

Dignity in the end of life care

To Joel and Stella

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LISE-LOTTE DWYER

Dignity in the end of life care

What does it mean to older people and
staff in nursing homes?

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Abstract

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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.

- I. Franklin L-L, Ternstedt B-M, Nordenfelt L. Views on dignity of elderly nursing home residents. *Nurs Ethics* 2006; 13 (2): 130-146.
- II. Dwyer L-L, Ternstedt B-M, Nordenfelt L. Three nursing home residents speak about meaning at the end of life. *Nurs Ethics* 2008, 15 (1): 88 -100.
- III. Dwyer L-L, Andershed B, Nordenfelt L, Ternstedt B-M. Dignity as experienced by nursing home staff. Revised submission.
- IV. Dwyer L-L, Andershed B, Ternstedt B-M, Lennart Nordenfelt. Nursing home staff's reasoning about death and dying. Manuscript.

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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, Ternstedt *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, Ternstedt *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 Duarte (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).

Palliative care:

- provides relief from pain and other distressing symptoms
 - affirms life and regards dying as a normal process
 - intends neither to hasten nor prolong death
 - integrates the psychological and spiritual aspects of the patient's care
 - offers a support system to help the family cope during the patient's illness and in their own bereavement
 - uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
 - will enhance quality of life and may also positively influence the course of illness
 - 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.
- (WHO 2004 p. 14)

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, Sjöden 1991), 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

	Study I	Study II	Study III	Study IV
Aims	To explore the views on dignity expressed by elderly people living in a nursing home.	To acquire a deeper understanding of how three older women created meaning in their everyday life in a nursing home.	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.	To investigate nursing home staff's way of reasoning about older persons' death and dying.
Methods	Data collection: Repeated interviews (a total of 39 interviews) Data analysis: Hermeneutic method	Data collection: Secondary analysis of 12 interviews from study I Data analysis: Hermeneutic method	Data collection: Interviews (a total of 21 interviews) Data analysis: Qualitative content analysis	Data collection: Focus group discussions. (a total of 7 discussions) Data analysis: Qualitative content analysis
Participants	12 older people over an 18-month period	3 older people over an 18-month period	21 staff members	20 staff members

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

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

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 syntonik way of dealing with this crisis results in wisdom, while 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 syntonik 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).

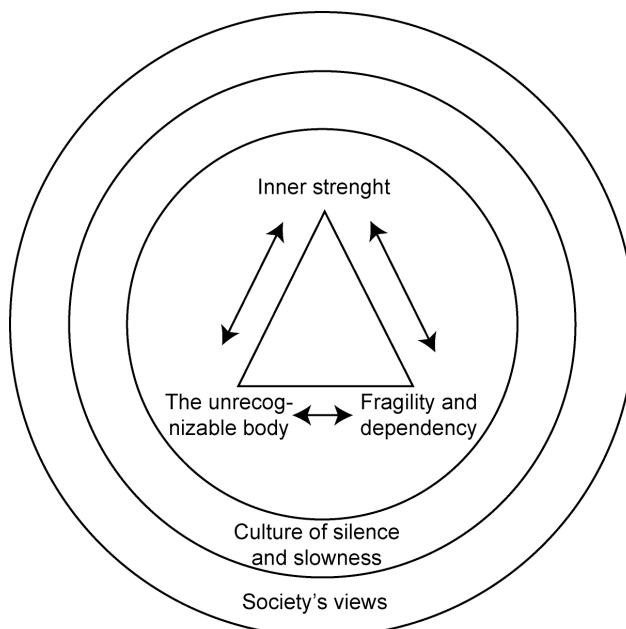


Figure 1: Interacting aspects of older people’s views concerning dignity in every day life when living in a nursing home.

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.

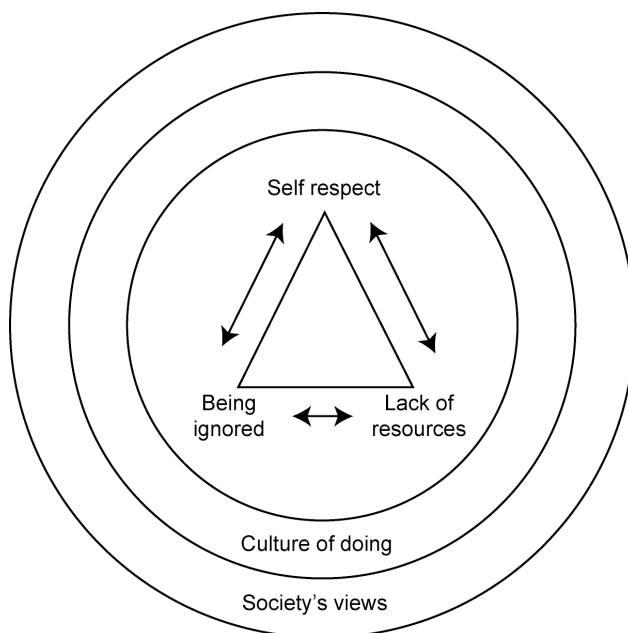


Figure 2:

Interacting aspects of staff views concerning dignity in every day life when working in a nursing home.

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.

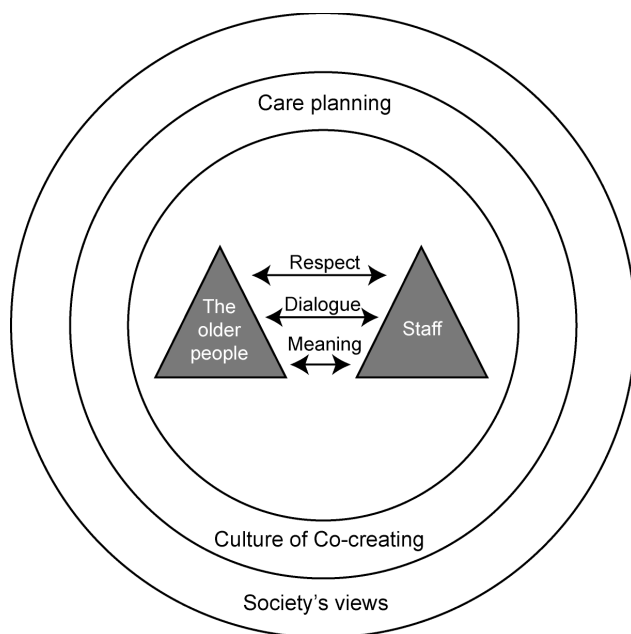


Figure 3:

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 Ternstedt 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

Föreliggande avhandling utgår från ett vårdvetenskapligt perspektiv som karaktäriseras av en helhetssyn på människan. Avhandlingens ontologiska utgångspunkter ansluter till ett humanistiskt-existentialistiskt perspektiv. Människan ses som en meningssökande varelse med möjligheter till val och utveckling hela livet. Det anses även gälla människans allra sista tid i livet. När vårdvetenskapens intresseområden beskrivs nämns ofta fyra konsensusbegrepp. Dessa är: människan/personen, hälsa, miljö och vårdande. Fokus för denna avhandling har huvudsakligen varit på begreppet person och då avses äldre personer som lever nära döden på sjukhem samt personal som arbetar där.

I Sverige dör varje år cirka 90 000 personer. Av dessa är ca 60 % 75 år eller äldre. Det är inte ovanligt att de allra äldsta tillbringar den sista tiden av sitt liv inom någon form av särskilt boende. Enligt de statistiska prognoser som gjorts beräknas andelen äldre påtagligt öka i det västerländska samhället. Flera av de allra äldsta beräknas leva i ensamhushåll, detta gäller särskilt kvinnor över 85 år. Ett antal vetenskapliga studier har visat att vissa äldre i livets slutskede löper en större risk för underbehandling i jämförelse med yngre personer med t.ex. en cancersjukdom. Det beskrivs särskilt gälla smärtlindring. Några få studier visar även att överbehandling kan förekomma t.ex. genom att livsförlängande åtgärder sätts in utan att detta är i den äldre personens intresse. Platsen för död (vårdformen) och den kunskap som finns bland personal inom en viss vårdform antas vara av betydelse för den äldres möjligheter till en god vård och en värdig död. Senare studier har uppmärksammat de skillnader som finns när det gäller yngre personers och äldres döende och död. Det framkommer då tydligt att den palliativa vårdens filosofi inte omfattar de äldre i samhället, som vore önskvärt. De äldre beskrivs vara diskriminerade. Mot bakgrund av detta har Världshälsoorganisationen (WHO) utifrån forskning om äldres döende och död, sammanställt en skrift som heter 'Better Palliative Care for Older People' med syftet att även äldre naturligen ska få tillgång till palliativ vård. Den kunskap som finns om god palliativ vård behöver exempelvis nå ut till de särskilda vårdformerna.

Den palliativa vårdens filosofi bygger på den moderna hospicerörelsen som startade i Storbritannien i slutet av 60-talet. Det som då betonats är att den som ska dö ska bli sedd och vårdad utifrån den person han/hon har varit. Personen ska ses i sitt sociala sammanhang och fysiska, psykiska, sociala och andliga/existentiella behov uppmärksammas och lindras. Stöd till hela familjen blir väsentligt liksom teamarbete för att mer optimalt kunna främja den sjukes och familjens livskvalitet avseende olika dimensioner under den gemensamma tid de har kvar. Vården och omsorgen av äldre styrs ytterst av hälso- och sjukvårdslagen samt socialtjänstlagen. Gemensamt för de båda lagarna är att vården och omsorgen ska vila på en humanistisk grund där respekten för den enskildes behov ska vara en viktig utgångspunkt. Begrepp som självbestämmande, delaktighet, integritet och trygghet är återkommande. Ofta används i dessa sammanhang även begreppet värdighet; ett begrepp som sällan upplevs vara konkretiserat på ett sätt som främjar tillämpning.

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

karaktärsegenskaper. 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.

Studie III: att utforska vad personal anser vara ett värdigt liv och en värdig vård. Studie IV: att fördjupa förståelsen för, och kunskapen om, hur personal resonerar om äldres döende, död och vård, efter en äldre persons död.

Metod

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

Delstudie I. Data har samlats via upprepade intervjuer med 12 äldre som bodde på två sjukhem i en och samma stadsdel. För att inkluderas i studien skulle den äldre, hälsomässigt, befinna sig i en tidig palliativ fas och ha intakt förmåga att kunna ge sitt samtycke till deltagande. De äldre följdes via upprepade 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 innehållsanalys. Både det manifesta och det latent innehåll 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, Ternstedt 2001, Ternstedt *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 uppgiftscentrerad med fokus på kroppslig omvårdnad. De beskrev sig ha svårt att hinna med samtal eller att delta i andra sammanhang. Personalen kämpade med det som 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 äldre och för personalens upplevelse av identitetsvärdighet.

Delstudie I. Det framkom att det ibland var lättare att beskriva hot mot värdigheten än vad som främjade den. De äldres upplevelse av värdighet var i hög grad relaterad till upplevelsen av den egna kroppen. När kroppsliga funktioner sviktade utgjorde de ett hot mot värdigheten. Detsamma gällde ett tilltagande beroende av andra och en ökad sårbarhet. Dessa hot balanserades ofta av att de äldre gav uttryck för en känsla av sammanhang eller tillhörighet. Känslan av sammanhang/tillhörighet behövde inte vara knuten till personer utan kunde representeras av en känd trakt eller av att det särskilda boendet var beläget inom ett område som varit och var viktigt för personen. Personalens förhållningssätt föreföll även kunna vara en buffert emot upplevelser av kränkning. Hur den äldre personen kom att uppleva sig själv och den egna värdighet föreföll ha samband med hur personen kunde balansera den icke igenkännbara kroppen och det tilltagande beroendet. Känslan av sammanhang och den inre styrkan föreföll kunna balansera förlusterna och beroendet. Värdigheten föreföll i hög grad vara relaterad till den enskilda personens identitet.

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 här benämns en inre dialog med 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. Världighetsbefrämjande var att bli bekräftad och att få känna sig stolt över sitt arbete. Hoten mot såväl de äldres som den egna världigheten har beskrivits vara brist på resurser och att bli ignorerad eller marginaliserad.

Delstudie IV. Av denna studie framkom att döende, död och vård i samband med livets slut inte var ett vanligt samtalsämne inom de fyra särskilda vårdformerna. Det framkom även att personalen hade ringa vetskap om de sex frågeområden som intervjuerna belyst. Personalen hade dock ofta en uppfattning om hur och vad den äldre tänkt inför sin död. En sådan allmän uppfattning var att många äldre själva fattar ett inre beslut om att dö, när de själva är beredda att göra detta. När den äldre slutar att äta eller dricka så tolkas det ofta som ett uttryck för att personen är färdig med livet och beredd att dö. När det gällde gruppdynamiken så väckte särskilt två områden starka känslor. Den ena frågan gällde vad som kan anses vara en optimal symtomlindring, den andra frågan det rimliga i att ha någon vid sin sida när man dör och om det då spelar någon roll vem denne är.

Diskussion

Det övergripande syftet med avhandlingsarbetet har varit att nå en djupare förståelse av vilken innebörd äldre personer och personal på sjukhem lägger i begreppen världighet, döende och död. Begreppet världighet, som det har diskuterats i de olika delstudierna förefaller vara relaterat till personens självbild och integritet. Det gäller både de äldre och personalen. Hoten mot världigheten har även tolkats vara desamma. Klyftan mellan formulerade ideal och vårdens och omsorgens vardag beskrivs vara stor. Döden är också något outtalat som bara sker utan någon större uppmärksamhet. Kunskapen om de äldres tankar och känslor och vem den äldre är som person, är begränsad. En och samma boendeform karaktäriseras även av olika vårdkulturer. De äldre lever i tystnadens kultur och personalen i görandets. Det är då svårt att skapa möten mellan människor och samtal beskrivs förekomma i begränsad omfattning. Bristen på delaktighet i utformandet av vardagen på det särskilda boendet är tydlig. Hur dessa förhållanden ska förstås kan diskuteras. Resultaten ger uppslag för vidare studier. Av vårdarnas beskrivningar framgår att den stress de upplever när de inte kan ge den goda vård som uttrycks som idealt uttrycks i samhället och hos dem utgör, en moralisk konflikt som skapar dåligt samvete. Vårdarna behöver stöd i sitt arbete. En viktig fråga som de olika delstudierna tillsammans väcker är hur goda vårdkulturer kan samskapas, där både de äldres och personalens erfarenheter och drivkrafter tas tillvara. Många har engagerat berättat om sina erfarenheter av att bli vårdad respektive att vårda. Det framkommer att döden både förefaller vara undàngömd och en händelse som inte väcker någon större uppmärksamhet. Det kan å ena sidan tolkas som något positivt att döden utgör ett naturligt inslag i verksamheten. Det är å andra sidan mycket som talar emot detta. En individualiserad vård och en god död torde kräva att vårdarna har kunskap om den person de vårdar. Av denna studie framgår att kunskapen om vem den äldre personen varit och hur hon tänkt varit begränsad. De redovisade resultaten har dock vissa begränsningar vilka bör beaktas. Endast ett fåtal äldre har intervjuats, vilket dock till delar vägs upp av att intervjuerna skett över tid och utgör inte ett enstaka nedslag i de äldres vardag. Föreliggande resultat bör kompletteras med fler studier som fokuserar på hur det är att leva respektive arbeta, nära döden på sjukhem.

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REFERENCES

- Addington-Hall J, Lay M, Altmann D, McCarty M. (1998) Community care for stroke patients in the last year of life: results of a national retrospective survey of surviving family, friends and officials. *Health & Social Care in the Community* 6(2), 112-119.
- Ahronheim JC. (1997) End-of-life issues for elderly women: incurable and terminal illness. *Journal Am Med Women's Assoc* 52(3), 147-51.
- Andershed B. (1998) *Att vara nära anhörig i livets slut. Delaktighet i ljuset – delaktighet i mörkret.* (Akademisk avhandling) Uppsala: Uppsala universitet.
- Andersson L. (2002) Ålderism. I: Andersson L. (red.) *Socialgerontologi*. Lund: Studentlitteratur.
- Andersson M. (2007) *Äldre personers sista tid i livet. Livskvalitet, vård, omsorg och närståendes situation.* (Akademisk avhandling) Lund: Lund Universitet.
- Australian Government Department of Health and Aging. (2004) *Guidelines for a palliative approach in residential aged care. The national palliative care program.* Canberra: Australian Government Department of Health and Aging.
- Avis M, Jackson JG, Cox K, Miskella C. (1998) Evaluation of a project providing community palliative care support to nursing homes. *Health & Social Care in the Community* 7, 32-38.
- Beauchamp TL, Childress JF. (1994) *Principles of biomedical ethics*. UK: Oxford University Press.
- Beck Friis B, Strang P, Sjödén PO. (1991) Work stress and job satisfaction in hospital based home care. *Journal of Palliative Care* 7(3), 15-21.
- Bottomff JL, Steele R, Davies B, Garossino C, Porterfield P, Shaw M. (1998) Striving for balance: palliative care patients' experiences of making everyday choices. *Journal of Palliative Care* 14(1), 7-17.
- Buber M. (1970) *I and Thou* (W. Kaufman, Trans.). New York: Scribner.
- Clare J, DeBellis A. (1997) A palliative care in south Australian nursing home. *Australian Journal of Advanced Nursing* 14(4), 20-28.
- Cronqvist A, Theorell T, Burnes T, Lützn K. (2004) Caring about – Caring for: Moral obligations and work responsibilities in intensive care nursing. *Nursing Ethics* 11(1), 63-76.
- Corley M, Minick P, Elswick RK, Jacobs M. (2005) Nurse moral distress and ethical work environment. *Nursing Ethics* 12(4), 381-390.
- Dahlberg K., Dahlberg H & Nyström M. (2008) *Reflective Lifeworld Research*. (Second edition) Lund: Studentlitteratur.

Eldh AC. (2006) *Patient participation – what it is and what it is not.* (Academic dissertation) Örebro: Örebro University.

Erikson J. (1997) The night stage. In: *The life cycle completed.* Extended version. (E.H. Erikson). New York, London: W.W. Norton & Company.

Eriksson K. (1994) *Den lidande människan.* Stockholm: Liber utbildning.

Enes Duarte SP. (2003) An exploration of dignity in palliative care. *Palliative Medicine* 17, 263-269.

Fawcett J. (1989) *Analysis and evaluation of conceptual models of nursing.* Philadelphia: P.A. Davis Company.

Feigenberg L. (1977) *Terminalvård.* Lund: Liber Läromedel.

Fenton E, Mitchell T. (2002) Growing old with dignity: a concept analysis. *Nursing Older People* 4, 19-21.

Fläckman B, Fagerberg I, Häggström E, Kihlgren A. & Kihlgren M. (2007) Despite shattered expectations a willingness to care for elders remains with education and clinical supervision. *Scandinavian Journal of Caring Science* 21(3), 379-89.

Fläckman B, Sörlië V, Kihlgren M. (2008) Unmet expectations: why nursing home staff leave care work. *International Journal of Older People Nursing* 3, 55-62.

Froggatt KA. (2001) Palliative care in nursing homes: where next? *Palliative Medicine* 15, 42-48.

Fry PS. (1990) A factor analytic investigation of home-bound elderly individuals concerns about death and dying, and their coping responses. *Journal of Clinical Psychology* 46(6), 737-748.

Fryback PB. (1993) Health for people with a terminal diagnosis. *Nursing Science Quarterly* 147-159.

Gadamer HG. (1989) *Truth and method.* London: Sheed & Ward.

Gallagher A. (2004) Dignity and respect for dignity- two key health professionals' values: Implications for nursing practice. *Nursing Ethics* 6, 588-99.

Gibbs L, Addington Hall J. (1998) Dying from heart failure: lessons from palliative care. *BMJ* 317, 961-62.

Glasberg A-L. (2007) *Stress of conscience and burnout in healthcare. The danger of dealing one's conscience.* (Academic dissertation) Umeå: Umeå University.

Grande GE, Addington-Hall JM, Todd CJ. (1998). Place of death and access to home care services: are certain patient groups at a disadvantage? *Social Science & Medicine* 47, 565-579.

Haddock J. (1996) Towards further clarification of the concept 'dignity'. *Journal of Advanced Nursing* 24, 924-31.

Hallberg Rahm I-L. (2004) Death and dying from old people's point of view. A literature review. *Aging Clinical and Experimental Research* 16, 87-103.

Hansebo G, Kihlgren M. (2004) Nursing home care: changes after supervision. *Journal of Advanced Nursing* 45(3), 269-279.

Hallberg IR, Norberg A, Eriksson (1990) A comparison between the care of vocally disruptive patients and that of other residents at psychogeriatric wards. *Journal of Advanced Nursing* 15(4), 410-416.

Hermerén G. (1986) *Kunskapens pris. Forskningsetiska problem och principer i humaniora och samhällsvetenskap*. Stockholm: Humanistisk – samhällsvetenskapliga forskningsrådet.

International Council of Nurses. (2000) *Code of ethics for nurses*. Geneva: ICN.

Jacelon CS, Conelly TW, Brown R, Proulx K, Vo T. (2002) A concept analysis of dignity for older adults. *Journal of Advanced Nursing* 48, 76-83.

Jakobsson E. (2007) *End-of-life care in Swedish county – patterns of demographic and social conditions, clinical problems and health care use*. (Academic dissertation) Göteborg: The Sahlgrenska Academy, Göteborg University.

Karlsson I., Ekman SL., Fagerberg I. (2008) To both be like a captain and fellow worker of the caring team: the meaning of nurse assistants' expectations of Registered Nurses in Swedish residential care homes. *International Journal of Older People Nursing* 3(1), 35-45.

Kihlgren M. (1992) *Integrity promoting care of demented patients*. (Akademisk avhandling) Umeå: Umeå universitet.

Källström Karlsson I-L, Ehnfors M, Ternstedt B-M. (2006) Patient characteristics of women and men cared for during the first 10 years at an inpatient hospice ward in Sweden. *Scand Journal of Caring Science* 20(2), 113-121.

Källström Karlsson I-L, Ehnfors M, Ternstedt B-M. (2008) Five nurses experiences of hospice care in long-term perspective. *Journal of Hospice and Palliative Nursing*. (Accepted).

Leininger M (1981). *The phenomenon of caring: Importance, research questions and theoretical consideration*. In: Leinger M (Eds). *Caring: an essential human need*. Proceedings of three national caring conferences. Thorofare. New Jersey:Charles, B. Slack, p 3-15.

Lindqvist O. (2007) *Att leva med kroppsliga förändringar vid obotlig cancersjukdom med fokus på prostatacancer: "Jag är frisk – bortsett från att jag har cancer som är dödlig, men det är liksom en annan sak"*. (Akademisk avhandling) Umeå: Umeå University.

Lloyd L. (2002) Dying in old age: promoting well-being at the end of life. *Mortality* 5, 171-188.

Lützn K, Cronqvist A, Magnusson A, Andersson L. (2003) Moral stress: synthesis of a concept. *Nursing Ethics* 3, 312-322.

Lynn J. (1997) Measuring quality of care at the end of life. A statement of principles. *Journal of the American Geriatrics Society* 45(4), 526-527.

Magnusson F. (1996) Den äckelsköna döden. Bilder av döendet i dagens sjukvård. *Kulturella perspektiv* 2, 22-33.

Mattiasson A-C, Andersson L. (1995) Organizational environment and the support of patient autonomy in nursing home care. *Journal of Advanced Nursing* 22, 1149-1157.

Mattiasson A-C, Andersson L. (1997) Quality of nursing home care assessed by competent nursing home patients. *Journal of Advanced Nursing* 26, 1117-1124.

McCarthy M, Addington Hall, J Altman, D. (1997) The experience of dying with dementia: a retrospective study. *International Journal of Geriatric Psychiatry* 12, 404-9.

McIntyre M. (2003) Dignity in dementia: Person-centered care in community. *Journal of Aging studies* 17, 473-84.

Medicinska forskningsrådet. (1996) *Riktlinjer för god medicinsk forskning*. Stockholm: Medicinska forskningsrådet.

Melin Johansson C. (2007) *Patients quality of life. Living with incurable cancer in palliative homecare*. (Academic dissertation) Göteborg: Institute of Health and Care Sciences. Göteborg University.

Morrison RS, Morris J. (1995) When there is no cure: palliative care for the dying patient. *Geriatrics* 50(9), 12 (comment).

Noddings, N. *Caring, a feminine approach to ethics & moral education*. Berkeley: University of California Press, 1984.

National Board of Health and Welfare. (2004) *God vård i livets slut. En kunskapsöversikt om vård och omsorg om äldre*. Ternstedt B-M. Eds. Stockholm: National Board of Health and Welfare, Sweden.

National Board of Health and Welfare. (2006) *Vård i livets slutskede: Socialstyrelsens bedömning av utvecklingen i landsting och kommuner*. Stockholm: National Board of Health and Welfare, Sweden.

National Board of Health and Welfare. (2007) *Forskning som speglar vården i livets slutskede. Kunskapsöversikt*. Ternstedt B-M. Ed. Stockholm: National Board of Health and Welfare, Sweden.

Nordenfeldt L. (2004) The varieties of dignity: *Health Care Analysis* 12(2), 69-81.

Nygren B. (2006) *Inner strength among the oldest old. A good aging.* (Academic dissertation) Umeå: Department of Nursing, Umeå University.

Nyström A, Segesten, KM. (1990) Peace of mind as an important aspect of old people's health. *Scandinavian Journal of Caring Science* 4, 55-62.

Parse R.R (1987) *Nursing Science: Major paradigm, Theories and Critiques.* Saunders Philadelphia.

Payne SA, Langley-Evans A, & Hillier R. (1996) Perceptions of a good death: a comparative study of the views of hospice staff and patients. *Palliative Medicine* 10, 307-312.

Patton MQ. (2004) *Qualitative research & evaluation methods.* California, Sage.

Qvarnström U. (1979) *Upplevelser inför döden. Samtal vid livets slut.* Stockholm: Natur och Kultur.

Qvarnström U. (1993) *Vår död.* Stockholm: Almqvist & Wiksell.

Randers I, Mattiasson AC. (2003) Autonomy and integrity: upholding older adult patients dignity. *Journal of Advanced Nursing* 45(1), 63-71.

Rinell Hermansson A. (1990) *Det sista året. Omsorg och vård vid livets slut.* (Akademisk avhandling) Uppsala: Uppsala universitet.

Ross MM, Fisher R, MacLean MJ. (2000) End of life care for seniors: the development of a national guide. *Journal of Palliative Care* 16(4), 47-53.

Ross MM, Macdonald B. (1994) Providing palliative care to older adults: context and challenges. *Journal of Palliative Care* 5-10.

Russel P, Sander R. (1998) Palliative care: Promoting the concept of a healthy death. *British Journal of Nursing* 7, 256-261.

Sahlberg-Blom E, Ternstedt BM, Johansson JE. (2000) Patient participation in decision making at the end of life as seen by a close relative. *Nursing Ethics* 7 (4), 296-313.

Seedhouse D, Gallagher A. (2002) Undignified institutions. *Journal of medical Ethics* 28(6), 368-372

SOU 2001:6 *Döden angår oss alla. Värdig vård i livets slut.* Slutbetänkande från kommittén om vård i livets slutskede. Statens offentliga utredningar.

Street A. (2001) Constructions of dignity in end-of-life care. *Journal of Palliative Care* 17(2), 93-101.

Strandberg G. (2002) *Dependency on care.* (Academic dissertation) Umeå: Department of Nursing, Umeå University.

- Ternstedt B-M, Andershed B, Eriksson M, Johansson I. (2002) A good death. Development of a nursing model of care. *Journal of Hospice Palliative Nursing* 3, 153-60.
- Thomé B, Dykes A, Hallberg I. (2004) Quality of life in older people with and without cancer. *Quality of Life Research* 13(6), 1067-80.
- Thorne S, Connie C, Dahinten S, W Hall, A Henderson, Reimer S. (1998) *Journal of advanced nursing* 27, 1257-1268.
- Thorne S, Pesut B. (2007) From private to public: negotiating professional and personal identities in spiritual care. *Journal of advanced nursing* 58 (4), 396-403.
- Tishelman C. (1993) Who cares? Patients' descriptions of age related aspects of care and care in Stockholm. *Cancer Nursing* 16(4), 270-282.
- Tishelman C, Bernhardson BM, Blomberg K, Börjeson S, Franklin L-L, Johansson E, Leveälahti H, Sahlberg-Blom E, Ternstedt BM. (2002) Complexity in caring for patients with advanced cancer. *Journal of Advanced Nursing* 45(4), 420.
- Tornstam L. (1998) *Åldrandets socialpsykologi*. Stockholm: Rabén Prisma.
- Travelbee J. (1971). *Interpersonal aspects of nursing*. Philadelphia: F.A. Davis Company.
- Vachon MLS. (1993) Emotional problems in palliative medicine: patient, family, and professional. In: *Oxford textbook of palliative medicine*. (Eds. Doyle D, Hanks GWC & MacDonald N.) New York: Oxford University Press.
- Vachon MLS. (1998) Caring for the caregivers in oncology and palliative care. *Seminars in Oncology Nursing* 14(2), 152-157.
- Wallerstedt B, Andershed B. (2007) Caring for dying patients outside special palliative care settings. Experiences from a nursing perspective. *Scandinavian Journal of Caring Science* 21, 32-40.
- Wadensten B (2003) Theory-driven guidelines for practical care of older people, based on the theory of gerotranscendence. *Journal of Advanced Nursing* 41(5), 462-70.
- Watson J. (1995) Post modernism and knowledge development in nursing, *Nursing science Quarterly* 8(2), 60-64.
- Weisman (1974) *The realization of death. A guide for the psychological autopsy*. New York: Jason.
- Weman K, Fagerberg I. (2006) Registered nurses working together with family members of older people. *Journal of Clinical Nursing* 15(3), 281-9.
- Worth Health Organisation (2004) *Better care for older people*. Davis E, Higginson IJ (Eds.) Geneva: Worth Health Organisation.

World Health Organisation (2004) *The solid facts. Palliative care*. Davis E, Higginson IJ (Eds.) Geneva: World Health Organisation.

Westerhof G J, Bohlmeijer E, Valenkamp MW. (2004) In search of meaning: a reminiscence program for older person. *Educational Gerontology* 30, 751-766.

Westin L, Danielson E. (2006) Nurses' experiences of caring encounters with older people living in Swedish nursing homes. *International Journal of Older People Nursing* 1, 3-10.

Whitaker A. (2004) *The last home: family ties, ageing and death in a nursing home*. (Academic dissertation). Stockholm: Department of Social Work, Stockholm University.

Ödman P-O. (1979) *Tolkning, förståelse, vetande hermeneutik i teori och praktik*. Stockholm: Almqvist & Wiksell.

Ödman PO. (1992) Interpreting the past. *Qualitative Studies in Education* 5, 167-184.

Öhlén J. (2000) *Att vara i en fristad. Berättelser om lindrat lidande i palliativ vård*. (Akademisk avhandling). Göteborg: Göteborgs universitet.

PAPER I



VIEWS ON DIGNITY OF ELDERLY NURSING HOME RESIDENTS

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Key words: dignity; dignity and end-of-life care; nursing and dignity; palliative care and dying; self-image

Discussion about a dignified death has almost exclusively been applied to palliative care and people dying of cancer. As populations are getting older in the western world and living with chronic illnesses affecting their everyday lives, it is relevant to broaden the definition of palliative care to include other groups of people. The aim of the study was to explore the views on dignity at the end of life of 12 elderly people living in two nursing homes in Sweden. A hermeneutic approach was used to interpret the material, which was gathered during semi-structured interviews. A total of 39 interviews were transcribed. The analysis revealed three themes: (1) the unrecognizable body; (2) fragility and dependency; and (3) inner strength and a sense of coherence.

Introduction

In recent health care publications issues on dignity have often been raised with reference to palliative care and dying.¹⁻³ In 2002 palliative care was defined by the World Health Organization as

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 (p. 14).⁴

The number of elderly people is increasing in the western world, so it is necessary to extend palliative care to other health care settings. Traditionally, palliative care has almost exclusively been applied to people dying of cancer in hospices or to those treated elsewhere by specialized palliative care teams. Palliative care needs to be developed to meet the requirements of an ageing population and, when other treatments have been withdrawn, such care should be available.⁴ Skilbeck *et al.*⁵ argue for the need to broaden the definition of palliative care to include people with other

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illnesses. Their study of people suffering from chronic obstructive airways disease illustrates the need for managing both health care and social care.

The holistic view of the person, on which palliative care is based, was highlighted as early as the 1850s when Florence Nightingale introduced a well-being framework with the focus on the person, the body and the environment.⁶ Today there is agreement that maintenance of patients' dignity and quality of life is a central part of nursing. The international *Code of ethics for nurses* states that inherent in nursing is the respect for human rights, including the rights to life, to dignity and to be treated with respect.⁷

The concept of dignity

Fourteen studies on dignity are presented here; they are described and explored from a nursing perspective or with relevance to it. Seven are based on a theoretical perspective,⁸⁻¹⁴ three on empirical methods,^{2,15,16} and four used a combined theoretical and empirical approach (Table 1).^{1,3,17,18} Common to these studies is respect for an ill person as an individual. Mairis¹⁵ suggests that dignity exists when individuals are capable of having control over their behaviour, their environment and the way in which they are treated by others. The concept also includes understanding information and being capable of making choices. Haddock⁸ defines dignity as having the possibility of feeling important and valuable in relation to other people, and being treated as such in situations that can be experienced as threatening. She highlights the distinction between having dignity, being treated with dignity and actively giving dignity to other people. Even though dignity is a dynamic subjective belief, it has characteristics that are shared among people and require consideration. McIntyre,⁹ together with Haddock,⁸ highlights the relevance and importance of dignity for all those involved in caring situations and emphasizes the importance of relationships with regard to dignity. In a study by Zingmark *et al.*¹⁹ good care for people suffering from Alzheimer's disease is described as relationship centred, and Fenton and Mitchell¹⁰ argue that dignity for elderly people who are receiving care is a state of physical, emotional and spiritual comfort.

Street¹⁷ broadens the understanding of dignity as being embodied and socially constructed over time, as well as being a subjective, multidimensional, situational and contextual concept. Street and Love¹ explored dimensions of privacy and dying related to dignity in palliative care settings by a study that showed the importance of listening to dying persons' needs and desires. In terms of providing respectful care, the dying process differs between individuals. Privacy in dying means not only having a private room but also includes respect and acknowledgement of dying persons' psychological, social and spiritual space. Maititi and Trorey¹⁶ argue that the concept is difficult to define owing to its subjective, multidimensional and even relative aspects. Jacelon *et al.*¹¹ have described dignity as an outcome while carrying out nursing actions, for example, when meeting the needs of patients and family members in a satisfactory way. Gallagher¹² identifies two key values of dignity in the nursing context: when others mostly benefit from our actions towards them; and when we are benefiting ourselves, for example, through self-respect. According to Gallagher¹² and to Edlund,¹³ dignity can be considered both subjectively and objectively with regard to basic human rights. Edlund describes dignity in terms of unconditional and relative values that can change over time and are related to our culture and society. This is close to what Nordenfelt¹⁸ describes as *Menschenwürde*, which is part of being human

Table 1 Studies on the meaning of dignity

Reference	Country	Design	Aims	Results
Mairs, 1994 ¹⁵	UK	Empirical study on nursing in general	To explore the meaning of dignity and to clarify the concept in order to benefit clients and to increase knowledge in nursing	Dignity exists when an individual is able to exercise control over his or her behaviour and environment, and over the way in which he or she is treated by others
Haddock, 1996 ⁸	UK	Theoretical study concerning dignity in nursing	To clarify further the meaning of dignity and thus illuminate the humanity of both patient and nurse	Dignity is when one can feel important and valuable in relation to others, being able to communicate this to others as well as being treated as such by others in threatening situations
Street, 2001 ¹⁷	Australia	Theoretical-empirical study of patients at the end of life	To open up the debate on dignity at the end of life by exploring discourses of dignity as relational and embodied	Dignity at the end of life is subjectively socially constructed through relationships with others; it is also embodied because it involves experiences of bodily function losses and decay
Fenton and Mitchell, 2002 ¹⁰	UK	Theoretical study concerning dignity and elderly people	To analyse the concept of dignity as it relates to elderly people receiving care	Dignity is a state of physical, emotional and spiritual comfort
Ternstedt <i>et al.</i> , 2002 ¹⁴	Sweden	Theoretical study concerning patients at the end of life	To provide a framework for care planning, documentation and evaluation of the quality of care given at the end of life	The framework provided six criteria of importance for experiencing a good death: self-image, self-determination, symptom control, social relationships, synthesis and summation, and surrender
Jacelon <i>et al.</i> , 2002 ¹¹	USA	Theoretical study concerning elderly people	To explore the common usage of the word dignity among nurses and critically ill older adults	The word dignity is commonly used in three ways: behaviour, respect for self and others, and the cognitive attribute of feeling dignified or having dignity
Chochinov <i>et al.</i> , 2002 ³	Australia	A theoretical-empirical study concerning terminally ill patients	To assess the extent to which patients who are near the end of life perceive that they are able to maintain a sense of dignity, and to identify how various demographic and disease-specific variables are related to the issue of dignity in terminally ill people	Most people have a sense of a strong personal dignity; however, it is more likely that people in hospitals or other care settings have their dignity undermined

Table 1 (Continued)

Reference	Country	Design	Aims	Results
Edlund, 2002 ¹³	Sweden	A theoretical-empirical study on human dignity	To increase knowledge on the concept dignity within the caring sciences	Dignity is a set of absolute values and a set of relative values
Enes Duarte, 2003 ²	UK	An empirical study concerning dignity at the end of life	To explore the meaning of dignity to patients, relatives and professionals	The meaning of dignity contains four themes: relationships and belonging, having control, being human, and maintaining the individual self
McIntyre, 2003 ⁹	UK	A theoretical study concerning persons suffering from dementia	To explore dignity among persons suffering from dementia	Dignity is referred to as irreducible and fundamental to our moral worth and our personal dignity as socially constructed
Nordenfelt, 2004 ¹⁸	Sweden	A theoretical study on the meaning of dignity	To explore a set of notions of human dignity	There are four types of dignity: the dignity of <i>Menschenwürde</i> , the dignity of merit, dignity as moral stature, and dignity as identity; dignity of identity is seen as especially important for older people because it changes over time
Maititi and Trorey, 2004 ¹⁶	UK	An empirical study concerning dignity among patients in hospital	To explore the concept of dignity in terms of the circumstances of patients in hospital	Dignity is a multidimensional, subjective and relative concept in the sense that it is expressed in different ways between different people and is evaluative because subjective judgements are used to determine it
Gallagher, 2004 ¹²	UK	A theoretical study on the meaning of dignity	To explore respect for dignity and respect for one's own dignity and self-respect	Nurses need to aspire to do better in demonstrating their ethical views; a more comprehensive ethical competence incorporates seeing, reflecting, knowing, doing and being
Street and Love, 2005 ¹	Australia	A theoretical-empirical study concerning privacy and dignity at the end of life	To explore the dimensions of privacy evident in the views of health care professionals practicing in different inpatient palliative care settings	The results provide an understanding of the spatial, psychosocial and moral dimensions of privacy

and is the same for all people. Nordenfelt also suggests three other types of dignity: dignity as merit, dignity as moral stature and dignity of identity. Dignity of identity as well as self-image, as discussed by Ternstedt *et al.*,¹⁴ concerns the worth and self-respect that one ascribes to oneself as well as the worth and value ascribed by others. *Menschenwürde* and dignity of identity are closely related types of dignity according to Nordenfelt because both are grounded in basic human properties such as the conditions for life and autonomy. Consequently, when an individual's *Menschenwürde* is violated, the person's dignity of identity is violated at the same time. However, there are differences between *Menschenwürde* and dignity of identity. As noted above, Nordenfelt considers that *Menschenwürde* is part of being human and is the same for all people. A person's dignity of identity can however change over time, owing to age or the deeds of others, which can result in physical, psychological or emotional change or harm. Enes Duarte² refers to dignity as a concept composed of different dimensions concerning relationship and belonging, being human, having control and maintaining one's self. These dimensions may alter in response to threats to a person's dignity. Chochinov *et al.*³ discuss dignity in relation to terminally ill people as a resilient construct that requires end of life care that promotes dignity in various ways. Dignity of identity can therefore be considered as of particular relevance when it comes to elderly people in vulnerable situations.

Current definitions of dignity indicate it as being subjective, multidimensional and influenced by our sociocultural environment and personal histories.^{1-3,8,9,12,15-18} Dignity comprises an internal aspect, which is one's personal, subjective valuing of oneself, and an external aspect, which is the valuing of oneself by others.^{1-3,12,16-18} The consideration of dignity in palliative care has, however, been questioned by Sandman, who argues that a problem with the concept is that it is used in numerous ways and lacks clarity when discussed in relation to death and dying.²⁰

Aim of the study

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

Method

A hermeneutic approach was chosen as a method of increasing understanding of elderly people's views concerning their dignity while living in a nursing home near the end of their life. Data collection and analysis were carried out according to the principles described by Ödman.^{21,22}

Settings and sample

Elderly persons living in two nursing homes were included in the study. Neither home had an explicit care philosophy such as, for example, the assumptions on which palliative care is based. Both nursing homes are located within the same geographical area in a major town in Sweden. The accommodation provided for residents is a single room with a kitchen or a kitchenette and a private bath and toilet. The furniture is the

residents' own with the exception of adjustable beds, which fulfil working environment requirements. The dining area as well as the TV area is communal in both nursing homes, although most people have their own TV and often prefer to watch this in private.

The study was of 12 people aged over 85 years (10 women and 2 men). All participants were Swedish and had different sociocultural backgrounds. The data were collected according to the starting points and principles described by Ödman.^{21,22} The interviews were conducted over a period of 18 months during 2002 and 2003. A purposeful sampling technique (a homogeneous sample) was used to select participants.²³ Nurses employed at the nursing homes identified a total of 16 possible participants out of a maximum of 30. The inclusion criteria were: the residents were in an early palliative phase (nearing the end of life, which is an extension of the traditional meaning of palliative care that has a focus on an individual's last months, weeks or days); they were able to talk; they did not suffer from memory loss; and they understood the purpose of the study and the meaning of their own participation. Three people declined to participate. One person took part in only one interview and was excluded from the study because the plan was to interview the participants several times.

Ethical considerations

The participants received individual oral and written information about the study from the nurses in the nursing home. A letter of informed consent was signed in the presence of a nurse when the oral information about the study was given and the participants had agreed to participate. The interviews were carried out over a period of time, so it was important to give repeat information about the study at each interview and also to be sensitive to any signs of a wish to discontinue participation. Moody²⁴ discussed the difficulties of enhancing autonomy in long-term care and questioned the standard ideal of informed consent. Instead, he suggested the term 'negotiated consent' be used in matters concerning elderly people in long-term care settings. Negotiation is based on equality between the people involved rather than on a power differential, for example, between researcher and participant. In this study, the interviewer (LLF) aimed to create an open environment when carrying out the interviews so that the participants could speak freely. The interviewer was continuously aware that elderly people's autonomy can change over time owing to different circumstances. In consideration of changes in elderly people's everyday lives, it was important to look for evidence of participants not wishing to continue with the interviews. This resulted in some cancelled interviews and sometimes in shorter interviews than originally planned. The quotations used in the 'Findings' section were translated from Swedish to English, so some grammatical changes have been made, although with great care in trying to avoid the risk of altering their content. The authors have maintained the confidentiality of each individual by using quotations that cannot be linked to any one person. Approval to conduct the study was granted by the local Research Ethics Committee (171-01).

Interviews: data collection

The study was carried out over a period of 18 months during 2002 and 2003. Data were collected by audiotaped interviews conducted in the nursing homes by the first author

(LLF). The participants were interviewed two to four times depending on their personal circumstances at intervals of three to six months (see Table 2). The semistructured interviews involved four to six questions. The questions were open ended and covered attitudinal, conceptual and practical concerns related to everyday life in the nursing homes. The interviews focused on the present state of the elderly persons' health and their current situation compared with their previous life, descriptions of what it is like to live in a nursing home, and what provided meaning in their everyday life. The aim was to promote a trustworthy relationship so that these elderly persons could feel free to say what they wished. The first interview was designed to create confidence between the interviewer and the participant through an ordinary conversation. Questions were added during the next interview to acquire further understanding of the topics that had been raised previously and of new areas such as thoughts about death. The questions were related to how each participant upholds a sense of dignity in everyday life and also when thinking of the future, which often included thoughts of death. Each interview took between 30 and 90 minutes and enabled the participants to explore and explain their views of their everyday life. A total of 39 interviews were conducted.

Analysis

The analysis followed the hermeneutic process of Ödman^{21,22} and was characterized by moving from the text as a whole to the situational meanings and circumstances present in the text. The researchers' pre-understanding was based on practical experience gained from nursing elderly people (LLF), research on palliative care (BMT) and research on basic concepts from a philosophical perspective (LN). One of the authors (LLF) analysed the texts stepwise and moved also between the different steps and from the parts to the whole and back again (the hermeneutic circle). The parts gave meaning to the whole and vice versa. The steps were as follows:

1. The whole text from each interview was read to acquire an overall understanding of its content and what the participant wanted to convey.

Table 2 Interviews conducted with each participant

Participant no.	Interview 1	Interview 2	Interview 3	Interview 4
1	✓	✓	✓	✓
2	✓	✓	✓	✓
3	✓	✓	Feeling ill, so only a short conversation took place	Dead
4	✓	✓	✓	✓
5	✓	✓	✓	✓
6	✓	✓	✓	✓
7	✓	✓	Too ill to continue the study	Cancelled
8	✓	✓	Dead	
9	✓	Too sad to participate	✓	✓
10	✓	✓	✓	Cancelled
11	✓	✓	✓	✓
12	✓	✓	✓	Dead

2. Each person's interviews were read again and analysed against the background of the participant's situational context in order to reach a deeper understanding of the story.
3. A summary of each participant's analysed interviews was written and his or her perspectives were compared with each other. On this level the parts and the whole texts were compared thoroughly to make sure that they matched each other. Anything that could be interpreted as contradictory to the matching data was sought.
4. The hermeneutic understanding obtained from step 3, based on steps 1 and 2, resulted in the identification of three themes: the unrecognizable body, dependency and fragility, and inner strength and a sense of coherence (Table 3).

An inductive method was used for steps 1–3.

Findings

For most of the elderly people in this study, moving into the nursing home brought many great changes in their everyday lives, which were drawing to a close. They had lost their own homes and only one participant described the nursing home as 'home'.

Table 3 Development of the three major themes

Parts of participants' stories	Subthemes from the compared analysed summaries of the interviews	Major theme
I can't do anything. Since they amputated my legs I just wheel around in my wheelchair. I just lie here; you see I can't move, my body just won't let me. I used to be very active and travel a lot. I need help with everything; I can't even go to the bathroom by myself.	Living in a body that doesn't function as it used to do	The unrecognizable body
I need help with everything; I can't even go to the bathroom by myself. It is horrible when you need help with everything. I am afraid of the day when I can't even get out of bed.	Not being able to take care of one's self and having to put up with situations of exposure	Dependency and fragility
I try to see something positive in each day; ie look at a beautiful flower outside my window or so. I have my family and the staff is nice here.	Finding positive parts in everyday life despite different losses	Inner strength and a sense of coherence

Instead it was mainly perceived as a place that was necessary because of their inability to take care of themselves. Severe reductions in bodily function affected their capacity to handle their basic everyday needs and made them feel that they did not have a choice about moving into a nursing home. They were well aware of their need for assistance for up to 24 hours a day. In that sense the nursing home meant safety for these elderly people because they knew they could receive help at any time. Their views concerning their dignity and their experience of both themselves and their life in the nursing home were often related to how they experienced their own body and could be classified into three themes: the unrecognizable body, fragility and dependency, and inner strength and a sense of coherence. It seems easier to give examples of what is undignified instead on what dignity is. The first two themes are more related to the experience of indignity and are important aspects of elderly people's everyday life in a nursing home. This became obvious during the interviews as the participants described how the attitudes of others affected their inner strength, dignity of identity, and self-image and could either encourage or hinder their sense of dignity of identity.

The unrecognizable body

A keenly felt experience among these elderly people was no longer being able to control their bodily functions and movements. Transgression of boundaries and exposure caused their experience of lack of respect for their integrity. These experiences were a threat to their self-image and identity. Losing certain bodily functions meant an almost inevitable dependency, which the elderly people experienced as violating and difficult to handle despite their reconciliation with their situation on another level. They believed they were losing control over their everyday life and basic needs. They could no longer present themselves as they were used to doing. This was in terms of both how the participants viewed themselves and how others viewed them. Bodily losses related to ageing can be experienced as a violation of a person's dignity.

One participant described the experience of feeling as helpless as a little baby and how that challenged that individual's personal view of self.

It's horrible not being able to take care of myself. I can always get help but it's horrible to wake up when you wet your own bed. Everything you do you're dependent on others. For example, when you need to go to the toilet. It doesn't feel good to ask for help going to the toilet, just like babies.

Not being able to control their own body concerning elimination seemed to be especially difficult. The body was regarded as unrecognizable or even as shameful because of how it behaved, looked or smelled. It was as if they had a strong fear of not being clean. Their bodily losses limited everyday life and the boundaries between them and others were sometimes experienced as ruptured. This particular limitation meant another dependency, which was experienced as frightening by many.

I never thought of myself as getting old. I always said, I'm not afraid . . . but now I am afraid; you see, the more dependent you get, the more frightened you get. Can you understand?

Those who were around these elderly people and their attitudes influenced the participants' experience of dignity. One described the following experiences:

When I lost my hearing people started to ignore me. They didn't treat me as a human being any more and then when I lost my eyesight there was nothing left. I couldn't go anywhere and couldn't do anything. For example, I can't hold the telephone and it's impossible for me to put it back if no one helps me. My friends want me to contact them as well but I can't without asking the girls and they have so much to do and are in such a rush so I forget to ask when they are in here.

This person described how other people's reaction changed as the loss of vital bodily functions increased, leading to further dependency on others and to a changed self-image. This participant's confidence was affected and different situations in normal everyday life were described as being avoided because of the shame and embarrassment of not being able to present the body in a desirable way. This resulted in more isolation from others. Not asking for help despite needing it could indicate a lack of confidence but also an awareness of the staff's considerable workload and not wanting to disturb them.

Fragility and dependency

The elderly participants appeared to be very fragile. Their life situation was characterized by fears and anxiety about the future and the further loss of control and increased dependency, and the exposure to which this could lead. Greater dependency and loss of control mean reduced autonomy. Some stories revealed feelings of fear and desperation over the actions of staff. They often expressed a lack of negotiation about how best to meet an elderly person's needs and desires, which was instead experienced as insulting and as a threat to the sense of self. These stories are examples of the need for negotiation and making sure that the outcome of nursing actions benefits the person and does not cause harm.

The environment was also described as passive and the attitudes of the staff were of importance to the elderly people's views of themselves. Two stories illustrate this.

You see ... it feels as if they treat us as if we don't understand anything even though we have lived a whole life. Why doesn't anyone speak to us? It is almost as if we are blockheads just because we are old ... I suppose that is how it goes. There is nothing here for us; everything is supposed to be done quickly and fit into the right box. We are told when to eat, when to shower, everything. And no one ever says a word, no one says a word.

This illustrates the participants' experience of not being seen or treated in a personal way. Instead, attitudes towards them are stereotyped and neglectful. The silence and lack of conversation surrounding them is explicit and provides an environment of 'living in silence'.

I wish my son would visit me ... but I suppose he is busy and has other things to do. You see, his wife is ... I don't really know but they never come here. I wish I had someone to talk to. They never have time for us here, not even to say a word; it's like we are nothing.

The elderly people's view of the organization was that it did not provide the possibilities for meeting individual personal needs. They thought they were not being seen as the persons they are. Some had been abandoned by their next of kin and the days followed each other in silence and without conversation. This lack of

conversation made some of them feel invisible and had a negative affect on the fullness of their everyday life.

Inner strength and sense of coherence

The two earlier themes illustrate a quite dark picture of being old and living in a nursing home. Daily life contains much loneliness. Other people, for example staff, are there physically but not emotionally and this makes it difficult to find meaning in everyday life. At the same time elderly people can represent a powerful force, which was visible in their different strategies for handling life in a nursing home. Supportive attitudes from both staff and next of kin seemed to help to strengthen the elderly people's possibilities of maintaining dignity of identity despite all the threats to which they were exposed. The darkness contained light and the quotations below express the importance of them feeling involved and belonging. The core of feeling valued and being of worth is illustrated as finding meaning in an otherwise narrow everyday life.

I have a family with grandchildren and that is nice. I don't see them often but my wife is coming to see me almost every day. But I just want to go home. It's OK here but it's not home with staff coming and going. Nothing happens here. I miss my social life in my home.

This shows that thoughts of the grandchildren, even though they did not visit often, helped this person to see himself as a significant link in an important context, which helped him to experience a sense of coherence even though he missed his home. Family as well as significant others were of importance for his experience of a sense of self and meaning in everyday life.

The next quotation expresses that staff can have a key role in elderly people's everyday life and their experience of dignity.

It's hard to find meaning in daily life when you can't do anything on your own. But I have my family. It is a big family and that is what keeps me going. Also I have a great contact person here at the nursing home. She helps me with everything and she is lovely. There is also a man who is wonderful. They have a lot to take care of, you see everyone likes them.

The capability of enjoying the small things in life despite different losses was apparent in most of the elderly people in this study.

I'm scared of being dependent, tied to the bed and not being able to take care of myself, but there is no point in worrying. I try to enjoy the moment. The sun is shining or a flower is blooming . . . things like that.

Photographs or other things that reminded the participants of important events strengthened their feeling of belonging and coherence.

Look at these pictures. It is my child, grandchild and her newborn. Can you believe, we are four generations.

The feeling of still serving a purpose was important for the experience of having personal value. To serve a purpose was expressed as, for example:

I'm a mother and a grandmother and my whole family is lovely. I help the others at mealtimes. It helps them and the staff.

Helping others brought out feelings of importance and the person had a part to play in everyday life in the nursing home. In this way she felt confirmed in an otherwise

pretty narrow life. Small things were greatly appreciated: a phone call or a short visit was a highlight in the participants' daily life. These events strengthened their identity and their experience of having a value.

Discussion

The aim of this study was to explore elderly people's views of dignity when living in a nursing home towards the end of their life. Through their stories about specific caring situations and everyday life at the nursing home the meaning of dignity has been highlighted. It seems that it was easier for these elderly people to describe dignity when their dignity had been threatened or violated. Ageing, with all its losses, can itself be experienced as a threat or violation. The participants described repeatedly how their increased bodily losses led to further dependency. Especially difficult was not being able to control their bladder and bowels, when their body became perceived as unrecognizable. This affected at least one of the aspects of dignity (dignity of identity) described by Nordenfelt¹⁸ as well as by others, including the values of actions and being, and maintaining the individual self.² Elderly people's views on dignity as they appear in this study can be illustrated by a triangle where each corner represents a theme (see Figure 1).

The three themes (the unrecognizable body, fragility and dependency, and inner strength and a sense of coherence) interact and can both promote and hinder a

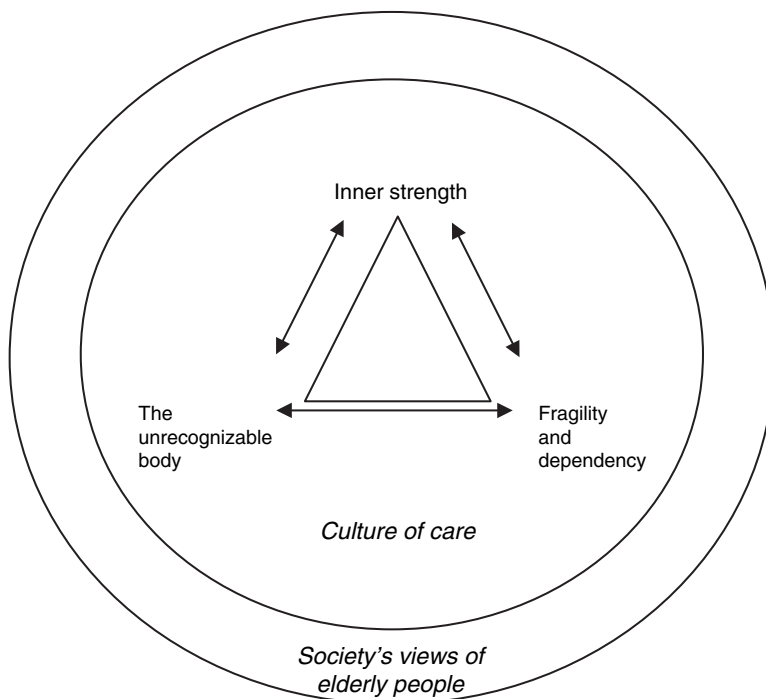


Figure 1 Interacting aspects of elderly people's views concerning dignity in everyday life when living in a nursing home and nearing the end of life

person's dignity of identity, depending on personal as well as organizational circumstances. This interaction appears in a certain context or culture of care and could be described as an 'inner struggle'.

The participants' stories and experiences of everyday life were often related to their body and its decay. As discussed by Street¹⁷ and by Nordenfelt¹⁸ it seems as if not being able to control their personal behaviour or the environment in which they live affects elderly people's feelings of worth and value. Body changes affect personal autonomy and dignity of identity. According to Street, dignity as personhood or self-worth contains the individual's past, secrets, successes, life's work, and current strengths and interests within their context. Inherent in dignity as personhood is respect for all aspects of the person.¹³ This is close to what Sahlberg-Blom *et al.*^{25,26} describe as an important starting point in palliative care: to tend to each individual's needs on the basis of his or her personal view of self and self-image. Helping a dying person to maintain a positive self-image until death is assumed to promote possibilities of experiencing a good death.²⁶ Respect for the person within a caring relationship has been proved to help people to maintain a feeling of dignity.^{27,28} Dignity as personhood typifies dignity and personal worth. Loss of dignity, as loss of autonomy and fear of an unworthy existence, can relate to a person's self-worth or personhood. In this study dependency in the nursing home setting was described as challenging the feeling of being needed. It is apparent that being needed is essential to the feeling of having worth. All the losses that had affected these people's lives both physically and psychologically made it difficult to define the meaning of value and worth.

Dependency means a potential risk of exposure and further loss of control of the personal situation. Strandberg has investigated dependency on care,²⁹ finding that there is a demand to negotiate how best to meet the needs of a patient in a dependent caring relationship. Her study also emphasizes nurses' potential to use their position and power in a fruitful way, whereby they use their capabilities and offer different possibilities to meet the needs and desires of each person in need of care.

In this study, lack of conversation and the silence surrounding elderly people is demonstrated, and life in the nursing home setting is experienced as safe and secure but boring. In a relatively new Swedish dissertation, Whitaker³⁰ reports that elderly people in a nursing home setting have some kind of inner strength and also a sense of coherence. Chochinov *et al.*³ argue that, despite various psychological and physical challenges, people who are at the end of their life experience a strong personal sense of dignity.

Street¹⁷ has described dignity as both embodied and relational. The experience of dignity is an interaction between the person, others and society. As stated by Haddock,⁸ this reveals the significance of others and their attitudes in ensuring that elderly people feel they have dignity. Haddock discusses the importance of having the possibility of feeling essential and valuable in relationships with others, especially in situations that can be experienced as threatening. Her distinction between having dignity, being treated with dignity and actively giving dignity to others embraces all those involved in caring situations. This is in line with the themes that emerged to illustrate the findings in our study, that elderly people struggle to maintain their dignity at the end of their life while living in a nursing home.

The participants' dignity of identity was to a great extent also connected to others' attitudes towards them as persons. What happens in the caring relationship between

older people and staff mirrors the organization and their prioritizing concerning, among other things, ongoing education and support for the staff. On the other hand, the organization mirrors different values of society when it comes to resources and priorities between different sectors. There is a risk that dedicated staff who are not given the opportunity to care for elderly people in accordance with the aims set out in guidance documents, as well as with their own values, are exposed to moral stress.³¹

In our post-modern society, youth and strength are highly valued and this raises questions about how this affects persons with weakened bodily functions who are in vulnerable situations. One question that can be raised is whether a lack of conversation and a shortage of resources in the care of older people mirrors such a view on the part of society and has consequences in clinical practice concerning attitudes towards elders. It would be interesting to study this further because the care of elderly people raises issues and questions for nurses with regard to how to promote possibilities for maintaining identity and dignity at the end of life.

It is important to address the need for tailored palliative care for all those who need it in different health care settings in order to provide dignified care at the end of life. Studies have shown that elderly people with chronic illnesses and people who lack a social network are more likely to be undertreated than others.³¹⁻³⁵ Just like younger people, elderly people need sufficient palliative care at the end of life.⁴ Andrews³⁶ suggests that places where people die, such as nursing homes, need to move towards more sensitive nursing care that incorporates respect for each individual because there is a lack of respect for personal boundaries in these settings. Privacy is a question of place and space and also of protecting the individual from unnecessary intrusion.

Elderly people's perception of dignity in nursing home settings is not unidimensional. The dignity of older persons has been interpreted as embodied, relational, situational and contextual. It is therefore a fragile matter that needs to be addressed in different care contexts. In the everyday care context of strain it seems as if supportive relationships with others could help elderly persons to maintain or construct a 'new' identity with which it is acceptable to live. What can be of particular interest in our study is the relationship between the threat to one's dignity and the inner strength the elderly people show in trying to maintain their self-image, identity and dignity. This needs to be addressed in nursing care and studied further.

Our study was limited to the experience of elderly people living in nursing homes who did not have cognitive or speech impairment. It would be of great value to add observational studies to the interviews and also to examine the interactions between elderly people and care staff. This would provide a broader understanding of older people's everyday experience and their dignity as their life draws to a close. Nevertheless, the findings from the interviews have provided in-depth illustrations of everyday life in nursing homes. To ensure validity and reliability, a demand in hermeneutic research is that the interpretations have an inner logic and are consistent, and that throughout a study it is possible for readers to follow the interpretations. Objectivity and validity in human science research means approaching things directly. An attitude of openness throughout the research process is therefore important.³⁷ It is possible that the participants perceived the interviews as therapeutic because they had the chance to talk repeatedly about their experiences from the past and present and their thoughts about the future. A question that must be raised is the study's validity and reliability. Although different areas have been highlighted and spoken about over time, it has to some extent been possible to check the reliability of the answers received

in the interviews. On the other hand, it is possible that a person can change his or her views without interfering with the validity and reliability of the study. We tried hard to increase the study's validity and reliability during the interviews and also when analysing the data. One question asked was if the elderly people's stories represent grounded experiences or were simply eye-catching moments. We have searched for other alternative interpretations. A demand in hermeneutic research is that the interpretations are logical and consistent as well as reflecting the actual situations. We actively tried to meet these demands and our result is on the whole congruent with other research on dignity. However, this study adds the perspective of elderly people's views on dignity at the end of life when they are living in nursing homes.

Implications for nursing

This study showed that understanding dignity has important implications for the quality of care provided in nursing homes. From the elderly people's stories it is clear that in order to keep a sense of dignity people need to be seen and respected for who they are. Care focusing on and aiming to promote an elderly person's identity and dignity demands interest and a desire to know the person. It is important to address this in particular and to find out individuals' views of themselves and how they value themselves in this particular context. This demonstrates how difficult and sensitive it can be to tailor care to individual needs. It also highlights the importance of doing so in order to provide dignified care at the end of life. Beginning to understand how different bodily function losses affect elderly people and what it is like to be dependent reveals a range of possible ways of developing care for people who are near the end of their life. However, recognition of the importance of place and space enhances opportunities to develop care for elderly people in nursing homes. If dignity at the end of life is an aim of the care given in nursing homes, then it is important that the staff reflect on their own views of dignity in terms of ageing and elderly people in order to resolve the critical issue of how staff members can support people's dignity towards the end of life. Education and supervision could be part of such care. If dignity is understood in a multidimensional manner, nursing home staff will be able to develop a range of options for caring for elderly people.

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References

- ¹ Street AF, Love A. Dimensions of privacy in palliative care: views of health professionals. *Soc Sci Med* 2005; **60**: 1795–804.
- ² Enes Duarte SP. An exploration of dignity in palliative care. *Palliat Med* 2003; **17**: 263–69.
- ³ Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Dignity in the terminally ill: a cross-sectional cohort study. *Lancet* 2002; **360**: 2026–30.
- ⁴ Davies E, Higginson J eds. *Palliative care. The solid facts*. World Health Organization, 2004.
- ⁵ Skilbeck J, Mott L, Smith D, Page H, Clark D. Nursing care for older people dying from chronic obstructive airways disease. *Int J Palliat Nurs* 1997; **3**: 100–106.
- ⁶ Nightingale F. *Notes on nursing*, commemorative edition. Lippincott, 1992.
- ⁷ International Council of Nurses. *Code of ethics for nurses*. ICN, 2000.
- ⁸ Haddock J. Towards further clarification of the concept 'dignity'. *J Adv Nurs* 1996; **24**: 924–31.
- ⁹ McIntyre M. Dignity in dementia: person-centred care in the community. *J Aging Stud* 2003; **17**: 473–84.
- ¹⁰ Fenton E, Mitchell T. Growing old with dignity: a concept analysis. *Nurs Older People* 2002; **4**: 19–21.
- ¹¹ Jacelon CS, Connelly TW, Brown R, Proulx K, Vo T. A concept analysis of dignity for older adults. *J Adv Nurs* 2004; **48**: 76–83.
- ¹² Gallagher A. Dignity and respect for dignity – two key health professional values: implications for nursing practice. *Nurs Ethics* 2004; **6**: 587–99.
- ¹³ Edlund, M. *Människans värdighet: ett grundbegrepp inom vårdvetenskapen*. (Human dignity: a basic caring science concept [Dissertation].) Åbo Academy, 2002 (in Swedish).
- ¹⁴ Ternstedt B-M, Andershed B, Eriksson M, Johansson I. A good death: development of a nursing model of care. *J Hospice Palliat Nurs* 2002; **3**: 153–60.
- ¹⁵ Mairis ED. Concept clarification in professional practice: dignity. *J Adv Nurs* 1994; **19**: 947–53.
- ¹⁶ Maititi M, Trorey G. Perceptual adjustment levels: patients' perception of their dignity in the hospital setting. *Int J Nurs Stud* 2004; **41**: 735–44.
- ¹⁷ Street A. Constructions of dignity in end-of-life care. *J Palliat Care* 2001; **17**(2): 93–101.
- ¹⁸ Nordenfelt L. The varieties of dignity. *Health Care Anal* 2004; **12**(2): 69–81.
- ¹⁹ Zingmark K, Sandman PO, Norberg A. Promoting a good life among people with Alzheimer's disease. *J Adv Nurs* 2001; **38**: 50–58.
- ²⁰ Sandman L. What's the use of human dignity within palliative care? *Nurs Philos* 2002; **3**: 177–81.
- ²¹ Ödman P-O. *Tolkning, Förståelse, Vetande Hermeneutik I teori och praktik*. (Interpretation, understanding, knowledge: hermeneutics in theory and practice.) Almqvist & Wiksell, 1978 (in Swedish).
- ²² Ödman P-O. Interpreting the past. *Qualitative studies in education* 1992; **5**: 167–84.
- ²³ Patton MQ. *Qualitative evaluation and research methods*. SAGE, 1990.
- ²⁴ Moody H. From informed consent to negotiated consent. *Gerontologist* 1998; **26**: 64–70.
- ²⁵ Sahlberg-Blom E, Ternstedt B-M, Johansson J-E. Patient participation in decision making at the end of life as seen by a close relative. *Nurs Ethics* 2000; **7**: 296–313.
- ²⁶ Sahlberg-Blom E, Ternstedt BM, Johansson JE. Is good quality of life possible at the end of life? An explorative study of the experiences of a group of cancer patients in two different care cultures. *J Clin Nurs* 2001; **10**: 550–62.
- ²⁷ Randers I, Mattiasson AC. Autonomy and integrity: upholding older adult patients' dignity. *J Adv Nurs* 2003; **45**: 63–71.
- ²⁸ Walsh K, Kowanko I. Nurses' and patients' perception of dignity. *Int J Nurs Pract* 2002; **8**: 143–51.
- ²⁹ Strandberg G. *Beroende av vård*. (Dependency on care [Dissertation].) Umeå University, 2002 (in Swedish).
- ³⁰ Whitaker A. *Livets sista boning: anhörigskap, äldre och död på sjukhem*. (The last home: family ties, ageing and death in a nursing home [Dissertation].) Stockholm University, 2004 (in Swedish).

- ³¹ Cronqvist A, Theorell T, Burns T, Lützén K. Caring about – caring for: moral obligations and work responsibilities in intensive care nursing. *Nurs Ethics* 2004; **11**: 63–76.
- ³² McCarthy M, Addington Hall, J Altman, D. The experience of dying with dementia; a retrospective study. *Int J Geriatr Psychiatry* 1997; **12**: 404–409.
- ³³ Gibbs L, Addington Hall J. Dying from heart failure: lessons from palliative care. *BMJ* 1998; **317**: 961–62.
- ³⁴ Ahronheim JC. End-of-life issues for elderly women: incurable and terminal illness. *J Am Med Womens Assoc* 1997; **52**: 147–51.
- ³⁵ Thomé B, Dykes A, Hallberg I. Quality of life in older people with and without cancer. *Qual Life Res* 2004; **13**: 1067–80.
- ³⁶ Andrews GJ. Towards a more place-sensitive nursing research: an invitation to medical and health geography. *Nurs Inq* 2002; **9**: 221–38.
- ³⁷ Dahlberg K, Drew N. A lifeworld paradigm for nursing research. *J Holist Nurse* 1997; **15**: 303–17.

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PAPER II



THREE NURSING HOME RESIDENTS SPEAK ABOUT MEANING AT THE END OF LIFE

*Lise-Lotte Dwyer, Lennart Nordenfelt and
Britt-Marie Ternstedt*

Key words: dying; end of life; meaning; older people; palliative care

This article provides a deeper understanding of how meaning can be created in everyday life at a nursing home. It is based on a primary study concerning dignity involving 12 older people living in two nursing homes in Sweden. A secondary analysis was carried out on data obtained from three of the primary participants interviewed over a period of time (18–24 months), with a total of 12 interviews carried out using an inductive hermeneutic approach. The study reveals that meaning was created by: having a sense of physical capability; having a sense of cognitive capability; having a sense of being needed; and having a sense of belonging. Meaning was created through inner dialogue, communication and relationships with others. A second finding is that the experience of meaning can sometimes be hard to realize.

Background

When one's existence is threatened, as for example when a person is nearing the end of life,^{1,2} existential issues concerning meaning become more urgent. Older people's age-related losses such as losses of social relationships, social roles, physical capacities and independence can be a challenge to their sense of meaning in daily life.³ Western society's strong emphasis on autonomy and independence can also result in older people being marginalized in mainstream society and not being assigned the same rights as during other phases of their life.^{3,4} Whitaker⁵ describes how older people's tiredness is not always related to ageing but is influenced by the inactive care culture constituted by the nursing home. The care culture reflects underlying values and ways of thinking⁶ and can both promote and hinder an older

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person's experience of meaning in everyday life. This is in line with Lloyd,⁷ who highlights the need for long-term support to enhance older people's end of life.

The concept of meaning is used in different ways depending on the context. Westerhof *et al.*⁴ describe the concept of personal meaning by separating its cognitive and motivational components. They state that the cognitive component of meaning relates to how a person attempts to identify significance in searching for a sense of coherence. An example of this could be reflecting on one's life. The motivational component includes the search for a purpose in life as well as having realistic goals and intentions. This approach is close to what Skaggs and Barron⁸ describe and define as global meaning. They also talk about situational meaning, which concerns one particular situation. When the situational and global meanings are not congruent, the search for meaning emerges. The situation the person is in may be limiting the person's ability to recognize his or her own potential. This tension emerges, for example, when older people who had earlier managed to live independent lives then become dependent on others. The gap between the global and the situational meaning is then evident. It is reasonable to assume that the way in which older persons create meaning in such situations may influence their sense of dignity of identity. Dignity of identity was described by Franklin *et al.*⁹ as hindered if there is an unrecognizable body, fragility or dependency. Inner strength and sense of belonging were described as promoting an older person's dignity of identity. Research in palliative care has only recently started to include and focus on the needs of older people,¹⁰⁻¹² who are increasingly cared for in nursing homes until their death. This means that nursing homes are significant places for dying^{13,14} and places where the creation of meaning occurs. Meaning is understood here in the general sense of one's self and one's life having a value, with a focus on everyday life.

Aim

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

Design

An inductive hermeneutic design was chosen. A primary study involving 12 older people's views on dignity⁹ was carried out over a period of 18–24 months, with a total of 39 interviews. A secondary analysis was then conducted on 12 interviews with three women identified from among the 12 original participants. These women's interviews were chosen because of their richness and the reflective content that revealed various ways in which meaning was experienced and created. The three women were interviewed on four occasions in their private rooms at the nursing homes. Short informal conversations were also held with the women between the scheduled interviews. The narratives told by the women oscillated between events providing meaning from the past and present. Extracts from each interview that were interpreted by the first author (LLF) and are especially meaningful have been combined to make three narratives.¹⁵

Participants and the nursing home context

The three women lived in two nursing homes in the same geographical district. They had lived most of their lives in the same area. All lived in single rooms with their own furniture. Cooking facilities were provided, which none of the women could take advantage of because of their physical condition and lack of strength; all rooms had private bathrooms. There was a communal dining area and TV room.

Alice and Martha were both 95 years old and Sophia was 93 when the interviews took place (names have been changed). They had lived in the nursing home for between two and four years and suffered from various physical ailments that greatly limited their possibilities of carrying out normal everyday activities.

Data analysis

- 1) The analysis followed the principles for hermeneutics described by Ödman.¹⁶ The guiding principle was openness towards what the women had told about their past, present and future from the point of view of what gave meaning to their life. Understanding of the women's experiences proceeded gradually.
- 2) The transcripts were first analysed as a whole, with the text providing a broad understanding of what the women experienced as bringing meaning into their life.
- 3) The stories were then read and analysed part by part to acquire a more detailed understanding. Four themes were identified as significant with regard to meaning in everyday life: physical capability, maintained cognitive capability, being needed by others, and having a sense of belonging.
- 4) Three additional themes were identified as describing the women's struggle to acquire a sense of meaning in everyday life. Meaning was created through communication, relationships with others, and an 'inner dialogue'. These themes are illustrated in Table 1.
- 5) The analytical procedure was characterized by moving from the whole to parts of the text and vice versa, searching for significant events related to meaning in the stories (hermeneutic circle).
- 6) In conclusion, one of the authors (LLF) listened to the tapes again to discover possible contradictions or alternative interpretations.

The authors' pre-understanding is based on practical experience from nursing older people (LLF), research in palliative care (BMT) and research on basic concepts from a philosophical perspective (LN).

Table 1 Creation of meaning in everyday life in a nursing home

Sources of meaning	Meaning was created through
Having a sense of physical capability	An inner dialogue
Having a sense of cognitive capability	Relationships with others
Having a sense of being needed	Communication
Having a sense of belonging	

Ethical considerations

The three women gave informed consent to participate in the first study. They were informed during the interviews that they may be used in a second study. The first author has ensured the confidentiality of each individual by using stories that cannot be linked to any one person. Approval to conduct the study was granted by the local Research Ethics Committee (171–01).

Findings

Through Alice, Sophia and Martha's willingness each to share part of their life-story it has been possible to acquire a deeper understanding of how these three women experienced and created meaning when they were nearing the end of their life. Meaning in their present lives was closely related to their earlier lives. This was expressed as still wanting to be needed, having a sense of physical and cognitive capability, having a sense of belonging, and having communication and relationships with others (Table1). The main finding of this study can be described as the inner dialogue being an important facilitator of creating meaning. The inner dialogue, together with an inner strength and having contact with others, seems to have facilitated the creation of meaning in life as a whole, including both the past and the present. One of the women found it difficult to find any meaning in her present life and her inner dialogue focused more on her striving to come to terms with her life as it had turned out and to reach for closure. Despite the women's bodily losses and dependence on others they had a wish to be involved in their daily life at the nursing home. These three women's stories revealed both similarities as well as differences about what provided meaning for them in their everyday life. The differences mainly consisted of what the women thought about and focused on in their inner dialogue (i.e. what they considered provided meaning in their lives).

Alice

Alice had been a housewife and she talked about her family with warmth. She related that they had always been a close and loving family. Family values had always been important to Alice, and her room was filled with family pictures and private things that she gladly talked about.

I moved in here after a hospital stay. It's a nice place but I miss doing things together with others. But it's difficult because many suffer from memory loss so it's not working. But I have my family and they're very dear to me; we are a big family.

Alice speaks of her life as being overall a happy one and she believed that her family cared for her and that they were doing everything they could for her. She felt needed by her family and she spent a lot of her time thinking about them in the past and in the present. This contributed to her sense of meaning. When Alice was alone in her room she spent most of her time looking at family photos and engaging in an

inner dialogue in which she mainly thought of her family and the meaning of being a wife, a mother and a grandmother, which she has greatly appreciated.

Alice had in a way accepted the nursing home environment because it meant security for her. She had lost many of her physical bodily functions and was now in a wheelchair. She said that ageing for her was not only a decline of her physical body and bodily capacities, it also affected her feeling of freedom in everyday life. Everyday goals changed over time as her physical health worsened.

Do you know what makes me happy? To be able to go to the toilet on my own. It gives me satisfaction not having to ask for help with everything. I'm so grateful that I can take care of myself as much as I can.

To be able to tend to her basic intimate needs and not have to ask for help with everything gave Alice a sense of meaning. It was important to her to keep her physical competence and independence.

She also described the end of life as a time when loss of friendships happens, which caused emotional and existential suffering.

An old friend of mine who used to visit me regularly is very ill and that makes me quite sad because we've known each other for many years. But you see that's what being old is. Your friends die and that's why it is wonderful to be close to my family. It's my family that feels important to me.

Although she had a close relationship with her family, Alice missed everyday togetherness and conversation with others. The nursing home residents did not interact with each other apart from at mealtimes, thus the staff played an important role in her finding a sense of meaning.

I'm particularly fond of two of them. I think we know each other quite well; they know most things there are to know and they know how I want things to be.

It was important to Alice that the staff knew her as the person that she experienced herself as, and that they respected her values and lifestyle.

Alice's inner dialogue and her creation of meaning were mainly related to her family and the importance of being both a mother and a grandmother. In this instance her sense of meaning was close to her dignity of identity and her sense of coherence. Big events, such as christenings and weddings, meant a lot to Alice and she was always invited to join any family events. Her family made her feel needed and important and that meant a lot to her. Alice's relationship with her family and to some extent some of the staff can be seen as having a central role in her creation of meaning.

Sophia

Sophia had lived a single life without children. Her family life comprised brief contact with her niece and her niece's daughter. At the time when the interviews took place Sophia was the most dependent of the three women. She was bedridden and totally dependent on the staff to see to her everyday needs. Sophia was also the one most critical of the nursing home as a place for caring. She experienced the

atmosphere there as cold and she spoke of the lack of a basic care philosophy respecting older people's needs. Throughout the research conversations Sophia often returned to how she had lived and enjoyed an active, independent life, and she often said:

I have lived my life my way with friends and lots of travelling.

Her wish was to end her life by just falling asleep and she described her daily life at the nursing home as a 'non-life'.

I want my life to end now. I can't feel at home here; I never have done and I never will. No one talks to me except for you. No one has time for us, but that's how it is, getting old: they don't want to know in some strange way. Maybe they think we're from outer space, I don't know. I've told you before that if there was only some warmth and dignity in this care then maybe it could be called care, but there is no warmth or dignity. I have my books and sometimes I watch TV but I can't turn it on or off so that's whenever they feel like doing it.

Sophia enjoyed reading and sometimes she watched TV but to do that she was also totally dependent on the staff. She said:

It's up to them when they decide they've got the time to turn on the TV or radio.

Sophia experienced feelings of abandonment and neglect. She expressed several times how she was longing for proper or just short conversations with others.

In the quotation below Sophia expressed a sense of there being no meaning. She felt not needed and was unable to do anything. She felt as if she had no purpose in life.

Meaning in life when you're lying like this? No, I wouldn't say there is. I just want to fall asleep and never wake up, that's what I want. I'm no good to anyone lying here; this life has no meaning at all. It would be valuable to have more contact with my family or someone that had the time to listen. In this place I haven't been able to have any contact with anyone; I just lie here sick and all I do is think of old times, everything that's been fun. There's no point lying here thinking why this or that happened. No, I think of my travels.

Thus Sophia described difficulties regarding creating meaning in her present life. She described her participation in this study as providing a sense of meaning through the interaction and conversations. She expressed thoughts of how it might have been different if she had had more contact with her family or someone else at this point in her life. She found it difficult to establish contact with anyone in the nursing home, and the lack of someone to talk to was clearly expressed as adding to her lack of a sense of meaning. The quotations above illustrate to some extent how Sophia's inner dialogue and her dignity of identity partly provided her with a sense of meaning as she thought of her past life, chiefly her travels and her independence. It seems as if Sophia was stranded by the limitations of her body, her dependence, and the nursing home culture. Although her memories provided her with retroactive strength that helped her to bear her situation in the nursing home,

her everyday life and life goals were too far away for Sophia to create meaning. Sophia died one night in her sleep, a few months after the last interview.

Martha

Martha had been a widow for many years and her present family included one daughter, one son (one child died young) and her grandchildren. She described her relationships with them as relaxed. Martha was brought up in a family with very strict religious beliefs that have to a large extent guided her life. She had tried to follow the Ten Commandments throughout her life and doing 'good' for others had been a guiding principle for her. Martha married young and she and her husband moved to a city. Her husband died when they were both in their fifties. Their children were quite young at the time of her husband's death and Martha started to save money to start a small business. She lost her eyesight three years ago. Martha's inner dialogue reveals how she always tried to accept life as it is, in good and in bad times. She described herself as a fighter, as a person who never gave up. She greatly missed her eyesight because she felt limited and dependent in everyday life because she could not do everything that she was used to doing.

This is a trial in my life that I just have to go through. When you don't see, you don't see, and that's how it is, but I'm satisfied with life anyway, it would be impossible otherwise.

The conversations with Martha were characterized by a great deal of reflection on life's ups and downs, and also her inner dialogue with a strong emphasis on her cognitive capacities that provided her with a sense of meaning. She emphasized all her good memories and said:

Sometimes I laugh at things I've done. I went through a difficult time when my husband passed away and I had two teenagers to take care of on my own. I thought to myself, what do I do now? There was really no choice but to buy a house, so I looked in the paper and bought a house.

You see, I feel as if I have everything left inside my head. When I think of the difference between being young and old I think, when you're younger you have all those great expectations about the future that might go up and down all the time. Then, when you get older you're more stable, you know more of what life is about and maybe it's time to start thinking of what mistakes one has made or what has been good. Life is up and down for everyone, I believe, and it also depends on how you feel on the inside and how you meet difficulties. I've always said try, try and it'll be all right as long as you're healthy, and so I'll keep on fighting. You know you can't change anything in your life.

Martha also expressed a clear engagement regarding societal issues, which she had a wish to discuss with others. She was especially interested in class differences and women's equal rights. Martha related that the worst thing was that she believed that class differences were coming back and the status of women was decreasing, and she wanted to change that. When she spoke of today's issues concerning women's situation, she related how things were when she was a young woman and,

as an example, she raised the issue of how unmarried women who became pregnant had to carry the blame on their own.

Martha's experience of meaning was mainly related to an intact cognitive ability and characterized by her wish to contribute to others' quality of life, for example by participating in this study, which mirrored her engagement in social issues. Her expectation was that this study would contribute to another view of older people and provide means for better care. In her inner dialogue her family played a big part and so did the work in her shop: conversing with imaginary customers, adding up items and stacking shelves. In addition Martha related that she was not prepared to die until her grandchild had graduated from university. She felt needed and had a sense of dignity of identity as the supportive grandmother, and this strengthened her meaning in life.

Overview

The three women's stories about being at the end of life included feelings of a sense of meaning in everyday life. In addition to a sense of meaning there were also sources of no meaning in one woman's story. The sense of a lack of meaning was mainly related to little interaction with others and living in total dependency (Table 2).

Discussion

The aim of this study was to acquire a deeper understanding of how three older women created meaning in their everyday life in a nursing home. The study reveals that global meaning at this point in their lives was significant. Meaning was facilitated first and foremost through inner dialogue. Interaction with others was also significant to some, which shows that situational meaning can always be a factor for creation of meaning. Meaning in everyday life was to a certain extent a question of

Table 2 Summary of the conditions for creation of meaning

Participants	Having physical/cognitive capability	Having a sense of being needed by others	Having a sense of belonging	Having a sense of meaning
Alice	Partly physical capability/cognitive capability	Children and grandchildren	Family and staff members	Yes
Sofia	Total dependency/cognitive capability	No children	No close significant others	Weak
Martha	Partly physical capability/cognitive capability	Children, and grandchildren	Family	Yes

having physical capability, having cognitive capability, and feeling needed and experiencing a sense of belonging. This is in line with other authors' findings concerning the end of life.^{2,17} Creating meaning occurred via an inner dialogue and significant others. A finding in a previous study by Franklin *et al.*⁹ was that older people who were at the end of their life while living in nursing homes revealed an inner strength in their retention of having a sense of dignity of identity. It seems that inner strength can support a beneficial inner dialogue, the creation of meaning, or bearing a difficult situation. The one woman who expressed a sense of lack of meaning in her current situation used inner dialogue to endure her life despite her wish to die.

The inner dialogue and the inner strength

The three women's ways of actively searching for meaning draw attention to Frankl¹⁷ and his thoughts about 'man's search for meaning', even though being to close death. Frankl emphasizes the creative, experiential and attitudinal values. The first values concern what one does and achieves; the second concern one's perception of, for example, an aesthetic experience or bird song; and the third one's attitude to the world, to life, and, not least, to death: a situation that we cannot change. Through inner dialogue, including thoughts and memories, the three women described values that can be set in relation to the three values described by Frankl. The telling of their life stories and experiences seems to have helped to bring vitality into their everyday life and thereby also a sense of meaning. The inner dialogue may be seen as a question of a conscious choice and attitude towards something they could not change, but only relate to (i.e. what Frankl has described as attitudinal values). The meaning we have given to inner dialogue seems, in the sense of promoting a person's well-being, to be close to what Nyström and Segesten¹⁸ describe as peace of mind. The women showed, despite their clearly expressed situation of dependency, a strong will to create meaning in their daily life. Whether and how the women's personalities influenced their experience and creation of meaning has not been studied. However, they had lived their lives quite independently and were to a great extent self- and co-determining, and felt frustration to be made passive and no longer listened to.

Not unexpectedly, the women's stories revealed a gap between the global and the situational meaning described by Skaggs and Barron.⁸ An example of such a gap with regard to the three women in this study is to be seen in their having to adapt to the new, more limited conditions that followed their physical dependency. The women's inner dialogue can be analysed in relation to the cognitive and motivational aspect of the concept of meaning described by Westerhof *et al.*⁴ The inner dialogue mirrors the women's desire to create meaning and maintain positive beliefs. The concepts of meaning, maintained self-image and identity seem to have points of contact that would be of interest in further study.

It seems, however, that these women's health status affected their sense of meaning. Sophia was the one with the poorest health, needing the most help from others, and was closest to death. Her daily life was mostly characterized by despair and aversion. This clearly influenced her state of mind and experiences. She expressed alienation and a wish to die. Sophia's experiences bring to mind a study by Nyström and Segesten¹⁹ in which older people in nursing homes often expressed a sense of powerlessness. Sophia described a sense of powerlessness in her present situation at

the same time as the inner dialogue provided her with some strength helping her to bear the situation as it had turned out for her.

The meaning of the care culture

The attitudes of staff and the care culture can both promote and hinder older people's experience and creation of meaning.

Promoting the experience of meaning was most supported by their perception of how well their body functioned, the feeling of being needed and confirmed by those around them, and the fact that the inner dialogue consciously focused on events that strengthened their sense of self.

Factors hindering the creation of meaning were the increased emotional and physical bodily losses, dependence on others and the lack of interaction. Inadequate dialogue with staff added to the experience of not being involved in daily life. Opportunities for influencing their everyday life were fewer than the women wished.

Similar results were shown in a study regarding relatives and their involvement in the care of severely ill persons. Andershed and Ternstedt²⁰ found that a humanistic attitude characterized by respect, openness, sincerity, confirmation and connection with respect to both patients and relatives promoted partnership between a severely ill person, relatives and staff. The three women in the present study described the nursing home environment as mostly hindering their experience of meaning. Everyday life seems to have been controlled more by staff routines than by residents' needs. Whitaker⁵ noted the same phenomenon. She described the nursing home environment as both a place where older people are living the last days of their life and a workplace for the staff. The older people and the staff are described as living in two different cultures. The staff live in what she calls the hurry or pressed culture and the older people live in a waiting or expecting culture. These two cultures rarely interact.

As suggested by Yalom²¹ and Frankl¹⁷ a person's sense of meaning is specific to that person and dependent on the situation. The findings in our study, as well as those of previous studies,^{3-5,7} confirm the subjective nature of meaning. To be able to meet nursing home residents' various needs in their creation of meaning, staff members have an ethical responsibility to listen to and engage in dialogue with older persons.²² This dialogue can be seen as an important starting point and condition for person-centred and individualized care. From an older person's perspective, judging by what the three women narrated, the dialogue is central. To be able to tell one's story and to reveal one's life to someone who actively listens could be a main component in being able to keep as much as possible of one's personal identity and be respected for the person one is and for the life one has lived, and thereby experience a sense of meaning.²³⁻²⁵ Discussion about implementing palliative care philosophy into nursing homes seems relevant to the aim of enhancing nursing homes as high-quality places in which to end one's life. As studies have shown, it is important, however, to transform the palliative philosophy, primarily developed for cancer patients, to fit in with the needs of older people who are dying.²⁶

The care culture and care environment mirror the attitudes held by society and representatives of elderly persons' care. The perspective taken by society can involve a view of older people as either not being part of mainstream society or being a

valuable resource.²⁷ Lloyd³ described older people as being in a transition phase from society's point of view and as having been 'put' into a liminal space because they no longer have the same rights they used to have. This quite easily results in older people's needs not being met. Ageing can be viewed as a 'failure' and an undesirable condition in a culture that strongly emphasizes autonomy, strength and youth, which can influence the allocation of resources and the quality of care. Scott-Cawiezell *et al.*⁶ note a challenge for future progress regarding a sustained improvement in nursing home care because of the diversity of roles and education among staff. The results of the present study could represent a culture in which older people's experiences and knowledge gained from a long life are not valued as resources. Instead, the three women described the nursing home as limited regarding their own development. What this study also reveals is that the culture of care, including the attitudes of staff, can both hinder and promote individuals' experience of the creation of meaning.

Limitations and strengths of this study

Our study was limited to the experience of three older women living in two nursing homes in a large city in the same geographical area. This would have implications for the results if the aim had been to generalize them. However, the goal was to provide in-depth illustrations of how inner dialogue can help to create meaning in everyday life when living in a nursing home. The interviews were conducted over 18–24 months, thus supporting the trustworthiness of the results. Jervis²⁷ discussed the interaction between participants and researchers as a give and take relationship, with the area of interest becoming apparent and meaning emerging. To improve the credibility of the interpretations, participant checking was effected during the interviews by feedback from the participants on the accuracy of the interpretations of their experience. The second author also read the compounded stories and together we searched for alternative interpretations. A demand in hermeneutic research is that interpretations are logical and consistent, as well as reflecting actual situations.¹⁶

In order to preserve the original versions of the quotations and to avoid the risk of changing their content, grammatical changes have been made with great care.

Implications for nursing

Nurses are in a key position to assist people through changes in their life and be aware of individual differences and how people can variously experience ageing and being close to death. This highlights the need for person-centred care in which individual conditions and possibilities for creating meaning are promoted. Having fruitful relationships are essential for creating meaning. Nurses can therefore have a key role in person-centred nursing home care. They can involve older persons in their own care and create an environment for maintaining their self-image and dignity of identity by listening, communicating and respecting them for who they are. One condition for providing person-centred individualized care is that nurses try to understand what previous meaningful experiences older people have had. Listening with openness and respect to what older persons narrate therefore constitute an important starting point in the care of elderly people living in nursing homes when nearing the

end of their life. It also seems important to analyse on what values the care is based and to implement humanistic values whereby older persons are not marginalized but instead treated with respect, openness, sincerity, confirmation and connection with regard to themselves and their relatives. This study shows that one aspect of improving nursing home care could be promoted by education in communication and interaction.

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References

- ¹ Strang S. *Spiritual/existential issues in palliative care* [Dissertation]. Göteborg: Göteborg University, 2002.
- ² Milberg A. *Family member's experiences of palliative care* [Dissertation]. Linköping: Linköping University, 2003.
- ³ Lloyd L. Dying in old age: promoting well-being at the end of life. *Mortality* 2002; **5**: 171–88.
- ⁴ Westerhof GJ, Bohlmeijer E, Valenkamp MW. In search of meaning: a reminiscence program for older persons. *Educ Gerontol* 2004; **30**: 751–66.
- ⁵ Whitaker A. *Livets sista boning: anhöriga och dödpå sjukhem. (The last home: family ties, ageing and death in a nursing home* [Dissertation].) Stockholm: Stockholm University, 2004.
- ⁶ Scott-Cawiezell J, Jones K, Moore L, Vojir C. Nursing home culture. A critical component in sustained improvement. *J Nurs Care Qual* 2005; **20**: 341–48.
- ⁷ Lloyd L. Mortality and morality: ageing and the ethics of care. *Ageing Soc* 2004; **24**: 235–56.
- ⁸ Skaggs B, Barron C. Searching for meaning in negative events: concept analysis. *J Adv Nurs* 2006; **53**: 559–70.
- ⁹ Franklin L-L, Ternstedt B-M, Nordenfelt L. Views on dignity of elderly nursing home residents. *Nurs Ethics* 2006; **13**: 130–46.
- ¹⁰ Froggatt K, Field D. Issues for palliative care in nursing and residential homes. In: Katz J, Peace S eds. *End of life care in care homes: a palliative care approach*. Oxford: Oxford University Press, 2003: 1–13.
- ¹¹ Gott M, Seymour J, Bellamy G, Clark D, Ahmedzai S. Older peoples' views about home as a place of care at the end of life. *Palliat Med* 2004; **18**: 460–67.
- ¹² Kristjanson L, Walton J, Toye C. End of life challenges in residential aged care facilities: a case for a palliative approach to care. *Int J Palliat Nurs* 2005; **11**: 127–29.
- ¹³ Froggatt KA. Palliative care in nursing homes: where next? *Palliat Med* 2001; **15**: 42–48.
- ¹⁴ Davies S, Seymour J. Historical and policy contexts. In: Hockley J, Clark D eds. *Palliative care for older people in care homes*. Buckingham: Open University Press, 2003: 4–33.
- ¹⁵ Yin RK. *Case study research design and methods*. Thousand Oaks, CA: SAGE, 1991.
- ¹⁶ Ödman P-O. Interpreting the past. *Qual Stud Educ* 1992; **5**: 167–84.
- ¹⁷ Frankl V. *Man's search for meaning*. London: Hodder and Stoughton, 1987.

- ¹⁸ Nyström A, Segesten KM. Peace of mind as an important aspect of old people's health. *Scand J Caring Sci* 1990; **4**: 55–62.
- ¹⁹ Nyström A, Segesten KM. On sources of powerlessness in nursing home life. *J Adv Nurs* 1994; **19**:124–33.
- ²⁰ Andershed B, Ternstedt B-M. Development of a theoretical framework describing relatives' involvement in palliative care. *J Adv Nurs* 2001; **34**: 554–62.
- ²¹ Yalom I. *Existential psychotherapy*. New York: Basic Books, 1980.
- ²² Meiers SJ, Tomlinson PS. Family–nurse co-construction of meaning: a central phenomenon of family caring. *Scand J Caring Sci* 2003; **17**:193–201.
- ²³ Brody H. My story is broken can you fix it? Medical ethics and the joint construction of narrative. *Lit Med* 1994; **13**: 79–92.
- ²⁴ Moore S, Metcalf B, Schow E. Aging and meaning in life: examining the concept. *Geriatr Nurs* 2000; **21**: 27–29.
- ²⁵ Randall L, Kenyon G. Time, story and wisdom: emerging themes in narrative gerontology. *Can J Aging* 2004; **23**: 333–46.
- ²⁶ Ellershaw JE, Murphy D. The Liverpool Care Pathway (LPC) influencing the UK national agenda on care of the dying. *Int J Palliat Nurs* 2005; **11**: 132–34.
- ²⁷ Jarvis L. The missing family: staff perspectives on and responses to familial non-involvement in two diverse nursing homes. *J Aging Stud* 2006; **20**: 55–66.

PAPER III

Dignity as experienced by nursing home staff

ABSTRACT

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Background. Dignity is a concept often used in end-of life care, but the meaning is rarely clarified. Staff member's views and experiences of dignity are therefore needed to be illuminated.

Aim. The aim of this study 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.

Methods. The study is based on interviews with 21 nursing home staff members, analysed by means of qualitative content analysis.

Findings. The meaning of older people's dignity has been 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 meant showing the older person respect by providing for the person's physical needs, respecting the person's identity and integrity. Staff members' 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, feedback from others and the feeling of doing good. A common threat against a person's dignity of identity was lack of resources and being ignored.

Relevance to clinical practice. Nursing could offer a range of possibilities to enhance the dignity of both the older people and staff. However a prerequisite is that the organisation is willing to provide support, continuous education and supervision to foster personal growth.

INTRODUCTION

In Sweden, as in other developed countries, the population is becoming older and, of the 90 000 people who die each year, approximately 60% are 80 years and over (The National Board of Health and Welfare, 2006) and many of them die in nursing homes. According to several studies, it is not unusual for older people in the end-of-life phase to suffer unnecessarily (Addington Hall & Higginson, 2001; Froggatt, 2001; Lloyd, 2002; Goodman *et al.*, 2003; Hansson *et al.*, 2002; Froggatt & Payne, 2006; Bliss & While, 2007; Cortis & Williams, 2007), as they have limited access to palliative care compared to younger people (Addington Hall & Higginson, 2001) and are thus marginalised (Lawton, 2000; Lloyd, 2004). In the collaborative report “Better Palliative Care for older People”, the World Health Organisation emphasises that palliative care should be implemented in nursing homes (WHO, 2004). The essence of palliative care can be said to be a protection of the dignity of dying people (Walsh & Kowanko 2002).

In recent years there has been a renaissance in the use of the concept of dignity as well as multiple suggested definitions of its meaning. Many of the descriptions of the concept are very similar. Dignity is often defined as having both a subjective and an objective dimension. The objective dimension outlined by Gallagher (2004) is universal and fundamental to human rights. All humans have a value due to their humanity. Nordenfelt (2004) talks about “Menschenwürde” to denote a universal dignity that is common to all humans, irrespective of their status or situation. The difference between universal and other types of dignity is that the former is constant and can never be lost. Universal dignity can therefore be seen as a basis for other aspects of dignity, which may be of a more temporary or contingent nature. Examples of other types of dignity are dignity of merit or dignity of moral stature as described by Nordenfelt (2004), who also states that dignity of identity is an especially relevant concept in the care of older people. Dignity of identity is the dignity we attach to ourselves as autonomous people with a life-history and relationships to others. This kind of dignity is not constant and can be threatened by the actions of others and even by aging itself (Nordenfelt 2004; Franklin *et al.*, 2006; Dwyer *et al.*, 2008).

According to Street (2001), a person’s dignity is socially constructed and has both an embodied and a relational aspect. The experience of what is dignified can therefore differ, depending on the situation and how it is perceived by the individual. Thus dignity can be said to be linked to a person’s identity, self perception and perceived self-respect (Ternstedt *et al.*, 2002; Franklin *et al.*, 2006; Dwyer *et al.*, 2008). This is made explicit in studies in which e.g. older people at the end of life describe how their dignity has been violated (Franklin *et al.*, 2006).

Gallagher (2004) provides two important professional values that can be of assistance in the encounter between healthcare professionals and patients in everyday nursing practice. She highlights the distinction between “other-regarding dignity” and “self-regarding dignity” (Gallagher 2004 p. 591). Other-regarding dignity is about promoting the dignity of others and includes activities that strengthen their dignity. Such is described in several different ways including maintaining dignity (Randers & Mattiasson 2004), preserving dignity (Anderberg *et al.*, 2007) and dignity-conserving care (McClement *et al.*, 2004; Chochinov 2007). Maintaining dignity implies upholding a person’s autonomy (Randers & Mattiasson 2004). Preserving dignity is characterized by individualized care, restoring control, showing respect, advocacy and sensitive listening (Anderberg *et al.*, 2007). Dignity-conserving care has been described as continuity of self, role preservation, generativity, maintenance of pride, hopefulness, autonomy/control, acceptance and resilience or a

fighting spirit (McClement *et al.*, 2004; Chochinov *et al.*, 2002). Common to the definitions of this concept is their emphasis on the value of the older or dying person being able to maintain his/her autonomy for as long as possible. The importance of autonomy for the sense of dignity has, however, been questioned by Wainwright and Gallagher (2008). They hold that a strong emphasis on autonomy can result in people with impaired cognitive ability being treated with less respect. Self-regarding dignity means that staff members not only promote the dignity of others but also need to be aware of and appreciate their own dignity. According to Gallagher (2004 p. 591), “the nurse owes the same duties to self as to others, including the responsibility to preserve integrity and safety, to promote competence, and to continue personal and professional growth”. In Gallagher’s studies, there is even a correlation between how the nurse promotes the dignity of others and how he/she respects his/her own dignity and well-being (Seedhouse & Gallagher, 2002; Gallagher, 2004). In order to promote dignity, the relationship between the patient and the nurse is of importance (Haddock, 1996; Fenton & Mitchell, 2002; Seedhouse & Gallagher, 2002; Jacelon *et al.*, 2004). Staff members are challenged to recognize and take account of the individual’s vulnerability. Although this area is starting to be acknowledged and focused upon in recent studies (Wendy *et al.*, 2003; Whitaker, 2004; Sung *et al.*, 2005; Whittaker *et al.*, 2007) there is a need to study how staff members view and reason about the meaning of dignity in everyday care both for themselves and the older person.

AIM

The aim of this study 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.

METHOD

In order to obtain a broad contextual description of nursing home staff members’ experiences of dignity, the study employed an inductive qualitative content analysis method and data were collected by means of interviews.

Sample and setting

Purposeful sampling was used to obtain variation and information-rich interviews (Patton, 2004). The informants were chosen to correspond to the professions represented in the nursing homes. After having received written and oral information about the study, the managers and head nurses of four nursing homes asked the staff in the course of regular staff meetings whether they would be willing to share their experiences and participate in the study. Twenty-one participants from four units at one private and two municipal nursing homes were included in the study. They comprised four managers representing each unit, five RNs (registered nurses) and twelve NAs (nurses assistants). Variation within the group in terms of age, gender, work experience and ethnicity is shown in Table 1. The nursing homes were located in the same area of a Swedish town. They all provided single rooms and 24-hour staffing. A physician visited the nursing homes once a week and examined the elderly persons assessed by the RNs as requiring medical attention.

Table 1. Characteristics of the participants in this study

	Managers (n=4)	RN's (n=5)	NA's (n=12)
Gender			
female	4	5	8
men			4
Age (year30-60)	45-60	35-60	30-60
Earlier experience in care	4	5	10
Other ethnic background	0	1	4

Interviews

The individual interviews were carried out with the 21 participants in a secluded area in each nursing home. An interview guide was designed to cover experiences, attitudes and values related to the participants' experience of caring for older people. All respondents were asked to describe their everyday work, how they experienced the older person's dignity and how dignity could be promoted or hindered in everyday care. The participants were also asked what dignity meant to them and how it was actually promoted or hindered in their place of work. Follow-up questions were posed when necessary, such as: What did you do then? What did you think about that? The interviews, which were conducted by the first author and lasted between 30 and 90 minutes, were audio taped and subsequently transcribed. The authors' pre-understanding was based on practical experience of nursing older people (LLD), palliative care research (BMT, BA) and research on basic concepts related to philosophy (LN).

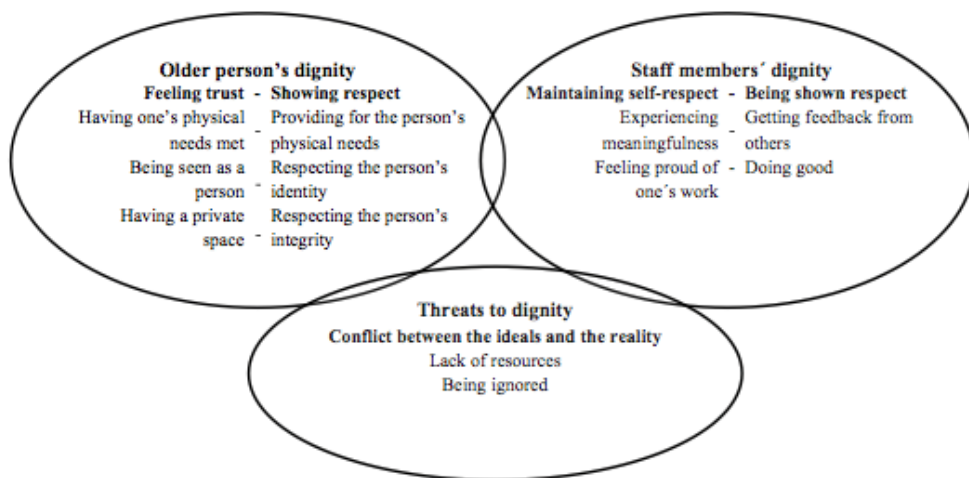
Data analysis

The transcribed interviews were subjected to qualitative content analysis as described by Patton (2004). Firstly, each interview was read through to obtain an idea of the whole. Thereafter, the text was re-read and significant words and key phrases concerning experiences related to what dignity meant to older people (the "what aspect") and how it could be promoted or hindered ("the how aspect") were separated, marked and coded. These codes were then grouped together and sub-categories formulated. The codes and sub-categories were constantly compared with each other and with the entire interview texts with regard to the meaningful content (Table 2). The same analytic process was then carried out with focus on what dignity meant and how it could be promoted to the staff. In figure 1, staff members' views on what dignity meant to the older people and themselves and how it could be promoted are illustrated by two pairs of main categories: Feeling trust-Showing respect and Maintaining self-respect-Being shown respect. The first set of pairs describes the "what aspect" and the second the "how aspect". Two single sub-categories were also identified that described threats to dignity, which were the same for both the older people and the staff. These two sub-categories formed the third main category: Conflict between ideals and reality.

Table 2. Analytical process of dignity.

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

Figure 1. Staff members' experiences on what dignity means for the older person's and themselves



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 (Patton, 2004; Thorne, 2004). During the analysis, alternative interpretations of data were also searched for. The sub-categories and main categories were reflected on by the authors until consensus was reached.

Ethical considerations

The managers at each nursing home received oral and written information about the study, which they passed on to the RNs and the NAs at staff meetings. Staff members who reported an interest in participating in the study were scheduled for individual interviews. During the interviews the interviewer strove to be sensitive to and respect topics with which the participants felt comfortable or uncomfortable. The authors were careful to ensure the confidentiality of each individual by using quotations that could not be linked to any one person. Although some grammatical changes had to be made when the quotations were translated from Swedish into English, great care was taken to avoid changing their content. Approval to conduct the study was granted by the local Research Ethics Committee (171-01).

FINDINGS

Dignity was a concept that was rarely used in everyday conversation. However, the staff members had an idea about its meaning, which became especially obvious in the discussions about factors that promoted or hindered dignity. The analysis of the interviews revealed several similarities between what staff members described as dignity for the older person nearing the end of life and what dignity meant to them in their professional role. They emphasised the importance of both themselves and the older person being seen. The gap between the ideals and the reality was often used to exemplify the negative effects of threats to dignity on both the older person and the staff.

The older person's dignity

Feeling trust – Showing the older people respect

The nursing home was described by the staff as a place where the older person knows that his/her basic care needs are met, which led to a sense of trust in everyday life. Trust was defined as the older person feeling seen and respected for the individual he/she was and perceives him/herself to be.

The need for a private sphere was also deemed important. Dignity was promoted by meeting the older person's basic needs as well as respecting his/her identity and integrity and achieved when the older person felt that the care he/she needed was provided.

Having one's physical needs met - Providing for the person's physical needs

Promoting older people's dignity meant providing for their basic physical needs that were mainly related to eating, keeping clean and toileting.

We are here for the older people, to make their life as good as possible, respect them, help them to keep clean, make sure they eat and so on (NA)

In view of the older people's great dependency, the staff devoted most of their time to physical care. Guidelines were developed in one of the nursing homes to ensure that these needs were met.

We have folders with directions that tell us exactly how to do everything (NA)

These guidelines were considered normative and seen as a help in the everyday care of the older people, particularly for staff members with no previous care experience or education. Irrespective of the presence of guidelines, the participants mainly described the care as being focused on the 'doing' dimension. However, they repeatedly emphasised that they wanted to provide more than just basic physical care.

Well, there is lack of time and staff, so there is no time for anything out of the ordinary. But we are always talking about it. It's our aim to be able to provide more than just the everyday basics (NA).

As the quotation reveals, the staff lacked time and resources to do more than follow the recommendations set out in the practical guidelines, which led to feelings of not doing enough for the older person. In this regard the care did not promote the older person's feeling of trust in an optimal way.

Being seen as a person – Respecting the person's identity

Dignity was also conceptualised as being seen as a person and respected for the person one is. Respect for each individual's identity as well as his/her way of thinking and being is a central component of the care.

I mean, Anna has lived for 88 years and has lots of ideas about what she likes and wants. We can't stop asking her what she wants just because she has moved in here; we are working in her home (M).

Many of the staff members tried to provide care that they believed promoted the person's identity within the limitations imposed by the older person's health status and the organization. It was described as important to respect the older person's self-determination and not make decisions over his/her head. Instead, the staff made efforts to promote the old person's self-determination.

We are here to help; it's the older person who makes the decisions about what she wants and the type of help required. Of course we have to respect them, we are here to help, not make decisions on their behalf...there are times when we have to make decisions that go against their wishes but only if there is a health risk involved (NA).

Examples were also provided of involving the older person as much as possible in the everyday care so that he/she could continue doing the things he/she had done throughout life.

One of the older men here, he likes to help us with everyday things, he vacuums the rooms with us...and helps us unpack groceries. It takes longer but it's worth it because it makes me feel good when they feel good (NA).

Meaningfulness in everyday life was strengthened for this man, as he was involved in doing things that he enjoyed at the same time as helping others. This was seen as strengthening his self-image and feeling of trust.

In order to promote the older person's identity in a phase of life characterised by loss, it was considered important to individualise the care. Attentiveness to the various needs of older people was highlighted in the interviews.

A great deal depends on the everyday attitude, how one works and respects the individual – you have to remember that just because they live together in the same place doesn't mean that they want the same things. We have to listen. What does she want? Does she want a shower or to have breakfast? We can't treat everyone the same; we have to listen (NA).

Although there was awareness among the staff that each person is unique with different needs, they expressed more or less explicitly that the organisation was designed in a way that may jeopardise person-centred care, as the older people were at risk of being treated as a homogeneous group with similar needs. Staff attitudes were also described as important in terms of the older person's perception of dignity. The staff members strove to provide "deeper" and more individualised care, where the older person's individual wishes and needs were met and respected. Individualised care was the most frequently suggested method of promoting older people's dignity. The possibilities for so doing, however, were described as limited.

Having a private space - Respecting the person's integrity

The nursing home was viewed as both a private and a public place. Private since it was the older people's home at the end of life and their own room was a sphere where they kept their belongings and could be themselves.

It's their room with their things; we are guests in their home, that's what's different from working in a hospital (RN).

Having a private space and privacy was not only about physical space, but also about the older person's inner space and sense of integrity. Privacy was described as essential for the older people's feeling of trust and dignity.

Staff members' dignity

Maintaining self-respect - Being shown respect

The staff members' experience of their own dignity was conceptualised as maintaining self-respect, which was mainly described as being dependent on the attitudes of others. Feedback from the older person, relatives or managers was of considerable importance. Dignity and self-respect were strengthened when the staff felt that they had "done something good" for the older person. Doing good could involve relatively small things. The staff described themselves as an important source of help to the older people in their everyday life. They mainly looked upon their job as a matter of giving and receiving, and their sense of self-respect was strengthened when they felt confirmed and proud of their work.

Experiencing meaningfulness – Receiving feedback from others

It was important for the staff members' self-respect to experience everyday work at the nursing home as meaningful and to be confirmed by others.

There was a lady who used to ask me to help her put curlers in her hair, which I usually did, and when I worked the evening shift she used to ask me if I would have coffee with her. Her daughter often brought me flowers, things like that feel really good (NA).

To be seen and acknowledged for what one did strengthened staff members' sense of coherence and of being part of something meaningful.

Feeling proud of one's work – Doing good

On a deeper level, feeling proud of one's work and working with older people in end of life care promoted a sense of self-respect. The staff felt proud of their work when experiencing that their actions had led to a sense of well being for the older person. Doing good was often related to fulfilling emotional and psychological needs.

It's about being close and, you know, the fact that you get a lot back. Everything you do you just sense it (i.e. doing good) ... that's what means so much in this job (NA).

Having a satisfactory working relationship with one's colleagues was expressed as important for doing a good job and also helped to strengthen one's self-respect. If a staff member felt the need for extra support for some reason, it would be discussed within the working team.

Threats to dignity

Conflict between the ideals and the reality

The staff expressed that threats to dignity were the same for both themselves and the older person. It was obvious that the staff struggled in their everyday practice to cope with the gap between their ideals and the reality, which had an impact on the older person's care and dignity. The gap was a source of conflict for many staff members, who expressed the wish for support.

Lack of resources

Lack of resources included lack of time, difficulty in recruiting competent and motivated staff as well as lack of teamwork. This resulted in feelings of being unable to provide adequate care for the older people, which experience was described as frustrating.

You want to do so much, you know, the best for everyone, but it's just not possible. The responsibility is too great and there is just not enough time for everyone... (Crying)... I don't know what to do, I want to do so much more...(RN)

This quotation illustrates a major problem and the staff often expressed that they did not have enough time to provide individualized care, which can be seen as hindering the aim of dignified care. The difficulty in recruiting interested and competent staff was considered a threat to the older person's feelings of trust and sense of dignity.

It has been very difficult to recruit staff. It's almost as if we hire anyone who walks in here. Really, sometimes, right off the street and it can be seen in how they view the older people (M).

A genuine interest in the older people was described as a condition of care that promotes dignity. Lack of interest was described as a bigger threat to the older person's dignity than staff without adequate education. Interest, competence and attitudes also have an impact on team performance.

Some groups work very well together and it shows in the care they provide. Others are just not good together and that also shows. I have one group that works very well and another that doesn't and I can definitely see the difference in the care provided. The staff members' attitude towards their work is very important (M).

Some staff members felt strongly that the care they provided did not accord with their personal definition of deeper, more dignified care, which they described as a conflict between the ideals and the reality. The inability to provide the care they deemed necessary for meeting the older people's needs led to frustration and moral distress.

Being ignored

Dignity was challenged when both staff members and the older people felt that they were not taken seriously. An example was when the staff considered that their managers did not listen to them, which made them feel worthless.

The ordinary staff work hard, but the managers talk more about figures and the budget than about the old people. The old people are supposed to be well cared for, but the organisation wants profit. And where are we, the lay staff? I don't know. There is no real respect for ordinary working people...this is what I feel disappointed about, it's as if we don't exist...(NA)

The following quotation expands on the feeling of not being seen by politicians and officials.

I wish that all those people from the different health and welfare departments would listen more to our wishes and maybe come here and stay for a day or so just to see what we are doing. I'm proud of my job; it doesn't feel right to be always looked upon as worthless because we work with older people. I wish those who make political decisions would come here and see what we are doing (NA).

The professional role was related to how staff members were treated by others. Caring for older people was part of staff identity and therefore important for self-respect and dignity. The dignity of both staff members and older people was damaged when they were ignored, an aspect mainly referred to by the NAs.

Discussion

The concept of dignity was rarely used by the staff in this study. However, they talked about its meaning in terms of respect and descriptions of events that they characterised as promoting or violating dignity. Similar descriptions were found in an earlier study where older people in nursing homes expressed their views on dignity (Franklin *et al.*, 2006). During the analysis, the meaning of dignity was found to be explicit and closely related to self-image and identity irrespective of whether it referred to the dignity of the staff or the older people. This meaning is close to dignity of identity as described by Nordenfelt (2004). In our study, dignity promoting care could be described as the “how aspect” of dignity. This means that providing for the person’s physical needs in combination with respecting his/her identity and integrity promoted the feeling of trust i.e. the “what aspect” of dignity. When the staff experienced that the older people felt trust they expressed an increased sense of meaningfulness and pride, which maintained their self-respect. A similar result was presented by Westin and Danielson (2007), who found that nurses who were present in the encounter with the older person experienced meaningfulness in their work, which increased their confidence and self-esteem. These results can be related to Gallagher’s (2004) description of how other-regarding dignity and self-regarding dignity are interrelated. A likely consequence of this is that, when the staff, for various reasons, are unable to provide dignity-promoting care, the older person’s feelings of trust (other-regarding dignity), and the staff members’ self respect (self-regarding dignity) are threatened. In our study such threats were characterized by a lack of resources and being ignored.

Threats to dignity were often understood in relation to the gap between ideals and the reality, which staff members frequently described as a problem in their strive towards a deeper level of care i.e. more than just basic physical care. This was particularly mentioned by the nursing assistants, which is not surprising as their everyday work involves looking after the older people’s basic physical needs. Many of them complained about a lack of support and guidance in their everyday work, which was also illuminated in a recent study by Karlsson *et al.*, (2008). The nursing assistants wanted the RNs to be more involved in and to guide everyday care. How the staff in the present study handled frustration and moral stress was not studied explicitly. However, a growing body of nursing literature has reported that the nursing environment involves a risk of exposure to moral stress

(Severinsson & Kamaker, 1999; Lützén, *et al.*, 2003) or conscience stress (Dahlqvist *et al.*, 2007). Common to these two concepts is that tension can arise when external factors hinder staff from providing the level of care they consider appropriate. Corley *et al.*, (2005) identified both poorly trained staff and a shortage of staff as external factors that could increase moral distress. Other studies revealed that even internal factors such as high expectations on oneself can also lead to moral distress. The present study also indicated difficulties in recruiting motivated and trained staff, which accords with many other studies (Cartwright 2003, Whittaker *et al.*, 2007, Sung *et al.*, 2007, Fläckman *et al.*, 2007). According to Fläckman *et al.*, (2007), staff members leave nursing homes due to unmet expectations and lack of job satisfaction. For this reason society will face a challenge in the future due to the increasingly older population. One way of dealing with this could be to adjust and implement palliative care philosophy for the care of older people as highlighted by Froggatt (2001), Rahm Hallberg (2004); National Board of Health and Welfare (2004) and emphasised by the WHO (2004). A natural part of palliative care philosophy is dignity, support for and continuous education of staff.

Methodological considerations

The interviews with the 21 participants provided an insight into how dignity was experienced by both staff and older people. However, it can be questioned as to whether the selection of participants based on reporting one's interest to the manager can be regarded as a voluntary act, since the staff may be considered to be in a situation of dependency, which could have influenced what they chose to discuss. This was taken into account and the interviewer (LLD) attempted to be sensitive to it. Another weakness could be the fact that most of the respondents were nursing assistants and therefore the result is based more on their views than those of registered nurses and managers. However, the intention was not to compare different professional categories, but rather to obtain the views of different groups representing the nursing home culture, thus ensuring both deep and broad descriptions of dignity. The purpose was to strengthen trustworthiness by explaining the links between data, the analytic process, findings and discussion and comparing the results to those of other studies dealing with the same area of interest (Thorne, 2004). However, it would be valuable to carry out further studies focusing on the situation of staff over time by means of a combination of observations and interviews.

Conclusion

This paper illuminates how nursing home staff experienced what dignity meant to the older people and to themselves and how it can be promoted or hindered. It was clear that dignity was a concept that the staff rarely used. One of the main findings was that the staff experienced tension between the ideal they wanted to realize and the care they considered possible to provide. This threatened their sense of self-respect, meaningfulness, as well as the possibility of providing dignity promoting care. The staff lacked support and thus was at increased risk of developing moral and conscious stress. Implications for nursing are the possibility of enhancing dignity and self-respect for both older people and staff. One way of ensuring this would be to implement palliative care philosophy to suit older people's needs. This requires an organisation willing to support staff and provide them with continuous education and supervision to thus promoting personal growth and clinical competence. It is of paramount importance to feel proud of one's work and have a sense of self-respect.

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REFERENCES

- Addington-Hall JM., Higginson IJ. (2001) Discussion. (In: Addington-Hall JM, Higginson IJ., eds. *Palliative Care for Non-Cancer Patients*). Oxford University Press, New York.
- Anderberg P., Lepp M., Berglund A.L. & Segesten K. (2007) Preserving dignity in caring for older adults: a concept analysis. *Journal of Advanced Nursing* 59 (6), 635-643.
- Black H. (2004) Moral imagination in long-term care workers. *Omega* 49(4), 299-320.
- Bliss J., While A. (2007) District nursing and social work: palliative and continuing delivery. *British Journal Community Nursing* 12(6), 268-272.
- Cartwright J., Keyser-Jones J. (2003) End-of-life care in assisted living facilities. *Journal of Hospice and Palliative Nursing* 5(3), 143-151.
- Chochinov HM., Hack T., Hassard T., Kristjanson L J., Mc Clement S. & Harlos M. (2002) Dignity in the terminally ill: a cross-sectional cohort study. *The Lancet* 360, 2026-2030.
- Chochinov HM. (2007). Dignity and the essence of medicine; the A, B, C and D of dignity conserving care. *British Medical Journal* 28:335, 184-187.
- Corley M., Minick P., Elswick RK. & Jacobs M. (2005) Nurse moral distress and ethical work environment. *Nursing Ethics* 12(4), 381-90.
- Cortis JD., Williams A. (2007) Palliative and support needs of older adults with heart failure. *International Nursing Review* 54(3), 263-70.
- Dahlqvist V., Eriksson S., Glasberg AL., Lindahl E., Lütznén K., Strandberg A., Sörlie V. & Norberg A. (2007) Development of the perceptions of conscience questionnaire. *Nursing Ethics* 14(2), 181-93.
- Dwyer L., Nordenfelt L. & Ternstedt B-M. (2008) Three nursing home residents speak about meaning at the end of life. *Nursing Ethics* 15(1), 97-109.
- Fenton E., Mitchell T. (2002). Growing old with dignity: a concept analysis. *Nursing Older People* 14(4), 19-21.
- Fläckman B., Fagerberg I., Häggström E., Kihlgren A. & Kihlgren M. (2007) Despite shattered expectations a willingness to care for elders remains with education and clinical supervision. *Scandinavian Journal of Caring Science* 21(3), 379-89.
- Franklin L., Ternstedt B-M. & Nordenfelt L. (2006) Views on dignity of elderly nursing home residents. *Nursing Ethics* 13(2), 130-146.

- Froggatt KA. (2001) Palliative care and nursing homes: where next? *Palliative Medicine* 15, 42-48.
- Froggatt K., Payne S. (2006) A survey of end-of-life care in care homes: issues of definition and practice. *Health and Social Care in the Community* 14(4), 341-348.
- Gallagher A. (2004). Dignity and respect for dignity – two key health professionals’ values: Implications for nursing practice. *Nursing Ethics* 6, 588-99.
- Goodman C., Woolley R. & Knight D. (2003) District nurses' involvement in providing care in residential care home settings. *International Journal of Palliative Nursing* 9(12), 521-527.
- Haddock J. (1996). Towards further clarification of the concept “dignity”. *Journal of Advanced Nursing* 24(5), 924-31.
- Hanson L., Henderson M. & Menon M. (2002) As Individual as Death Itself: A Focus Group study of Terminal Care in Nursing Homes. *Journal of Palliative Medicine* 5(1), 117-125.
- Jacelon CS., Conelly TW., Brown R. & Proulx K. (2004) A concept analysis of dignity for older adults. *Journal of Advanced Nursing* 48, 76-83.
- Karlsson I., Ekman SL., Fagerberg I. (2008) To both be like a captain and fellow worker of the caring team: the meaning of nurse assistants’ expectations of Registered Nurses in Swedish residential care homes. *International Journal of Older People Nursing* 3(1), 35-45.
- Lawton J. (2000) *The Dying Process: Patient's Experiences of Palliative Care*. Routledge, London.
- Lloyd L. (2002) Dying in old age: promoting well-being at the end of life. *Mortality* 5(2), 171-188.
- Lloyd L. (2004) Mortality and morality; ageing and the ethics of care. *Aeging & Society* 24, 235-256.
- Lützn K., Cronqvist A., Magnusson A. & Andersson L. (2003) Moral stress: synthesis of a concept. *Nursing Ethics* 3, 312-322.
- McClement SE., Chochinov HM., Hack TF., Kristjanson LJ. & Harlos M. (2004) Dignity preserving care: application of research finding to practice. *International Journal of Palliative Nursing* 10(84), 173-9.
- National Board of Health and Welfare. (2004) *God Vård i Livets Slut. En kunskapsöversikt om vård och omsorg om äldre* (Good care at the end of life, List of periodicals about care of the elderly). The National Board of Health and Welfare, Stockholm, Sweden.

- National Board of Health and Welfare. (2006) *Vård I Livets Slutskede: Socialstyrelsens bedömning av utvecklingen i landsting och kommuner* (End-of-life care: The National Board of Health and Welfare's assessment of the development in city councils and municipalities). National Board of Health and Welfare, Stockholm, Sweden.
- National Board of Health and Welfare. (2007) *Forskning som speglar vården i livets slutskede. Kunskapsöversikt*. (Research in end of life care. A literature review.) Ternstedt B-M. (Ed) National Board of Health and Welfare, Stockholm, Sweden.
- Nordenfeldt L. (2004) The varieties of dignity: *Health Care Analysis* 12(2), 69-81.
- Patton MQ. (2004) *Qualitative research & evaluation methods*. Sage, Thousand Oaks, California.
- Rahm Hallberg IR. (2004) Death and dying from old people's point of view. A literature review. *Aging Clinical and Experimental Research* 16, 87-103.
- Randers I., Mattiasson AC. (2004) Autonomy and integrity: upholding older adult patients' dignity. *Journal of Advanced Nursing* 45(1), 63-71.
- Seedhouse D., Gallagher A. (2002) Undignified institutions. *Journal of Medical Ethics* 28(6), 368-72.
- Severinsson EL., Kamaker D. (1999) Clinical nursing supervision in the workplace - effects on moral stress and job satisfaction. *Journal of Nursing Management* 7(2), 81-90.
- Street A. (2001) Constructions of dignity in end-of-life care. *Journal of Palliative Care* 17(2), 93-101.
- Sung H., Chang S. & Tsai C. (2005) Working in long-term settings for older people with dementia: nurse's aids. *Journal of Clinical Nursing* 14, 587-593.
- Ternstedt B-M., Andershed B., Eriksson M. & Johansson I. (2002) A good death. Development of a nursing model of care. *Journal of Hospice and Palliative Nursing* 3, 153-60.
- Thorne S., Reimer Kirkham S., O'Flynn-Magee K. (2004) The analytic challenge in interpretive description. *International Journal of Qualitative Methods* 3(1), 1-21.
- Walsh K., Kowanko I. (2002) Nurses' and patients' perceptions of dignity. *International Journal of Nursing Practice* 8(3), 143-51.
- Wendy M., Skinner J., Rowe G. & Gork C. (2003) Views of job satisfaction and dissatisfaction in Australian long-term care. *Journal of Clinical Nursing* 12, 168-176.
- Westin L., Danielson E. (2006) Nurses' experiences of caring encounters with older people living in Swedish nursing homes. *International Journal of Older People Nursing*, 1, 3-10.

World Health Organisation (2004) *Better care for older people*. Davis E., Higginson IJ. (Eds.) Geneva: WHO.

Whitaker A. (2004) *The last home: family ties, ageing and death in a nursing home*. (Academic dissertation). Stockholm: Department of Social Work, Stockholm University, Sweden.

Whittaker E., Kernohan GW., Hasson F., Howard V., & Mc Laughlin D. (2007) Palliative care in nursing homes: exploring care assistants' knowledge. *International Journal for Older People Nursing* 2, 36-44.

PAPER IV

Nursing home staff's reasoning about death and dying

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ABSTRACT

Aim. The aim of this study was to explore how staff at nursing homes reason about older people's dying, death, and the care provided.

Background. Nursing homes has become a more common place of death during resent years. At the same time there is an aim of broadening the palliative care philosophy to involve other groups than those suffering from cancer. One group is older people.

Method. The study is based on focus group discussions (FGDs) and includes 20 nursing home staff members reasoning about seven older people's death. The focus groups were analysed by a content analysis method.

Findings. The reasoning of dying and death are presented in five themes: Alleviation of bodily suffering, Meaningfulness in everyday care, Thoughts on and attitudes of death, Taking care of the dead person and Ethical reasoning and use of self. The staff's ethical reasoning resulted in a bad conscience for not being able to provide the care they wished for. This was a threat to both their sense of dignity as well as of the older person's sense of dignity. The care culture could be described as representing by slowness, silence and a of doing.

Conclusions. To provide a 'good' death there is a need to vision a care based on a co-creating relationships between staff and the older person.

Relevance to clinical practice. To provide a dignified care for older people, attention needs to be drawn to the knowledge about the dying person's and the staff's needs at end of life within the nursing home context.

Introduction

Dying and death is frequently described as a taboo-laden area that people avoid talking about. At the same time, studies have revealed that people who are about to die have a need to express their thoughts and feelings about death (Fry 1990; Rappaport et al 1993; Bolmsjö 2002; Strang 2002; Albinsson 2002; Whitaker 2004). This is a cornerstone in palliative care. However, older people do not have access to palliative care to the same extent as younger people (Grande et al. 1998; WHO 2004; Källström Karlsson et al. 2006). Characteristic of the death of older people is that it extends over a long period of time and is often described as “slow death” or gradual burnout (Rinell Hermansson 1990; Whitaker, 2004) as well as they often suffers from many different diseases and several functional impairments. Studies have also shown that older people are at greater risk of both under and over treatment compared to younger people (Gibbs & Addington-Hall 1998; Addington-Hall et al. 1998; Lynn 1997). In Sweden, 90,000 people die each year, of whom approximately 60 % are 80 years, or over (National Board of Health and Welfare, 2006) and many of them, usually the frailest older people, die in a nursing home. It has been shown that the principles of palliative care need to be amended and implemented in the care of older people (Avis et al. 1998; Morrison & Morris 1995; Froggatt 2001; Hallberg 2004; WHO 2004).

According to Weisman (1972; 1974), an “appropriate” or “good death” is one a person might choose if he/she had the option. This means that the dying person him/herself is the only one who knows what a good death means to him/her. The care must therefore be based on respect for the patient’s identity, needs and will (Ternstedt et al. 2002). The emphasis on autonomy has increasingly been questioned, not least in view of the fact that dependence is very pronounced at the end of life (Wainwright & Gallagher 2008). A consequence of this is that the way in which the older person perceives the care provided and his/her sense of dignity will be influenced by the attitude to older people that characterises their environment (Franklin et al, 2006; Dwyer et al. 2008). There is a great need to study how end-of-life care is constructed in the encounter between the staff and older people. The present study is a step in this direction.

Aim

The aim of this study is to investigate nursing home staff members’ reasoning about older persons’ death and dying.

Method and participants

To reach the aim of this study a qualitative approach was chosen. Data were generated by means of focus group discussions (FGDs), 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). Focus group discussions are also relevant when interaction and group processes could be a help in clarifying perceptions of importance for the results (Kitzinger 1995). We proposed that the interaction between the focus group members could encourage discussion of the complex phenomenon of caring for a dying person and what they knew about him/her. The analysis of the focus group discussion was carried out and inspired by content analysis as described by Patton (2004).

Twenty staff members (16 nursing assistants and 4 registered nurses) in four nursing homes in a town in Sweden agreed to participate in the study after they had received information about the aim from their managers. Sixteen were women and four were men. Three were born outside Sweden. A total of seven focus group discussions were held and

after each session the participants were asked to reflect on what they knew about the older person and his or her dying and death. The interviews were audio-taped and six were transcribed verbatim by professional transcribers and one by hand due to problems with the tape-recorder. The findings of this study are based on the descriptions of the dying and death of six women and one man, aged between 83 and 95 years.

Data collection

The focus group discussions were carried out in a secluded area in the nursing home. The focus was on deepening the understanding of the dying person as an individual and of his/her dying. An interview guide was used, comprising six themes based on the psychological autopsy as developed by Weisman and Kastenbaum (1968). Psychological autopsy was intended to evaluate and deepen the understanding of the deceased person's last months, as well as the extent to which people with different illnesses received adequate care and experienced an appropriate death. The method was initially developed in the psychiatric field in order to increase understanding of the background of suicide (Schneidman 1969). Weisman (1972, 1974) later presented a geriatric version, which has been used in nursing research in Sweden by Andersson-Segesten (1989) and Rinell Hermansson (1990). The method has been further developed and adjusted to a palliative nursing context and called the six S's, which are an abbreviation of the model's six keywords; Self-image, Self-determination, Social relationship, Symptom control, Synthesis/Sense of coherence and Surrender. The six S's are described as an operationalization of palliative care philosophy and are useful for care planning, documentation and evaluation of care (Hermansson & Ternstedt 2000; Ternstedt et al. 2002) (Table 1).

Table 1 Six question areas used in the data collection and analysis.

Self-image	Self-determination	Social relationships	Symptom control	Synthesis/sense of coherence	Surrender
What was known about the person?	What decisions was important for the person to be involved in?	What relationships were important to uphold?	What symptom relief did the patient have?	What provided meaning in end of life?	What did the person need to prepare before death?
What had been and what was important to him or her?	What did the person wish to do in every day life?				

The discussions were led by a moderator (LLD) and one observer (BMT) and started with a short introduction of the aims of the study and the person whose death, dying and care the focus group was going to focus upon. During the discussions, many conversations naturally referred to the areas that pertain to the six keywords. In those interviews, where the subject did not arise naturally, follow up questions following the question areas in table 1 were asked, such as who was 'Anna'? (Anna is a fictitious name). Please tell me about her, what did she like to do in everyday life? How did you perceive her end of life? What were her thoughts about death?

Two to five staff members from the same unit participated in each focus group discussion. When planning the study, the aim was to include five to six, which proved impossible due to organizational factors. The number of participants was dependent on the workload and

number of staff at work on the day the focus group discussion took place. The focus group discussion lasted between one and two hours. The participants were interviewed on a single occasion over a six-month period (2006 - 2007), between two weeks and four months after the person's death.

Data analysis

The analysis of the focus group discussions was analyzed by a qualitative interpretative content analysis as described by Patton (2004). Firstly, each interview was read through to obtain an impression of the whole. In the next stage the texts were searched for codes related to the six keywords and the questions set out in Table 1 in an open manner in order to capture other areas relevant to the aim. Similarities and differences in the codes were analysed and grouped together. Thereafter, the text was re-read, and significant words, statements and key phrases concerning experiences related to how the participants reasoned about the person's death and dying were separated, marked and coded. Codes that described this reasoning were grouped together and categories formulated. The codes and categories were constantly compared with each other, with the codes within the six keywords and with the whole text. The relationships between categories were identified and sorted into core elements and thereafter into the following five main themes: Alleviation of bodily suffering and pain; Meaningfulness in everyday life; Thoughts on and attitudes to death; Taking care of the dead person, and Ethical reasoning and use of the self.

Trustworthiness

As issues of rigour and credibility are important considerations when using qualitative methods, the authors' pre-understanding and the research process were described as accurately as possible and quotations were included in order to illuminate the findings (Patton, 2004; Thorne, 2004). The subcategories and main categories were discussed between the authors and the analysis proceeded until consensus was reached. The authors' pre-understanding is based on practical experience of nursing older people (LLD), palliative care research (BMT, BA) and research on basic concepts related to philosophy (LN).

Ethical considerations

The managers at three nursing homes asked the staff (nursing assistants (NAs) and registered nurses RNs) whether they would be interested in participating in the study. Those who volunteered were scheduled for focus group discussions. The participants received information about the study, confidentiality and the right to withdraw at any time. Although some grammatical changes had to be made when the quotations were translated from Swedish into English, great care was taken to avoid changing their content. Approval to conduct the study was granted by the local Research Ethics Committee (171-01).

Findings

When the staff reasoned about the deceased person's last months and weeks it was mainly described as an expected outcome. Alleviation of bodily suffering and pain and Meaningfulness in everyday life was two themes that were deemed important for a good death. However, different opinions of what was considered adequate pain relief caused conflicts among staff members. Meaningfulness was mainly described in terms of the next of kin, their relationship and the time they spent together with the dying person. The third theme reveals that the older dying person's thoughts about and attitudes to death and their feelings about dying were not explicitly known. The fourth theme describes how the dead person was taken care of. Routines for taking care of the remains appeared to have existed

in each unit, mainly based on the beliefs of the staff about what older persons in general would have wanted. The fifth theme concerned ethical issues that the staff encountered in their daily work. Ethical reasoning mainly dealt with how they handled the perceived gap between their personal ideals of dignified care at the end of life and what they were able to provide in reality.

Alleviation of bodily suffering and pain

The older people suffered from different illnesses and other health problems. They were not always diagnosed medically but all had a great need of help, which was described as increasing over the final months. The staff mentioned that many of the older people suffered from back problems and joint pain. A common feature was a feeling of insecurity among staff members when describing the older people's illness and health problems, even when they themselves had initiated the discussion. Some believed that they lacked the knowledge and education to discuss such a subject.

Two questions proved especially sensitive in three of the seven FGDs, namely whether the older person's pain relief had been optimal and the controversial dilemma of dying alone and whether or not it was in line with the ethics of a good death. The discussion between some of the participants became quite heated and the atmosphere in the room was tense.

Case example from FGD

Differing opinions about the older person having sufficient pain relief led to conflict among the staff. The following excerpt concerned the care of Anna, who had suffered from pain for about two years.

Celia: She was given Paracetamol but I don't think that is sufficient for pain relief, I mean I worked in a hospital.

Karen: No, she was also given different kinds of pain relief but her bowels started to bother her.

Cecilia: I don't think she had sufficient pain relief. I wouldn't want my end of life to be like hers.

Karen: But they couldn't give her any more.

Celia: I don't know, maybe it's lack of knowledge, but I still think that she didn't get enough pain relief.

Karen: But that is something that we nursing assistants can't really do anything about. We can report it – that's all.

Karen blamed herself for the older person not receiving optimal pain relief and described feeling both angry and sad because she felt attacked by Celia. The discussion between them also affected the other participants, who chose not to get involved. However, some of them felt that the pain relief was not as good, since RNs no longer actively participated in the care. A similar discussion occurred at another focus group discussion at a different unit and nursing home, and the group interaction was affected in a similar way. According to the staff, it was relatively common for the older people to suffer from pain before death. The RNs and the physicians that made decisions about extra pain relief did not have any personal contact with the person in pain. An uncertain attitude to the older person's pain was described in terms of feeling powerless with respect to symptom control. Some of the participants considered that they lacked the knowledge or education to comment on this aspect. In summary, most of the older people had suffered from pain at the end of life.

Meaningfulness in everyday life

This theme illustrates how the six dimensions are interwoven. The staff emphasised that the most important factor for maintaining meaning in the older person's everyday life was the visits from his/her next of kin. These visits were described as bringing light and happiness into the older person's life. An example given was a woman whose face lit up when her husband arrived, thus, to feel loved was essential. The older person's sense of security was also improved by visits from next of kin. It was agreed that the staff were also important for the older person, especially those who had no next of kin.

Case example from FGD

Ruth was 95 years old and very popular. She spent her last few days in the nursing home and found meaning in doing, for as long as possible, what she always had done, i.e. reading magazines and watching TV.

Sara: She was tired, some days she just did not want to get out of bed and that's ok I guess (mild laugh). I mean if you're 90 plus then I think that's ok, as long as you're not in bed all day, every day.

Susanne: It was like that when she was at home as well, one week she would just stay in bed and then she was different.

Sara: It was very different, I mean different days.

Susanne: And the days she was awake she read magazines... yes lots of magazines and she also watched a lot of TV, especially in the beginning.

The interviewer: Did she speak about her life at all?

Susanne: Sometimes she did, when we had coffee. But it was really difficult as she was deaf. It was difficult to hold a conversation because she could not hear anything.

This discussion shows how Ruth's experience of the content of everyday care shifted from day to day mainly in accordance with her physical strength. Some days she had a need to be with others, while on other days she wanted to be alone and rest. From the conversation above, the staff implicitly expressed that they tried to interpret what Britta wanted, in other words the staff attempted to respect Ruth's self-determination. It was described as difficult to hold a conversation with her, as she suffered from a hearing impairment.

Fear of social and existential loneliness threatened the older people's sense of meaning and could result in what has been interpreted as existential anxiety. This concerned for example Mindy, one of the participants in a focus group discussion: *Arlene did not like being alone. She wanted someone to come and visit her and talk to her all the time. When she was alone she used her alarm and wanted to get out of bed and join us in the kitchen. ... She only used the alarm when she was lonely and wanted someone to sit down with her and talk if nothing else.*

Arlene had a need to talk about her life. She became worried and anxious when she was left alone and sought togetherness with others. It was rare for the staff to have the time to sit with her and listen to her stories. However, when it happened, her well-being seemed to increase. In this focus group discussion, the person's wishes were explicitly or implicitly concerned with social relationships, a sense of coherence and self-determination.

Thoughts on and attitudes to death

None of the participants in any of the focus group discussions knew what the older people thought about their imminent death and whether they wished to arrange anything beforehand. It was obvious that death was not something that the staff discussed with the older person, his/her next of kin or among themselves, thus they lacked knowledge of what the older people thought about death. Although the staff did not talk about death with the older person, they often had beliefs as to his/her attitude to death. One was that the older

person in some cases decided when to die. This was exemplified as the older person ceasing to show an interest in eating and drinking, which subject was raised in almost all focus group discussions and seen as a breaking point in the older person's health status.

Case example from FGD

When Pat a decided that she wanted to die, it was very quick. The staff also described how some of the older people prolonged their life and resisted death until their children or someone close to them could be by their side. Pat's death was described as follows:

Janet: She was sitting up on Sunday, I think she ate pretty well and on Monday she only ate a little. After that, she refused to eat or drink. One of her children was abroad and due back a week later. It seemed that she would have died much earlier if she had not waited for her son to come home. From Monday until Wednesday she was "unconscious", totally in her own world, she just lay in bed. On Thursday some close friends came ... and it seemed as if she knew that they were there. ... When I went to her room and told her that her son would soon be here it was almost as if she understood and for a little while she was with us again. When he finally arrived on the Friday and had been with her for about fifteen minutes, she died.

Christie: I don't think she realised that it would be so fast. I think she was aware of how bad her condition was but she never mentioned death ...I have no impression of her being worried or scared ... She had a will to live but all of a sudden she just stopped ...I think that's why it seemed so dramatic, the sudden change in her status. It changed totally from one day to the next. It was so quick...she decided not to live any longer.

The interaction in the focus group was characterised by a need to understand both what Pat was thinking and how she had reflected upon herself and her life. Her story reveals that the staff believed that Pat waited to die until her son came home. The participants also reflected upon Pat's zest for life and had the same understanding of her end of life.

According to the staff, death was often assumed to be a release from suffering. They characterized the end of life as a slow deterioration in different physical and mental functions. As a result, many of the older people's deaths were expected, although it could also be sudden and unexpected.

Taking care of the dead person

When it came to taking care of the dead person, the staff described various rituals that were very similar and did not seem to be connected to the specific unit in which the person lived, but instead to the staff's own beliefs and experiences. Different rituals appeared within the same unit and became obvious when the staff reflected on them. Whether the dead person should be dressed in a white shirt or ordinary clothes was one example of the variation in staff perceptions.

All participants stated that they strove to do what the older person or next of kin wanted in an attempt to make death into something more pleasant. The rituals involved washing the dead person if necessary, tidying up his/her room, lighting a candle, putting a flower into the dead person's hand when crossed over his/her chest and placing the Bible on the bedside table. After a person's death, the staff could grieve the dead person and experience a feeling of emptiness due to their relationship with him or her. The focus group discussions revealed that existential issues were not mentioned to any great extent, other than when the older person him/herself raised the subject. Death was surrounded by

silence, although there was consensus on the subject of an older person's ability to decide when he/she wanted to die (surrender). The rituals related to taking care of a dead person's body were rarely discussed. In some of the focus group discussions, a wish for a common policy and agreement on how to care for a person at the end of life was expressed.

Ethical reasoning and use of self

The analysis also showed that many of the participants wished that they had done more for the dead person. They argued that the organisation often prevented them from doing what they really wanted for the older person. Cutbacks resulting in reduced staff and nurses no longer playing an active role in the care were some reasons given to why the staff felt unable to provide the care that they deemed appropriate. Implicit was a lack of support from managers and employers. Another moral dilemma concerned the issue of dying alone. Some staff members expressed feelings of guilt because they had not been with the person when he or she died and were upset that he/she had died alone. Such cases were often described and discussed in the focus group discussions, of which the following is an example.

Case example from FGD

Wendy: I think that all of us were hoping that she would cease holding on to life.

Jane: I do believe that you can to some extent decide yourself when it's time to die. You have a choice when it comes to death.

Helen: I feel anxious when I think about Ester's death. She was in constant pain.

Jane: What were we supposed to do? ... If you don't know what to do you cannot do anything.

Wendy: I think we could have done more.

Marie: Ester was not really alone, but we should have been there for her because we knew that she was dying.

Whitney: But she did have someone with her all night, she had someone sitting beside her since the previous night.

Wendy: Yes, but none of us stayed with her.

One of the participants revealed that she wished she could have done more for Ester and that was why she found it difficult to feel satisfied about how life turned out for Ester. She continued: *I wish that I could have done more for her, I didn't do enough and that doesn't feel too good. But you can't be everywhere. What I think about is that I should have done this and that. I wanted to but it was not possible because there was so much else to do. There were other people who had to be looked after. But I felt that I wanted to be with Ester but it was impossible. It feels horrible.*

A long conversation ensued about doing one's best within the organisational framework. In order to improve the care for older people, some participants believed that the whole organisation would have to accept that nursing homes are places where people die. One staff member explained this as follows: *You have to realize that death is a part of this job. I mean you shouldn't be surprised that people die here. Some colleagues may need more training. New staff members need help to be able to provide good care, part of which is the realisation that people die here. ...but no one wants to talk about it.*

Discussion

The aim of this study was to investigate how the staff reasoned about the older persons' death and dying. All focus group discussions revealed that the participants wanted to reflect on the older people's death and dying, although it was something that was rarely discussed. A surprising result was that death was surrounded by such great silence. The term palliative care was not used at all. Only a few participants used the term end-of-life-care. This was seen in all focus group discussions and there were no differences between

the various units. The reason for the silence and invisibility of death in the nursing homes can be related to lack of understanding of palliative care philosophy as discussed by Watson and co-authors (2006). A few participants emphasised the importance of recognizing that nursing homes are places where people both live and die. Until nursing homes are recognized as places for death and dying, the care cannot be developed and palliative care philosophy implemented. There is reason to believe that if people do not view nursing homes as places of death and dying, the resources needed to provide such care will not be made available. Watson et al. (2006) describe lack of knowledge of palliative care and the dying process as part of the barrier to the implementation of an integrated pathway. The present study provides a basis for such an interpretation to be considered reasonable on both an individual and an organisational level. On the former level, the relationship between staff and older people is characterised by lack of conversation, especially about existential issues. None of the participants knew what the older people thought or their wishes concerning their end of life. This is surprising, since many of the older people reflected on in this study had lived in the nursing home for up to two years and a similar result was presented almost twenty years ago in a study by Andersson-Segesten (1989) that employed the same method as the present one. The 1989 study was based on an analysis of twelve deceased patients' end of life care and death and revealed that staff lacked knowledge of the dead person such as religious beliefs, perceptions of impending death, meaning, fear and joy. As in our study, the staff members were unaware of the patients' thoughts, feelings and reactions (cf. Franklin et al. 2006; Dwyer et al. 2008). This raises the important question of how knowledge of palliative care and its philosophy has been implemented in contemporary society. Only then will end-of-life care meet the diverse needs of older people who live in nursing homes (Froggatt 2006). Since the early 1980's a number of palliative units have been established in Sweden. Conferences and courses have been held and the number of scientific publications has increased (National Board of Swedish Health and Welfare 2006). Our study shows that many staff members considered that they lacked sufficient education within the area to discuss issues such as pain relief and existential questions.

This study reveals that the older person is to some extent viewed as a unique human being with life-long experience and a life story. However, it seems that few of the staff members had the time to individualise the care. To a large degree, older people still appear to be treated in a stereotyped way despite the various ideals (WHO 2004).

Models for individualising care, promoting dignity and providing the possibility to experience a good death have been developed and tested in different care settings. The retrospective autopsy that provided the framework that guided this analysis is one example (Andersson-Segesten 1989; Rinell Hermansson 1990; Rinell Hermansson & Ternestedt 2000; Ternestedt et al. 2002). The model with the six keywords often called the six S's, which cover physical, psychological, social, existential and spiritual needs, is aimed at promoting the implementation of palliative care philosophy. They are seen as an integrated whole, which originates from the individual's self-image, identity and lifestyle. The model is used in research (Andersson-Segesten 1989), care planning, documentation and evaluation (Hermansson Rinell & Ternestedt 2000; Ternestedt et al. 2002). Another dignity promoting model within palliative care is the therapy developed by Chochinov and co-workers (2002a; 2002b).

The fact that older people at the end of life lack adequate care and sufficient pain relief is disclosed in several studies (Lynn 1997; Lynn et al. 1997; Costantini et al. 2002). One of

many reasons for this seems to be lack of knowledge. It is relatively obvious that the view of older people is mirrored in the resources provided and current societal values (Strandberg 2002).

Studies show a gap between societal intentions and the capacity to implement and provide person-focused end-of-life-care for older people. They indicate that the care is task orientated rather than person-centred (Wetle et al., 2005). Andersson-Segesten (1989) believes that a possible reason for this could be that staff members are not always familiar with the older person's earlier life. It has been suggested that palliative care philosophy could increase awareness of the needs of the dying person, which might contribute to him/her receiving good quality care irrespective of the setting (WHO 2004).

Methodological reflections:

Our impression is that the focus group discussions stimulated the dialogue and raised important thoughts and reflections about caring for dying people. It was also clear that the nurse's assistants and the registered nurses talked about caring for the dying in somewhat different ways. The discussions also provided insight to different professional's work and experiences and provided time to talk about them. The interaction between the participants demonstrated that certain questions pertaining to organisational control are especially sensitive and lead to conflict. This implies that the organisation can be an obstacle to the provision of good palliative care and that staff education and support are important.

Conclusions

The results show that staff members have a great interest in and will to offer and provide dying people with good end of life care. The nurses assistants did, however, feel prevented from doing so, mainly because of lack of knowledge, education, time and organisational barriers. The registered nurses did express that the expectations on them and what they were supposed to deliver to some extent exceeded what was impossible to meet. The care was mainly described as task-orientated. The results also show that the staff had limited knowledge about what the older, now dead person, thought and felt about death and dying. Death was surrounded by a great silence and the staff seemed to have limited knowledge of how the older person had lived his/her life before moving into the nursing home, even in cases where he/she had lived there for a longer period. The alleviation of physical pain was described as an important factor that enabled a good death. It was claimed that symptom relief was not optimal, mainly due to organisational barriers. The lay staff clearly wished for the RNs to play a more active role in the 'hands on' care as they had more knowledge about pain and pain relief. Meaningfulness in everyday life was another important criterion for a 'good death' and was described as the older person's need of relationships and being able to have a sense of coherence. Conversations and the possibility to sum up one's life were only mentioned as being important to a few of the dying older people. Many staff members repeatedly expressed their wish to offer and provide more optimal care, but described they felt restricted by organisational factors. In some cases this was interpreted as moral stress. The staff members' need for education and support was evident. It was also clear that Palliative care philosophy should be implemented and that both the organisation and the provision of care need to be reviewed. There is a need for further research in this area.

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References

- Avis M, Jackson JG, Cox K, Miskella C. (1998) Evaluation of a project providing community palliative care support to nursing homes. *Health & Social Care in the Community* 7, 32-38.
- Addington-Hall J, Lay M, Altmann D, McCarty M. (1998) Community care for stroke patients in the last year of life: results of a national retrospective survey of surviving family, friends and officials. *Health & Social Care in the Community* 6(2), 112-119.
- Albinson L. (2002) *Palliative approach to dementia care. Leadership and organisation, existential issues and family support.* (Academic dissertation). Uppsala university: Uppsala, Sweden.
- Andersson-Segesten K. (1989) The Last Period of Life of the Very Old. A Pilot Study Evaluation the Psychological Autopsy Method. *Scandinavian Journal of Caring Science* 3(4), 177-181.
- Barbour RS. (2005) Making sense of focus groups. *Medical Education*, 39(7), 742-750.
- Bolmsjö IÅ. (2002). Existential issues in palliative care. (Academic dissertation) Lund: Lunds university, Sweden.
- Chochinov HM, Hack T, McClement S, Kristjanson L & Harlos M. (2002a) Dignity in the terminally ill: a developing empirical model. *Social Science & Medicine* 54, 433-443.
- Chochinov HM, Hack T, Hassard T, Kristjanson L, McClement S & Harlos M. (2002b) Dignity in the terminally ill: a cross-sectional, cohort study. *The Lancet* 361(21/28), 2026-2030.
- Costantini M, Vitebori P & Flego G. (2002) Prevalence of pain in Italian hospitals: results of a regional cross sectional survey. *Journal of Pain and Symptom Management* 23, 221-230.
- Dwyer L, Nordenfelt L & Ternstedt B-M. (2008) Meaning at the end of life -as narrated by three nursing home residents. *Nursing Ethics* 15(1), 88-100.
- Franklin L, Ternstedt B-M & Nordenfelt L. (2006) The views on dignity of twelve elderly nursing home residents. *Nursing Ethics* 13(2), 130-146.
- Froggatt K & Payne S. (2006) A survey of end-of-life care in care homes: issues of definition and practice. *Health and Social Care in the Community* 14(4), 341-348.
- Fry PS. (1990) A factor analytic investigation of home-bound elderly individuals' concerns about death and dying and their coping responses. *Journal of Clinical Psychology* 46(6), 737-748.
- Gibbs L, Addington Hall J. (1998) Dying from heart failure: lessons from palliative care. *British Medical Journal* 317, 961-62.

- Grande GE, Addington-Hall JM, Todd CJ. (1998) Place of death and access to home care services: are certain patient groups at a disadvantage? *Social Science & Medicine* 47, 565-579.
- Hallberg RI-L (2004) Death and dying from old people's point of view. A literature review. *Aging Clinical Experimental Research* 16, 87-103.
- Hermansson AR & Ternstedt B-M. (2000) What do we know about the dying Patient? Awareness as a means to improve palliative care. *Medicine and Law* 19(2), 225-344.
- Kitzinger J. (1995) Introduction focus groups. *British Medical Journal* 311, 299-302.
- Källström Karlsson I-L, Ehnfors M, Ternstedt B-M. (2006) Patient characteristics of women and men cared for during the first 10 years at an inpatient hospice ward in Sweden. *Scand J Caring Sci* 20(2), 113-121.
- Lynn J. (1997) Measuring quality of care at the end of life. A statement of principles. *Journal of the American Geriatrics Society* 45(4), 536-527.
- Lynn J, Teno JM, Phillips RS, Wu AW, Desbeins N, Harrold J, Classens MT, Wegner B, Kreling B & O'Connor AF. (1997) Perceptions by family members of the dying experience of older and seriously ill patients. *Annals of Internal Medicine* 126, 97-106.
- Morrison RS & Morris J. (1995) When there is no cure: Palliative care for the dying patient. *Geriatrics* 50 (9), 12 (comment)
- National Board of Health and Welfare. (2006) *Vård i livets slutskede. Socialstyrelsens bedömning av utvecklingen i landsting och kommuner*. Stockholm: National Board of Health and Welfare, Sweden.
- National Board of Health and Welfare. (2004) *God vård i livets slut. En kunskapsöversikt om vård och omsorg om äldre*. Ternstedt B-M. (Ed.) Stockholm: The National Board of Health and Welfare, Sweden.
- Patton MQ. (2004) *Qualitative Research & Evaluation methods*. California: Sage.
- Rappaport H, Fossler RJ, Bross LS & Gildea D. (1993). Future time, death anxiety and life purpose among older adults. *Death studies* (17), 369-379.
- Rinell Hermansson A. (1990) *Det sista året. Omsorg och vård vid livets slut*. (Academic dissertation). Uppsala: Uppsala universitet.
- Schneidman E. (1969) *Suicide, lethality and psychological autopsy*. In: Schneidman, E & Ortega, M (eds). Boston: Little Brown.
- Strandberg G. (2002) Dependency on care. (Academic dissertation) Umeå: Department of Nursing, Umeå University.

Strang S. (2002) Spiritual/existential issues in palliative care with special reference to patients with braintumours and their spouses. (Academic dissertation) Göteborg: Göteborg University, Sweden.

Ternstedt B-M, Andershed B, Eriksson M & Johansson I. (2002) A good death. Development of a nursing model of care. *Journal of Hospice and Palliative Nursing* 3, 153- 60.

Wainwright P, Gallagher A. (2008) On different types of dignity in nursing carer: a critique of Nordenfelt. *Nursing Philosophy. An international Journal for Health Care Professionals* 9(1), 46-54.

Watson J, Hockley J, Dewar B. (2006) Barriers to implementing an integrating care pathway for the last days of life in nursing homes. *International Journal of Palliative Nursing* 12(5), 234-240.

Webb C & Kevern J. (2001) Focus groups as a research method: a critique of some aspects of their use in nursing research. *Journal of Advanced Nursing* 33(6), 798-805.

Weisman AD & Kastenbaum R. (1968) The psychological autopsy. A study of the terminal phase of life. *Community Mental Health Journal* Monograph No 4. New York: Behavioral Publications, Inc.

Weisman AD. (1972). *On dying and denying. A psychiatric study of terminally ill*. New York: Behavioral Publications Inc.

Weisman AD. (1974). *The realization of death. A guide for the psychological autopsy*. New York, London: Jason Aronson, Inc.

Wetle T, Shiled, Teno J, Miller SC & Welch L. (2005) Family perspectives on end of life care experiences in nursing homes. *Gerontologist* 45(5), 642-650

Whitaker A. (2004) *The last home: family ties, ageing and death in a nursing home*. (Academic dissertation) Stockholm: Department of Social Work, Stockholm University.

World Health Organization (2004) *Better palliative care for older people*. Copenhagen: World Health Organization.

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Doktorsavhandling/Doctoral thesis with focus on Nursing.