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.