Chapter 1

General introduction
This thesis focuses on personal dignity in nursing homes. This topic is studied from different perspectives and with different methodologies. Before describing the study results, this chapter first introduces the concept of dignity, and discusses its philosophical roots and occurrences in empirical work. The chapter will subsequently outline why a focus on personal dignity in nursing homes is important and which needs for research we identified. At the end of this chapter, the objectives and methods of the study described in this thesis will be addressed.

Ageing population

The world’s population is ageing. People are living longer and the proportion of people living to old and very old ages has increased in the last decades and will continue to increase in the future. Whereas 11% of the Dutch population was older than 65 years of age in 1980, this increased to 16% in 2012 and is estimated to increase further to 26% in 2040. The percentage of people above 80 years of age shows a similar trend: from 2% in 1980, to 4% in 2012 and 9% in 2040. Along with an increasing number of people living to older ages, more people will live a relatively longer period of life with the consequences of decline due to chronic diseases, such as cerebrovascular disease, cardiovascular disease, cancer or dementia. Older people reaching the end of life frequently suffer from more than one chronic condition. Multi-morbidity causes a wide range of physical, psychological and social problems, and consequently complex needs for care and support towards the end of life. Admission to a long-term care facility, like a nursing home, is sometimes inevitable. These changes in body and living situation may give rise to existential distress and may invoke a loss of dignity.

The concept of dignity

Each language has ambiguous and flexible concepts, which lack definitional specificity. One of these complex concepts is ‘dignity’. Although the term is used in everyday language, it is ambiguous in its interpretation and application. Such ambiguity has led some to conclude that dignity is a redundant or even useless concept that we would be better off without, because ‘it means no more than respect for persons or their autonomy’. Others however view dignity as a moral absolute or first principle, and a necessary addition to other guiding principles in medical ethics. Several authors have for example argued that dignity should be considered a central principle in palliative care, and that conserving dignity can be seen as a goal of the care given. Although formulating a general applicable definition of dignity is impossible, the many ways it has meaning for different people in different settings is worth our investigation. To obtain a better understanding of this complex concept, we will start by taking a glance at the philosophical roots of ‘dignity’.

Chapter 1
A brief history of dignity

One of the earliest references to dignity is by the philosopher Aristotle (384-322 BC), who speaks of dignity as one of the fourteen moral virtues of a person.19,20 A few centuries later, Cicero (106-43 BC) writes about the concept of dignity in two meanings. He refers in his writing to dignity as the public recognition of one’s social position, and secondly to dignity as the intrinsic and characteristic quality by which human beings are distinct from other beings.21,22 The fact that human beings are endowed with reason distinguishes them from animals or plants. Whereas dignity as public recognition is not stable or permanent, the notion of intrinsic dignity is a very stable and lasting one.

The idea of rationality as the basis of the dignity of human beings was connected to the notion that human beings are created in the image of God by the Fathers of the Church during the first centuries and the early Middle Ages. During Renaissance and Enlightenment, the idea of intrinsic worth was taken up in various ways apart from the Christian tradition. The philosopher Pico della Mirandola (1463-1493) put man at the centre of the universe and proclaimed the freedom of man as his dignity. The 18th century philosopher Immanuel Kant (1724-1804) stated that human beings possess dignity because they are rational, autonomous creatures with intrinsic value who can pursue and determine their own ends.23,24 Kant’s accounts have had a big influence on contemporary thinking. His philosophy is associated with the Universal Declaration of Human Rights from 1948, which states that ‘all human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood’.

Rather recently, a third type of dignity has emerged: subjectively or experienced dignity.22 It is completely different from social or intrinsic dignity, because it entirely rests on what individuals say they feel. It is related to one’s self-esteem and self-respect, and is often largely co-determined by the cultural horizon in which one interprets oneself. Whereas some people can experience loss of dignity when they no longer are able to live in their homes, other people can feel deprived of their dignity when they cannot lead what they consider to be a meaningful life.

The many appearances of dignity in literature

Although three ‘main’ versions of dignity (intrinsic, social and subjective) can thus be distinguished, nowadays a range of classifications of dignity appear in theoretical and empirical work. For example, dignity has been described as an objective phenomenon and as a subjective one, as public and as private, as individual and as collective, as internal and intrinsic and as external and extrinsic, as hierarchical and as democratic, as unconditional and static and as contingent and dynamic, as inherent, bestowed, or achieved, and as descriptive.
and prescriptive. Even more confusion is caused by the several terms that co-exist in literature (e.g. basic dignity, human dignity, social dignity, relational dignity, emotional dignity, attributed dignity and personal dignity). There appears to be little consensus about the definition and use of these terms.

One theoretical account that may be helpful in identifying features of dignity in relation to health care comes from the Swedish philosopher Nordenfelt. Nordenfelt distinguishes between intrinsic and contingent value, but divides the latter into three, and thus distinguishes four varieties of dignity:

• Dignity of Menschenwürde pertains to all human beings to the same extent and cannot be lost as long as the persons exist.

• Dignity of merit depends on social rank and position. There are many species of this kind of dignity and it is very unevenly distributed among human beings. The dignity of merit exists in degrees and it can come and go.

• Dignity of moral stature is the result of the moral deeds of the subject; likewise it can be reduced or lost through his or her immoral deeds. This kind of dignity is tied to the idea of a dignified character and of dignity as a virtue.

• Dignity of identity is tied to the integrity of the subject’s body and mind, and in many instances, although not always, also dependent on the subject’s self-image. This dignity can come and go as a result of the deeds of fellow human beings and also as a result of changes in the subject’s body and mind.

Whereas dignity of Menschenwürde can be regarded as a universal human dignity, the other three types are tied to individual persons. Dignity of merit, dignity of moral stature and dignity of identity have therefore been combined and called personal (senses of) dignity: the worth of a particular person.

**Personal dignity**

*Personal* dignity is the form of dignity which is referred to in this thesis. It considers the worth we attach to ourselves – including our social rank, deeds and level of integrity. The way persons view themselves is dependent on several factors: one’s past and anticipated future, personal goals, society, culture, social relations and relationship to one’s body. Furthermore, personal
dignity is related to persons’ self-esteem, sense of ‘worthy to be’ and perceptions of being (worthy to be) respected by others. *Personal dignity*, as opposed to *basic or human* dignity, can be taken away or enhanced.\(^{14,26-29}\) When persons fail to give meaning to something that happens to them, a loss of personal dignity may be experienced.\(^{27}\)

Looking at the end of life, conditions that – in our time and age – might frequently be seen as invoking a loss of personal dignity are: becoming incompetent or dependent, lack of privacy, or incontinence for urine and/or faeces. However, whether this is the case for a specific individual depends on his/her attitude and experiences. People with strong religious beliefs for instance, may be able to give meaning to suffering in the terminal phase of an illness, while non-religious people might see this as pointless.

A fractured sense of personal dignity has been found to be associated with depression, hopelessness, and a desire for death.\(^{30}\) Accordingly, it is one of the most frequently mentioned reasons for requesting euthanasia or physician-assisted suicide\(^ {31-35}\) and for formulating an advance directive in the Netherlands.\(^ {36}\)

**Empirical research on personal dignity**

Since the concept of personal dignity is subjective, individuals will differ in their understanding of (living or dying with) dignity and a generally applicable definition cannot be formulated. It is however possible to identify common themes that may affect dignity, taking into account that the importance of these themes in their impact on dignity varies from person to person and from one context to another.

Because dignity becomes especially important when cure is no longer possible, empirical research on patients’ sense of dignity has primarily focused on the end-of-life stage, investigating how terminal cancer patients in the last months of life understand dignity. Chochinov et al. (2002) developed the ‘Model of Dignity in the Terminally Ill’, based on a qualitative study in which interviews with 50 terminally ill cancer patients were performed.\(^ {37}\) The model suggests that an individual’s perception of dignity is related to and influenced by three major areas: illness-related concerns (i.e. those issues deriving from the illness that relate to one’s level of independence and symptom experiences); dignity-conserving repertoire (i.e. the personal approaches that individuals use to maintain their sense of dignity); and social dignity inventory (i.e. environmental factors that influence the quality of an individual’s interaction with others). The ‘Model of Dignity in the Terminally Ill’ served as a basis for ‘dignity therapy’ – aimed at enhancing or restoring the sense of dignity in patients nearing death and helping them to achieve closure,\(^ {38}\) and as a basis for the Patient Dignity Inventory (PDI) – a measurement instrument that could be used by clinicians to detect end-of-life distress.\(^ {39,40}\)
A model that is applicable to a wider patient population is the ‘Model of Dignity in Illness’ (see Figure 1 on page 30). This model is created based on a qualitative interview study with 34 people who had a variety of illnesses and still lived at home, and illuminates the process by which serious illness can undermine patients’ dignity. According to this model, illness-related conditions do not affect patients’ dignity directly but indirectly by affecting the way patients perceive themselves in three components shaping self-perception: (a) the individual self: the subjective experiences and internally held qualities of the patient; (b) the relational self: the self within reciprocal interaction with others; and, (c) the societal self: the self as a social object in the eyes of others. While both the ‘Model of Dignity in the Terminally Ill’ and the ‘Model of Dignity in Illness’ recognize the importance of the attitude of care professionals and of social support for the maintenance of patients’ dignity, the latter model extends to include a view of the broader relational and societal domains and provides a detailed description of these.

With regard to the care for older people, the comprehensive Dignity and Older Europeans study has resulted in a large number of publications. This cross-cultural project involved 1320 participants (older people of whom most lived at home and care professionals) from 6 European countries. Dignity appeared to be a rich and round concept for participants in this study. The following key dimensions of dignity were found: personal identity, respect, recognition, participation and control.

**Personal dignity in nursing home care**

In addition to the populations mentioned above (cancer patients, patients with a variety of illnesses still living at home and older people), the long-term care setting is a setting in which personal dignity is of great importance.

In the Netherlands, institutional care for the elderly is provided in two co-existing kinds of accommodation: residential care homes and nursing homes. Older people with less complex problems receive care in residential care homes, while disabled people with chronic physical diseases or with progressive dementia who need plural, more complex continuing care and monitoring, which are beyond the range of the service in residential care homes, are accommodated in nursing homes. Nursing homes, in turn, can have general medical wards (long-stay units for people with physical illnesses) and/or psychogeriatric wards (long-stay units for people with dementia). While GPs continue to manage patient care in the residential care homes, they hand-over such care to specialized elderly care physicians once a patient is transferred to a nursing home. The Netherlands is the only country in Europe that offers this unique nursing home specialization.
In 2008, there were 1300 residential care homes, 300 general medical nursing home wards and 400 psychogeriatric nursing home wards in the Netherlands, in which a total of 165,000 people received long-term care (100,000 in residential care homes, 28,000 in general medical nursing home wards and 37,000 on psychogeriatric nursing home wards).\textsuperscript{49} Approximately three quarter of the people living in nursing homes were female, with a mean age of 83 years.\textsuperscript{49} Projections of the ageing population show that the demand for continuing care (as given in residential care homes and nursing homes) will increase with 40% by 2030 in the Netherlands.\textsuperscript{50} The actual use of institutional care will however be much lower, because medical advancements in home care enables more people to stay longer at home, supported by home care. For many years, the total number of people receiving care in institutions has decreased, while the average age of people living in institutions has simultaneously increased.\textsuperscript{49} On top of that, the average time that people spend in a nursing home has considerably diminished over the last decades.\textsuperscript{51} These trends do not only apply to the Netherlands, but can be seen in most developed countries.\textsuperscript{52-54}

Above mentioned trends imply that the population living in institutions has become increasingly frail, resulting in nursing homes to increasingly provide complex care for people at the final months of their life.\textsuperscript{49,51} In line with the above, nursing homes are common sites of death.\textsuperscript{55} One-third of all deaths in the Netherlands in 2003 occurred in residential care homes or nursing homes.\textsuperscript{56} The every-day care given in nursing homes thus turns more and more into palliative care, in which conserving patients' dignity is regarded an important goal and central principle.\textsuperscript{10,16-18}

Nursing home residents' vulnerability to loss of dignity

Nursing home residents are exposed to diverse risk factors, making them vulnerable to loss of personal dignity.\textsuperscript{57,58} They not only face threats to dignity arising from having one or more illnesses, but are also confronted with a new and unfamiliar living environment, little privacy, are often heavily reliant on staff and increasingly lack social networks. Furthermore, the current restrictions of available budgets and the scarcity of human resources in nursing homes might pose a threat to the maintenance of nursing home residents’ dignity.

To protect these vulnerable nursing home residents from losing personal dignity, it is important to understand the concept of dignity from the residents’ perspective throughout their entire admission period in the nursing home. Besides, understanding staff members’ perception of dignity is important, because the relationship between health care staff and patients has been described as vital for promoting dignity.\textsuperscript{16,59,60}
Empirical research in nursing homes

The available knowledge on the way dignity is perceived in the nursing home comes from a small number of studies. In the United Kingdom, researchers explored the generalizability of Chochinov’s ‘Model of Dignity in the Terminally Ill’ to older people in nursing homes. Although the main categories of the dignity model were broadly supported, subthemes relating to death (i.e. death anxiety and aftermath concerns) were not supported by the residents’ stories, and two new themes emerged: ‘old age is not an illness’ (symptoms and loss of function were regarded as due to old age rather than to illness) and ‘feelings of loss’ (of home, family, friends, important roles, function and independence, freedom and future).

A qualitative study performed in Germany concluded that the basic prerequisite for the preservation of dignity among nursing home residents was the existence of (dignifying) relationships and encounters, and that residents went to great lengths to avoid jeopardizing these relationships by becoming a burden.

A Swedish study among 12 nursing home residents also described that feeling involved and being of value to others gave meaning to the otherwise limited scope of the daily lives of nursing home residents. Three themes were identified that illustrated positive and negative aspects of ageing and vulnerability in relation to dignity: ‘the unrecognizable body’, ‘fragility and dependence’ and ‘inner strength and a sense of coherence’. According to Swedish nursing home staff members, older persons’ dignity was promoted by providing for their physical needs, and respecting their identity and integrity. In line with other studies among nursing home staff members, threats to staff’s own dignity were revealed, caused by ethically difficult situations and moral conflicts created by lack of time and resources in the nursing home. The different care cultures in which older people live and staff work were described by this Swedish study as follows: the older people were living in a culture of silence and slowness, while staff worked in a task-oriented culture which could be labelled as a culture of doing. According to Dwyer, these two cultures existed simultaneously and hindered person-centred, dignity-promoting care.

Need for further research

As described above, different studies have begun to elicit the aspects that influence personal dignity, also in the nursing home setting. More empirical research is however needed to improve our understanding regarding dignity at the end of life. Understanding the causes of dignity-related distress could help to improve the care given in nursing homes. In addition, results from other studies might not be generalizable to other countries where the nursing home system is different.

Furthermore, there is lack of a longitudinal perspective on dignity. Insight in whether views on
dignity change over the course of time – i.e. when people reside in a nursing home for a longer period of time – and what factors play a role in this will contribute to care that better supports residents to maintain their dignity throughout their admission period.

What can also contribute to dignity-conserving care is a better understanding of staff members’ current views on resident’s dignity and staff’s current efforts and experiences while trying to promote the dignity of individual nursing home residents in daily practice. Little is yet known about these matters, since earlier studies mainly focused on staff’s perceptions on their own dignity while working in the nursing home.

Whereas above-mentioned needs for further research mainly focus on understanding aspects that influence dignity in the nursing home, a further need exists for a valid and feasible measurement instrument that enables to study the prevalence of factors that influence nursing home residents’ dignity. No such instrument for the nursing home setting does exist yet. Above that, the availability of a measurement instrument can give information regarding those who are most at risk of losing dignity, and can be used to better target more effective, dignity-conserving care to an individual nursing home resident. Although patients themselves are the preferred source of information about their dignity, they may not always be willing or able to provide information due to medical conditions as fatigue, cognitive decline or aphasia. In these cases, information must be obtained from proxy informants such as family members or caregiver staff. Knowledge on comparability of proxies’ and patients’ answers is then required to interpret this information appropriately.

**Objectives of this thesis**
This thesis consists of two parts, each with different objectives, methodologies and research questions.

**Part I: Understanding personal dignity in the nursing home**
The general objective of the first part is to gain a deeper understanding of what personal dignity means in nursing homes. A qualitative study using in-depth interviews has been conducted to reach this objective. Interviews were conducted with nursing home residents as well as with nursing home staff. The research questions addressed in Part I are as follows:

1. How do recently admitted nursing home residents experience dignity and, according to them, which factors preserve or undermine dignity?

2. How does nursing home residents’ personal dignity develop over the course of time? And what factors contribute to this development?
3. How do nursing home staff view and promote the personal dignity of individual nursing home residents in daily practice? And what are staff’s experiences with preserving dignity in the nursing home?

Part II: Developing, testing and applying a measurement instrument for personal dignity
The general objective of the second part of this thesis is to develop and apply a reliable, valid and feasible measurement instrument to measure factors that influence personal dignity in a general patient population and, more specific, for people living in long-term care facilities. Two studies, one in which questionnaires were administered to people with (an) Advance Directive(s), and one in which nursing home residents and their proxies received questionnaires, have been conducted to reach this objective. The following research questions are addressed in Part II of this thesis:

4. How can a valid, reliable and feasible instrument measuring factors affecting personal dignity be developed? Is it necessary to adapt this instrument for the long-term care setting?

5. To what extent can different types of proxies assess nursing home residents’ dignity?

6. Which characteristics of nursing home residents relate to factors influencing their dignity?

Methods
In order to reach the objectives, and to answer the research questions, several studies were performed; some in which qualitative research methods were used, and others in which quantitative research methods were applied. For the objective described in part I a qualitative approach was most suitable, since in-depth information was needed in order to identify and understand all factors relevant to personal dignity in nursing homes. In order to being able to, now and in the future, study the prevalence of these factors, a valid measurement instrument needed to be developed (part II). This required a quantitative approach. This section presents the main characteristics of both the qualitative and quantitative studies. The methods are described in more detail in the separate chapters of this thesis.

Qualitative studies
A longitudinal qualitative interview study was performed among a group of 30 nursing home residents who lived on the general medical wards (long stay-units for people with physical illnesses) of four nursing homes in the Netherlands. From admission onwards, these residents were followed over the course of time for 18 months, and interviewed at an interval of six
months, until the resident deceased, withdrew from the study due to another reason or until the data collection period ended. In some occasions this interval was shortened, e.g. when a resident’s health status deteriorated rapidly or when a resident moved to another unit. The data collection period ran from May 2010 to December 2012 and the interviews were guided by a topic list. In the first interview, nursing home residents were questioned about their view on personal dignity and the factors that undermined or preserved this. The subsequent interviews mainly consisted of the same questions, but focused on changes in health status, living circumstances or coping capacities, and its relation to perceived dignity. A total of 91 interviews with nursing home residents were conducted.

By participating in the study, these 30 residents gave permission to ask both their elderly care physician and primary attending nurse about their views on the personal dignity of the resident concerned. Because physicians and nurses generally cared for more than one of the participating residents, 13 physicians and 15 nurses were eventually identified to be responsible for these 30 residents and were asked to express their view on the personal dignity of the resident(s) they cared for. In-depth interviews with elderly care physicians and nurses were conducted from July 2010 to August 2011 and followed shortly after the first interview held with a particular resident. The interviews were guided by a topic list and consisted of a general part, in which the interviewees were questioned about their view on and experiences with dignity and dignified care in their daily work in the nursing home, and a larger more specific part, in which they expressed their view on the personal dignity of a particular resident.

Both the interviews with nursing home residents and staff were audio-taped, transcribed verbatim and analyzed according to the principles of thematic analysis. Transcripts were first read and re-read to become familiar with the data, codes were ascribed to meaningful text units, and grouped together in order to identify themes.

Quantitative studies
The development, testing and application of an instrument that measures factors influencing personal dignity is based on two cross-sectional studies. The development of the Measurement Instrument for Dignity AMsterdam (MIDAM) resulted from a study among a Dutch cohort of people with an advance directive (AD). From October 2005, a cohort of people with one or more of the four most frequently used ADs in the Netherlands received a written questionnaire every 18 months. In the second cycle of data collection of spring 2007, an already existing instrument for dignity (the prototype Patient Dignity Inventory) was added to the questionnaire. Evaluation of respondents’ answers revealed some shortcomings of the prototype Patient Dignity Inventory. This prompted us to develop a new measurement instrument, which we evaluated and further developed by analyzing 292 questionnaires of
the third data collection round (autumn 2008). Infrequently endorsed items and conceptually similar items were omitted, so as to make the MIDAM more feasible to use in practice.
To create an instrument applicable to people living in long-term care facilities, we added 13 items to the MIDAM on the basis of the results from above-mentioned qualitative interview studies, e.g. items about ‘waiting for help’, ‘a small room’ and ‘difficulties with adjusting to structures in the nursing home’. The extension “for Long-Term Care facilities” was added to the name of the instrument. To assess its content validity, construct validity and intra-observer agreement, questionnaires containing the MIDAM-LTC were administered face-to-face to 95 nursing home residents living on the general medical wards of six nursing homes. Again, infrequently endorsed items were removed from the instrument to increase its feasibility for use in practice. Descriptive and multiple regression analyses were then used to determine associations between residents’ personal dignity on the one hand and variables that possibly influence dignity such as sex, age, religion, cultural background, length of stay in the nursing home, attitude to life, socio-economic status and level of dependency on the other hand. In addition, each participating resident’s contact in the care record (often a family member), responsible physician and nurse were approached to also participate in the study, and to fill in the MIDAM-LTC with the nursing home resident in mind. Accuracy of proxy reports were assessed by calculating agreement percentages between the different answers of residents and proxies.

Outline of this thesis
Chapters 2 to 8 of this thesis are based on articles that have been published in or submitted to a peer-reviewed scientific journal. This implies that the various chapters overlap, especially with regard to the methods sections, which have been maintained in each chapter so that they can be read independently.

Chapter 2 describes the experiences of nursing home residents with regard to their dignity, and the various factors that could preserve or undermine this.
Chapter 3 reports on the way nursing home residents’ dignity developed over the course of time – from admission onwards – and the mechanisms by which residents were able to maintain or regain their dignity.
Chapter 4 concentrates on the perceptions of nurses and elderly care physicians regarding the personal dignity of individual nursing home residents. It additionally provides insight into their experiences with preserving dignity in the nursing home.
Chapter 5 gives account of the development and the evaluation of a measurement instrument for factors affecting self-perceived dignity (the MIDAM). It describes the considerations to
develop a new instrument and how the instrument was filled in by a sample of people with one or more advance directive(s).

Chapter 6 describes how an already existing instrument (MIDAM) was adapted into an instrument applicable for the long-term care setting (MIDAM-LTC), and how its content validity, construct validity and intra-observer agreement were tested in a sample of 95 nursing home residents.

Chapter 7 reports on the extent to which the responses of different types of proxies (family members, nurses and elderly care physicians) corresponded with the responses of 95 nursing home residents when they both assessed the resident’s dignity, using the MIDAM-LTC.

Chapter 8 presents the results of a study investigating the associations between on the one hand nursing home residents’ characteristics and on the other hand factors that influence their dignity.

Finally, chapter 9 discusses the main findings and interpretation of these. In addition to some methodological considerations, implications for practice and policy, and suggestions for further research will be considered in the final chapter of this thesis.
References


36. van der Brugghen J, Rurup ML. “Ik wil dat mijn wil gerespecteerd wordt”: Onderzoek naar de motivatie om een wilsverklaring op te stellen en de verwachtingen van mensen die recent een wilsverklaring hebben opgesteld. VU University Medical Center, 2006.


Chapter 1


General introduction