Chapter 9

General discussion
The general objective of the first part of this thesis was to gain a deeper understanding of what personal dignity means for nursing home residents as well as for nursing home staff. In the second part, we aimed to translate the factors we found relevant to personal dignity into a reliable, valid and feasible measurement instrument, and to apply this instrument to study the factors that influence nursing home residents’ dignity in a quantitative manner.

The final chapter of this thesis will discuss the findings of the studies described in the previous chapters. First, some methodological issues will be reflected upon, followed by an overview of the main findings and interpretation of these. Subsequently, implications for policy, practice and further research will be considered.

Methodological reflections

This thesis is based on several studies; some in which qualitative research methods were used, and others in which quantitative research methods were applied. These methods were used complementary to each other. Beyond contributing to a deeper understanding of personal dignity in nursing homes, the data of the qualitative study provided a conceptual framework which we used in the development of the MIDAM-LTC. Furthermore, the knowledge and experience gained in the qualitative study helped us in interpreting the results of the quantitative study.

Qualitative studies (Chapters 2, 3 and 4)

Qualitative research aims to study people in their natural social settings and to collect naturally occurring data, focusing on the meanings the participants attach to their social world. The method of in-depth interviewing aims to delve deep beneath the surface of superficial responses to obtain true meanings that individuals assign to events or experiences, and allows the respondent to tell their own stories in their own words, with prompting from the interviewer. Following from this, a qualitative approach using in-depth interviews was most suitable for the main objective of the first part of this thesis.

In qualitative research, the researcher is his/her own research instrument. To go beyond only gathering anecdotic information required some skills from me as an interviewer. I have attempted to obtain ‘rich’ data by displaying an attitude of openness towards the nursing home residents’ stories, and to minimize my own, potentially biasing, role. In addition, I used techniques like asking ‘main’ questions, ‘probing’ questions and ‘follow-up’ questions to obtain more depth in the conversations. Although open-ended questions were prepared beforehand and established in a topic list to ensure that all research questions were addressed, I did not ask these questions in an established order, but followed on the information the respondent
provided. Because the question ‘What means dignity to you?’ is almost impossible to answer, the topic list contained different framings of the concept, e.g. ‘What makes your life worth living?’, ‘When do you feel you have dignity or lack dignity?’ or ‘To what things, people etc. do you attach value?’. Most nursing home residents were able to reflect extensively on these questions. It was however easier for most of them to give examples of episodes when they felt undignified and what caused this, than the opposite. To ensure that respondents spoke about ‘dignity’ and not about related concepts like ‘quality of life’ or ‘pleasure’, During the interviews, I regularly returned to the concept of dignity by asking ‘how does this (what you just told me) relate to your sense of dignity?’.

Issues of methodological rigour are important when employing qualitative research. We took several measures to guarantee the methodological rigour of our study, by leaning on methodological traditions and following criteria for developing knowledge in qualitative research. The design of our research was a qualitative descriptive one – enabling the researcher to stay close to the data and presenting them in everyday language – with some grounded theory overtones. For example, we used the technique of constant comparison, which is associated with grounded theory, in the ongoing process of data collection and analysis. The interview transcripts were analyzed following the principles of thematic analysis. Other measures that we undertook to enhance methodological rigour were independent coding of several interview transcripts by two researchers, and peer debriefing – discussing the analyses with fellow researchers with different backgrounds.

The fact that we noticed considerable overlap between our themes and the themes in the Model of Dignity in Illness (see Figure 1 on page 30) strengthens the validity of our findings. Also the series of interviews we conducted over the course of time contributed to the study’s internal validity. By following the nursing home residents over a period of 18 months and interviewing them each six months, they could share more of their life world than would have been possible with a single interview. Conducting repeated interviews additionally had the advantages that certain aspects could be deepened if they were insufficiently discussed in a former interview, and that more rapport could be created between the interviewer and respondent, which might have led to less social-desirable answers.

In order to strengthen the study’s external validity, purposive sampling was used to reach maximum variation among the characteristics that could potentially influence dignity, both in selecting the nursing home residents and the different nursing homes. We succeeded to study a heterogeneous population with respect to age, gender and illness. It was however more
difficult to reach variation concerning cultural background, as the nursing home population is predominantly ‘white’. Data saturation was achieved in our study; after analyzing 20 interviews, the evolving code list remained unchanged at each subsequent interview. This means that the number of participants was sufficient to identify all core factors relevant to dignity in the nursing home.

The first interview with each nursing home resident took place a few weeks after his/her admission to the nursing home. By doing this, we could best study changes in personal dignity over the course of nursing home admission. However, we have not consistently gathered information about a resident’s former place of residence. Some residents were admitted straight from home, whereas others had previously resided in the hospital or a rehabilitation unit. Being admitted straight from home presumably generated a larger impact on residents’ dignity as compared to the dignity of people who already had time to adjust to institutional life. Although we could have been more sensitive to this and could have taken this into account in recruiting the residents, we were nevertheless able to thoroughly explore the developmental patterns in dignity during nursing home stay and the factors that contributed to this. This was also the result of a low rate of loss to follow-up: 22 nursing home residents (out of 30) could be interviewed a multiple times.

The interviews with nursing home staff followed shortly after the first interview with a particular nursing home resident. In addition to questions about staff’s views and experiences with dignity in their daily work in general, I asked them about their view on the personal dignity of this particular resident and how they provided dignity-conserving care to him/her. In this way, elderly care physicians and nurses were forced to become more concrete in the answers they gave, which can be seen as a major strength of this study. However, a limitation of our study is that not all physicians were able to reflect elaborately on their view of the resident, because they did not have had the chance yet to spend much time with the resident.

Interviewing nursing home residents and staff entailed some challenges. Finding time to conduct the interviews was sometimes difficult. It was necessary to avoid busy times of the day such as mealtimes or regular visits to hairdressers, physiotherapy or activity groups. I spent a great deal of time waiting for nursing home staff to finish their work or enabling to respond to calls, and for residents to finish their activities. In addition, interviews were often postponed if the resident did not feel well, had an unexpected visitor, or simply did not feel like participating at that moment. Furthermore, talking about undignified situations caused several nursing home residents to become emotional, which required sensitivity of me as an
interviewer, to ensure that the interviews were not too burdensome for the residents. Despite these challenges, my impression was that nursing home residents, and to a lesser extent also staff members, appreciated my visits and being given the opportunity to talk about important parts of their lives. This study allowed an often unheard vulnerable group of nursing home residents to express their views. However, a limitation of this thesis may be the fact that only those nursing home residents who were cognitively able to speak about dignity, and who had the capacity to communicate and provide informed consent were included in the study. Although some participating residents suffered from mild cognitive decline, we do not know whether our results can be generalized to residents with more severe cognitive problems.

Quantitative studies (Chapters 5, 6, 7 and 8)
A quantitative approach was most suitable for the main objective of the second part of this thesis: to develop, test, and apply a measurement instrument for personal dignity. Survey studies were used to gather information on the properties of the MIDAM and MIDAM-LTC, on inter-observer agreement regarding dignity, and on the relationship between MIDAM-LTC items and other variables.

The MIDAM can be regarded as a successor and refinement of the prototype Patient Dignity Inventory (PDI). The reason for developing the MIDAM was the finding that the prototype PDI had some limitations. For example, the prototype PDI asked patients the extent to which they believed that specific issues were or could be related to their sense of dignity, thus questioning a putative association with dignity. Because the developers of the prototype PDI also recognized this to be a shortcoming, they revised their instrument, which since then asked for the extent to which an item was felt to be a problem within the last few days. However, the term ‘problem’ has multiple meanings; it can refer to the presence of an item, to its impact on someone’s life, or a combination of those. In addition, it is not clear whether it relates to the concept of dignity any longer, or more general to distress. Because of this lack of clarity, we consider it important that an instrument distinguishes between the presence of an item and its influence on dignity. After all, in order to exert influence on dignity, a symptom or experience must be present in someone’s life. The distinction between these two questions prevent respondents who do not suffer from a certain symptom or experience to rate its putative association with personal dignity.

We tested and shortened the MIDAM based on the answers of a subgroup of people with a poor health and in possession of one or more advance directives (ADs). It can be argued that the results of this survey study cannot be generalized to the general population, since only a
small part of the Dutch population possesses an AD. Nevertheless, the AD cohort comprised a relevant group for the development and testing of the MIDAM. Because concerns for loss of dignity are an important reason to draw up an AD, many participants in this cohort have probably thought about dignity and end-of-life-issues before and were likely to have more profound views on these issues than the general public. Hence, by selecting a study sample of people with ADs, we actually increased the chance that all relevant aspects influential to dignity were covered. This is important to ensure good content validity, especially in models with causal indicators. Furthermore, by selecting ill and severely impaired people, we tried to create a sample in which personal dignity was most likely to be threatened.

That qualitative and quantitative research methods can complement each other can best be observed in the process of creating the MIDAM-LTC; information from the in-depth interviews was used to add items specific for people living in long-term care institutions to the MIDAM. Because the MIDAM-LTC was then administered face-to-face to each participating resident, we were able to minimize the amount of missing answers. In addition, we could assess whether a nursing home resident was able to understand the questions, and if not, this resident could be excluded from the study. This contributed to a good quality of the data obtained. Furthermore, ten nursing home residents and three family members were asked to fill out the questionnaire while thinking aloud. In this way, we obtained insight in the way the items were understood, and gathered information about the reasons for their low or high influence on dignity. However, a limitation of our study is that data were collected in a relatively small sample of nursing home residents, which may have been insufficient to study some issues adequately, e.g. the associations between cultural background and factors influencing dignity.

We examined the intra-observer variation (between two measurements in 49 nursing home residents) and the inter-observer variation (between nursing home residents and proxies) by calculating agreement percentages. This is contradictory to most other studies that use Intra Class Correlation coefficients (ICCs) and Cohen’s Kappa values. As these latter measures are relative measures of agreement, they are not sufficiently informative when the aim is to examine the probability of other (or the same) raters obtaining the same answer. Besides, ICCs and Kappa values are highly dependent on the heterogeneity of the study sample, because they relate the measurement error to the variability between persons. A high level of agreement can therefore be accompanied by a misleadingly low Kappa value. Therefore, we chose to report an absolute measure of observer variation: agreement percentages. Furthermore, the percent agreement statistic has a strong intuitive appeal, is easy to calculate, and easy to explain.
Because a limitation of the MIDAM-LTC is that it cannot provide relevant information in people with more severe cognitive incapacities, we were interested in the extent to which proxies could be used for this. The response rate among elderly care physicians and nurses was very high (respectively 100% and 99%), and good among family members (62%). It is however debatable whether all residents were sufficiently known by the physician, since 10% of residents were not seen by the physicians within the last month. This might have reduced the extent to which their answers corresponded with those of nursing home residents. In addition, the time lapse between the resident and proxies filling out the MIDAM-LTC might have caused us to find less agreement than exists in reality, although the majority of proxies returned the questionnaire within two weeks. We are therefore a little uncertain about the exact magnitude of the agreement, but the general patterns and the differences among the different proxies observed in the study are nevertheless informative.

**Main findings and interpretation of the results**

Although this thesis consists of two parts, each with a different focus and methodology, the main findings of both parts will be combined and discussed as a whole. In this way, we can better describe how findings obtained via either qualitative or quantitative approaches complement each other. The majority of the main findings will be discussed by organizing them according to the framework of the Model of Dignity in Illness\(^9\) (see Figure 1 on page 30). This model has been proven to be applicable to the nursing home setting, and has also been used to describe the results of the studies in Chapter 2 and 3.

**The diverse nature of factors influencing dignity**

Many different aspects undermining or preserving personal dignity emerged from the interviews with nursing home residents and staff, as well as from the survey studies. These aspects showed considerable overlap with those in the Model of Dignity in Illness, in spite of the fact that this model was created based on interviews with patients who lived at home. The weight given to certain aspects and domains influential to dignity however differed between nursing home residents and patients living at home.

In line with the above-mentioned model, we found that illness symptoms or the admission to a nursing home did not directly lead to an undermined sense of dignity (Chapter 2). Nursing home residents explained they could dissociate their symptoms and situation from violating their dignity, because they considered neither themselves nor anyone else responsible for this to have happened to them. What could however cause a decline in personal dignity were the consequences of the illness symptoms and nursing home admission, by threatening aspects
of a resident’s individual self as well as aspects of a resident’s social world. Dignity appeared to be strongly influenced by a psychosocial, spiritual and relational dimension, implying that focusing merely on symptom management and medical care is insufficient to preserve nursing home residents’ dignity. We will elaborate on these dimensions in the next paragraphs.

The individual self
With regard to the individual experience of a nursing home resident, a low level of autonomy, a sense of meaninglessness, a change in identity and not being able to accept the situation were reported as most important factors undermining personal dignity (Chapter 2). A low level of autonomy has frequently been reported as a factor undermining dignity. Moreover, it is not only dignity that can be undermined by a low level of autonomy; Rodin (1986) described detrimental effects on the total health of older people when their control of their activities was restricted. Reversely, interventions that enhanced options for control by nursing home patients were found to promote health. Even the illusion of perceived control has been found to be health-promoting. As sense of autonomy thus relates strongly to health in general, it is not surprising that upholding an individual’s autonomy is universally regarded as an important aspect of dignity-conserving care.

Also in our longitudinal interview study, we found that having a sense of control over one’s life was an important mechanism by which people could maintain or regain their dignity after nursing home admission (Chapter 3). The acquirement of a feeling of control could be supported by adequate coping strategies, getting acquainted with the new living structures in the nursing home and therefore feeling more at ease, and by physical improvement or more freedom of movement (Chapter 3). Many different coping strategies were reported that could protect dignity from being violated, such as acceptance, resilience, living in the moment, focusing on joyful things, comparing yourself with others who have a worse health status, ascribing symptoms as belonging to the ageing process, standing up for yourself, being indifferent for comments of others and having religious beliefs (Chapter 2). Coping strategies that concern the reinterpretation of life and the reorientation of goals and achievements (such as acceptance, resilience, focusing on what is still possible and using self-enhancing comparisons) have been termed ‘accommodation’. Accommodation is a strategy of inner adjustment, which involves the acknowledgement that one has changed with regard to abilities, social roles and psychological or emotional state, and requires the ability to reinvent oneself again. Most nursing home residents in our longitudinal interview study seemed capable to use this accommodative strategy, and consequently regained dignity over the course of time. Some residents were however not able to accommodate; we for example noticed that
nursing home residents who strongly emphasized being independent as a requirement to feel dignified had more difficulties to adjust to their new realities (Chapter 3). Also having a non-optimistic attitude to life might hinder the ability to use the strategy of accommodation; our quantitative study showed that people with a non-optimistic life attitude were more likely to report a higher number of factors causing dignity-related distress compared to people with an optimistic life attitude (Chapter 8). These findings confirm the theory of Brandtstadter & Greve (1994); accommodation leads to successful ageing and growing old with dignity.22

Our interviews with nursing home staff revealed that views of nurses and physicians are consistent with this theory. When physicians and nurses were asked to reflect on a resident’s dignity, they often took the resident’s character, attitude to life, cognitive abilities, resilience and appearance into account (Chapter 4). In assessing whether or not a nursing home resident felt dignified, they considered the resident’s ability to keep his/her individuality and identity as most deciding factor. If a resident had lost his/her individuality and suffered from the ‘hospitalization syndrome’ (i.e. becoming bound up in the daily rhythm of the nursing home in such a way that someone forgets to think him/herself) staff evaluated this as undignified. In line with this, they believed that caring with dignity was more or less similar to conserving a resident’s individuality and autonomy (Chapter 4). Finding out who the patients are as persons, what is important to them, and what they value has also elsewhere been reported to be fundamental for dignity-conserving care.23,24

Nevertheless, our findings showed that tailoring dignity-conserving care to an individual appears hard to bring about in daily practice. When nursing home staff members were asked what they could do to preserve a particular resident’s dignity, they often brought up more general aspects which could apply to most of the nursing home residents, i.e. showing respect and safeguarding privacy (Chapter 4). An explanation for staff’s difficulty to be patient-specific might be found in the limited resources available in nursing homes. Given the staff shortages and limited time available for each resident, physicians and nurses possibly focus on dignity-conserving aspects they are capable of providing, while trying to survive the busyness of their working day. Also, an adopted task-oriented approach in which one is required to adhere to professional standards emphasizing the quality of the basic ADL care might contribute to this general focus of nursing home staff members.25 In agreement with other research, we believe that nursing homes could benefit from a shift from a task-focused staff-directed model of care to a model that provides and supports individualized resident-directed care, with the intent to support self-determination, dignity and choice for nursing home residents facilitated by the continuation of their routines and preferences.26
The relational self
Next to factors in the domain ‘the individual self’, illness could influence personal dignity by threatening aspects of one’s ‘relational self’, which refers to dignity as formed within dynamic and reciprocal interactions. With regard to nursing home care, dignity could be undermined by needing assistance with personal intimate care, having to wait for help, being patronized by nurses, not being treated with respect, receiving little attention, feeling a burden to the busy nurses and a general atmosphere of hastiness (Chapter 2). Whereas waiting for help was an important aspect undermining dignity in the first interview – because residents felt neglected or could not make it to the toilet in time – it became less important later on as residents gained more understanding that they were not the only one who needed help (Chapter 3). In addition, the way in which staff responded to such potentially embarrassing situations could lessen its detrimental effect on nursing home residents’ dignity. For example, if nurses reacted very naturally as if being incontinent was very normal, this helped nursing home residents to maintain their dignity (Chapter 3). Nevertheless, waiting for help remained a frequently mentioned aspect when asked what could improve in the nursing home as to enhance their dignity. Also according to staff, violation of dignity within the nursing home was most present when residents had to wait for help when they urgently needed to go to the toilet, and, when too late, needed help with changing clothes (Chapter 4). From our quantitative study, we know that ‘waiting a long time for help’ particularly impinged on the dignity of the most heavily dependent nursing home residents (Chapter 8). This association is not surprising as one can imagine that ‘waiting a long time for help’ has the greatest impact on the lives of the heaviest dependent residents, who cannot do anything else while waiting for the nurse or solve things in another way.

Receiving little attention and a general atmosphere of hastiness is a major problem in Dutch nursing homes. The Netherlands Institute for Social Research reported that 44% of nursing home residents feel that staff members do not have enough time to discuss important issues and 41% of nursing home residents feel that carers rush off to the next task. This can leave nursing home resident feeling treated inattentively and merely an object of care (Chapter 2). Several nurses indicated that hurriedness and working routinely were necessary to survive the busyness (Chapter 4). However, rushing off might even not be efficient in terms of time profits. There is a greater risk that nurses forget something or that a nursing home resident presses the alarm, and that the nurse must return to the resident’s room (Chapter 4).

An important finding in this thesis was that while certain aspects of nursing home care could undermine a resident’s personal dignity, good professional care had the potential to preserve
or promote it as well. From the perspective of nursing home residents, good professional care included being treated with respect and attention, being listened to, being taken seriously and receiving help when needed (Chapter 2). According to staff, good professional care entailed treating residents with respect – including listening to the resident’s wishes and caring with attention – and safeguarding residents’ privacy (Chapter 4). Noteworthy is the different weight given by residents and staff to the theme of privacy. Aspects related to privacy were less prominent in the interviews with residents than in those with staff. This could be the result of nursing staff already doing a good job in taking care of someone’s privacy. It might also reflect the different lifeworld of nursing home residents and staff. People’s preferences regarding – especially environmental – privacy may actually change because of getting ill or ageing; we for example noticed that some residents who shared a room with others mentioned this to heighten their feelings of safety and comfort, especially at night (Chapter 2). In recent years however, the preference when building new nursing homes has been for single room with en-suite bathroom facilities – reflecting the cultural ideas on life and autonomy. Accordingly, the proportion of Dutch nursing home residents living in a single room has increased significantly from 21% in 2000 to 55% in 2008.²⁹

Unlike privacy, residents emphasized much more than nursing home staff the importance of receiving social support from relatives and society – and not feeling a burden or stigmatized – as influential to their dignity (Chapter 2). These findings are rather similar to the results of a study of Baillie (2009) who noticed that for patients in a hospital setting dignity was enhanced by having contact with fellow patients suffering the same fate, and by having a good relationship with the staff, whereas staff members were largely unaware of the beneficial effects of these relational factors, and were more focused on privacy matters.³⁰ Being able to participate in the life of close ones and receiving visitors gave nursing home residents a sense of belonging to others; a finding that is supported by a study of Dwyer et al. (2008) that described how a sense of belonging created meaning in everyday nursing home life.³¹ However, the protective effect of receiving social support was absent for many nursing home residents. Their social network had shrunk thoroughly because of multiple losses in their families and circle of friends. Several residents reported that the longer they resided in the nursing home, the less frequent they received visitors (Chapter 3). That feelings of loss and lack of social networks can make nursing home residents vulnerable to lose personal dignity has also been described by other authors.³²,³³

Some positive developments were also observed in our longitudinal qualitative study: although residents initially reported that making new contacts within the nursing home...
barely happened, or reported that they felt no need to make new contacts, residing longer in a nursing home could nonetheless contribute to the number of acquired new contacts with other nursing home residents. These contacts were often made during organized activities. Also, residing longer in the nursing home contributed to residents getting familiar with the nursing home staff, and made residents feel more confident to display their wishes. In this way, being socially involved with staff and other residents could support people to feel worthwhile, which was found to be an important mechanism for residents to maintain or regain their dignity (Chapter 3). Our findings are supported by a review of qualitative studies on ‘living well in care homes’ that describes how close relationships with others were integral for good care home life. Whereas connectedness and involvement with peer residents could contribute to friendships, belonging and reassurance of being important to others, the lack of this could impinge on privacy, loneliness, boredom, autonomy and self-identity, and could be seen as a reflection of how ‘far residents had fallen’.34

The societal self
Aspects within the last domain – the societal self, referring to the individual as a social object seen through the eyes of the generalized other through which the societal discourse on illness and age may be manifested – could also influence personal dignity. An important finding in this thesis was that nursing home residents, shortly after admission, felt discarded by society and no longer part of it. Some felt useless and said they only burdened society economically. Above that, in getting older and less able to function, they felt stigmatized by society, e.g. when other people treated them as if they were demented or insane. They felt not taken seriously anymore or undervalued simply because of their illness or age (Chapter 2). Over the course of time, these aspects were less frequently mentioned as threatening dignity (Chapter 3). One possible explanation for this is that being amongst disabled others caused residents to feel less deviant from others in what had become their ‘new’ small society.

The importance of this new small society has been recognized by other authors. For example, Philipsen and Stevens (1997) stated that long-term care facilities need to formulate their own lifeworld in order to support and fully engage the patients within their care.35 The separation of nursing home residents from society allows this construction of a different type of lifeworld to take place. However, when analyzing residents’ answers on the MIDAM-LTC, we found that the protective mechanism of ‘being amongst disabled others’ probably applies less to male nursing home residents than to female residents; men were more likely than women to report more items having dignity implications (Chapter 8). This observed gender difference contrasts with findings from other studies performed in different settings than the nursing
These other studies found that women mentioned more psychological and social issues as challenging aspects of living with a disease, and therefore had more difficulties than men to keep their dignity or quality of life intact. As described earlier, the nursing home as a lifeworld can apparently provide some social support and psychological relief, especially to female residents. That men benefit less from this protective mechanism of ‘being amongst disabled others’ might be explained by the fact that they are a minority in nursing homes. As a consequence, men may experience their admission to a nursing home, dependency on (female) nurses and technical aids, and loss of their status in society more as a failure than women.

A second explanation for the finding that aspects in the domain of ‘the societal self’ were less frequently mentioned over the course of time is that living in a nursing home protects residents against exposures to disrespect and societal discourses on ageism in the outer world. Negative attitudes on ageism are widespread in society. Our modern society, where esteem and dignity are closely related to one’s role and function in society, might contribute to the initial feelings nursing home residents had about playing a ‘role-less role’ and having become redundant and even a burden to society. This does not only apply to Dutch nursing home residents; a Swedish study found that life in a nursing home meant feeling like a stranger in an unfamiliar culture/environment, being excluded from ordinary life and living while awaiting death. This exclusion from ordinary life is also reflected in nursing home residents often being excluded from research. Nowadays, more voices are raised against these negative attitudes on ageism. According to some, there is a type of dignity peculiar to the elderly; the elderly have a dignity of wisdom and a highly general dignity of merit, which results from their lifelong efforts and achievements, and for which they deserve our gratitude.

It is not only the residents who may feel marginalized, also the institutions ‘nursing homes’ have a negative image in society. This is because they are associated with terrible diseases, physical and cognitive decline and dependency. Although the population is ageing, there is shortage of people who apply for a training to become an elderly care physician, and shortage of nurses who want to work in a nursing home. Instead, pediatrics is one of the most favorite specialisms among Dutch medicine students; whereas elderly care medicine is at the bottom of their preference list. Jobs in elderly care are undervalued in society; nursing home staff members are not regarded as heroes in success stories in which patients are spectacularly healed. It is less accepted to acknowledge that life is finite and that medicine has its limits. These negative discourses reflect on the people who do work in a nursing home; they have to deal with conflicting values and barriers related to the nursing home context (Chapter 4).
Staffing shortages, lots of paperwork, and a lack of time and attention that they can spend on residents cause many staff members to feel that they would like to provide more in the care of older people than they are able to deliver.

**Assessment of factors influencing dignity**

During the process of developing, adapting and applying the MIDAM and MIDAM-LTC, we have gained insight in the prevalence of factors influencing dignity. Because personal dignity is influenced by causal indicators, it was important to have many possible influencing factors listed in the instrument. After all, the presence of only one factor can already have implications for someone’s sense of dignity. On the other hand, the instrument had to be feasible to use in practice. A balance between comprehensiveness and feasibility was therefore required. We were able to shorten the MIDAM from 31 to 26 factors (Chapter 5) and the MIDAM-LTC from 39 to 31 factors (Chapter 6). This relatively small reduction in the number of items listed shows the variety in aspects that patients ascribe to their dignity, which was also reported by Chochinov et al. (2002).

Looking only at the presence of items, the most prevalent factors were found in the domain ‘Functional status’ in both the general patient population and nursing home residents (Chapter 5 and 6). The high rates found for items in this domain were not surprising given the selection criteria we applied to obtain both study samples (i.e. having an illness and being severely impaired for the general patient population, and living on a unit for people with physical illnesses for nursing home residents). However, the influence on dignity of items in the domain ‘Functional status’ was generally small, especially in the general patient population (Chapter 5). Only ‘incontinence’ was ranked a top-10 score in both members of the NVVE and NPV. In the group of nursing home residents (Chapter 6), ‘not able to carry out usual activities’ and ‘impaired sight despite using aids’ were the items in the domain ‘Functional status’ that were ranked within the top-10 of items undermining dignity. Most of the 13 added items specific for long-term care facilities were frequently present in the nursing home population. However, their mean influence on sense of dignity was also generally rather small. In both Chapter 5 and 6, the highest mean scores for influence for dignity could instead be found in the domain ‘Evaluation of self in relation to others’. For nursing home residents, ‘feeling worthless for friends and family’ and ‘not looking well groomed’ were the items within this domain with the highest mean scores for influence on dignity (Chapter 6).

These findings confirm the results of our qualitative study. As explained above, we found that nursing home residents could dissociate their physical symptoms and nursing home admission
from violating their dignity (Chapter 2). In the qualitative study as well as the quantitative study, it were rather the consequences of the illness and nursing home admission on the psychosocial, spiritual and relational dimension that appeared to strongly influence dignity than the illness symptoms itself. This observation is what sets dignity as a construct apart from the concept of ‘quality of life’ which is more directly determined by the symptoms of illness. Quality of life is defined as a subjective integration of all aspects of one’s life deemed relevant, or more simply by a person’s degree of happiness. Whereas overall quality of life exceeds health-related quality of life, which in turn is more than health status only, dignity goes beyond quality of life because it also brings one’s perception of being worth of respect from themselves and from others along. As such, personal dignity stresses more importance on the evaluation of oneself in close relation to others than the concept ‘quality of life’ does. Nevertheless, dignity and quality of life are overlapping and related constructs and the relation between both concepts is not entirely clear. According to Nordenfelt (2009), quality of life may be both a cause and an effect of (sense of) dignity. Although the interrelatedness between both concepts was not specifically studied, we feel that their relation is somewhat different; while a low level of quality of life can be accompanied by a high level of personal dignity, the other way around (a high level of quality of life being accompanied by a low level of personal dignity) will rarely occur.

Following from this, personal dignity might be a more stable construct than quality of life, but more research has to be done to confirm this. In Chapter 6 we described that an adequate intra-observer agreement on the MIDAM-LTC was attributable to more than 83% of the residents who gave a practically consistent score for each item’s influence on dignity over a week, and to more than 80% of the residents who did this for the single item score for overall personal dignity. These high percentages indeed imply that personal dignity is a quite stable construct over a period of one week. However, as described earlier, we noticed that personal dignity could be subject to change in the long run (Chapter 3).

Investigation of the associations between nursing home residents’ characteristics and factors influencing dignity (Chapter 8) shed light on the differences in prevalence of these factors within different groups. In earlier paragraphs, we already reflected on the findings that non-optimistic, male and heavily dependent nursing home residents were more likely than optimistic, female and less dependent residents to have their dignity undermined. Chapter 5 also gives insight in the differences between two groups with regard to factors influencing dignity: members of the NVVE (Right to die-NL), for most of whom religion does not play an important role in their lives, and members of the NPV (Dutch Patient Association), for most of whom Christianity
does play an important role in their lives. Members of the NVVE reported all but one item (out of 31 items) to exert more influence on their dignity than members of the NPV reported. We did however not examine whether these differences were significant since the purpose of the study was to develop the MIDAM and not to investigate the association between religion and dignity. Nevertheless, in Chapter 8 we described that having a religion protected nursing home residents from having their dignity undermined by ‘feeling depressed’ and ‘difficulties with adjusting to the nursing home’. This might be attributed to religious people finding solace within their faith, by accepting that their own influence on the situation is small, or believing that they will have dignity anyway (Chapter 2).38,46,50

The nursing home as an environment of multiple forms of dignity
Nursing homes may be regarded as melting pots of multiple forms of dignity. Not only nursing home residents have to keep a good level of personal dignity, also nursing home staff members and family members have their own dignity which they bring along to the situation.

In our interview study among nursing home staff, several nurses and physicians reported that they intended to give care according to the concept ‘treat others as one would like others to treat oneself’ (Chapter 4). Although this so-called ‘Golden Rule thinking’ seems to be a promising strategy for providing dignity-conserving care, a review of Kothari and Kirschner (2006) showed that it actually results in inaccurate predictions of patients’ wishes or beliefs, because of differences in demographic characteristics between nursing home staff and residents (e.g. age, cultural background), but also because of the existence of significant limits on people’s ability to accurately imagine unfamiliar situations.51

That ‘Golden Rule thinking’ plays a role in proxies’ views on dignity in the nursing home can also be discerned from the results in the study described in Chapter 7. This study revealed that nursing home staff’s and family members’ ability to accurately assess a resident’s subjective dignity is limited. Agreement percentages on the MIDAM-LTC were moderate, and patterns of deviation were found and described (Chapter 7). The answers on the open-ended question offered a clue as to what may lie at the root of the moderate agreement percentages. We asked physicians, nurses and family members whether or not they would fill out the MIDAM-LTC the same way if it were themselves in the situation of the nursing home resident, and if not, which items would influence their personal dignity differently. The answers revealed that many proxies thought that their dignity would be comprised to a larger extent under similar circumstances than they thought that the nursing home residents’ dignity was. This was reflected in the significantly lower rate all proxies gave to the single item score for dignity as
compared to the residents, and also in the result that proxies tended to think that residents’
dignity was violated to a larger extent than nursing home residents indicated themselves (once
proxies recognized that an item was present in the resident’s life) (Chapter 7).

In addition to generating inaccurate predictions, ‘Golden Rule thinking’ may hamper the
individualized aspect of giving dignity-conserving care, as staff members project their own
norms and views regarding ‘dignified treatment’ on all nursing home residents. Being
conscious of one’s own views, the point of departure from which nursing home staff members
give care, is therefore important.28 ‘Treating others as one would like to be treated oneself’
does not necessarily lead to a discrepancy in values and preferences between a staff member
and a particular resident. But when it does; this could undermine a resident’s sense of dignity.
Therefore, it is vital to regularly ask a resident for his/her wishes instead of assuming what
they are. When a resident cannot indicate his/her wishes anymore, a variation on the Golden
Rule may be needed in order to overcome differences in demographic characteristics: ‘Treat
others as your father or mother would like to be treated’.

This directive may however not be easy to implement in practice. In daily practice, nurses
have to shift between efficiency, organizational rules and routines, and on the other hand
dedicated care, humane treatment, involvement and concern for the well-being of residents.52
As a result of these conflicting values and the scarcity of caring personnel, we found that
nursing home staff members experienced undignified situations in the nursing home. They
frequently mentioned that they would like to provide more in the care of older people than
they were able to deliver (Chapter 4). How staff handled their frustration and moral stress was
not specifically studied in this thesis. Boeije (1997) described various strategies that nurses
working in a nursing home used to cope with the problems they encountered. Three of them –
‘consultation on care priorities’, ‘acceptance of residents’ impairments’ and ‘normalization of
daily life’ – were recommended to use, as they offer the best prospects for providing personal
care to residents.52

Furthermore, we found that nursing home staff could encounter conflicting values in situations
in which they had to choose between respecting a resident’s autonomy and the dangers of
self-neglect, or between respecting a resident’s autonomy and distress or offence caused to
others (Chapter 4). In these situations, staff members often tried to come to a compromise; to
create a situation that was dignified for the resident and compatible to their own professional
attitude. However, there were also situations in which the moral conflicts nursing home staff
experienced while working in the nursing home could hamper their own dignity (Chapter
4). A concept analysis of dignity by Jacelon et al. (2004) concludes that dignity is reciprocal; when one behaves with dignity, others respond in like manner. This implies that a dignified nurse will demonstrate behaviour that shows respect for self, patients and co-workers, while patients who treat others with respect and are grateful, receive better care. Thus, a nursing home staff member also needs to feel valued in order to be able to care with dignity. Also Gallagher (2004) describes how an inextricable link exists between how a caregiver respects the dignity of others (other-regarding dignity) and how he/she respects his/her own personal and professional dignity (self-regarding dignity). Because of this link, it seems important to optimize the working conditions for nursing home staff in order to enhance the extent to which they feel dignified themselves while working in the nursing home. This will ultimately benefit the nursing home residents they take care of.

Recommendations for policy and practice
The findings of the studies described in this thesis lead to several recommendations for policy and practice. Because personal dignity is determined by the interplay of different factors, not only the nursing home residents themselves but also nursing home staff and family members must take their role in its maintenance. Although the longitudinal qualitative study showed that many nursing home residents were able to regain their dignity over the course of time, this does by no means imply that one can just wait for a resident to adjust to the new situation. Good professional care requires nursing home staff and family to take an active part in helping residents with this process.

To preserve nursing home residents’ personal dignity, it seems important to optimize the aspects in the three different domains of the Model of Dignity in Illness – individual, relational and societal self – and to enhance factors that protect dignity from being violated (see Figure 1 on page 30). Dignity-conserving care must be aimed at enhancing a resident’s feeling of being in control over one’s life and enhancing the feeling of being regarded as a worthwhile person. This thesis has given insight into ways nursing home staff can facilitate and create optimal conditions to help a nursing home resident recover these feelings. For example, a psychologist, social worker or spiritual caregiver could help a nursing home resident to use the strategy of accommodation in order to obtain a new perspective on life in which a resident is able to focus on the joyful things. This seems particularly helpful for nursing home residents who are male, non-optimistic and/or heavily dependent as we found these characteristics to predispose residents to lose personal dignity. Secondly, we believe it is important to explain the structures, habits and activities that the nursing home offers soon after admission. This might accelerate the process of settling down and, hence, enhances feelings of mastering
the situation. Furthermore, nursing home staff should support residents to have as much autonomy as possible, e.g. by listening seriously to a resident’s wishes, giving the resident the opportunity to choose between meals or different sets of clothes, and providing him/her an electric wheelchair or physiotherapy. Additionally, nursing home residents should be supported to be socially involved with others. A resident’s social network might for instance be enhanced by encouraging contacts between residents, e.g. by placing residents together with compatible mental abilities or by offering a diverse range of activities where residents can meet each other. Also family members should be encouraged to visit the nursing home resident not only after recent admission, but also after a longer period of time. They could be more actively involved in the caring process, for example by making use of family members’ capacities and qualities during mealtimes or activities or by providing them with a newsletter. Finally, it seems important to positively influence societal discourses on elderly people in nursing homes. More attention should therefore be given to positive news from nursing homes as a counterweight to the often negative stories heard in the media.

Increasing the capacity of nursing home staff seems important with regard to the care that will become more and more complex in the near future. Ideally both the numbers and quality of nursing home staff should be increased to avoid residents having to wait for help and suffering from a dearth of attention. But also a more efficient task prioritization and organization, in combination with a decrease in amount of paperwork and a culture in which conflicting values can be discussed could also contribute to an environment in which both the nursing home resident and nursing home staff member experience a good level of dignity.

With regard to the attitude of nursing home staff, it is important for them to realize that the way they treat residents can have an impact on residents’ dignity, either hampering or preserving it. To enhance nursing home residents’ personal dignity, a focus on the background and preferences of the individual resident is required. As we found that the Golden Rule ‘Treat others as one would like to be treated oneself’ entails the risk of giving general dignity-conserving care that is barely tailored to individuals, it seems important that nursing home staff members become more aware of their own norms and values, and that they realize that residents might not always want to be treated the way staff members would like to be treated themselves. If a resident is able to communicate, ‘Treat others as they would like to be treated’ must be the departure point from which care is given.

More training can help nursing staff to acquire skills that equip them to give good professional care. But also a measurement instrument can assist caregivers in providing dignity-conserving
care, by identifying the factors that undermine a patient's personal dignity. The MIDAM-LTC can be used as an inventory of possible factors influencing dignity from which conversations with the nursing home resident can take place repeatedly throughout the admission period. Although we found a good level of intra-observer agreement over a period of one week – indicating that personal dignity was constant within this time period – we observed that sense of dignity could change over a longer period of time. This emphasizes the importance of assessing residents in relation to their dignity needs at various points in their nursing home stay and matching these needs with appropriate nursing activities. This is also relevant as we observed that proxies' ability to accurately assess a nursing home resident's personal dignity is limited. By using the MIDAM-LTC repeatedly throughout the resident's admission period, the extent to which answers of residents and proxies correspond will probably rise over the course of time, which will be particularly relevant in case a resident becomes cognitively impaired and cannot speak for him/herself anymore.

**Recommendations for future research**

In both the qualitative and quantitative studies, we were not able to sufficiently examine the association between cultural background and personal dignity. As an increasing number of people with a non-Dutch cultural background will need care in the future, this association is worth investigating. In addition, as the population ages, more and more people will suffer from dementia in the future. Research on dignity in this patient population is difficult and challenging, but some pioneer researchers have entered this area and created some insight in the personal experiences of mild to moderate dementia patients by conducting interviews and participant observations.55-57 Further research is however needed to contribute to a deeper understanding of the (care) needs of patients with dementia, and of how to assist them in their need to remain a dignified human being. Thirdly, it would be interesting to further explore the additional information that is gathered by measuring dignity in addition to quality of life, considering that dignity and quality of life have some overlapping domains. More research with regard to patients' and caregivers' understanding of the differences and similarities between the concepts ‘personal dignity’ and ‘quality of life’ is therefore needed.

With regard to the MIDAM-LTC, we recommend the instrument to be tested in a larger group of nursing home residents, and also in patient groups residing in other long-term care facilities than the nursing home, in order to establish its psychometric properties. The instrument could further be tested on its user-friendliness and utility when used in practice. Also the potential for the MIDAM-LTC to be integrated into standard nursing home care practice needs to be explored. It would be interesting to examine how nurses and physicians would apply the
MIDAM-LTC in instances they would deem appropriate, to determine if nurses and physicians would be able to utilize the MIDAM-LTC to identify various sources of dignity-related distress, and to explore how the MIDAM-LTC would be able to guide or shape nurses and physicians’ work within long-term care facilities. Further research could also guide follow-up procedures once the MIDAM-LTC has been administered to a nursing home resident and factors undermining dignity have been identified. Reflective questions – that can be used to learn more about the identified issues, patient’s ideas and preferences on how to deal with them – and suggested care actions per item of the MIDAM-LTC could for example be formulated and evaluated. Last, to provide the long-term care setting with a feasible instrument, we only focused on factors that undermine dignity. An instrument measuring both undermining and preservative factors would require a different structure, and would possibly become too complex to be understood by respondents. Therefore, a separate instrument focusing on factors that preserve personal dignity in long-term care settings could be developed and tested.

**Final remarks**
It may not be easy to operationalize these recommendations. Operationalizing dignity requires investment and professional will to reward dignity-promoting practice and to respond speedily to those practices and behaviors that diminish dignity. Although dignity has been identified as a complex phenomenon and there are still gaps in our understanding of dignity, promoting it in the everyday practice of nursing homes is neither mysterious nor unachievable. An increased sensitivity towards factors undermining dignity is an important step towards more effective dignity-conserving care which will benefit people living in long-term care institutions.
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