006 b). It also requires nurses to be closely involved with people’s concerns, and the need of a dependable nurse-patient relationship becomes even more necessary (Liu et al. 2006). However, many patients who are living with serious chronic diseases, no matter
what the diagnosis is, feel better when they have good relationships with healthcare providers (Fox & Chesla 2008).

Our findings suggest that nurses should be prepared to create close relationships with patients who are living with cancer and their families. Thus, nursing education should include a reflective approach to develop inter-subjective caring skills that are not merely attuned to medical care. Through the use of narratives, nursing students can become accustomed to reflecting on their feelings, reactions and caring actions, and this can lead to the creation of each nurse’s unique caring identity (Gastman 1999). Moreover, developing a close relationship with people with cancer and their families requires nurses to be assisted by a supportive organisation and the provision of necessary resources for their work.

Methodological issues
In a phenomenological hermeneutic study the transcribed text is in focus, and in this study the translation of the narrated experiences was a challenge. The interviews were done in Farsi and then translated into English. The authors have Iranian and Swedish backgrounds and English is a second language. It is possible that some important aspects of the interviews were lost during the course of this study. However, we worked with the text in a thorough and systematic manner. The translations and interpretations were checked and discussed by studying the original text repeatedly. The analysis should therefore be judged in terms of our transcultural backgrounds. The first author functioned as a cultural agent to ensure that the concepts were understood and linked to the Iranian cultural context. The phenomenological hermeneutic approach also implies an awareness of pre-understanding, which allows opportunities to elucidate the phenomenon. Specifically, we were familiar with caring relationships with people with cancer and the environment of an oncology unit. However, throughout the entire research process reflections were necessary about how this influenced the interpretation.

CONCLUSION
This study indicates that closeness is the foundation for Iranian nurses’ care in oncology settings, since they are involved in relationships with people who are severely distressed by knowing that they are living with cancer. This closeness could result from the nurses’ personal and professional experiences and on their own life stories. This life story perspective provides a realistic foundation for professional caring that can support people’s well-being and contribute to
satisfying the needs of patients and their relatives. The findings also suggest the importance of addressing the cultural contexts in which fruitful caring relationships are to be created.
References


Paper IV
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Caring for dying people: Nurses’ experiences in the contexts of private homes and a special unit in hospital settings in Sweden

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Abstract

Background: Most people need to be cared for at the end of their lives by professionals. To care for a person who has to face inevitable death in the near future is a demanding and delicate task. Few studies have focused on the nurses’ perception of caring for dying people in home care or in a hospital setting. There is no study that actually explored the phenomenon in both these contexts.

Aim: The aim of this study was to elucidate the meaning of nurses’ experiences of caring for dying persons at home and in a special unit in a hospital.

Data Sources: Four registered nurses working in private homes and four registered nurses working in a specific unit in a hospital setting in the Northern part of Sweden were interviewed, during the spring of 2008, about their experiences of caring for dying people.

Method: The study was planned and carried out with a phenomenological hermeneutic approach.

Results: A naive reading guided a structural analysis which resulted in three main themes: Meeting patients and family members as unique persons, learning in a challenging environment, and gaining personal strength. The interpreted comprehensive understanding conveyed a meaning that caring for families with a member awaiting the end of life created a situation where the presence of an inevitable death demanded nurses to create close relationships with each unique person involved. It made them reflect on values in life and thereby develop professional and personal identity and gain self-esteem.

Conclusions: Developing professional care for dying people demands nurses to meet patients as unique persons and support their well being through positive stimulation of all means of perceiving the world through the human senses. The meaning of this founding value is being developed into a process and needs to be supported by caring context, including teamwork with reflective practice, and counselling based on nurses’ personal and professional histories.

Key words: Meaning, nurses, palliative care, professional development, personal identity.
What is already known about this topic?

- Palliative care is a holistic way to address the needs of patients and families and enhance the quality of life at the end.

- The main goal of palliative care is honoring and protecting dying persons in a way that dignity is preserved.

- Caring for dying people requires the nurses’ close relationships with the person who is dying and his or her family members in order to be able to meet different needs.

What this paper adds

- Meeting each patient as a unique person with family members, and not merely a patient in general, is the main shared founding value.

- Caring for dying people provides nurses an opportunity to develop their personal and professional identity.

- Developing professional care is integrated into a learning process and supported by the context in which nurses were able to reflect on their own personal and professional life histories.

1. Introduction

Death is an inevitable reality that all people share. Death is a truth that cannot be avoided by man. This truth causes anxiety that is recognizable when a person and his or her family members receive a diagnosis of an incurable disease. Such a message always triggers an existential crisis that involves the patients’ and families’ emotions and perceptions. It leads them to experience an existential isolation (Sand and Strang, 2006) as well as feelings of helplessness and powerlessness (Sand et al., 2008). A life threatening disease such as cancer involves patients and their families for a long time, thus the family members who assume caring work and have a supportive role become exhausted. Even though people often prefer to die at home and be cared for by their family members, they still need professional services and support (Proot et al., 2003). During the last few decades, the number of people living with life threatening diseases has increased. They need to lead a meaningful life, even when they are at the end stage and may have only months to live. Considerations invoked the hospice care movement from the 1960s onwards (Walter, 1996).
The philosophy of palliative care includes relief from pain, affirms life and regards dying as a normal process, integrates the psychological and spiritual aspects of patient care, offers a support system to help families cope, uses a team approach to address the needs of patients and families, enhances the quality of life, and can be utilized in conjunction with curative aspects of care (WHO, 2006, p.1). In this sense, the focus of palliative and hospice care seems to be on the person in his totality and total particularity. Corresponding to the philosophy of palliative care Sabatino (1999) states that death presents the greatest challenge to care, although not in the manner we might expect, because all attempts to cure reach their limit and care givers are confronted with a very basic helplessness. Regarding the philosophy of palliative care, nurses’ communication and relations are greatly significant, both in the team and with the patient and the next of kin (Berterö, 2002). It also requires the nurses’ sameness, closeness and connection (Hawthorne and Yurkovich 2003), ultimately expanding the nurses’ understanding of the human journey so that they can share their lived experience (Stanley, 2000). Nurses are committed to the care of dying persons and their family members in order to assist them in a number of ways, such as providing information, recognizing their needs, providing emotional support and teaching (Krisman-Scott and McCorkle, 2002).

A few studies have actually explored the meaning of caring for dying people, although they have tended to focus on the nurses’ perceptions of their role. Byrne and McMurray (1997) reported that nurses were transformed by the experience of caring for dying persons. Caring was embodied in the interactions with the dying person and extended to the person's family, and the nurses developed strategies to cope with their experiences. It is also reported that hospice care is seen as a challenge involving control, frustration as well as relationships (Berterö, 2002). Hospice care also strives to adopt a well organized and purposeful approach, and enhances the well-being of the persons (George et al., 2002). Furthermore, comfort care was felt by hospice nurses as bringing a sense of peace and relief for the emotional anguish and spiritual pain (Evans and Hallett, 2007). The studies discussed above have contributed to the understanding of the phenomenon of caring for dying people by using different methods of analysis for the nurses’ experiences at home or in hospital settings. Adding to this body of knowledge, a qualitative study with a narrative data collection was conducted among Swedish registered nurses who worked in private homes and in specific units in a hospital to elucidate the meaning they give to caring for people at the end of life in Sweden.
2. Context
The promotion of palliative care emanates from the needs of dying patients and their families, the increasing percentage of older people, the number of deaths from cancer (The National Board of Health and Welfare, 2005) as well as from a reaction against the denial of death within the traditional health care system (Fürst, 2000). There has been a change in the setting where people prefer to die, from hospitals to special types of housing or patients’ homes, where primary healthcare teams are responsible for the greater part of the extended home care (Berterö, 2002). The advanced home care is by definition linked to in-patient units with round-the-clock admission services for home-care patients. In-patient units in hospitals also provide palliative care but to a lesser extent than home care (Fürst, 2000). Caregivers close association with hospitals makes resources and expertise easily accessible although, whenever possible, advanced care is provided at home (Beck-Friis, 1997).

3. The study
3.1. Aim
The aim of this study was to elucidate the significance of nurses’ experiences of caring for dying persons at home and in a special unit in a hospital.

3.2. Design
Data were collected by means of qualitative research interviews, which were transcribed verbatim. The text was analyzed using a phenomenological hermeneutic interpretation influenced by the philosophy of Ricoeur (1976) to understand the meaning of caring for dying people. The method has been developed by Lindseth and Norberg (2004) and has been used by researchers such as Sävenstedt and Håggeström (2005) and Rasmussen et al. (1997). The lived experience of a person cannot be transferred directly to another person, but its meaning can be transferred and shared (Ricoeur, 1976). According to Gadamer (1976), we understand others through the interpretation of language, which is the fundamental mode of operation of our being-in-the-world and the all-embracing form of communication of the world.

3.3. Participants
During the spring of 2008, the head nurses of a hospital ward and a home care team were contacted and informed about the aim and method of the study. They were asked to give an information letter to the nurses, asking them to participate. Those who were willing to participate were asked to drop an email to one of the researchers. All the district nurses who
were invited to participate accepted and gave their informed consent. The sample consisted of eight female registered nurses, four of whom worked in a special unit in a hospital setting and the rest in private homes with access to hospital facilities. The registered nurses working in the hospital setting had between seven and 36 years of nursing experience and the home care nurses had between 14 and 37 years. Those who worked in hospital settings had a mean of about nine years, whilst those in home care had a mean of 12 years experience of working with palliative care. The ages of the hospital nurses ranged from 35 to 58 years and the home care nurses’ ages ranged from 37 to 56 years.

3.4. Ethical considerations
The Swedish law about research ethics regulates and defines the research where human beings are involved. According to this law, the above project did not need approval from any external, official, regional or ethical committee as the invited participants were independent persons who were able to take their own decisions and the data collection did not include delicate data about the person’s health. The nature of the study was explained to the nurses and they were informed that they could withdraw at any time if they so wanted. Confidentiality was guaranteed as no names or facts were to be stated in data or report that enabled anybody, other than the researchers, to identify a single participant. Speaking about terminally ill patients and the experiences related to this subject has an emotionally charged nature and may be a painful reminder of various situations. This risk was handled by the researchers by being attentive and sensitive to the interviewees’ emotional reactions. The researchers also gave the participants sufficient time to consider their participation in the study.

3.5. Data collection
The collection of data was performed by two of the authors; T.H with the nurses working in the hospital setting and S.S with the nurses working in private homes. In depth, individual, unstructured audio-taped interviews with a narrative approach were conducted with the participants at a place and time chosen by them. According to Van Manen (1997), the art of a hermeneutic interview is to keep the meaning of the phenomenon open and to go on asking questions. The participants were asked to talk about their experiences of being with people at the end of life. Clarifying and encouraging questions were used such as: Can you explain in detail what you mean when you say…? Can you give an example? The researchers and the interviewees spoke their native language. During the interviews, the researchers attempted to
strike a balance between free story telling and keeping the content within sight of the aim. The interviews were performed in one session with each nurse and the sessions lasted between 55-65 minutes. The interviews were transcribed verbatim and analyzed consecutively by the authors.

3.6. Analysis

The analysis process started with the translation of the transcribed interviews from Swedish into English. The translation was performed by first identifying significant units, condensing them, and re-formulating them in English to facilitate the analysis process among the four authors. The formulated clauses in English were thoroughly checked in several steps by going back to the original Swedish transcription during the whole process of analysis by the three Swedish-speaking authors.

The formulated clauses in English were analyzed using the principles of phenomenological hermeneutics influenced by Ricoeur and described by Lindseth and Norberg (2004). The analysis and interpretation of the text involved a dialectic movement between understanding of the whole and parts of the text through three methodological phases. In the first phase, the interviews were read with an open mind to gain a naive understanding of the meaning of caring for dying persons as well as to initiate the creation of an approach for further structural analysis. Next, a structural analysis was done, in which parts and structure of the text were de-contextualized and systematically analyzed to invalidate or validate the naive understanding. Finally, a comprehensive understanding was formulated. This was based on a dialectical movement between understanding and explanation, between the whole and the parts of the text, and was the final version of several possible interpretations of the text that the authors unanimously agreed upon (cf. Lindseth and Norberg, 2004).

3.7. Results

3.7.1. Naive reading

The text conveys a message that the meaning of caring for dying is seen as an invitation to a private sphere and privilege that creates an ethical demand to meet the needs of unique persons and their families. Nurses are invited to share an understanding of their world through sharing their narratives to support a process of finding meaning in the time that remains within the confines of the narrow space in a hospital setting or in the patients’ ordinary homes. The nurses seem to be aware of the meaning of the term ‘fully present’ as being there for the person and families. Nurses’ reflection on their personal and professional experiences
together with working in an approving, caring context including successful team work seems to support the nurses’ learning and develops their personal and professional identity. This development, evaluated by nurses as a positive process over the years somehow reflected on their high self-esteem and confidence.

3.7.2. Structural analysis

In the structural analysis, the text was divided into meaning units that were further condensed, compared across the interviews, grouped, and labelled. Finally, the labelled groups of the meaning units were abstracted into three themes and eight subthemes (Table 1).

Table 1: The structural analysis ended with three themes and eight subthemes

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
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<tr>
<td>Meeting patients and family members as unique persons</td>
<td>Active listening</td>
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<td>Acting whilst interacting</td>
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<td></td>
<td>Being invited into the family</td>
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<td>Learning in a challenging environment</td>
<td>Appreciating the caring context</td>
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<td></td>
<td>Reflecting on experiences</td>
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<td>Gaining personal strength</td>
<td>Becoming self-confident</td>
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<td>Re-examining self values</td>
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<td></td>
<td>Becoming humble</td>
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3.7.2.1. Meeting patients and family members as unique persons

Meeting each person as a unique human being, not merely as a patient in general, and with honesty as a means to create trust was seen as a prerequisite for providing good care to people who are dying, and their families. This illustrated an integrated view on the palliative care that was often expressed in the text. The person who was dying and her or his family members were seen as united. The text units elucidating this meaning were sorted under the subheadings: Active listening, Acting whilst interacting, and Being invited into the family.

3.7.2.1.1. Active listening

The nurses emphasized the importance of active listening to the dying persons and their families rather than focusing on the physical aspects of care. This required nurses to be fully present especially when patients and/or family members appeared low or upset. Spending time with people in these situations, listening to them and talking with them improved the nurses’ caring interactions to the extent of having a healing effect. Nurses saw that as being
containers for people’s negative feelings and anxiety. Being a good and active listener meant being able to remain silent and just listen. Nurses experienced that people were grateful for their nonverbal communication with them. Nurses felt that listening to people, and becoming aware of their situation and wishes, comforted the people. It also constituted a means to become aware of a person’s needs and preferences, of what they perceived through their senses as tasteful or beautiful:

Suddenly she sat up and told me: “Thank you for listening to me, I feel much better now”. To me, it was comforting for her that I knew what she was going through.

I listened to her; she wanted to get back home, and to be in their sitting room watching the sun going down. I facilitated her leaving. She went home, assisted by her family and died after three days.

To share meanings about existential matters, the nurses tried to be honest about beliefs and values to enable a trustful conversation with the person who was dying. When they got involved in such matters, they attempted to respect the persons’ beliefs and faiths even if their views were different. Sometimes nurses felt that persons needed further existential counseling, and then they referred them to the church or to a priest. In the text it was obvious that it was essential to have courage to be there, to listen and talk with honesty to persons who were afraid of being confronted with their serious prognosis, and to be open for talks about it. There were experiences that such conversations could assist persons to face their own death:

He asked me if he is about to die or not. I dared to be there and confront the issue and could tell him that his time had come. He was really satisfied.

3.7.2.1.2. Acting whilst interacting
The text revealed that the best utilization of time was to actively interact with the person who was dying, whilst carrying out practical caring actions. Therefore, the provision of physical care was often described as combined with emotional care. It was described as providing physical care together with psychological care, not in distinct steps, but as meeting physical needs whilst meeting the dying persons’ emotional needs. Such interactions, even as the nurses were performing their physical tasks, assisted the nurses in creating a trustful relationship where the person’s dignity as a unique person could be maintained. The dying person could be invited to actively keep control over the various steps involved in carrying out painful procedures:
We utilized the time and made this conversation during our practical work, like giving injections. When we do the injection, we tell a joke or use other means in order to make the person relax.

We were there all the time and she was allowed to have the whole procedure under her command. This made it easier for us to deal with such a difficult situation.

3.7.2.1.3. Being invited into the family

The nurses viewed some kind of invitation into the family net as a prerequisite for being able to provide good care with continuity until the dying persons’ life had come to an end. The nurses’ ways of supporting the families were expressed differently by nurses working in the hospital and nurses working in home care. In the home care setting, the nurses were invited to the families’ ordinary daily lives and the family members’ means of caring for their dying person. Nurses in the hospital setting had to provide the family members with the opportunity to take part in the care of the patient. In both contexts the invitation into the family net also meant being involved in ongoing family conflicts. A common conflict described in the context of home care was a disagreement between the patient and the other family members about whether the care, when dying, should take place in the home or in the hospital. In the hospital setting, the nurses described conflicts between different family members that hampered their presence together in the room of the dying person. In both situations the nurses understood that their role was to offer assistance and support when requested, but never to try to solve the conflicts. Supporting the family meant preparing them for the moment of death. The nurses’ counseling of the family members often continued after death had occurred:

She wants to stay at home and the family doesn’t want that. I talked with them. We arranged everything so that it turned out well and with dignity.

I use to be in contact with the family even after the death; it is natural that we meet, to talk and finalise everything.

The sensing of the need to support the family was especially relevant at the moment of death. Some families wanted to share this moment together without professionals, whereas others wanted professional carers’ presence. It was emphasized that the invitation had to be based on trust emanating from honesty and providing clear information about the person’s real condition, so as to prepare the family members for facing the inevitable death of their loved one. In the home care setting, the invitation into the family also meant trusting the family
members’ ability, taking risks and accepting that the persons and their relatives would find things out in their own way. Improper or misunderstood communication in the hospital setting could jeopardize the quality of care as nurses had experienced unpleasant and frustrating situations, for example, when the persons were dying and their relatives had not been properly informed about the persons’ real condition:

*The children were holding on to him and they cried and were sad, but they knew as they had been informed that he was peacefully sleeping on drugs.*

*They usually turn up when you are about to leave or at the end when they have collected enough courage. They have to figure out for themselves what they want.*

*The situation in which persons or relatives had not been informed about the fact was unpleasant; it was a mess for them.*

### 3.7.2.2. Learning in a challenging environment

While many nurses identified that caring for dying people required them to grow and develop their own way of caring, the text revealed that they had earned this development. Their development was integrated with the learning process in which they took part. The theme was developed from the subthemes: Appreciating the caring context and Reflecting on experiences.

#### 3.7.2.2.1. Appreciating the caring context

When the interviewed nurses compared the present caring context with their experience of previous caring contexts they indicated an appreciation of the present. Part of the appreciation was the possibility of being part of a context that supported palliative care. For the home care nurses the appreciation meant, among other things, that there were few given tracks or routines and the job was independent compared to when they worked in a hospital. The text showed that nurses found it stimulating to help persons who were dying to have possibilities to remain at home, even when a person needed advanced technical care. In the persons’ homes nurses did their job independently according to their competence. One nurse said that in home care, she was a “person”, whereas in the hospital ward she was one of the “sisters”; one in a flock of others with white coats and name tags. When she compared the two settings, she found her present caring context very stimulating and challenging as it provided a different and better foundation for a person-to-person relationship:
At the ward you are just a “sister”, you are one of the others. In the hospital you have a lot of power and the patient is powerless, naked in his bed, dressed in patient clothes.

In the hospital you can always behave the same way, but here you have to adjust and you cannot behave the same way among different persons.

Nurses who worked in the hospital setting were also aware about their caring context and reflected on the differences they had experienced in other wards. They talked mainly about their opportunities to meet the whole human being in palliative care. They stated that by developing trustful relations with patients, they learned how the patients’ themselves could master pain if they were given the opportunity to “command” caring procedures. Another thing they learned from the patients was to think positively about drugs with severe side effects. Such experiences provided motivation for caring for people at the end of life:

*She told me that she thought of the specific chemotherapeutics as helpers to fight the cancer cells. Such experiences motivated me to stay with them. This is something you can find here, not in the other wards.*

3.7.2.2. Reflecting on experiences

The nurses’ professional development was mainly supported by the professional experiences they had gathered working with dying people and their relatives. The awareness emanated from reflections on their own feelings, reactions and actions in relation to previous and ongoing relations to themselves, patients, family members and workmates. Nurses felt that the closeness and feedbacks received from these relationships were sources of learning and development. A negative feedback was seen as an opportunity to reconsider the caring behavior:

*Hearing some feedback from relatives, mainly the negative ones, gives me a chance to think about how I meet people and then change it. I was grateful when they told me that my behavior was not good.*

*All these encounters I had and what I learned from them over the years has helped me to develop both professionally and personally.*

The nurses’ personal philosophical foundations and personal experience assisted them to give meaning to caring for dying people. They described how their own experience of having a dying family member had affected their approach to these patients. One of them talked about
how her belief in life as a circular process facilitated her caring relationship with people at the end of their lives:

*I believe that life is not just pleasure; it is also laboring and anxiety provoking. This insight helps me to continue with this work.*

Nurses expressed that it was stimulating and essential to be a part of a team. They stressed the importance of trusting each other and sharing common values among the members of the team about the meaning of patient centered care. Trustful relationships and shared commonalities constituted a positive climate of care once it could be achieved. Such sharing of values referred to the colleagues and other professionals involved in the total care of the person who was dying. Working in teams enabled the nurses to manage difficult situations and make decisions. It was important to have consensus when important decisions were to be made. One nurse talked about the sincere efforts she had made in vain to deal with children who were left on their own when their mother had died. She had to leave the matter with another member of the team. She described that as a moment that developed her trust in her workmates:

*I felt it as a progress in my own way that I could trust the other member of the team to take care of the motherless children and not face a breakdown myself.*

Structured and professionally-led group discussions and reflections in the team were felt by nurses as an effective approach to face the problems and also to develop their professional care both individually and as a team. Being open and reflecting on experiences, actions and feelings provided nurses with opportunities to learn. Nurses who worked in the home care setting discussed problems related to the persons or their families in a supervised session led by a professionally educated counselor. Nurses working in the hospital setting expressed appreciation about such counseling, which they had had some time ago. They felt frustrated by the lack of such supervision that could help them to handle their emotional labor:

*I learned together with my workmates in a group discussion with our supervisor. That enabled me to understand the particular situation, so the next time I could handle a similar situation much better.*

The emotional part is trying as one has to function as a container. So it is a matter of having the means to get rid of these also. We had supervision for some time but unfortunately, we do not have it right now.
3.7.2.3. Gaining personal strength
Caring for dying people was enriching as the nurses’ understanding of persons and their family members’ supported their personal development. This was reflected in the text in various expressions that could be grouped under the subheading: Becoming self-confident, Re-examining self values and, and Becoming humble.

3.7.2.3.1. Becoming self-confident
The text revealed that nurses became confident and self-reliant with fewer uncertainties about their caring abilities. The nurses’ high self-esteem emanated to a great extent from the value of their presence for persons and their families. They recognized that by caring for dying people they would be exposed to several painful moments, so they had to accept emotionally difficult situations without attempting to avoid them. They saw themselves as able to keep a balance between being professional and being close to the persons who were dying and their families, even if they could not always alleviate their problems. When nurses viewed themselves as competent in caring for people who were dying, the text revealed satisfaction about having improved their sense of self and self-esteem:

*The feeling of being able to understand her, and meet her last will was really satisfying. We learn how to control our feelings, be professional and not be influenced by anxieties in order to be able to work.*

The nurses’ self-confidence assisted them to stay close to the persons who were dying and their families. They did not need to distance themselves from the persons involved in the process of dying. From their experience, they learnt that they could handle situations much more difficult than what they had anticipated. One nurse talked about her strong integrity that led her to remain self-reliant and yet let the persons who were dying and their family members come as close as they needed to in a specific situation:

*I have quite strong integrity and every person can come under my shell and trust me.*

In some situations nurses relied on their intuition. They talked about being able to know something immediately without any conscious use of reasoning. This was also expressed as having learnt to follow “gut feelings” as a metaphor for intuition. Through this experience, the nurses could recognize when a person was about to die. The nurses used such intuitive knowledge to inform, counsel, instruct and prepare family members for the approaching death:
I learned to trust my intuition and told the family that she was close to death. The family was grateful because I informed them, so they were prepared to face her death.

3.7.2.3.2. Re-examining self values

Closeness to the dying persons and their relatives, and sharing their experiences of good or bad relations, provided the nurses with many opportunities to discover different and newer ways of interpersonal relationships:

-I am more concerned about relational problems because I encounter many aspects of family relations. If it is possible to have such good relations, maybe I should start looking now.

The nurses claimed that they had changed their outlook on their lives, and had discovered that their views on many things had changed. They had come to value the dignity of life and to enjoy as well as take care of the every day moments. Having cared for people who were dying and their families made nurses re-examine their own attitudes towards life and accept that death is a part of life:

-Sometimes I think death is not difficult for me... For me death is a part of daily life. This way of thinking has developed over the years.

3.7.2.3.3. Becoming humble

The revised view on life and death was considered to be a part of growth as human beings and there were expressions about becoming humble in general and towards their fellow human beings in particular. They had accepted that they did not need to have an answer to everything. They knew more about focusing on possibilities and how to deal with various matters within their own competence. They got used to reviewing their reactions, thinking in a positive way, but at the same time considering their own shortcomings and constructively working on those:

-I have learned a lot about my own reactions and to dare to look at my own shortcomings and work with them.

The nurses had become aware about the fact that there were limitations in what the health care system could provide in order to save a person’s life and that was somewhat disheartening. Caring for patients who would soon die and not being able to help brought feelings of frustration. There was sadness, especially in situations where the nurses identified themselves
with the patients’ situation as when the patient was about the same age or had children about the same age as the nurses’ children:

*I look at them as on my own children and then many bad thoughts turn up. This is a very difficult part of the work. There is so much that is beautiful and nice but this is the black side.*

### 3.7.3. Comprehensive understanding

The meaning of caring professionally for dying people can be interpreted as being invited to provide professional care in a context where the existential space is “a private and last waiting room”. The invitation to this room is demanding and the reality of death is always invisibly present like the air in the room. The existential time has run out for any possible exit for the person who is going to die within an unknown but near future. Being in the last waiting room demands nurses to alleviate pain and suffering whilst supporting the dying persons’ dignity and well being as well as preparing the family members for the coming separation. To care professionally in this last waiting room, in a literal sense, can take place in the context of a private home or in a special unit in a hospital ward. Care, in these different contexts, actualizes the common values of honoring persons and their families as unique persons and thereby develops the nurses’ professional identity including their self-confidence and positive changes in their values. This development was supported by the nurses’ learning from their personal and professional life histories and team reflective practices. Both hospital and home care nurses were able to reflect on their own experiences in a team, but the latter did so under specific supervision. The nurses’ development of their professional identity seems to be stimulated by their satisfaction of being invited to care for the dying person in the “last waiting room”.

### 4. Discussion

The meaning of caring professionally for people at the end of life and their family members was comprehensively understood as being invited to care professionally within the context of the existential space that could be seen as “a private and last waiting room”. The reality of death was invisibly present as the only possible exit for the person who was going to die within an unknown but near future. There was a founding value of honoring the persons who were dying with dignity as unique persons, a value that guided the nurses’ delivery of care to the dying persons and their families. This is consistent with the philosophy of palliative care described as honoring and protecting those who are dying, and conveying by word and action
that dignity resides in people (Field & Cassel, 1997). The results in this paper showed that preserving dignity in the nurses’ practice meant getting involved in interpersonal caring relationships with persons and their families, grounded in honesty, trust and with respect for the involved peoples’ autonomy. The value of dignity was reflected in each nurse’s active effort to understand the patient's situation from his or her perspective within a person-to-person relationship. This is similar to Fagermoen’s (1997) results regarding nurses’ professional identity. The meaning of care for dying persons, as revealed in the text, was about person-to-person relationship. It was essential for achieving knowledge about each unique person and his or her family members to be able to provide them with open and correct information in a way that they could understand and ultimately support the dying person to live his or her remaining life as meaningfully as possible. This also prepared them to face the moment of death. For many dying patients and their families, being able to access information and knowing the details of their condition and how death will arrive are critical aspects of a dignity-conserving strategy (Chochinov, 2006). According to Fagermoen (1997), values that guide the nurses’ actions and interactions are expressed in the nurses’ actions in relation to others.

The meaning of care for dying persons was also comprehended as the development of nurses’ professional identity emanating from working in an appreciative caring context. All nurses were appreciative of the context in which they worked, although their different caring activities together with their different personal and professional life histories influenced the culture of their organizations. According to Bauman (2000) culture is the continuous and unending structuring activity that constitutes the core of the human mode of being in the world. This was reflected in the home care nurses’ experience of their caring context that enhanced their competence, autonomy and interpersonal caring relationships with persons compared to previous experiences of working in a hospital setting. Similarly, home palliative care nurses in a study of Berterö (2002) perceived that they were in control over the caring situation being in charge of the patient and the relatives when caring for dying patients. In both contexts, the nurses’ professional identity was developed in interaction with other nurses and professionals in a team work, where common values and a caring culture were developed. Bradby (1990) described it as the consequence of a ‘collective passage’ (p. 1223) of people starting at the same time, and being ‘all in the same boat’ (p. 1223). Hertting (2003) also found that insecurities concerning professional identity could result in nurses holding each other back by being insecure about professional statements.
The nurses’ development of professional identity was integrated with the learning process emerging from reflections on their relational experiences with the dying persons and their family members. This is in line with Fagermoen’s (1997) view that professional identity emerges through a process of self-formation in which social interaction and self-reflection are basic processes. The text revealed that an important part of constructive and developing reflections was made together with workmates. Reflective practices are empowering where they help caregivers to make decisions, share and support ideas and views and create an identity that strengthens team cohesion (Ghaye, 2005). The nurses’ team reflective practices contributed to their learning and the development of their professional identity. Reflection is a process of reviewing an experience of practice to describe, evaluate, and so inform learning about the practice (Reid, 1993). In the context of home care, team reflective practices were made in special counseling sessions mainly when nurses faced difficult situations, whereas hospital nurses felt frustrated because of the lack of such counseling in care work. Similar experiences are also reflected in R. Uys et al.’s (2005) study of district nurses’ caring work with chronic patients. It was found that the access to special counseling helped the district nurses to cope with stress resulting from the caring relationships with those patients and improved their job satisfaction.

According to the findings, nurses’ development of their professional identity was reflected in their perception of their self-esteem and in their re-examination of self values on life and death. Similar findings are reported by Olthuis et al. (2007), Gaydos (2004) and Wright (2002) who found that nurses reflected on their own mortality awareness as a consequence of dealing with the reality of death and dying. The nurses’ increased self-confidence and maturity contribute to their development as professional carers and are somehow interwoven together. “Self-knowledge, tolerance of stress and trust in one’s own capacity and feelings were found to be the personal characteristics of a nurse with a developed professional identity.” (Öhlén & Segesten, 1998, p. 722). Being a hospice nurse requires interpreting professional activities in the light of being a person, which makes professional development a key contributor to increased self-esteem (Olthuis et al., 2007).

5. Methodological considerations
In a phenomenological hermeneutic study, the transcribed text is in focus. In this study, the translation of the narrated experiences has been a challenge. The interviews were made in Swedish and translated into English during analysis. The authors have Iranian and Swedish
backgrounds and English is a second language. It is possible that some important aspects in
the interviews may have been lost during the course of this study. However, the authors have
worked with the text in a thorough manner, where the translations and interpretations have
been checked and discussed by studying the original text several times. The analysis must be
judged from the authors’ trans-cultural backgrounds. However the Swedish co-authors
functioned as cultural agents to ensure that the concepts were understood and linked to the
Swedish context. The phenomenological hermeneutic approach also implies an awareness of
pre-understanding, which allows opportunities to elucidate the phenomenon. The authors were
specifically familiar with the caring for dying persons and the environment in home care and
hospital settings. However, reflections were necessary on how this influenced the
interpretation throughout the entire research process. Moreover, all nurses were chosen both
to work and to participate in this study, so that the research findings may not be reflective of
the nurses’ experiences elsewhere.

6. Conclusions

The development of professional care for people in “the last waiting room” demands that
nurses support the patients’ well being through positive stimulation of all means of perceiving
the world, for example, offer beautiful views, tasty meals. This was the main value followed
among nurses in private homes or a specific unit in a hospital to meet each patient not just as a
general patient, but a unique being and part of a family. The value can be manifested
differently depending on the caring context. In private homes nurse are temporal, professional
“guests” and have to be sensitive to the unwritten rules and atmosphere prevailing in each
family. In hospitals, the patients and the relatives are temporary guests; therefore, nurses have
to be even more sensitive to the way of meeting each unique person. The meaning of this
founding value develops over the years into a process and needs to be supported by caring
context, including teamwork, with reflective practice and counseling based on nurses’
personal and professional histories.
7. References


