Dignity in the end of life care
To Joel and Stella
Lise-Lotte Dwyer

Dignity in the end of life care
What does it mean to older people and staff in nursing homes?
Abstract

The discussion of a palliative care and a dignified death has almost exclusively been applied to people dying of cancer. As people are getting older and are living longer, nursing homes have become an important place for end-of-life care and death. Dignity is a concept often used in health care documents but their meaning is rarely clarified.

The main aim of this thesis was to gain a deeper understanding of what dignity meant to older people in end of life care as well as to nursing home staff. The thesis comprises four studies. The first and second study involved older people living in nursing home settings studied from a hermeneutic perspective. In the first study twelve older people in two nursing homes were interviewed two to four times over a period of 18–24 months during 2002–2003. Altogether, 39 interviews were analyzed by a hermeneutic method. Dignity was closely linked to self-image and identity. The themes of unrecognizable body, dependence and fragility constituted threats to dignity. The third theme, inner strength and sense of coherence, seemed to assist the older people in maintaining dignity of identity. In the second study the aim was to acquire a deeper understanding of how three older women from study I, created meaning in everyday life at the nursing home. A secondary analysis was carried out and showed meaning in everyday life was created by an inner dialogue, communication and relationships with others. The third study was to explore nursing home staff members’ experience of what dignity in end-of-life care means to older people and to themselves.

Totally 21 interviews with staff were carried out and analyzed through a qualitative content analysis. The meaning of older people’s dignity was conceptualized as feeling trust, which implied being shown respect. Staff members’ dignity was conceptualized as maintaining self-respect. Dignity was threatened in situations where staff experienced themselves and the older people as being ignored and thereby marginalized. The fourth study was carried out through focus groups discussions with 20 staff members about seven older peoples dying death and care. The analyses showed that conversations and discussions about death were rare. Death was surrounded by silence. It was disclosed that the older dying person’s thoughts and attitudes of death were not explicitly known. A dignified death meant alleviation of bodily suffering and pain and meaningfulness. The staff’s ethical reasoning mainly concerned their experience of a gap between their personal ideals of what a dignified end of life should include and what they were able to provide in reality, which could result in conscious stress. Staff members need training and support. End of life care demands competence and teamwork.

A challenge for future care of older people would be to develop a nursing home environment in which human dignity is promoted.

Keywords: dignity, meaning, caring, end of life care, palliative care, older people, and staff

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Original publications

The thesis comprises the following four papers, which will be referred to in the text by their Roman numerals.


III. Dwyer L-L, Andershed B, Nordenfelt L, Ternestedt B-M. Dignity as experienced by nursing home staff. Revised submission.


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INTRODUCTION
This thesis is part of an interdisciplinary project entitled ‘The importance of the home as the final place of care – Ethics in the spheres of the home and the institution’. The project involves cooperation between nursing researchers, philosophers, theologians and ethnologists at five institutions of higher education in Sweden: Ersta Sköndal University College, Borås University College, Linköping University, Södertörn University College and Örebro University, within the research school Health, Care and Values. The aim was to identify the care conditions in different types of accommodation from the perspective of older people and staff. Four theses were planned within the project and this is the second one. My thesis focuses on dignity in relation to older people at the end of life and the staff who care for them. The overall aim is to seek a deeper understanding of the concept of dignity from a caring science perspective.

Pre-understanding
Pre-understanding plays a significant role in hermeneutics and it is considered impossible to grasp a phenomenon without it. According to Gadamer (1989), the reader cannot understand a text in the same way as its author, but can acquire a new understanding. Pre-understanding can be seen as the ground on which new understanding is built (Ödman 1979; Ödman 1992).

My practical nursing experience mainly involves working with older people in nursing homes and in community care. The older people I met were all dependent on the staff for help with the activities of everyday life. This made them vulnerable, both physically and sometimes emotionally, and I often wondered about how they experienced dignity in their lives. In 2001, participation as a research assistant in a project that focused on the collaboration between research, education and clinical practice in cancer nursing called ÖS (Örebro/Stockholm) provided me with an insight into palliative care philosophy.

As my practical nursing experience is rooted in the care of older people, I began to reflect on the concept of dying with dignity from the perspective of older people, as their dying process often is of long duration. It became clear to me that older people did not have the same access to palliative care as other groups. The palliative care philosophy seemed to be mainly applied to people with cancer. In my opinion, this can be seen as discrimination against older people. When the opportunity arose to be part of the project entitled ‘The importance of the home as the final place of care – Ethics in the spheres of the home and the institution’ and write a thesis on this subject, it seemed natural to seek knowledge about how older people approaching the end of life experience dignity and the care they receive.
BACKGROUND
Caring – A human science

My thesis is based on a humanistic caring science perspective, which is concerned with ontological questions about what it means to be a human being. Each individual is seen as able to create meaning and as having the will to do so. Viewing the individual as a whole person or as a unity of body and mind is the foundation upon which caring is based. It means that a person can only be understood in relation to his or her life-story in the specific context in which he or she exists. The holistic view of the person on which caring science is based upon was highlighted as early as in the 1850s when Florence Nightingale introduced a framework in nursing with focus on the person, the body and the environment. To reach a deeper understanding of how older people and staff experience dignity, a human science approach was chosen. The hermeneutics of Gadamer (1989) is influenced by an existentialistic view of man, which corresponds to caring science based on a life-world perspective. A nursing theory with a similar perspective on the human being was presented by Joyce Travelbee (1971). This theory is based on a view of man influenced by existential philosophy. Its central concepts are the human being as an individual, suffering, meaning, interaction and communication. This view is of importance in the present thesis, despite the fact that Travelbee’s theory is not explicitly related to dying people. According to Travelbee, suffering is a fundamental human experience that affects everyone and thereby both generalized and unique. Travelbee describes two of the most typical reactions to suffering as: Why me? and Why not me? Suffering is described as related to what the individual human being values in life. Another core concept in Travelbee’s theory is meaning. According to Travelbee, a person who finds meaning in illness and suffering receives an answer to the questions ‘Why did this happen to me?’ ‘How am I going to get through this?’ Communication and relationships are key prerequisites in nursing care and the caring relationship is built on respect for and understanding of each individual. Being able to see the other person for who he or she is, involves re-evaluating the first impressions of a person and building the relationship step by step. Travelbee emphasizes the need to see the individuals behind the “labels” of nurse and patient (Travelbee 1971). She considers the human being as a unit made up of an inseparable body and mind, which is close to a life-world perspective. This perspective was also the starting point in a Swedish thesis describing experiences of suffering and relief of suffering, as expressed by people in an advanced stage of cancer. When the body changes due to illness and ageing, it affects one’s identity (Öhlén 2000). Identity originates in the lived body. The bodily and emotional losses to which a person is exposed challenge his or her self-image and experience of identity (Qvarnström 1993, Ternestedt et al. 2002, Nordenfelt 2004, The National Board of Health and Welfare 2007).

In literature as well as in everyday conversation, the concepts of caring and nursing are used synonymously as well as two concepts with different meanings. There is consensus about caring embracing different caring disciplines, for example occupational therapy, medical care and nursing. Caring is also described as the essence in nursing (Leininger 1981). This draws attention to Noddings (2002) that states that caring is basic in human life and that the human being is guided by an ethic of care in the caring of others. Values such as, concern, goodness and love to one self as well as to others, appears as fundamental starting points in care. In the literature, caring has often been described as ‘caring for’ and ‘caring about’. Caring for means doing something for another person, for example, in the case of helping him or her to eat and stay clean. Caring about is less action related and relates more to the way in which the carer shows an understanding and respect for the other
person’s being, his or her way of thinking and feeling (cf. Cronqvist et al. 2004). The latter also highlights the moral aspect of care, which includes the way in which care is provided.

Fawcett’s (1989) articulation of the four concepts within nursing science; person, environment, health and nursing, has served as a foundation for many of the models within the nursing theory discourse. Dahlberg and co researchers (2003) have to the four concepts added a life-world perspective, suffering/wellbeing and the subjected body. They as many others emphasize that the patient perspective should guide the care. Dignity is not explicitly mentioned. However, the international Code of Ethics for Nurses state that inherent in nursing is the respect for human rights, including the rights to life, to dignity and to be treated with respect.

Health is described by Eriksson (1994) as an integrated state of well-being. This means that a person who is going to die can experience health (Lindqvist 2007). Russel and Sander (1998) have discussed the concept of a healthy death and considered that a health-promoting care is an important aspect in end of life care. They define health as a person reaching his or her realistic goals. The nurses attitude will according to Russel and Sander (1998) involve advocating, communicating and enabling possibilities of promoting health. The environment in which the care is carried out is also of importance for a person’s health. Fryback (1993) is also of the opinion that a person can keep their health until death. Health is defined as having the capacity to hope, being able to have control over one’s life and being able to give and receive love. Fryback (1993) emphasises the person’s spiritual health, which involves the beliefs in something greater than oneself.

Ageing and living close to death
Out of the 90 000 people who die in Sweden every year, 60 % are over 80 years old (The National Board of Health and Welfare, 2006). Thus many older people die in nursing homes or other forms of sheltered accommodation. The average life expectancy in Sweden has never been as high as it is today, and the prognosis is that it will continue to rise. According to Statistics Sweden, the population over the age of 65 years will have increased by 13 % by 2010 and the proportion of people over the age of 85 by 20 %, of which 68.2 % will be women. In 2001, 30 % of those aged 85 and over lived in some type of sheltered accommodation (The National Board of Health and Welfare 2006). This development is also seen in studies from other countries, such as Canada, the USA and England. In a Canadian study, Ross and co researchers (2000) report that by 2031 one out of every four people will be over 65 years old. They consider it important to take this fact into consideration when planning for future health care, especially as older people often suffer from multiple illnesses and have significant care needs. In order to ensure quality of care for older people, some western countries such as Canada (Ross et al. 2000) and Australia (Australian Government Department of Health and Aging, 2004) have developed national end-of-life guidelines. No such guidelines have yet been introduced in Sweden, although the overall aim of the care of older people is set out in various policy documents. The National action plan for the care of older people, for example, stresses that they should be enabled to live an active life, provided with the opportunity to influence their environment and allowed to age with a feeling of security. End-of-life care should be of high quality, ease pain and discomfort and take place in a peaceful environment. Personal wishes should be accommodated as far as possible, help should be provided where required, no one should have to move unnecessarily between different forms of accommodation or hospitals and no one should have to die alone (Government Bill, 1997/98:113, author’s translation).
Although the concept of dignity is not explicitly expressed in this part of the action plan, there is a clear emphasis on its promotion.

In 1992, the so-called Ädel reform was implemented in Sweden, one aim of which was to promote continuity for older people. Responsibility for older and disabled people was placed on the municipalities, which also encompasses older people’s end-of-life care.

Older people as a particularly vulnerable group

Many studies show that some older people close to death are at a higher risk of not receiving adequate treatment and not having their needs met in a satisfactory way, especially older women with a limited social network (Ross & McDonald 1994, Clare & DeBellis 1997, Ahronheim 1997, Thomé et al. 2004) and older people with dementia or other cognitive impairments (Hallberg, Norberg & Eriksson 1990, McCarthy et al. 1997).

People with various chronic illnesses are also at risk of undertreatment (Gibbs & Addington-Hall 1998, Addington-Hall et al. 1998). However, some studies reveal that older people can be overtreated as a result of interventions without a specific aim. For example, Lynn (1997) described how older people were subjected to revival interventions that were of minimal interest to this age group. Under and overtreatment can be difficult to identify, which highlights the need to involve both the patient and his/her relatives in the care planning (Andershed, 1998; Eldh, 2006).

According to some researchers, undertreatment reflects the view of older people in contemporary society. Froggatt (2001) and Lloyd (2002) employ the concepts of marginalization and discrimination in their reports on the situation of older people. The “Better care for older people at the end of life” report from the WHO (2004) explicitly states that palliative care should involve older as well as younger people. The former do not have the same access to palliative care as their younger counterparts with cancer (Källström Karlsson et al. 2006). Grande and co researchers (1998) noted this and revealed that older women did not have the same access to palliative home care as other groups. Tishelman (1993) found that, in general, older people had less access to health care due to their age, which can be seen as an expression of ageism. The definition of ageism is that a person is discriminated against on account of his/her age and met by a stereotyped view often based on perceptions and myths, instead of being seen as an individual (Andersson 2002).

The need to ease suffering

Older people’s death and dying is characterised by suffering as a result of various diseases and the ageing process. Many have met death through the loss of relatives or close friends. The dying process of older people often lacks specific turning points (Ross, Fisher & MacLean, 2000, Jakobsson 2007, Andersson 2007) and is therefore more difficult to foresee. Their death and dying has been described as a “slow death” and as gradual burn out (Rinell Hermansson 1990, Whitaker 2004). The death of older people is often experienced as more natural and less dramatic than the death of a younger person (Payne, Langley-Evans & Hillier 1996, Ternestedt et al. 2002). However, studies that focus on the thoughts and existential needs of older people show that their needs are often congruent with those experienced earlier in life. In a relatively early study, Fry (1990) found that many older people expressed a fear of losing their self-respect and dignity, dying alone and of what follows death. Older people’s ways of coping with death are described as related to their beliefs and outlook on life (Fry 1990). Rinell Hermansson (1990) studied older
people’s attitudes to death at the end of life by means of interviews with relatives after the person’s death. Some viewed death as a part of life and did not fight it. Others resisted it to the end or were indifferent towards it, while some wanted to die. The wish to die could be integrated within the person but could also reflect temporary thoughts and feelings (Feigenberg 1977, Qvarnström 1979). Some studies that deal with older people’s situation describe meaningfulness, meaninglessness and dignity. Whitaker (2004) found that, among older people, everyday life was to a high extent characterised by meaninglessness. It was described as lacking in content and meaning and the nursing home was characterised as a culture of waiting. The relation between meaningfulness and quality of life has been described as important for severely ill cancer patients (Sahlberg-Blom et al. 2000; Melin Johansson 2007). Conversation and togetherness with others as well as participation in the care have been found to be vital (Thorne et al. 2008). The need to talk about life and death was emphasized by Feigenberg as early as 1977. It is reasonable to assume that older people are no different to patients with cancer in this respect. They have also a need to participate in their care which has been described in several studies (Mattiasson & Andersson 1995, Mattiasson & Andersson 1997, Bottorff et al. 1998, Randers & Mattiasson 2003).

The concept of dignity
A dignified death, an appropriate death and a good death are often used as synonymous but their meaning is rarely clarified. Weisman (1974) discussed an appropriate death by which he meant a dying and death that reflects the person’s identity and values. The concept of dignity is frequently used in daily nursing practice and has a significant role in both Swedish and international healthcare documents (The Health and Medical Service Act 1982:763; SOU 1997; Department of Health, 2001: International Code of Ethics for Nurses, 2000). A number of researchers have carried out studies connecting this concept to nursing activities. According to Haddock (1996) and McIntyre (2003), dignity is of relevance to all those involved in caring. Enes Duartes (2002), Fenton and Mitchell (2002), Seedhouse and Gallagher (2002) and Jacelon and co researchers (2004) emphasize the importance of the relationship between the patient and health care staff, stating that it is a vital element in the promotion of patient dignity.

According to Jacelon and co researchers (2002), dignity is related to basic humanity. Human dignity can be experienced subjectively as an attribute of how a person perceives him/herself and is revealed through a person’s behaviour towards self and others. Gallagher (2004) attributes two important values to the dignity concept. Self-regarding dignity refers to one’s own sense of personal dignity, while other-regarding dignity concerns others and includes activities that strengthen their dignity. This is close to what Haddock (1996) described as having dignity, being treated with dignity and actively giving dignity to other people. These studies highlight the fact that dignity is closely related to identity. Nordenfelt (2004), who discusses four types of dignity, states that a person’s dignity of identity is affected by ageing itself, as it is followed by for example, loss of autonomy. A person’s dignity of identity can also be affected by how a person is treated by others. Dignity of identity can be violated, while dignity of merit can be reduced by, for example, societal values. The third type of dignity, dignity of moral stature, can be affected when a person engages in questionable activities that have negative consequences for him/her or others. The fourth type of dignity, dignity of Menschenwürde, is a universal type of dignity that is common to all human beings due to their humanity, irrespective of status or situation. Universal dignity can never be lost unlike other types of dignity of a more
temporary nature. The temporary nature of dignity is also highlighted by Street (2001) she describe dignity as socially constructed and dependent on the situation.

**Death, dying and palliative care**
The hospice movement started in the late 1960’s at St Christopher’s hospice in London, UK. The hospice philosophy initially aimed at a middle road between under and over treatment. St Christopher’s hospice soon became a centre of excellence in terms of clinical care, education and research as well as a source of inspiration all over the world. The first definition of palliative care formulated by the WHO in 1989 was grounded in the hospice philosophy. Today, palliative care is seen as an intervention that can be offered alongside potentially curative treatment. The palliative caring process has been recognised as helping the patient through the final stages of life and to experience a ‘good’ death. The most recent definition from the WHO states: ‘Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual’ (WHO 2004 p. 14).

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<td>- provides relief from pain and other distressing symptoms</td>
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<td>- affirms life and regards dying as a normal process</td>
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<td>- intends neither to hasten nor prolong death</td>
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<td>- integrates the psychological and spiritual aspects of the patient’s care</td>
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<td>- offers a support system to help the family cope during the patient’s illness and in their own bereavement</td>
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<tr>
<td>- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated</td>
</tr>
<tr>
<td>- will enhance quality of life and may also positively influence the course of illness</td>
</tr>
<tr>
<td>- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.</td>
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(INTERNATIONAL WORKSHOP ON PALLIATIVE CARE)

Cicely Saunders states: ‘Palliative care begins from the understanding that every patient has his or her own story, relationships and culture, and is worthy of respect as a unique individual. This respect includes giving the best available medical care and making the advances of recent decades fully available, so that all have the best chance of using the time well’ (WHO 2004 p. 7). The palliative caring process has been illustrated as helping the patient through the final stages of life and reaching a ‘good’ death. One important essence in palliative care as in all nursing is that it has its starting point in the patient as a person.

**Care close to death – staff members’ job satisfaction**
Health care staffs are an important part of the care culture and those who work within care contexts where many die, such as sheltered accommodation, can be exposed to a high level of strain (Wallerstedt & Andershed 2007). As a result of concern for, and engagement in an older person’s life and care over a long period of time, health care staff described experiencing grief when an older person dies. Grief is stated to be part of the everyday
work when caring for older people (Magnusson 1996). Studies show that health care staff is exposed to extra stress (Beck Friis et al. 1991; Vachon 1993, 1998; Glasberg et al. 2007) and that factors related to job satisfaction often have a major impact. However, studies carried out within hospice care that focus on the working environment show that the experience of stress is rare (Beck Friis, Strang, Sjödén1991), which, according to Vachon (1993, 1998), is related to the tradition of continuous support inherent in palliative care philosophy. Källström Karlsson and co researchers (2008) found that a common care philosophy could be a shield against stress. The joy and satisfaction in carrying out an important task may reduce stress and increase the quality of the care, thus promoting the patients’ experience of dignity. The organizational structures, in regard to providing a ‘good’ palliative care differ between specialised palliative care units/hospice and nursing homes. Studies show that staff in community care are offered little support and encouragement (Weman, Fagerberg 2005) as well as education and supervision (Fläckman et al 2007). Hansebo and Kihlgren (2004) described how supervision could increase awareness of older people’s needs. Kihlgren (1992) have found that education for those working with older people suffering from dementia also can promote the older person’s integrity (Kihlgren 1992). The relationship between health care staff and patient has been described as vital for promoting dignity (Fenton & Mitchell, 2002, Seedhouse & Gallagher 2002, Jacelon et al. 2004). Supervision and support has also been described as one factor of importance for nurses’ willingness to remain in older people’s care (Fläckman et al 2007). From this perspective, it seems important to understand staff members’ reasoning about dignity.

**Rationale for the studies**

Studies published during recent years, including those by the WHO, have highlighted the importance of implementing the principles of palliative care philosophy in the care of older people. Due to the fact that some studies describe older people as being marginalized and discriminated against, it is necessary to study the meaning of dignity at the end of life from the perspective of older persons. Few studies on this subject have been carried out in the Swedish context. There is also a need to acquire knowledge about how staff members experience caring for dying older people with a focus on a dignified death and what dignity means to them. In view of the need to hire staff to care for older people in the future, it would be beneficial to illuminate how present employees experience their work. This need is all the more urgent in view of the growing number of older people in society and the assumption that health care resources will not increase at the same rate. It is thus important to acquire knowledge of how staff and patients in nursing homes experience everyday life with focus on dignity.
AIMS
The overall purpose of this thesis was therefore to gain a deeper understanding of what dignity means to older people in end-of-life care as well as to nursing home staff. The thesis is grounded in a human science perspective and comprises four studies, all of which were carried out using qualitative methods (Table 1).

Specific aims
The aim of study I was to explore the views on dignity expressed by elderly people living in a nursing home.

The aim of study II was to acquire a deeper understanding of how three older women created meaning in their everyday life in a nursing home.

The aim of study III was to explore nursing home staff members’ experiences of what dignity in end-of-life care means to older people and to themselves. An additional aim was to capture staff members’ views on what can promote and hinder dignity.

The aim of study IV was to investigate nursing home staff’s way of reasoning about older persons’ death and dying.

Table 1 Overview of the studies in this thesis

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<th>Study I</th>
<th>Study II</th>
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<td><strong>Aims</strong></td>
<td>To explore the views on dignity expressed by elderly people living in a nursing home.</td>
<td>To acquire a deeper understanding of how three older women created meaning in their everyday life in a nursing home.</td>
<td>To explore nursing home staff members’ experiences of what dignity in end-of-life care means to older people and to themselves. An additional aim was to capture staff members’ views on what can promote and hinder dignity.</td>
</tr>
<tr>
<td><strong>Methods</strong></td>
<td>Data collection: Repeated interviews (a total of 39 interviews) Data analysis: Hermeneutic method</td>
<td>Data collection: Secondary analysis of 12 interviews from study I Data analysis: Hermeneutic method</td>
<td>Data collection: Interviews (a total of 21 interviews) Data analysis: Qualitative content analysis</td>
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<tr>
<td><strong>Participants</strong></td>
<td>12 older people over an 18-month period</td>
<td>3 older people over an 18-month period</td>
<td>21 staff members</td>
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METHODS

Theoretical and methodological considerations

In study I, a hermeneutic interview and analysis method was chosen. Study II comprised a secondary analysis of twelve interviews with three participants from study I. A hermeneutic method was chosen in order to acquire a deeper understanding of older people’s experiences of dignity and meaning (Ödman, 1992). Understanding can be seen as a process where the interpretation is focused on viewing a phenomenon from the perspective of the informant. I therefore tried to create a dialogue with the older people during the interviews. Gadamer (1989) uses the expression ‘a fusion of horizons’ to denote a fusion between the horizons of the researcher and informant. The process is concluded when the researcher considers that he/she has arrived at a reasonable interpretation and tested it in relation to alternative interpretations. Such an interpretation relates to the whole and the parts in a logical way and describes them to the reader in a manner that is reasonable. A reasonable interpretation of existential conditions is that which creates a more plausible whole than others. This interpretation process helped to explain underlying meanings in the data where different statements from the encounter with the older person were compared. In the process, I started from the whole and tried to obtain an understanding of the parts. The relation between the whole and the parts is dialectic and has no particular ending. This movement between the whole and the parts is often exemplified as the hermeneutic spiral. Generalizations are not sought from a natural scientific perspective, as the individual’s life world encompasses his or her unique experience and is exclusive to him or her. However, if the study is carried out rigorously, findings from a study could be applied, or be of interest to people outside the study with similar problems (Dahlberg et al 2008).

An interpretative approach was also used in studies III and IV, where the method employed was qualitative content analysis as described by Patton (2004). In study IV focus groups discussions (FGDs) were chosen, which are deemed suitable when concerns, experiences, attitudes and perceptions related to a clearly defined topic or concept are searched for (Webb & Kevern 2001; Barbour 2005). FGDs are also relevant when interaction and group processes could be a help in clarifying perceptions of importance for the results (Kitzinger 1995)

Settings and participants

Studies I and II

Older people living in two nursing homes were included in these studies. Both nursing homes were located within the same geographical area in a major town in Sweden. The accommodation provided for the residents comprised a single room with a kitchenette and private bath and toilet. The furniture was the resident’s own with the exception of the adjustable bed, which fulfils work environment requirements. The dining and TV area in both nursing homes was communal; although most people had their own TV set and often watched TV in the privacy of their own room.

Head nurses employed at two units in the two nursing homes identified a total of 16 possible participants out of a maximum of 26. The inclusion criteria were: in an early palliative phase (nearing the end of life, which is an extension of the traditional meaning of palliative care that focuses on an individual’s final months, weeks or days); able to talk; not suffering from memory loss; and capable of understanding the purpose of the study and the meaning of their own participation. Three people declined participation, while one took
part in only a single interview and thus had to be excluded from the study since the aim was to interview the participants several times. This resulted in a total of 12 participants.

**Study III**

I interviewed the staff working at four nursing homes. Two of the 4 groups of staff worked in the nursing homes where studies I and II were carried out. The nursing homes were located in the same geographical area in a Swedish town. They all provided single rooms and 24 hour staffing. A physician visited once a week and examined those of the older people who were assessed by the RNs as requiring medical attention. Purposeful sampling was used in order to obtain variation and obtain information-rich interviews (Patton, 2004). After receiving written and oral information about the study, the nursing home managers and head nurses at the four nursing homes asked the staff at planned staff-meetings whether they would be willing to share their experiences and participate in the study. This resulted in a total of 21 staff in both private and municipal nursing homes agreeing to take part.

**Study IV**

Seven interviews (groups) with a total of 20 staff members from four nursing homes within the same geographical area as those in studies I, II and III were included in this study. They were interviewed about their experiences of the end of life and death of seven old people (six women and one man), all of whom were aged over 85 years. The head nurses in the four nursing homes were asked to report when an old person died. I reminded them by phoning each unit every two weeks. I arranged an appointment for focus group discussions after the head nurse or manager had asked interested members of staff what time would be convenient for them. The interviews were carried out with staff who had been involved in caring for the person who had died. One person declined participation; hence a total of 20 staff members took part in the focus group discussions.

**Data collection**

**Interviews**

All studies (I–IV) are based on audio-taped interviews, the overall purpose of which was to obtain descriptions of experiences from the perspective of older persons living in a nursing home and those of the staff who worked there and cared for the old people. I conducted between 2 and 4 interviews with each informant in studies I and II, in addition to informal conversations with the majority of them. Different themes were focused upon in the interviews, but the older persons willingly and repeatedly narrated about specific events. This meant that I obtained glimpses of the long lives they had lived. For each of the older persons, the interviews were compiled into an interpreted whole at individual level. However, for reasons of confidentiality, the results are reported at group level, which means that I brought together the interpreted whole of the 12 individual interviews into a comprehensive interpretation of the old people’s experiences. Three themes emerged; (1) the unrecognizable body; (2) fragility and dependence; (3) inner strength and sense of coherence (study I). In study II, the corresponding process was conducted, this time with focus on the creation of meaning. This secondary analysis was based on three purposefully selected interviews due to their richness and the reflective content, which revealed various ways in which meaning was experienced and created. The data in this thesis therefore contain older people and staff members’ descriptions of their everyday life in the nursing home. Every effort was made to ensure that the dialogue was characterized by openness. The researcher’s influence on and role in the interview situation need to be taken into account. Since the interviewer is an agent in obtaining information, his/her integrity, honesty and experience are important in all forms of research but especially when dealing
with human interaction and interpretation. Patton (2004) describes interviews as a type of interaction. The interviewer must be aware of the reaction of the informant and the kind of feedback that helps to maintain the flow of conversation. Interviewing the older people over a longer period allowed possibilities to re-evaluate interpretations from time to time.

Throughout this thesis, pre-understanding was addressed by a conscious decision to be as open as possible to the data. From an existential hermeneutic perspective, this means being aware that pre-understanding is always present; whether in the actual encounter with another person or when analyzing a text, it means being as open as possible to what is being said. I have attempted to follow this principle.

**Data analysis studies I and II**

In order to understand the older people’s views of dignity, I tried to capture each individual’s own perspective, i.e. their way of thinking, feeling and reasoning. In the process of understanding, I started with the whole and within this framework then moved to the parts of the text. The relation between the whole and the parts was dialectic and has no particular ending (the hermeneutic circle). This movement between the parts and the whole is not easy to present in the form of a table. I conducted between 2 and 4 interviews with each informant, in addition to informal conversations with the majority of them. Different themes were focused upon in the interviews, but the older persons willingly and repeatedly narrated about a specific event, which meant that I obtained glimpses of their long lives. For each of the older persons, the interviews were compiled into an interpreted whole at individual level. However, for reasons of confidentiality, the results are reported at group level and in order to do so, I brought together the interpreted whole of each of the 12 individuals into a comprehensive interpretation that described their experiences. This interpretation revealed three themes: the unrecognizable body; fragility and dependency; and inner strength and a sense of coherence (study I). In study II, the same analytical process was carried out with the focus on creation of meaning. A purposeful sample comprised three participants, who were interviewed on several occasions, resulting in a total of 12 interviews. The interviews were chosen due to their richness and the reflective content that revealed various ways in which meaning was experienced and created. From a hermeneutic perspective, generalizations are not sought, as an individual’s life world is his or her unique experience and exclusive to that person. This does not mean that a person cannot share his or her experiences with others. The way to reach understanding is through interpretation.

**Data analysis studies III and IV**

An interpretative approach has also been used in studies III and IV, and the analytical method employed was qualitative content analysis (Patton 2004). This method was chosen since the aim of the study was to explore the content of staff’s experiences of dignity and reasoning about death and dying, in contrast to the search for the deeper meaning of a specific phenomenon on an individual level, as in studies I and II. My starting point in the analysis in studies III and IV was the parts of the texts, as opposed to studies I and II, where the starting point was the whole text. The interpretations were formulated in terms of themes that reflected the staff’s perspectives on dignity concerning both themselves and the older people.

In order to describe the content analysis process examples of the coding process in study III is presented in Table 2. Qualitative content analysis, as described by Patton (2004), was applied to the transcribed interview texts in order to identify core consistencies and key
phrases. The analytical process started by reading the interviews repeatedly to identify key phrases, terms and practices related to the participants’ clinical setting that were relevant to the aim, after which the text was coded and categorized in a coding document for each participant. In the next step, the content of the coding documents was analysed, interpreted and compared between participants.

Table 2 Examples of the coding process

<table>
<thead>
<tr>
<th>Quotation from the interviews – codes</th>
<th>Sub-categories</th>
<th>Main categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is the older person we are here for…help them to stay clean, make sure they eat and so on (NA)</td>
<td>Having ones physical needs met – Providing for the persons physical needs</td>
<td>Feeling trust – Showing respect</td>
</tr>
<tr>
<td>…then we can’t just stop asking her just because she moved in here…we are working in their homes (M)</td>
<td>Being seen as a person</td>
<td></td>
</tr>
<tr>
<td>You want to do so much, you know the best for everyone, but it’s just not possible (RN)</td>
<td>Lack of resources</td>
<td></td>
</tr>
<tr>
<td>It has been very difficult to recruit staff. It is almost as if we have been hiring anyone who has walked in here (M)</td>
<td>Conflict between ideal and reality</td>
<td></td>
</tr>
<tr>
<td>Her daughter also quite often brought me flowers. Things like that feels really good (NA)</td>
<td>Meaningfulness- Getting feedback from others</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Maintained self-respect- Being shown respect</td>
<td></td>
</tr>
</tbody>
</table>
Ethical considerations

Studying the experiences of older people who are close to death can give rise to ethical dilemmas mainly due to the difficulties of giving informed consent and their dependency on the staff. A main ethical principle in all research is, however, not to cause harm (Hermerén 1986; Beauchamp & Childress 1994). When conducting the interviews, a guiding principle was to respect the other person’s integrity and personal space. As a researcher I tried to avoid forcing the interview in any way and instead listened to what the informants wanted to say. The researcher has to find a balance between wanting to know more and respecting the other person’s integrity. Informed consent was obtained in accordance with Medical Research Forum standards (Medicinska Forskningsrådet 1996). The nurse provided information about the study, after which the older person signed a letter of consent in his/her presence. During the interviews, the older persons were informed on several occasions that they could withdraw from the study at any time without any risk of negative consequences in terms of their care. All nursing home managers had received both written and oral information about the study. The managers or head nurses then asked the staff in the course of regular staff meetings whether they would be willing to share their experiences and participate in the study. All participants were guaranteed confidentiality. The quotations cannot be linked to any particular person. As the interviews in studies I and II were carried out over a longer period, it was important to provide information about the study at each interview and also to be sensitive to any signs of the person wanting to discontinue participation. This type of negotiation is based on equality between the people involved rather than on power, for example between researcher and participant. After the interviews, my impression was that the staff, but most especially the older people, appreciated my visits and being given the opportunity to talk about important parts of their lives. The interviews contributed to meaning in everyday life for the older people and staff. Approval to conduct the study was granted by the local Research Ethics Committee (171-01).
FINDINGS
Views on dignity of elderly nursing home residents (I)
The older people’s experiences of dignity were categorized in terms of the unrecognizable body, fragility and dependence, inner strength and sense of coherence. Their views were often related to the way in which they experienced the body. The interpretation indicated that it was sometimes easier to give examples of what was undignified rather than describing the meaning of dignity. The themes of unrecognizable body and dependence and fragility constituted threats to dignity. The third theme, inner strength and sense of coherence, seemed to some extent to create a balance between dignity and threats to dignity. In spite of difficulties in their daily life, the older people had a powerful force, an inner strength, which was visible in their different strategies for coping with living in a nursing home. Their experiences of dignity were interpreted as closely linked to self-image and identity. The attitudes of others could both promote and hinder the older people’s sense of dignity of identity, while feelings of being needed and belonging promoted it. The unrecognizable body was often described in terms of no longer being able to control one’s bodily functions and movements. Transgression of boundaries and exposure caused them to experience lack of respect for their integrity. Fragility and dependence mainly meant that the elderly person was very fragile and that his/her present situation was characterized by fear and anxiety about further loss of control, dependence and exposure. Greater dependence and loss of control negatively affected the older person’s autonomy. A sense of coherence was close to a feeling of belonging. Inner strength seemed to assist them in maintaining dignity of identity.

Three nursing home residents talk about meaning at the end of life (II)
This study is a continuation of study I. It reveals that sources of meaning were: having a sense of physical ability; having a sense of cognitive ability; having a sense of being needed; and having a sense of belonging having a sense of physical ability; having a sense of cognitive ability; having a sense of being needed. Meaning was created through an inner dialogue as well as communication and relationships with others. The main finding can be described as the inner dialogue being an important facilitator in the creation of meaning. The “inner dialogue” together with “inner strength” and relationships with others seemed to have facilitated the creation of meaning in life as a whole, including both the past and the present. A second finding was that the experience of meaning can sometimes be difficult to capture. One of the women found it impossible to find any meaning in her present life, and her inner dialogue focused more on her striving to come to terms with her present situation and to reach closure.

Dignity as experienced by nursing home staff (III)
The main finding concerns what the staff experienced as dignity and how dignity can be promoted in relation to the older people and themselves. The meaning of older people’s dignity (the what aspect of dignity) was conceptualized as feeling trust, which implied having one’s basic physical needs met, being seen as a person and having a private sphere. Dignity-promoting care (the how aspect of dignity) meant showing the older person respect by providing for the older persons physical needs, respecting the person’s identity and integrity. Staff member’s dignity was conceptualized as maintained self-respect, which implied experiencing meaningfulness and feeling proud of one’s work. Self-respect was promoted through being shown respect, by feedback from others and the feeling of doing good. Dignity was threatened in situations where staff experienced a conflict between the ideals and the reality. It was obvious that the staff struggled in their everyday practice to cope with this gap, which had an impact on the older person’s care and dignity. Being
ignored and lack of resources were described as a threat both to the older person’s feeling of trust and to the staff members’ self-respect. Another threat to dignity involved hindering the staff from providing a deeper level of care, i.e. more than just basic physical care. How the staff handled their frustration and moral stress was not specifically studied.

**Staff members’ reasoning about death and dying (IV)**

One main category was staff members’ limited knowledge about the older person as an individual. This lack of knowledge concerned how the older people had lived their life before moving into the nursing home, their interests, what gave meaning to everyday life and what thoughts they had about life and death. The latter was not something the staff generally spoke about. It was instead characterized by silence. The staff members’ descriptions have been conceptualized in the categories: Alleviation of bodily suffering and pain; meaningfulness; older people’s thoughts about and attitudes to death; Taking care of the dead body; and ethical reasoning and own actions. The staff members’ reports revealed that they felt comfortable taking care of the remains, which contrasted with how they felt about taking care of the older person before death. With regard to interaction in the focus groups, it was obvious that in some groups there was disagreement between group members about, for example, what constituted optimal pain relief. Some emphasized that the present pain relief regime was not in line with their personal standards, while others felt that it was adequate for the dying person’s needs. Organizational cutbacks, lack of resources, lack of education and little feedback about their work meant that the staff members could not remain true to their ideals and provide the care they considered the dying person needed, which could result in moral dilemmas. The results also show their relatively great interest in discussing questions pertaining to end-of-life care and what could be considered a dignified death. Many important issues were raised and reflected upon during the focus group discussions. The structure used as a guide during the conversations was based on six keywords; self-image, self-determination, symptom control, synthesis, surrender, and social relations, which are often used when planning, documenting and evaluating palliative care, since they can be seen as an operationalization of palliative care philosophy.
DISCUSSION
The overall purpose of this thesis was to obtain a deeper understanding of what dignity means to older people at the end of life, as well as to nursing home staff. The older person’s dignity is illustrated by means of two different perspectives; the older people’s and staff members’ descriptions and reasoning. The main findings in this thesis were summarized into four main areas, one of which revealed that, in the case of both older people and staff members, dignity is closely related to self image and identity. For the older people, this was particularly obvious in relation to their total experience of wellbeing, whether and in which situations they felt trust and whether and how they exhibited inner strength and created meaning in life despite increased dependence, while staff dignity was characterized as maintaining self-respect. The second main finding was that the nursing homes were experienced as silent places, both in terms of everyday conversations and existential issues such as thoughts of life, dying and death. The older people’s daily life was characterized by silence and a dual form of slowness. The third main result was that the staff was at risk of developing moral stress and feelings of guilt, despite being aware that they had little chance of providing the level of care deemed appropriate. Their work can be described as a culture of doing. The older people and the staff were thus living and working in two different care cultures. The fourth main finding is a description of what has been termed co-creating care. It focuses on the encounter between older people and nursing home staff from the older person’s perspective and life-world. The older person and staff work together in a co-creating relationship. This may be described as a shift of paradigm where the care is in a genuine way planned on the basis of the older person’s perspective and the staff’s professional knowledge.

The results are discussed in the following order: first the older people’s inner strength and strive for meaning, thereafter the culture of silence and slowness, the culture of doing, the co-creating care culture and finally methodological considerations.

**Older people's inner strength and strive for meaning**
As shown in this thesis, ageing and the end of life encompass both difficulties and reasons for rejoicing. The older people were struggling against an unrecognizable body, fragility and dependency and at the same time striving to obtain meaning. Their inner strength seemed, to some extent, to have balanced the threats to their dignity of identity. It is however, important to be aware that meaning can sometimes be difficult to experience. In study II, meaning was created through an inner dialogue, communication and relationships with others. The older people’s inner strength seemed to be closely related to what has previously been described as peace of mind (Nyström & Segesten 1990), resilience and self transcendence (Nygren 2006). Nygren (2006) concludes that inner strength is important for good ageing and is related to the experience of health in old age.

The results from studies I and II can even be understood from a life cycle perspective (Erikson 1997). According to Erikson (1997), every human being has the possibility to undergo psychosocial development throughout life. The human being has continuously to resolve eight psychosocial crises related to different phases of the lifecycle. If these psychosocial crises are resolved in a positive way, basic strength can be enhanced. The first crisis involves being able to balance the feelings of trust and mistrust. In order for the development to be positive, the feeling of trust must be stronger than that of mistrust. The eighth and final stage involves ageing and dying and comprises the crisis associated with the tension between feelings of integrity and despair. The syntonic way of dealing with this crisis results in wisdom, while the outcome of the dystonic approach is disdain (Erikson
1997). In our study, several of the older persons appeared to preserve their integrity, despite the difficulties they experienced, which Erikson terms an active interest in life until death.

When Joan Erikson reached an advanced age, she added a ninth stage to the theory that she developed together with her husband Erik Erikson. In the ninth stage, the syntonic element is challenged and there is a risk that the dystonic element will become dominant. However, she believes that it is possible to handle these challenges by means of what is often described as gerotranscendence. This is partly in agreement with the results of studies I and II and, to some extent, studies III and IV from the staff perspective. These studies revealed that the older person’s dignity and identity were threatened as a consequence of his/her unrecognizable body, increased dependence, fragility, ageing per se and other people’s attitudes. Study II disclosed how meaning in everyday life was experienced through having physical ability, having cognitive ability, feeling needed and experiencing a sense of belonging. The creation of meaning also took place via an inner dialogue and relationships with significant others. The inner dialogue refers to an inner conversation with oneself, in which the person reflects on meaningful events or relationships experienced earlier in life, which could possibly represent a form of transcendence.

The concept of transcendence is used by many researchers to describe how older people achieve reconciliation in spite of a lack of physical and psychological functions. Joan Erikson (1997) refers to Tornstam’s description of gerotranscendence (Tornstam 1998). In brief, gerotranscendence means a shift in perspective from a material and rational to a more cosmic and transcendental view of life (cf. Wadensten 2003). Two of the three women in Study II can be seen as having reached a stage of what Nyström and Segesten (1990) called peace of mind, which is close to gerotranscendence.

Travelbee (1971) emphasizes that the role of nurses is to support the patient’s search for meaning, when he/she is in a state of suffering. Supporting another human being is seen as the core of nursing due to its aim of helping the patient to find or create meaning.

Different care cultures

The different studies in this thesis make it clear that the older people were living in a culture of silence and slowness, while the staff worked in a culture that can be described as task-oriented and is here labelled the culture of doing. These two cultures exist simultaneously and hinder person-centred care. In article I, we stated that the caring relationship between the older people and staff often mirrors values in the care organization, such as the priority given to daily rituals. Furthermore, we assumed that the organization (the care culture) mirrors societal values. Our results show that a gap exists between the ideal contained in various documents that guide older people’s care and the resources the staff perceive to be available (Tishelman et al. 2002). Many studies have indicated that older people are marginalized, which could mirror ageism in contemporary society (Lloyd 2002, Westerhof et al. 2004; National Board of Health and Welfare, 2004).

By means of three figures (see Figures 1–3) I have tried to illustrate how different levels can interact. The inner circle reflects an individual level with focus on the interaction between the older person and the individual staff member (micro level). The second circle illustrates values on an organisational level e.g. different care cultures (meso level). The third circle represents values on a societal level (macro level). The figures and the
interaction as well as the relevance of all three care cultures can be seen as simplifying a complex reality, but at the same time hopefully promoting the broader meaning of health care in the nursing home context with focus on dignity in end-of-life care.

**Living in a culture of silence and slowness**

The nursing home as a place and a space appears to be characterized by silence, in terms of everyday conversations about existential issues such as thoughts about the lived life, the future and death (studies I-IV). The lack of individualized support was obvious. The older people seemed to live and die in a culture of silence. The lack of social interactions in nursing homes has also been described by Mattiasson and Andersson (1997) who emphasized that staff should have a moral obligation to uphold what they term the ‘humanizing element in nursing home care’ (Mattiasson & Andersson 1997).

![Diagram of Inner Strength and Culture of Silence and Slowness](image)

**Figure 1:**

Interacting aspects of older people's views concerning dignity in everyday life when living in a nursing home.

In the nursing home, daily life was also distinguished by slowness, due to failing abilities, and even boredom. Boredom appears to be similar to what Whitaker (2004) called a culture of waiting. The ageing process with increasing vulnerability and dependency constituted a threat to rituals and procedures in everyday life, as things are carried out at a slower pace (studies I-II). The result also revealed that the older people did not always ask for help due to a lack of confidence or awareness of the staff’s considerable workload and not wanting to disturb them. Sometimes the older people themselves withdrew from social interaction, due to the shame and embarrassment at not being able to present themselves in a desirable way (studies I-II). External factors such as societal attitudes to older people and their losses seemed to influence the older persons’ self-image, identity and dignity. This is similar to the study by Street (2001), who describes dignity as embodied and socially constructed over time. In my thesis, it appears that an individual’s inner strength and
feelings of belonging and connectedness were important for maintaining the dignity of identity. Living in a culture of silence and slowness can also promote a sense of peace of mind and promote gerotranscendence.

The results of studies I and II implicitly highlight the importance of being responsive to the needs of nursing home staff, in order to enable them to provide the older people with dignified care.

**Working in a culture of doing**
Several of the older persons’ descriptions revealed that the staff never had time for authentic encounters. The staff were constantly ‘busy doing’ in what has been conceptualized as a culture of doing. The staff experienced a gap between ideals and the reality, which they described as a barrier in their striving towards being able to provide a deeper level of care, i.e. more than just basic physical care. Often relationships were described as more instrumental than human interaction. The nursing assistants particularly mentioned this, which is not surprising as their everyday work involves looking after the older people’s basic physical needs. This was described as a source of frustration in their daily work and a threat to their dignity of identity (studies III-IV). There was no time to build relationships. This subject was also discussed in some of the focus groups (study IV). The retrospective analyses revealed that in many cases staff lacked knowledge about who the older person was and how he/she had lived his/her life before taking up residence in the nursing home.

![Figure 2: Interacting aspects of staff views concerning dignity in every day life when working in a nursing home.](image)

The staff reported experiencing a feeling of unease and moral stress when they did not have time to talk to the older persons and treating them as objects resulted in a guilty conscience. The ‘good’ that they wished to do was not always possible in the culture of
doing. In the literature this is described as moral stress (Lützén et al. 2003) and conscious stress (Glasberg et al. 2007). Lützén and co-workers (2003) define moral stress as a nurse, who is morally sensitive to a patient’s vulnerability, being hindered by external factors from providing the care he/she deems necessary for patient well-being. Corley et al. (2005) hold that lack of staff impedes the ability to provide the care that patients need and, as a result, many nurses experience moral distress or, as interpreted in study III, a negative impact on their self respect and dignity of identity. It was obvious that the staff lacked support and possibilities for professional growth.

Living and working in a co-created care culture - Reflections on the future
The above description of the two care cultures shows that the older persons lived in one culture and the staff in another, which created dissatisfaction among both groups. Westin and Danielson (2007) described how dependency and respect are mutually constructed and that the nurse holds professional responsibility for the outcome of the relationship. In her thesis ‘Dependency on care’, Strandberg (2002) outlined the meaning of the concept of co-creating. She characterized dependency from the patients’ perspective as a struggle to avoid feelings of worthlessness, powerlessness and loneliness as well as fear of not receiving care. This is in line with the findings in my thesis, where the expression threatened dignity of identity was employed. The staff in Strandberg’s studies fought a battle against the threat of not being able to cope with the arduous responsibility of holding another person’s life in their hands and finding the caring meaningful. This is also similar to study III, where staff struggled to be able to provide ‘good’ care. The organizational structure has a considerable impact on the encounter between staff and the older persons. When Strandberg (2002) explored the relationship between the staff and patient, she used the concept of co-creating, with reference to Buber (1970). Co-creating encompasses an encounter between ‘I and thou’. The staff’s basic stance is essential for this meeting to take place, where the aim should be to strive to be present and to create the conditions necessary for an inter-human encounter with the older person. Furthermore, this encounter should be qualitatively different from the more superficial and standardized everyday meetings that often take place between people, and the patient should be regarded as an autonomous actor in his/her own care. Criteria for such care are described in study IV (the six S’s) and can here be considered as a guide for care planning. This approach is congruent with Thorne et al. (2007), who outline a model based on Martin Buber and present the vision that the ethical and personal issues confronting patients and nurses are delicate matters that increase the importance of a patient-nurse encounter based upon relational reciprocity.
Figure 3:
Interacting aspects between older people and nursing home staff members in a care culture characterized of co-creating.

The results from the present thesis demonstrate that there is a lack of authentic human encounters in the studies. This is also indicated by the fact that staff lacks knowledge of older persons’ thoughts and conceptions at the end of life, i.e. before death. It is equally clear from the texts of the interviews with the older people, where their situation can be characterized as a cry for attention and to be listened to. This gives rise to the question of how the care culture can become ‘person friendly’ in the sense of promoting personal development and the identity and dignity of both staff and residents. Such care is associated with creating cultures where meaningfulness in daily life becomes a goal both for the nursing home residents and for those who work there. Feelings of being valuable and having worth are important. Such an approach would lead to a caring culture that builds on co-creating, with relational reciprocity providing a possible way for different cultures to meet and respect each other.

Methodological reflections
Limitations and strengths
A limitation of this thesis may be the fact that only those old people without any cognitive or speech impairments were included. A similar problem exists in relation to the staff, as a limitation in terms of staff is that many of them were not Swedish and thus may have chosen not to participate due to lack of fluency in the language. Another limitation may also be the decision to use interviews as the data collection method. It would be interesting to complement this study with observations. However, strength of the present study is that I have followed the older people over a period of about 12–18 months and thus have been able to share more of their life world than would have been possible with a single interview. It is reasonable to assume that the series of interviews over time strengthened the study’s validity. Another strength is that I interviewed older people and staff who lived and worked in the same nursing homes and therefore obtained a great deal of knowledge
about the care cultures and was able to share more aspects of the older people’s life world. I am of the impression that the older people experienced the interviews as a welcome interruption of the culture of silence. In studies III and IV, the choice of a content analysis method as opposed to hermeneutic analysis served to provide a clearer structure for handling the large amount of material. In my opinion, the focus group discussions stimulated interaction and encouraged dialogue between the nursing assistants and registered nurses. As such conversations rarely took place in everyday care, the focus group discussions provided time for the various professional categories to reflect and focus on their work with older people in a nursing home context.

**Trustworthiness**

Issues of rigour and credibility are important when employing qualitative methods. The authors’ pre-understanding and the research process have been described as accurately as possible. During the analysis consistent interpretations with an inner logic were sought in order to ensure that the reader can follow them throughout the study. Objectivity and validity in human science research means going back to the ‘things themselves’. I have therefore attempted to ensure an attitude of openness through the research process. A question can be raised as to the study’s validity and reliability. Although different areas were discussed over time, and it has, to some extent, been possible to check the validity of the responses in the interviews, it is possible that some of the participants changed their views. However, this should not reduce/affect the validity and reliability of the study. We have continuously searched for alternative interpretations. In study II, the secondary analysis carried out on data from three participants from the first study and comprising a total of twelve interviews contributes to the understanding of possible ways of creating meaning at the end of life. Studies III and IV sought the perceptions of nursing home staff, while the qualitative interpretative part of the content analysis aimed to organize and develop knowledge in an open manner in order to identify patterns among the participants. This procedure enabled the text to be condensed into a small number of content categories based on explicit coding rules. In study IV, the participants were consecutively selected, an approach that was generally successful and worked well, with the exception of the difficulties involved in gathering the planned number of participants for each FGD. High staff turnover and lack of resources resulted in few participants in some of the groups. Our impression was that the focus group discussions stimulated the dialogue, and it is possible that individual interviews would not have led to the same result. The interaction between the participants revealed that certain issues related to organisational control are especially sensitive and lead to conflict. This implies that the organisation can be a barrier to the provision of good palliative care and that education and support for staff are essential.

**Implications for nursing**

This study showed that understanding dignity has important implications for the quality of care provided in nursing homes. The descriptions of dignity provided by both the staff and the older people make clear that in order to maintain a sense of dignity, a person needs to be seen and respected for his/her identity and personal values. A co-creating care culture could be one way to introduce the philosophy of palliative care into the nursing homes. If the aim of maintaining dignity at the end of life is to be implemented in the nursing home context, it is important that the organisation and staff reflect on their own views of dignity in terms of ageing and dying as a means of resolving the critical issue of how staff members can support dignity. Education and supervision could be part of such an approach. If dignity is understood as a multi-dimensional construct, nursing home staff will
be able to develop a range of options for the care of people who live in nursing homes at the end of life.

**Summary of the results and suggestions for further research**

External factors, for example contemporary society, as well as internal factors such as the individual’s own personality, can hinder or promote dignity of identity. Studies I, II and III emphasize that confirmation is important for the perception of oneself, when the self is violated. This thesis did not aim to apply a particular theoretical framework when outlining the older people’s and staff members’ experiences of dignity. However, in all four studies, the concept of dignity of identity as presented by Nordenfelt (2004) has proved appropriate for describing both the older persons’ and the staff members’ dignity. This concept is close to what Ternestedt and co researchers (2002) describe as maintaining self-image. A framework for promoting a person’s self-image has been developed in order to provide more individualized care (see study IV) and to guide a striving for co-creating care where the older person’s self-determination serves as a starting point. The results are summarized below, where each point also indicates areas that would benefit from further research. These are:

- The way in which dignity is perceived appears to be related to a person’s self-image and identity.
- Older people described dignity as being related to their perceptions of their body and level of dependence. Threats appeared to be balanced by a feeling of inner strength.
- A sense of meaning in everyday life was created by means of an inner dialogue, which could help the older person to endure difficult situations.
- Dignity from the staff perspective was interpreted as self-respect, being confirmed and having a sense of pride in one’s work.
- Threats to dignity were found to be identical for the staff and the older people. Lack of resources, the older person’s needs being ignored and the conditions under which staff work contributed to diminished self-respect.
- The staff members were involved in a struggle between their personal ideals of a good and dignified death and those of society in general. In some cases this could lead to a moral conflict that gave rise to feelings of guilt.
- Staff members need training and support.

This thesis highlights the fact that it is important to reflect over how the nursing home culture can promote meaningfulness and participation for the people who live and work there. In this thesis neither the older people nor the staff felt that they could influence the care. An aim for future eldercare would be to develop a nursing home environment in which human dignity is promoted. Meaningfulness in everyday care may be promoted through co-creating on the part of those in need of and those providing care. The organization, education and need for support must be discussed and developed in line with this aim. End-of-life care demands competence and teamwork. In my opinion, palliative care philosophy should be implemented in nursing homes, a point also highlighted by other researchers.
SAMMANFATTNING PÅ SVENSKA, (SUMMARY IN SWEDISH)
Värdighet i livets slut skede – vad innebär det för äldre människor och personal på sjukhem?

Bakgrund


Begreppet värdighet har sitt ursprung i latinets dignitas. I svenska och engelska ordböcker har begreppet framförallt två olika betydelser där det ena är ett tillstånd av helhet och oskaddhet och det andra en sammanfattning av vissa moraliskt värdefulla
karaktersegenskaper. Respekt för vårdtagarens värdighet innebär, att vårdtagaren respekteras för de önskemål och värderingar som anses vara betydelsefulla för just henne men också en respekt för människors olika personliga sfär. En litteraturöversikt visar att begreppet studerats både via teoretiska analyser, empiriska studier samt en kombination av de båda metoderna. Sociokulturella faktorer, omgivning/miljö och personens egen livshistoria beskrivs vara faktorer som kan påverka upplevelsen av värdighet.

Forskningen inom området är begränsad. Få studier har primärt haft som syfte att studera äldre personers döende och död. Behovet av studier är här stort. Mot bakgrund av detta och mitt eget intresse för vård av äldre har föreliggande avhandlingsarbete genomförts.

**Syfte**

Det övergripande syftet med avhandlingsarbetet har varit att nå en djupare förståelse av vilken innebörd äldre personer och personal på sjukhem lägger i begreppen värdighet, döende och död.

Studie I: att utforska vad äldre personer som lever den sista tiden av sitt liv på sjukhem anser vara ett värdigt liv.

Studie II: att fördjupa förståelsen för hur tre kvinnor skapar mening i vardagen nära döden.


**Metod**

Ett förståelseinriktat kunskapsintresse är grunden för detta avhandlingsarbete. Data har samlats via intervjuer med olika informanter.

**Delstudie I.** Data har samlats via upprepa intervjuer med 12 äldre som bodde på två sjukhem i en och samma stadsdel. För att inkluderas i studien skulle den äldre ha hälsomässigt, befinna sig i en tidig palliativ fas och ha intakt förmåga att kunna ge sitt samtycke till deltagande. De äldre följdes via upprepa intervjuer om möjligt under en tidsperiod av cirka 12 månader. I planen ingick att varje äldre skulle intervjuas vid minst fyra tillfällen. Detta var av olika skäl, t.ex. sviktande hälsa, ej genomförbart. Sammantaget gjordes 39 intervjuer, vilka analyserades med hermeneutisk metod.

**Delstudie II.** En sekundäranalys gjordes av tre kvinnors berättelser om att leva nära döden på sjukhem och vad som gav mening. Ett ändamålsenligt urvalsförfarande tillämpades. Tre kvinnor valdes då ut både för att de varit villiga att berätta och för att deras intervjuer därmed var informationsrika. Analysen av datamaterialet gjordes med hermeneutisk metod.

**Delstudie III.** Ett ändamålsenligt urvalsförfarande tillämpades genom att den ansvariga chefen/sjuksköterskan vid fyra sjukhem inom samma geografiska närområde tillfrågade personal i samband med veckomöten om intresse att delta. Totalt kom 21 personer att intervjuas vilka analyserades via innehållsanalyser. Både det manifesta och det latent innehållet analyserades induktivt.

**Delstudie IV.** Personal vid samma sjukhem deltog i retrospektiva analyser av sju avlidna äldre personers sista tid i livet. Sju fokusgrupper genomfördes med två till fem deltagare i varje. Totalt deltog 20 personer i intervjuerna. Den guide som användes vid genomförandet byggde på sex frågeområden som utvecklats av Avery D. Weisman, en amerikansk
psykiater, för att öka kunskapen om personers psykosociala förhållande före sin död. Frågeområdena har anpassats till en svensk omvårdnadskontext och formulerats via sex S: Självbild; Självbestämmande; Sociala relationer; Symtomlindring; Summering och sammanhang samt Samtycke eller försoning med döden (Hermansson, Ternestedt 2001, Ternestedt et al 2002).

**Resultat**

Ett av huvudresultaten från studierna var att värdighet i hög grad föreföll vara relaterad till en persons självbild och identitet. Det föreföll gälla oavsett om man var den som tog emot vård eller den som vårdade. En konsekvens av detta blir att innehållet i vad som uppfattades som kränkning respektive som främjade för värdigheten, varierade från person till person. Ett annat huvudresultat var att de äldre levde i en kultur som karaktäriserades av tystnad och väntan medan personalen arbetade i en kultur som kännetecknades av görande. Vården och omsorgen var uppgiftscenterad med fokus på kroppsslig omvårdnad. De beskrev sig ha svårt att hinna med samtal eller att delta i andra sammanhang. Personalen kämpade med att de beskrev som ett gap mellan ideal och verklighet. De hade svårt att leva upp till de ideal och förväntningar som fanns både hos dem själva och andra på en god omsorg och vård i livets slut. En mekaniserad vård beskrevs utgöra ett hot både för den äldres och för personalens upplevelse av identitetsvärdighet.


Delstudie II. Dessa resultat ska ses som en fördjupning av studie I. För de tre kvinnorna var det för värdigheten viktigt att ha fysisk kapacitet, kognitiv förmåga, vara behövd och ha en känsla av tillhörighet. När dessa kapaciteter utmanades eller sviktade sökte och skapade kvinnorna själva mening via det som hår benämns en inre dialog av innebörden att kvinnorna föreföll ha ett rikt inre liv. Bristen på gemenskap med andra och bristen på samtal med andra var tydlig. Genom att tänka tillbaka på viktiga händelser i livet, på uppgifter man haft eller genom att aktivt tänka på sina barn, barnbarn eller barnbarns barn skapades mening i en tillvaro som i hög grad beskrevs vara enahanda. Den inre dialogen har tolkats vara ett sätt att skapa mening i tillvaron.

Delstudie III. Resultaten visade att det på en teoretisk nivå fanns likheter när det gällde vad personal beskrev vara värdighet i livets slutskede för den äldre samt för sig själv. För de äldre innebar värdighet att få känna sig trygg, få sina basala fysiska behov tillgodosedda, bli sedd som den person man var och att ha en egen privat sfär. En vård som byggde på respekt för den enskilda personen som person, dennes identitet och integritet ansågs främja den äldres upplevelse av värdighet. Personalens värdighet och vardag präglades av den
konflikt de upplevde mellan de ideal de ville förverkliga och de begränsade möjligheter till att göra detta som de beskrev sig ha. Självrespekten var hotad. Vårdighetsbegränsning var att bli bekräftad och att få känna sig stolt över sitt arbete. Hoten mot såväl de äldres som den egna vårdigheten har beskrivits vara brist på resurser och att bli ignorerad eller marginaliserad.


Diskussion

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