Chapter 2

Dignity and the factors that influence it according to nursing home residents: a qualitative interview study

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Abstract

**Aim:** To gain insight in the way nursing home residents experience personal dignity and the factors that preserve or undermine it.

**Background:** Nursing home residents are exposed to diverse factors which may be associated with the loss of personal dignity. To help them maintaining their dignity, it is important to investigate this concept from the residents’ perspective.

**Design:** A qualitative descriptive study.

**Methods:** In-depth interviews were conducted between May 2010 and June 2011 with 30 recently admitted residents of the general medical wards of four nursing homes in the Netherlands.

**Results:** Illness-related conditions were the starting point of a process which could affect personal dignity, by threatening aspects of one’s individual self and social world. Living in a nursing home was not a reason in itself to feel less self-worth, but rather seen as a consequence of functional incapacity. Nevertheless, many residents felt discarded by society and not taken seriously, simply because of their age or illness. Waiting for help, being dictated to by nurses and not receiving enough attention could undermine personal dignity, whereas aspects of good professional care (e.g. being treated with respect), a supportive social network and adequate coping capacities could protect it.

**Conclusions:** Contrary to the general view in society that living in a nursing home always undermines one’s dignity, good professional care and a supportive social network can preserve dignity as well. To support residents in their challenge of maintaining dignity, nursing home staff, relatives and society should pay more attention to the way they treat them.
Dignity and the factors that influence it according to nursing home residents

Introduction

With the increasing life expectancy in Western society, nursing homes have become an important place where people live out their lives. As a consequence, preserving dignity has become an important aim and central principle of the care given in this setting. Dignity consists of an internal aspect, which is one’s personal, subjective valuing of oneself, and an external aspect, which is the valuing of oneself by others. A fractured sense of dignity has been found to be associated with depression, hopelessness, and a desire for death. In contrast, the maintenance of dignity was found to be a significant predictor for satisfaction with nursing home staff and overall nursing home satisfaction in a study measuring the quality of life among nursing home residents in the United States.

Background

To facilitate care that promotes dignity, it is essential to gain insight into the factors that maintain or undermine it. Until recently, research on dignity has predominantly focused on the very last stage of life. For example, Chochinov et al. developed an empirical model of dignity based on interviews with terminally ill cancer patients. Our research group investigated the concept of dignity in a wider patient population, that is, patients with a variety of illnesses who still lived at home. It was found that illness could affect personal dignity via one or more of three intermediary domains of one’s self – the individual, relational and/or societal self – and that an individual’s coping capacities, a supportive social network and good professional care could protect against threats to personal dignity arising from different illnesses. The ‘Model of Dignity in Illness’ was developed, which is depicted and further explained in Figure 1.

Nursing home residents not only face threats to dignity arising from having one or more illnesses but are also confronted with a new and unfamiliar living environment and are often heavily reliant on staff. Thus, they are exposed to diverse risk factors, making them vulnerable to loss of personal dignity. Furthermore, the scarcity of resources (both financial and human) in nursing homes might also pose a threat to the maintenance of nursing home residents’ dignity. To protect this vulnerable group from losing personal dignity, it is important to understand the concept of dignity from the residents’ perspective.

Views of nursing home residents on dignity have already been explored in some studies, using various approaches (inductive or deductive), in different countries (Sweden, Germany and UK). These studies reported various themes and associations between themes. However, although the results in the above-mentioned studies do not necessarily conflict with each
This model illuminates how illness affects the personal dignity of patients. According to this two-step model, illness-related conditions do not affect patients’ dignity directly, but indirectly by affecting the way patients perceive themselves via three components shaping self-perception: (a) the individual self, (b) the relational self, and (c) the societal self.

(a) The domain of the individual self refers to the individual’s internal, private evaluation of himself as an individual and autonomous human being based on his personal experiences and his perception of his worth as an individual. Negative ways in which illness can affect the individual self is by threatening the patient’s sense of identity, meaning, autonomy and awareness. Dignity can be maintained or enhanced by adequate personal coping skills, e.g. the patient’s acceptance of diminished capabilities.

(b) The relational self refers to the individual’s sense of dignity as formed within dynamic and reciprocal interactions. Illness can threaten this through the inability to fulfil social roles, being dependent, feeling like a burden, and – in care relationships – loss of privacy, feelings of powerless and not being taken seriously. Being connected to others, being able to contribute to relationships rather than being a burden, and being cared for respectfully and sensitively can on the other hand prevent dignity from being violated.

(c) The domain of the societal self refers to the individual as a social object, seen through the eyes of the generalized other through which the societal discourse on illness and patients may be manifested. Being stigmatized, stared at, disbelieved and disrespected can be negative consequences of illness, whereas receiving respect and recognition as a worthy and competent member of society rather than being seen as a patient can help the patient to maintain personal dignity.
other, they might not be generalizable to other countries where the nursing home system is different. For example, the care for older people in the Netherlands is organized in a different way from such care in other countries, as it is provided in two co-existing kinds of accommodation. 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. As a consequence, Dutch nursing home residents may generally be more severely impaired than residents in other countries. As such, they form an interesting population in which to study personal dignity.

The study

Aim
The aim of this study was to answer the following research question: How do Dutch nursing home residents experience personal dignity and, according to them, which factors preserve or undermine dignity?

Design
To explore and describe these experiences and factors influencing dignity in everyday terms, a qualitative descriptive methodology was used, including in-depth interviews and thematic analysis.

Participants
Nursing home residents were recruited from four nursing homes in the Netherlands, with help from a physician, nurse or unit manager. To obtain variation in the degree of potential factors influencing dignity, these nursing homes were selected because they varied in location (3 urban, 1 rural) and privacy conditions (3 with private rooms, 1 with shared rooms). Above that, the sampling of participants was aimed at maximizing the range of residents’ characteristics (gender, age, cultural background, religion and type of illness). Eligible residents were those who were recently admitted to a long-stay unit for residents with physical illnesses, and able to understand the study, give informed consent and speak comprehensibly in Dutch. Residents with severe dementia were excluded from the study because of the complex subject matter of the interviews. We also excluded residents on rehabilitation wards, whose length of stay is often short.
During the inclusion period, 53 residents were approached to participate in this study. Seventeen declined, citing they felt physically or mentally unable to participate or had plans to move to another nursing home in the near future. One resident died soon after she received the invitation letter and a further five residents were excluded by the time of the interview, due to severe problems with hearing or speech, being sedated for palliative reasons or because they returned home. This resulted in 30 participating residents (characteristics shown in Table 1), who were interviewed within a few weeks after their admission. Seven of them lived in nursing home A, eleven in B, four in C and eight in nursing home D. The respondents ranged in age between 49 to 102 years and often suffered from multi-morbidity and deterioration of bodily functions because of old age (e.g. impaired hearing/sight). Most residents had a Dutch cultural background, whereas three respondents were born in Surinam, one in Indonesia and one in Poland.

**Data collection**

Interviews were conducted between May 2010 - June 2011 and lasted approximately 45-60 minutes. A topic-list was used as a guide in the interviews, containing questions such as ‘What factors are important for your sense of dignity?’ and ‘How does living in a nursing home affect your personal dignity?’. Questions were not asked in an established order, but followed up on the answers residents provided. The interviews were recorded and transcribed verbatim. The interviewer (MGOV) kept field notes, describing her reflections on the interviews and the study.

**Ethical considerations**

The study protocol was approved by the Medical Ethics Committee of the VU University Medical Center. Also, the Management Teams and Clients’ Councils in the nursing homes gave their approval for the research to be carried out. Informed consent of all participating residents was obtained.

**Data analysis**

Data collection and analysis was an ongoing process, using a constant comparison approach. Interviews were coded and analyzed with the aid of Atlas-ti software. In the first stage of analysis the interviews were re-read and codes were ascribed to the text sections, following thematic analysis. After 20 interviews were carried out and analyzed, the evolving code list remained unchanged at each subsequent interview, indicating that data saturation has been achieved.
In the course of the sequential analysis, we noticed considerable overlap with the codes derived from another study on personal dignity where interviews were conducted with patients with a variety of illnesses still living at home. This other study eventually resulted in the development of the Model of Dignity in Illness, but was in a developing phase by that time. Because of this considerable overlap in codes, we found ourselves able to use the framework of this model to organize and describe our findings.

Table 1. Characteristics of respondents

<table>
<thead>
<tr>
<th>Respondent</th>
<th>Characteristic</th>
<th>Age range</th>
<th>Illness(es)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Woman</td>
<td>81-90</td>
<td>CVA, COPD, rheumatoid arthritis</td>
</tr>
<tr>
<td>2</td>
<td>Man</td>
<td>≤ 60</td>
<td>CVA</td>
</tr>
<tr>
<td>3</td>
<td>Woman</td>
<td>≤ 60</td>
<td>Crohn’s disease</td>
</tr>
<tr>
<td>4</td>
<td>Woman</td>
<td>71-80</td>
<td>Not able to stand as a result of trauma</td>
</tr>
<tr>
<td>5</td>
<td>Man</td>
<td>81-90</td>
<td>CVA, problems with kidney</td>
</tr>
<tr>
<td>6</td>
<td>Woman</td>
<td>61-70</td>
<td>CVA, COPD</td>
</tr>
<tr>
<td>7</td>
<td>Man</td>
<td>71-80</td>
<td>CVA</td>
</tr>
<tr>
<td>8</td>
<td>Man</td>
<td>61-70</td>
<td>Multiple system atrophy</td>
</tr>
<tr>
<td>9</td>
<td>Man</td>
<td>≤ 60</td>
<td>Liver cirrhosis</td>
</tr>
<tr>
<td>10</td>
<td>Man</td>
<td>81-90</td>
<td>Heart failure</td>
</tr>
<tr>
<td>11</td>
<td>Woman</td>
<td>81-90</td>
<td>Arthrosis</td>
</tr>
<tr>
<td>12</td>
<td>Woman</td>
<td>&gt; 90</td>
<td>Arthrosis, macula degeneration</td>
</tr>
<tr>
<td>13</td>
<td>Woman</td>
<td>81-90</td>
<td>Ankle fracture, abscess</td>
</tr>
<tr>
<td>14</td>
<td>Woman</td>
<td>81-90</td>
<td>Cancer of pancreas, heart failure</td>
</tr>
<tr>
<td>15</td>
<td>Man</td>
<td>&gt; 90</td>
<td>Rheumatoid arthritis</td>
</tr>
<tr>
<td>16</td>
<td>Woman</td>
<td>81-90</td>
<td>CVA, heart failure</td>
</tr>
<tr>
<td>17</td>
<td>Woman</td>
<td>81-90</td>
<td>Huntington’s disease</td>
</tr>
<tr>
<td>18</td>
<td>Man</td>
<td>71-80</td>
<td>CVA</td>
</tr>
<tr>
<td>19</td>
<td>Woman</td>
<td>81-90</td>
<td>CVA, diabetes, aneurysm of aorta</td>
</tr>
<tr>
<td>20</td>
<td>Woman</td>
<td>61-70</td>
<td>Cerebral haemorrhage as a result of trauma</td>
</tr>
<tr>
<td>21</td>
<td>Woman</td>
<td>&gt; 90</td>
<td>Heart failure</td>
</tr>
<tr>
<td>22</td>
<td>Man</td>
<td>81-90</td>
<td>Proximal muscle weakness</td>
</tr>
<tr>
<td>23</td>
<td>Woman</td>
<td>71-80</td>
<td>Hydrocefalus (accumulation of fluid in brains)</td>
</tr>
<tr>
<td>24</td>
<td>Man</td>
<td>81-90</td>
<td>Neglect of self, diabetes, not able to stand</td>
</tr>
<tr>
<td>25</td>
<td>Woman</td>
<td>71-80</td>
<td>Myocardial infarction, heart failure, poliomyelitis</td>
</tr>
<tr>
<td>26</td>
<td>Woman</td>
<td>81-90</td>
<td>CVA</td>
</tr>
<tr>
<td>27</td>
<td>Woman</td>
<td>81-90</td>
<td>Arthrosis, osteoporosis, transient ischaemic attacks</td>
</tr>
<tr>
<td>28</td>
<td>Man</td>
<td>71-80</td>
<td>Paralyzed as a result of trauma, diabetes</td>
</tr>
<tr>
<td>29</td>
<td>Woman</td>
<td>≤ 60</td>
<td>Hydrocefalus as a result of an aneurysm in brains</td>
</tr>
<tr>
<td>30</td>
<td>Man</td>
<td>81-90</td>
<td>CVA, heart failure</td>
</tr>
</tbody>
</table>

CVA: Cerebrovascular accident, COPD: Chronic obstructive pulmonary disease
Rigour
The authors met regularly to discuss the evolving code list and to compare the emerging themes with the content of the transcripts and interview summaries. To ensure reliability of the coding procedure, several interviews were coded independently by the first and third author using the same evolving code list. This revealed high consensus between the two different coders, and any disagreements were solved by discussion. After organizing our codes according to the categories in the Model of Dignity in Illness, we verified this by re-reading all transcripts.

Results

The threatening effect of illness
In general, residents reported that their dignity was affected to a greater or lesser extent. The fact that they were admitted to a nursing home was not the main reason their dignity had been undermined; residents said that residing in a nursing home was not degrading in itself, but rather seen as an inevitable consequence of being ill and having lost functional capacity. Several nursing home residents even pointed out that, although they would have preferred to have stayed at home, they had no other choice and therefore were grateful that nursing homes existed:

“I’m glad there are such things as nursing homes. It would be a sorry state of affairs if they weren’t there. If they weren’t there, it would be undignified.” (Respondent 8)

Similarly, being ill or frail was not considered as a reason in itself for feeling less dignified than before; residents said that becoming ill just happened to them, without anyone to blame for having the symptoms (e.g. pain or fatigue):

“Well, I think pain is something medical, it is not related to my dignity...there’s no one to blame for that. It’s a consequence of the physical deterioration.” (Respondent 27)

However, what could cause a decline in personal dignity were the consequences of the illness and physical deterioration. These impinged on aspects in one or more of three domains: a) the individual self (the subjective experiences and internally held qualities of the patient); b) the relational self (the self in reciprocal interaction with significant others); and/or c) the societal self (the self as social object in the eyes of others), which will be described in the next paragraph.
Three domains being threatened by illness

The individual self
In the realm of the individual self, some residents stated that they no longer felt like the person they were before the illness. By moving to a nursing home, residents had left behind most of their belongings, their home, their familiar neighbourhood and sometimes even their spouse. In addition, some residents experienced a change in character caused by a particular illness (e.g. CVA) and could not recognize themselves anymore:

“That was the end of my normal life. And all the TIA’s I’ve had have given me a really weird voice. I think who’s that talking, so loudly, and then it’s me. I really hate that. Unfriendly, catty. Yeah, I never used to talk like that, I was always a giggler.” (Respondent 27)

Although the majority of residents appreciated the activities the nursing homes organized, these activities could not compensate for the feelings of meaninglessness some residents had. According to them, life was not worth living any more, because of feelings of boredom, loneliness or the lack of any prospect of a future improvement in their health. Several nursing home residents stated that they were finished with life and hoped to die soon. The nursing home was seen as a place where people had to wait for death to come. In contrast, other residents were able to maintain a feeling that life had been meaningful. They could, for instance, look back on their contributions to society or their achievements and this bolstered their personal dignity:

Interviewer: “What gives you your sense of dignity?”
Respondent: “Well, I’ve always been successful, I’ve had to build up everything myself. I never had any friends giving me a leg-up, so yes, I don’t owe anyone anything fortunately.” (Respondent 9)

To be able to make one’s own decisions was seen as a very important factor influencing dignity. Nursing home residents must comply with several structures and rules in the nursing home concerning mealtimes and wake-up times and, as a consequence, they felt that the will of others was sometimes being enforced on them. They could understand that structures were needed, but some missed their own way of living:

“At home you can do or not do what you want. Here, for instance, they say: ‘get out of bed’, ‘eat’. That kind of thing. And if you’re at home you think: ‘now I think I’ll get out of bed, now I’ll go and have something to eat’. You know, your own, you are completely on your own at home, your own life.” (Respondent 13)
Adequate coping capacities were found to protect personal dignity. Residents who could adjust to and accept their situation of living in a nursing home and relying on assistance were able to maintain a higher sense of dignity than residents who had more trouble in accepting this. Two other coping mechanisms related to this were resilience and living in the moment. Some residents mentioned that, now that they were confronted with their new reality, they tried to make the best of it and focused on the joyful things in life:

“I’m not so rebellious, I don’t say: ‘oh no, what are they doing to me’. I think it’s awful if you start reasoning like that. Well, yes, I find it quite easy to adapt to a situation, at any rate. So then you feel a bit more relaxed and more well, we’ll see what happens and well, there’s just no choice, so that’s it.” (Respondent 4)

Other residents coped with their own situation by comparing themselves with others whose health status was worse than their own. By doing this, they focused on the things they could still do in spite of their illness and this mechanism could protect their personal dignity from being threatened.

Being able to communicate and having cognitive acuity, so that one could have meaningful contacts with others, were evaluated as prerequisites for a life with dignity. Several residents mentioned that becoming demented would definitely affect their dignity, although others viewed forgetfulness as belonging to the ageing process. Some residents even mentioned ‘old age’ as an excuse for having lost functional capacity or their inability to remember things. As such, it appeared to be a coping mechanism that could prevent dignity from being violated.

“My mental abilities sometimes mean there are things I can’t remember. And then my daughter says: ‘Mum...’ And then I say: ‘One day you’ll be this old, you wait.’ Well, I don’t like it but you can’t do anything about it. And then I think, ‘well, I’m so old, I’m allowed to forget the occasional thing’. I make excuses for myself.” (Respondent 11)

Residents could maintain a good level of self-esteem by either standing up for themselves or being indifferent to the comments of others, and this protected their sense of dignity:

Interviewer: “How do you try to maintain that feeling of dignity?”
Respondent: “Well, by giving feedback, so not just saying: ‘Yes Sir, no Sir’, but protesting a little every now and again. For example, if they say: ‘We’ll be back in a sec’, and that’s obviously pretty flexible. And when they eventually come back I’ll say ‘That was a funny sec’.” (Respondent 20)
Finally, for the religious residents, their religious beliefs helped them to preserve personal dignity. They felt supported by their faith in periods of uncertainty and it gave them the courage to go on. It also helped them to accept their illness and functional incapacity.

**The relational self**

Besides threatening the individual self, illness-related conditions could threaten aspects of the relational self, e.g. being dependent on others for daily care. Especially, residents who needed assistance with personal intimate care expressed a fractured sense of dignity:

*Interviewer:* “Is help with going to the toilet more unpleasant than being pushed forward in a wheelchair?”

*Respondent:* “Yes, that has something to do with dignity. Not much of it remains then. You must undress...very unpleasant. And then you think ‘Ok, now I’m even going to pull my underwear down in front of this person.’” *(Respondent 11)*

A few residents who shared a room with others said they missed a place where they could be alone and withdraw from the others. However, most residents who shared a room felt that this did not undermine their personal dignity, but this depended on the relationship with their room-mates. On the contrary, they found the company pleasant and it increased their feelings of safety, especially at night. They explained that, if they needed acute help, their room-mate could alert the nurses for them.

Analysis of the interviews revealed that feeling part of a social network and receiving emotional and practical support from this network could act as a buffer against threats to personal dignity. Being able to participate in the life of close ones was important in preserving dignity and gave life meaning:

“My granddaughter, my son and daughter-in-law, we all went to the park. And then you can go with them on that thing [mobility scooter] and the little girl could stand on the front and then they can have a play. And you’re out there with them, you get to see things - and that makes me really happy. That gave me a great kick, that was wonderful. Yes, you’re a bit more involved.” *(Respondent 8)*

This protective factor was however absent for many nursing home residents. Their social network had shrunk thoroughly because of multiple losses in their families and circle of friends. Residents reported that making new contacts in the nursing home barely happened. They felt no need to make new contacts, or stated that the other residents were too ill, demented or deaf to have a conversation with.
Being dependent and needing care made some residents feel a burden to others. They expressed concerns about overloading their loved ones and the nursing staff with their requests for assistance. Some residents even refrained from alerting the nurses when they needed assistance because of a fear of becoming a burden to them.

“I’m a burden. When you’re ill you’re simply a burden, that’s how I see it. To your family, above all, to everyone, to the people around you. Because I’ve always felt you should never rely on other people, I can do everything myself. And now I’m like this.” (Respondent 8)

Personal dignity was also affected in the encounters with nursing home staff. Most residents articulated their satisfaction with the way they were treated by nursing home staff. They said that most nurses were friendly and helpful. Good professional care could prevent dignity from being threatened. Residents said that being treated with attention and respect, being listened to and being taken seriously were aspects of such good professional care:

Interviewer: “And does the fact that you are now living in a nursing home affect how dignified you feel?”
Respondent: “Yes, they’ll never come in without knocking, they always ask how you are. And if you are looking particularly good on a particular day, there’s a nurse from Surinam and he’ll say: ‘What lovely eyes you have.’” (Respondent 14)

In contrast, some nurses were thought to be bossy, rude or treating the nursing home residents as if the residents were unable to make decisions themselves. This negatively influenced residents’ feelings of being recognized and treated as an individual and could, as such, impinge on their sense of dignity:

“Some of them are sweet and friendly and I get on with them really well, but there are others here who think they’re the boss because they are the nurse and someone else is the victim. They should be polite and call me ‘Sir’ and say ‘Sir, would you mind turning over?’ and so on. But not ‘Now lie on your stomach, now turn over.’ Now that’s not dignified, you know.” (Respondent 24)

**The societal self**

The third domain that could be threatened by illness was the societal self. Women in particular thought that looking well-groomed was important in maintaining their dignity, not only for themselves, but also as a social object in the eyes of others:

“I would still really like to look good and I want to smell nice, that kind of thing. I think that does have to do with dignity, so that they don’t come up to you and think ‘Oh, she stinks’, and so on. I would hate that.” (Respondent 20)
Living in a nursing home made nursing home residents even more aware that they were no longer part of society. Some felt useless and said they only burdened society economically. This feeling was strengthened by negative attitudes in society on ageism, which most nursing home residents also had themselves. 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 any more or undervalued simply because of their illness or age:

“You notice that when you get old, people stop taking you seriously: ‘That person’s so old, we’ll just park him in a corner then he won’t bother us any more’. That’s often what happens. . . . Yes, you no longer count, you know. Young people today are more concerned with their own things than with all those old people. They don’t want anything to do with you.” (Respondent 11)

These feelings of being undervalued were strengthened by the scarcity of resources in the nursing homes. Residents pointed out that they were confronted with many different faces at their bedside because of the temporary workers hired by the nursing homes to overcome staffing shortages. As a consequence, residents said it was difficult to build a relationship with nursing staff. Despite residents’ understanding that nurses could not spend much time with them, their dignity could be violated by having to wait for help, a dearth of time and attention from nursing staff and a general atmosphere of hastiness:

“I feel that impatient haste with which they do everything, they are kind of jumping about next to you, desperate to move on. It’s a routine and that’s their approach to everything. I do find that inattentive, I do think it makes the patients feel less dignified.” (Respondent 5)

On the other hand, receiving good quality care, where residents could get showered or receive help when needed, could help them in preserving their dignity:

“The dignity thing was really bad in the nursing home where I was before. If there are 23 of you lying there and they only have 2 nurses to look after you, that really isn’t enough, so they’re understaffed and then they can’t look after you properly. In this nursing home, you get your shower when you should, you get cared for properly, no fuss, there’s no cheek. And if something’s up I can just call for them.” (Respondent 6)
In this study, we interviewed 30 Dutch nursing home residents about their self-perceived dignity and factors that preserve or undermine it. The factors that emerged from the interviews showed considerable overlap with those in the Model of Dignity in Illness, in spite of the fact that the model was created based on interviews with patients who lived at home. In line with the model, we found that threats to personal dignity developed from an individual being ill or frail and having lost functional capacity. Being ill not only threatened aspects of the individual self but also aspects of a resident’s social world. Living in a nursing home was not seen as degrading in itself, but rather as an inevitable consequence of having lost functional capacity. Although the Model of Dignity in Illness has been found to be applicable in the nursing home, the relative emphasis on the domains was different for nursing home residents compared to patients living at home. Bearing in mind that personal dignity is subjective and contextual, the aspects in the domains ‘the relational self’ and ‘the societal self’ were generally considered more important for nursing home residents. Older nursing home residents might be deprived of the protective effect of a supportive social network, because many of their family members and friends have died. Also, residents might feel stigmatized and discarded by society, while living in a nursing home. Our modern society, where esteem and dignity are closely related to one’s role and function in society, might contribute to the feelings of nursing home residents that they play a ‘role-less role’ and that they have become redundant and even a burden to society.

We found that being ill and living in a nursing home were not seen directly as reasons for an undermined sense of dignity. Residents explained that they could disassociate their symptoms and situation from violating their dignity, because they were not to blame for what happened to them. Possibly, pain and other symptoms were evaluated as belonging to the ageing process and so functional deterioration was more or less to be expected, both by themselves and by society. This finding raises the question whether dignity would be affected if the patient has more reason to feel responsible for his or her illness, e.g. when someone suffers from lung cancer after years of heavy smoking. It would be interesting to investigate this in more detail.

International comparison
When comparing our findings with other studies performed in nursing homes, many similarities in themes related to dignity across the different countries appear. For example, like the study in the UK, our study revealed that residents were not concerned about death; some residents even hoped to die soon. Furthermore, similar to the study in Germany, we
found that dignity was closely related to social ideas of value and that feeling a burden or feeling stigmatized by society could impinge on residents’ dignity. The distinction made in the German study between intrapersonal dignity and relational dignity can also be found in the different selves formulated in the Model of Dignity in Illness. In addition to the German model, we have recognized that positive experiences with relational dignity (e.g. having a supportive social network or receiving good professional care) and the individual having adequate coping capacities can protect dignity from being violated. This protective effect of receiving good professional care was also recognized in the Swedish study. In addition, Franklin et al. acknowledge that an individual’s dignity depends on personal and organizational circumstances. They mention briefly that postmodern society, where youth and strength are highly valued, might have an impact on older people’s dignity. In our study, we elaborated on this and discovered that residents frequently felt stigmatized and discarded, which could undermine their personal dignity.

Thus, in spite of the fact that residents in Dutch nursing homes are generally more severely disabled than residents in other countries (because Dutch older people with less complex problems are cared for in residential care homes), we have found no evidence that dignity is more severely affected or by entirely different factors in the Netherlands as compared to other countries.

**Limitations of the study**

Our study was limited to the experiences of residents who were admitted to a long-stay unit for people with severe physical diseases. Although this does not mean no resident in our study suffered from the early stages of dementia, we do not know whether our results can be generalized to residents with more severe dementia. Also, we interviewed the residents a few weeks after their admission to the nursing home. At this point in time, most of them were not yet used to their new situation, and had difficulties in adjusting and accepting it. It is possible that, later on, they experience their personal dignity differently, as one would expect if a phenomenon that Matiti and Trorey (2004) found in hospital also takes place in the nursing home. These authors described how patients in the hospital setting continuously perceptually adjusted to expected indignities; a self-protection mechanism where the patient accepted potential indignities without the loss of dignity that would exist under normal situations. To investigate whether this also occurs in nursing home settings, a recommendation for future research would be to follow the residents over a longer period of time.
Conclusion
This interview study has provided more insight into the factors that influence the personal dignity of Dutch nursing home residents, which are important to be aware of when aiming to provide dignity-preserving care. In supporting residents in their challenge of maintaining dignity, nursing home staff, relatives and society should be more aware of the way they address, treat and think about nursing home residents, so as to optimize aspects in the three different domains - individual, relational and societal self - and to enhance protective factors. 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. Furthermore, families should be encouraged to visit the nursing home and to be actively involved in the caring process. In addition, it seems important to positively influence societal discourses on older 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. Also, nursing home staff should realize that their attitude and the way they treat residents can have an impact on residents’ dignity, either maintaining or undermining it. More training can help nursing staff to acquire skills that equip them to give good professional care. Finally, ideally both the numbers and quality of nursing home staff should be increased\textsuperscript{24} to avoid residents having to wait for help and suffering from a dearth of attention.
References

Chapter 2


