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## Personal dignity in seriously ill patients

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2016

### **document version**

Publisher's PDF, also known as Version of record

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### **citation for published version (APA)**

van Gennip, I. E. (2016). *Personal dignity in seriously ill patients*. [, Vrije Universiteit Amsterdam].

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## GENERAL DISCUSSION

### RESEARCH AIMS

The primary aim of this research project was to provide insight into which factors or experiences, as perceived by those suffering from serious illness, related to their sense of dignity. The objectives pertaining to this aim were as follows: (1) to develop a generic model of personal dignity in illness that illuminates the process by which serious illness can undermine patients' dignity, and that is applicable to a wide patient population; (2) to explore how patients with mild to moderate dementia experience their personal dignity and which factors play a part in this; and (3) to explore how patients' experiences of personal dignity change over time with the progression or fluctuation of illness and to establish which mechanisms patients use to maintain or restore their sense of dignity during this process.

The second aim of our research was to improve our understanding of what death with dignity means. We approached this topic by investigating what makes a death dignified from the perspective of the surviving family, addressed in the following objective: (4) to investigate which factors affect the dignity of the death of older adults as perceived by family caregivers.

The third aim of the research project was to contribute further to the conceptual understanding of personal dignity by exploring the relationship between personal dignity and quality of life, two concepts related to well-being, addressed by the following objective: (5) to investigate the relationship between dignity and quality of life and the assessment of dignity within the quality of life context.

In this final chapter, an overview of the main research findings is presented and discussed, followed by a discussion of some methodological considerations. Subsequently, a theoretical reflection on personal dignity is given and implications and recommendations for the practice of care are discussed.

## MAIN FINDINGS AND INTERPRETATION OF RESULTS

### *The model of dignity in illness*

Personal dignity is a complex and multi-faceted concept. We developed a Model of Dignity in Illness, based on in-depth interviews among a diverse patient population, in terms of both the type and stage of illness, to provide an organizational framework and to illuminate the process by which serious illness can undermine, or enhance, patients' personal dignity (Chapter 2). When developing the model, we found that illness-related conditions do not affect patients' dignity directly but rather indirectly by influencing the way patients perceive themselves through three aspects that shape self-perception: (1) the *individual self*, which 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; (2) the *relational self*, which refers to the individual's sense of dignity as formed within dynamic and reciprocal interactions; and (3) the *societal self*, which 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.

Our model is based on the premise that suffering from a serious illness can affect the individual's sense of dignity by affecting perceptions of the self in three different contexts: that of the individual self, the self in interpersonal relationships, and the self in relation to society and the societal discourse conveying certain values and norms. The "looking glass-self" theory developed by Charles Cooley (Cooley, 1902) presents the idea "that the self is a social product" and that individuals learn to see and value themselves based on how society views them: "There can be no isolated selves. There is no sense of 'I' without its correlative sense of you, or he, or they... a reflection of the ideas about himself that he attributes to other minds." (Cooley, 1902). The individual accepts, embraces or unconsciously develops an image of the self based on society's viewpoint or acceptance (Yeung and Martin, 2003): "In imagination we perceive in another's mind some thought of our appearance, manners, aims, deeds, characters, friends, and so on, and are variously affected by it seeing ourselves as we imagine others see us (Cooley, 1902)." Thus, an individual's evaluation of himself, and hence his sense of dignity, is influenced by how he believes others perceive him and by the prevailing ideas and values held by the community and society in which he lives. Societal discourses on the ill and disabled and strongly influence how those who are afflicted with serious disease view themselves and how they believe they should present themselves to others (Pols, 2013). Expanding on Cooley's ideas and going beyond perception, George Herbert Mead's theory states that it is in interaction that the understanding of the self takes shape (Mead, 1938). Following Mead, it is not only by the perception and standards of others and society as a

whole that self-evaluation is formed, but also through the acts of others, for example in the execution of care practices.

When we developed the Model of Dignity in Illness, several models describing personal dignity had already been developed, the most well-established being the Model of Dignity in the Terminally Ill by Chochinov and colleagues (Chochinov et al., 2002). These models, however, were based on specific populations, either on nursing home residents (e.g. Haddock, 1996; Pleschberger, 2007) or on terminal cancer patients during the final months of life (Chochinov et al., 2002). We found it necessary to develop a new model, grounded in the experiences of patients with various chronic, potentially life-threatening illnesses, to provide for a more general applicable model. To this end, we included patients with illnesses commonly found in western societies, that is, patients with mild to moderate dementia, cancer, and severe chronic illnesses such as Crohn's disease, Parkinson's disease and HIV. Compared to the model developed by Chochinov et al. (2002), our model allocates a more prominent position to the social world of patients. In our model, a detailed description of social aspects is given in the relational and societal self. Additionally, social factors in our model are considered to be crucial protective factors, whereas in Chochinov's model the primary focus is on individual coping as a protective mechanism for maintaining dignity, i.e. the Dignity Conserving Repertoire.

While the Model of Dignity in Illness was developed based on the experiences of patients living at home, empirical research has shown that the Model of Dignity in Illness is also applicable to nursing home residents with physical illnesses (Oosterveld-Vlug et al., 2013, and 2014). Similar themes were brought forward by nursing home residents, although the relative emphasis residents put on the various themes differed from that of patients living at home. Furthermore, the indirect effect of illness on dignity was further confirmed in this study; being ill or frail in itself was not considered to be cause for feeling less dignified because, as residents reasoned, it was something that simply happened to them and for which no one was to blame. Similarly, admittance to the nursing home was in itself not seen as degrading because it was perceived as an inevitable consequence of being disabled. What could cause a decline in the sense of personal dignity, however, were the consequences of illness or loss of capabilities as described in the model, affecting how residents valued themselves.

### ***Factors affecting personal dignity***

Below, the factors found during our research that either bolster or diminish patients' sense of dignity in our model's three domains of self are discussed.

### *The Individual Self*

The main themes found in this domain with regard to dignity were identity, meaning of life, autonomy and cognitive awareness. Additionally, dignity could be maintained or enhanced by adequate personal coping skills. Most patients with cancer, early-stage dementia or chronic disease felt their illness had affected their identity (Chapter 2). The transition from being a healthy, self-reliant and capable individual to one who is limited by deteriorating health had a profound impact on most patients' sense of self. First of all, they now found themselves in the role of 'the patient'. Furthermore, limitations to their capabilities prevented the expression of the 'true self' by hindering the performance of certain activities considered central to their identity such as working or taking care of their family. Additionally, the illness itself, as well as medication, could result in behavior that was out of character, making patients feel unrecognizable, even to themselves. Some patients said they felt betrayed by their own body. No longer feeling like the person they once were and experiencing a sense of profound loss because of this could result in a sense of unworthiness and meaninglessness, and was a strong factor that contributed to the impairment of personal dignity. Associated with a sense of lost self are changes with regard to one's autonomy or sense of agency, i.e. to be in control of one's life and have the ability to make one's own decisions, which many considered to be a key component of being a full worthy individual (Chapter 2). Additionally, possessing sufficient cognitive awareness to express oneself as a means of confirming one's identity was considered essential to personal dignity. Concerns about remaining cognitively aware caused some patients to refuse their pain medication because it made them feel drugged. Also, lack of cognitive awareness resulting in the inability to communicate, to make contact and to express oneself was reported as a much dreaded effect of severe dementia (Chapters 2 & 3).

The 'accommodation strategy', defined by Brandtstädter and Greve (1994), is a coping strategy related to changes in identity. It involves the acknowledgement and acceptance of the fact that, due to progressive disease or aging, the individual has changed and must adjust his or her aspirations and self-evaluative standards in order to rebuild their identity. We found that if patients were successful in rebuilding their identity in a meaningful manner, they could maintain or regain their sense of personal dignity. Most patients who participated in our study were able to make the necessary inner adjustments. They could reclaim their sense of dignity by finding new meaning and purpose in life on which they could rebuild their sense of identity: by a reorientation of goals and achievements, by finding reward in other aspects of life, by focusing on the most

essential aspects of life, or by focusing on what still lay within the realm of their capabilities (Chapter 4).

We found that individuals with mild to moderated dementia in general could cope with their disease in a way that protected their sense of dignity. Our findings are in line with research carried out by De Boer et al. (2007) who found that people with dementia do not undergo their disease passively, and that they use different coping strategies to deal with its challenges. This realization is important because dementia is generally feared by many as an undignified state of being.

For patients with mild to moderate dementia, the home environment was found to play a significant role in the maintenance of personal dignity. A sense of meaning and purpose was discovered in engaging in pleasurable activities in and around the home, and in carrying out daily routines and chores. Patients with dementia maintained their personal dignity by deriving satisfaction from the smaller pleasures in life and by lowering their expectations of their capabilities, focusing instead on what was still possible. Another study which explored how individuals with Alzheimer's disease who lived at home coped with the changes they faced in daily life and social relations also found that individuals adjusted their activities, attitudes and values as part of a comprehensive coping strategy to preserve personal worth and dignity (Sørensen et al., 2008). Moreover, the house itself served as a reminder and symbol of one's life and achievements; it confirmed the patient's identity, their success in life, and was generally a source of pride. Thus, the significance of the house extended well beyond its basic functionality as a dwelling, becoming a symbol of the identity the participant had built up over a lifetime (Chapter 3).

Patients did state that there are limitations to what they are willing to accept. For example, many patients stated that conditions such as incontinence, becoming bedridden or cognitive degenerative would severely hamper their sense of dignity. They also expressed concerns about the progression of their disease and its consequences, and feared dying in an undignified state. Nevertheless, we found that patients did adjust their boundaries as time went on, finding dignity in situations they previously considered to be unacceptable.

Not all patients, however, were able to cope successfully with their illness and its consequences (Chapter 4). For example, patients for whom being independent was central to their identity had difficulty accepting their altered situation. Some of the patients did not manage to develop an accommodation strategy by which to re-invent themselves and find new sources of dignity, but rather continued to suffer from an ongoing decline in their sense of personal dignity. This situation resembles the 'immunized state', described by Brandtstädter and Greve (1994), in which the individual clings to his or her established identity and fails to adjust and re-invent themselves. While patients who were able to maintain or regain their dignity expressed the hope that they would be flexible enough to

accept and overcome future challenges, the latter group of patients expressed the opposite viewpoint: they hoped they would stick to the strict boundaries they had originally set with regard to personal dignity and not condescend to accepting a state they viewed as undignified; they hoped to die, either naturally or by euthanasia, before reaching this point.

While for most patients their sense of dignity was influenced by changes to their identity and the ability to fulfill the roles they had defined for themselves, patients who reported a strong and stable sense of dignity generally felt that their identity had not been affected by their disease (Chapter 4). Some patients stated that for them, dignity was unrelated to the changes brought about by their disease, such as dependency on others and the loss of capabilities; deep inside, they still felt like the same person.

### *The Relational Self*

The main themes in this domain which had a negative effect on personal dignity were the inability to fulfill social roles, being dependent on others, and feeling like a burden to others. Themes that affected dignity in a positive manner were being connected to others, being able to participate in social (family) activities, and being able to reciprocate and contribute to relationships rather than being a burden. Of particular relevance within the professional care relationship were respect for privacy, especially with regard to intimate bodily care, and being treated and recognized as an individual. Patients reported that at times they felt they were treated merely as 'a patient', or even 'object', rather than as a fully worthy individual; they felt they were not taken seriously, and they experienced a sense of powerlessness, required simply to submit themselves to the wishes of their caregivers. Care that did support patients' personal dignity was characterized by a respectful and empathetic attitude on the part of the caregiver, and by being fully and properly informed about their illness and treatment, as well as being consulted on important medical and care decisions (Chapter 2).

There is significant variation in what individuals regard as undignified in relation to dependency. A number of patients said they felt undignified, guilty and shamed by having to depend on others. This has also been noted by other authors (e.g. Buckley et al., 2007; Franklin et al., 2006). Others reported that being dependent did not diminish their sense of dignity; as one participant put it: "I took care of others all my life, now it's their turn." Personality and attitude throughout one's lifetime, as well as the type of activities one requires help with (e.g. cleaning the house or intimate bodily care), most likely have an effect how dependency on others is perceived.

We found that still having a sense of agency, i.e. having a sense of control and the feeling that one is delegating tasks rather than being submissive and passive, makes dependency on others easier to bear (Chapters 2 & 4). Rock (1988) states that

independence can be seen as a variable self-concept which relates to control and choice rather than any absolute measure of competence. Clark (2010) argues that it might therefore be concluded that loss of dignity is not an inevitable consequence of dependency because dignity can be maintained by providing opportunity for control and choice. In addition, we found that being able to reciprocate and contribute to the care relationship, for example by giving advice, helped to restore the inequality in the relationship and made dependency less keenly felt. Finally, the sense that one is important to and valued by others can ward off feelings of being a burden simply because one requires care. (Chapters 2 & 4).

Our study on patients with mild to moderate dementia has shown that the assistance of others can, in fact, make life with dignity possible (Chapter 3). Patients with dementia were well aware that only through the assistance provided by others, generally their partner, were they able to participate in activities that helped them preserve their personal dignity. The vital role played by the partner in helping out with chores, providing structure in daily life, keeping schedules and appointments, serving as a source of memory – all of this made a more or less normal life possible. In general, the patients suffering from dementia accepted this relationship of dependency and expressed gratitude for the help they received, as long as they maintained a certain degree of agency and felt that they were taken seriously, listened to, and that their wishes were respected.

We further found that family members and close friends can help to protect the patient's sense dignity as their support and presence could compensate, at least partially, for personal losses (Chapter 4). Many patients in our study shifted their focus from their achievements and competencies as a source of worthiness to the social meaning and importance they held for others. Rather than seeking status and admiration based on generally valued accomplishments, and the norms and conventions of society, they focused on intimate relationships that fostered well-being and bolstered their sense of dignity. Loss of individual capabilities could be accepted if one was important to others and felt appreciated, loved and supported, and that one could reciprocate in valued relationships. Thus, having a solid, supportive network and feeling loved and accepted appears to be one of the prerequisites for maintaining dignity as it can forestall the potentially detrimental effects of illness on the individual's sense of dignity.

Furthermore, for many patients, their partners or others close to them enable them to sustain their personal dignity by providing a sense of continuity of identity because they knew the person before the onset of their disease (Chapter 2 & 4). Patients with dementia stated that being among those who knew them when they were still healthy, fully capable individuals helped them feel dignified because those people still regarded them as complete individuals rather than as patients suffering from dementia. Because they felt they were still seen for "full" by people close to them, they considered



their mistakes, failures or shortcomings resulting from their cognitive impairment to be less shameful (Chapter 3).

A number of patients struggled with the fact that the illness limited them in the fulfillment of previously held social roles, e.g. a mother who now had to be 'mothered' by her daughter. They struggled with the feeling that they were failing others or that they had lost their value for others which diminished their sense of dignity. However, many patients did find alternative ways to be of value, e.g. offering support and advice to others, having more time to listen to others, etcetera, or discovered that they were loved and valued regardless of their perceived shortcomings.

Thus the role of others in sustaining dignity in patients extends well beyond treating them with respect and respecting their dignity. It is important to protect and respect patients' sense of agency and to listen to them, to give them opportunities to reciprocate and to convey that they have meaning and value to others, in short, to convey that they are fully worthy individuals who still count. Many patients believed that meaningful interaction with others was one of the essential prerequisites for maintaining their sense of dignity, especially toward the end of the illness trajectory. The close and constant presence of a supportive social network to which one feels emotionally connected may be a key factor in the individual's ability to maintain or regain a sense of dignity.

From the above it becomes clear that the absence of a supportive, loving network can have a detrimental effect on personal dignity. Our longitudinal study showed that patients whose dignity had been impaired shared certain characteristics that relate to relational aspects and that these could partly explain the patient's diminished sense of dignity (Chapter 4). First, there was a similarity in living arrangements: although some of these patients did have a partner, they all lived alone. Secondly, they all suffered from chronic or episodic pain, continual fatigue, and/or depression. Being exhausted by fatigue, consumed by pain or severely depressed makes it difficult to engage in meaningful interactions with others. The loss of such interaction may very well have a bearing on their sense of dignity.

### *The Societal Self*

The loss of certain capabilities, as well as physical and emotional changes brought on by disease, challenged patients' self-image and gave rise to concern with regard to the image others had of them. The main themes in this domain were understanding, respect and societal imagery (Chapter 2). Patients reported being confronted by an array of negative reactions which had a significant detrimental impact on their sense of personal dignity. They recalled incidents of misunderstanding, being stared at, and receiving insensitive or insulting remarks because of their symptoms (e.g. being called a drunk because of an

unsteady gait), or because of their appearance (e.g. being told to eat more because they were too thin). Moreover, they felt they were stigmatized as 'a patient', and patronized and treated disrespectfully. They made a tremendous effort to appear 'normal', not to deviate from social norms, and to hide their symptoms. They felt odd at times, and concerned with the way in which they were perceived by others. It was important to their sense of dignity to receive respect and recognition as a worthy and competent member of society, rather than being seen as 'a patient', and not to be judged with prejudice based on perceived shortcomings or abnormalities. In cases where the individual exhibited no apparent symptoms and looked healthy, they met with incomprehension, sometimes even disbelief, regarding their illness and incapacity.

We also found that in individuals with mild to moderate dementia, the sense of mastery they were able to maintain within their home environment with the aid of their partner often disintegrated in the outside world (Chapter 3). The patients expressed a strong need to preserve normalcy, and their inevitable failure to consistently behave in normative ways evoked feelings of shame and made them aware that part of their former self had been lost. It appears that individuals with dementia feel highly self-conscious, especially during the earlier stages, helpless and ashamed of their perceived deviations from social norms. Some participants in our study stated that they withdrew from social interactions in order to prevent loss of personal dignity. Social withdrawal as a strategy for preventing embarrassment is also described in other studies on the subjective experiences of dementia. Ostwald (2002) found that particularly those who still exhibited a relatively high degree of cognitive functioning preferred to limit their social contact with others as a way of coping with their dementia. A study by Clare (2003) also indicates that people with early-stage dementia avoided situations in which they might feel challenged by their difficulties with memory loss and thus feared they would not appear to be 'normal' when interacting with others. Research by Husband (2002) has revealed that upon receiving the diagnose of dementia, the most common concerns expressed by patients were the fear of others finding out that they had dementia and the fear of social embarrassment; the most frequently observed effects were social withdrawal and hyper-vigilance for evidence of cognitive failure.

Some patients with cancer or severe chronic disease also had a tendency to withdraw to the safe surroundings of their home environment and to limit their social interactions as much as possible to a close circle of family and friends as a way of maintaining their dignity (Chapter 4).

Being among people in similar circumstances helped patients to feel dignified because of mutual respect and understanding. This was also noted in a longitudinal qualitative study on nursing home residents (Oosterveld-Vlug et al., 2013). After living in the nursing home for some time, the residents generally no longer expressed the view

that their dignity was diminished because they felt that they were disregarded and undervalued by society and perceived as an economic burden to society. It appears that by becoming part of a community of equals, of disabled individuals, residents felt less deviant from others in their new small society.

#### *The three dimensions of self*

The three dimensions of self are described as separate entities in the Model of Dignity in Illness for the sake of analytic clarity and to provide an organizing framework. In reality, all dimensions of self are, of course, interwoven and intertwined, i.e. the individual self is always socially engaged and connected with others, and always part of society. This becomes clear from our data. To give a few examples from our findings: autonomy can be facilitated or prohibited by others; the meaning and purpose of one's life is partly determined by being of importance and value to others; one's sense of identity is strongly influenced by others; and, one's subjectively experienced dignity is shaped by the dominant discourses of society. Furthermore, all three dimension of self refer to how a certain individual *perceives* the world and the attitudes and behaviors of others. These observations are personal and subjective, and might be true or false from the perspective of the other, i.e. another individual may either be intentionally condescending or be perceived as such without intending to be so. Individuals differ in the ways in which they perceive the world and in the assessments they make. For example, in the same situation, some patients may be prone to feeling patronized while others feel well looked after.

#### *Development over time*

Our longitudinal research has illuminated some individual differences with regard to coping with the disease experience (Chapter 4). It has shown that while there is a small group of patients for whom dignity remains unaffected by their disease experiences (termed *stability*), most patients struggled, to a greater or lesser degree, to maintain their sense of dignity during the progression of their illness and the associated changes and losses it brought about. Our data showed that in this latter group, some patients were able to reclaim their dignity by adequate coping (termed *dynamic equilibrium*) whilst others were not (termed *downward trend*). They felt that they had lost too many of the competencies, capabilities and essential aspects of their lives that had previously given them a sense of dignity, and they had trouble accepting the situation brought about by their illness.

#### *Differences between disease types*

Similarity in themes was observed across different types of illness. In addition, in our longitudinal study we found that the three observed trajectories (stability, dynamic equilibrium, and downward trend) were similar for the different disease groups, suggesting that the type of illness has little effect on the specific pathways and the dynamics of the sense of personal dignity in patients. Another study focusing on the maintenance or loss of identity indicates that there is a basic similarity between the experiences described by both cancer and dementia patients (Gillies and Johnston, 2004). This is in line with the Model of Dignity in Illness which illustrates that it is not the illness itself that is directly responsible for a decline in feelings of self-worth, i.e. one does not feel less dignified because one has, for example, cancer. Rather, changes to the body and mind of the patient as a result of the illness leads to subsequent changes in the patient's personal and social circumstances, which in turn may undermine their sense of dignity, e.g. both cancer and rheumatism can lead to increased dependency on others, which in turn may damage the patient's sense of dignity, implying that the underlying dynamics and mechanisms responsible for a diminished sense of dignity are basically the same.

In the case of dementia, it is important to point out that the patient's progressively impaired insight into the developing cognitive problems during the more advanced stages of dementia will certainly affect the way the patient copes with changes to identity (Zanetti et al., 1999), and thus how they experience their sense of dignity. The first phase of dementia, when the patient is aware that he or she has dementia and notices cognitive decline, is perhaps the most difficult phase with regard to personal dignity. This was evident in the case of a woman with dementia who, during the first two interviews, expressed feeling sad at times because she felt she was losing her autonomy. During the last interview, however, her dementia had progressed and she was admitted to a nursing home. She was less acutely aware of her cognitive decline and quite content: "I feel like a queen... I'm enjoying myself. I like living here, the food is nice. In that sense I feel very lucky. Yes, I feel very worthy. I feel privileged because I'm healthy. I can still walk, I can... well I'm a bit forgetful, but it isn't that bad you know, I'll live through it. I just ask again. I don't feel any less dignified because of that."

### ***Death with dignity from the perspective of family members***

To die with dignity is important to both patients and those closest to them. We investigated death with dignity from the perspective of family caregivers of deceased older adults by means of a retrospective self-administered questionnaire. According to the majority of family caregivers (69%), their deceased relative had died with dignity. Two aspects or circumstances appear to affect whether a family caregiver experiences the death of the patient as dignified or not dignified. The first refers to the age at which the patient dies and whether the death was foreseen in a timely manner. Dying at an old age

(>80 years) and anticipated deaths (due to cancer or old age, and following a period of fatigue) are associated with a dignified death. The second aspect relates to the manner in which, and the circumstances under which, the patient dies. The state of mind of the patient during the last few weeks preceding death seems of particular importance to the dignity of death from the perspective of the family caregiver. For patients who had trouble thinking clearly at the end of life, more family caregivers perceived the death of their relative as being not dignified than dignified. Also, the patient's sense of psychological well-being during the final stage of life affects whether the death was dignified from the perspective of family caregivers. Awareness in the patient that death is nearing, being in a peaceful state of mind and ready to die, having a death wish 3 days before death, accepting things as they are, not feeling anxious or depressed, and having had the opportunity to say good-bye to loved ones all contribute to a death that was dignified according to the family caregiver. In addition to this, end-of-life care appeared to contribute positively to perceived dignity at the time of death when treatment choices had been clearly explained, when care was in accordance with the patient's wishes, and when the patient died at home.

## **METHODOLOGICAL CONSIDERATIONS**

### ***Qualitative research***

During the research project, I was supported and advised by a research team whose members were experienced researchers from various backgrounds. In addition, a well-trained, skilled interviewer assisted the team by conducting a number of interviews. A key goal of this research project was to gain insight into how people suffering from a life-threatening or severe chronic illness understand their personal dignity and what types of experiences influence their sense of dignity. In order to achieve this aim, we opted for a qualitative approach using in-depth interviews, thus enabling us to elicit personal stories and experiences expressed in the participant's own words (Bowling, 2002). In qualitative research, the interviewer is the research instrument (Kvale, 1998), and it is important that the interviewer is aware of his or her own attitudes, assumptions and role as an interviewer. In order to obtain meaningful in-depth information rather than a collection of anecdotes, the interviewer must be skilled, resourceful, persistent, and understand the art of asking difficult questions while maintaining sensitivity. The subject of dignity was addressed from various angles, while leading questions, e.g. suggesting themes relevant to dignity, were avoided. Rather, the experiences and terminology of patients themselves were used as a basis to follow up on. In instances where it was unclear whether a comment made by the participant related to their sense of dignity, the participant was

asked specifically if this affected his or her sense of dignity. Individuals differed in their ability to reflect on personal dignity and to verbalize their experiences; for some, it was easy to talk about dignity, while others needed more probing. All participants, however, were able to relate to the subject and discuss it. Many participants said they had enjoyed the interview experience because they were being listened to and had also gained insight into themselves by thinking about their personal dignity.

To ensure methodological rigor, various criteria established for qualitative research were followed (Patton, 1990; Britten, 1995; Boyatzis, 1998; Braun and Clarke, 2006). Data saturation, purposive sampling and maximum variation guaranteed reasonable validity and generalizability of our results. Content validity was further ensured by maintaining a focus on dignity in the interviews, and by following the principles of thematic analysis and using the technique of constant comparison to maintain integrity in the ongoing process of data gathering and analysis. In addition to providing a perspective of development over time, the longitudinal study added to the internal validity of our study. Interviewing patients a number of times afforded us the opportunity of discussing certain themes more in-depth a second time and established a deeper rapport between patient and interviewer, thus increasing the chance that more sensitive information would be provided and that patients are less inclined to supply socially desirable answers (Murray et al., 2009). Independent coding of a number of interviews by two researchers safeguarded the reliability of the coding process. Reliability was further ensured by listening to the recordings of the interviews that were conducted by our interviewer a number of times in order to grasp the emotional tone, the way in which answers were formulated, and the various nuances that provide the context for the verbatim transcripts. Comprehensive discussions within the research team at all stages of the research - research aim and design, recruitment of participants, data gathering and analysis, and written report - provided a further critical check of validity and reliability.

#### *Population specifics and generalizability*

The qualitative study was carried out in the Netherlands among participants of Dutch origin. While we aimed to establish a generic model, we cannot claim that the model is generalizable to other ethnic groups living in western countries. Other ethnic groups may hold different views of illness which, in turn, may affect the way they perceive personal dignity. For example, a study conducted in the U.S.A. investigated how Afro-Americans viewed and treated people with dementia living in their community. This study showed that in the Afro-American community dementia was not considered to be a disease but rather something natural that could happen to any elderly individual. People with dementia were not stigmatized as 'patients' and the community felt a sense of obligation to take care of them (Jett, 2006). Also, in western culture 'independency' and 'autonomy'

are valued to the extent that they appear to be prerequisites for personal dignity. However, in many cultures with close-knit communities, interpersonal dependency and family care is considered a matter of course. For example, in Asian and Muslim societies there is generally more respect for older people and taking care of them is viewed as a family's obligation and a sign of respect. For example, dependency on others is generally considered to be degrading in western societies, while being taken care of by one's adult children is a source of pride and dignity in Chinese culture (Chan et al., 2012).

All participants in our study had signed an advance directive (AD), either with the NVVE which supports euthanasia, or with the religiously oriented NPV which rejects extensive medical treatment and disapproves of euthanasia. This population was well-positioned to provide us with rich information because having signed an AD meant that they had thought about end of life issues. It is not known, however, whether their thoughts on dignity reflect the ideas of individuals without an AD. Nevertheless, we did not find substantial differences between NPV and NVVE members with regard to their understanding of dignity, despite the differences in world views which can be considered as two opposites in the end of life spectrum. This may suggest that the experiences with dignity as described in this thesis are not distinct to NVVE or NPV members.

What has not been discussed within this thesis are differences between gender and age. No significant differences were found between the dignity related themes brought forward by men and women, although the specific contents of the themes did at times differ along traditional lines, i.e. in general, men valued having a paid job more, while women valued looking after others and being able to do housework. Thus, while having a sense of meaning or purpose in life may differ in content between individuals and genders, the factor 'meaning of life' as such was reported as relevant to dignity by many patients, both men and women. Factors pertaining to dignity are discussed throughout the thesis in a general, transcending way, although its specific individual content does appear in the cited quotations. The same line of reasoning applies to differences in age.

### ***Quantitative research***

The results of our study on death with dignity from the perspective of the surviving family members were obtained by conducting a survey study among 163 family caregivers of deceased older adults (>55 years of age) making use of a posted self-administered questionnaire. Comparing our sample of 163 deceased older adults with all deaths in the Netherlands of individuals aged 55 and over in the same year, we found that while our sample was comparable with regard to gender, it did include fewer individuals over 80 years of age in comparison with the total number of deceased in the Netherlands in that

year. Since we found that old age is positively related to death with dignity according to family caregivers, it may be that the reported 69% of older adults with a dignified death according to family members is a lower percentage than that which would be found in a larger population. The underrepresentation of individuals 80 years old and over in our population is not likely to have influenced the analysis of factors associated with dignity, however.

## **THEORETICAL REFLECTIONS ON PERSONAL DIGNITY**

The introduction of the concept 'dignity' in the field of healthcare has not been without criticism. Sceptics of the concept argue that it is poorly defined, ambiguous and vague, even to the point of being little more than a clichéd rhetorical device (e.g. Macklin, 2003; Agich, 2007). However, conceptual analysis has since yielded a certain amount of definitional clarity, making dignity a more versatile concept (e.g. Nordenfelt, 2004; Jacobson, 2007). Furthermore, empirical research tapping into patients' experiences with regard to dignity shows that the concept has true content and meaning in the everyday world.

Some authors maintain a reductionist view on dignity, arguing that dignity means nothing more than having autonomy (Macklin, 2003). This thesis, however, has shown that personal dignity is a multi-faceted concept that cannot be replaced by other terms. Dignity includes many other well-established concepts, such as autonomy, self-perceived burden and stigmatization, all of which relate to the individual's sense of personal dignity. Dignity as a concept includes all of these themes, but which themes are relevant and prioritized differs between individuals. Reducing dignity to one of its components denies its complexity and multi-faceted nature. Furthermore, dignity cannot be replaced by inner concepts such as self-esteem because dignity comprises both an internal and external component, i.e. personal dignity is based both in internal individual experience and granted externally by others within social relationships.

Our research has demonstrated the importance of the social environment for patients' sense of dignity. This is also expressed in our model in which the social takes a prominent place in the form of the relational and societal self. Some authors argue that dignity is always a relational concept. De Lange, for example, claims that we should not consider dignity as a personal attribute, but as something established in relationships between people (De Lange, 2010). In his view, personal dignity is realized by the recognition of others and therefore loss of dignity can never be solely a subjective experience - only when an individual loses value in the eyes of others has he lost his personal dignity. To regard dignity as something that is bestowed within a relationship,



from one person to another, rather than something that depends on certain personal attributes such as the ability to care for oneself, does solve the problem of dignity in individuals who are impaired and, for example, lack autonomy, e.g. those suffering from dementia. However, as this thesis has shown, personal dignity is not only something that is given by others, in interpersonal relationships or a care situation. A sense of personal dignity also depends on how an individual feels about himself and on how he manages to cope with the disease experience. Regardless of what others say, one may still feel unworthy if one does not live up to one's own expectations.

Our study has shown that most people are resourceful in finding ways of maintaining their sense of dignity and giving new meaning to their lives. Precisely because dignity cannot be reduced to its separate components, individuals can remain dignified even though they are dependent or lack full autonomy, for example. We found that patients are capable of recognizing that there are multiple sources of dignity and tapping into these sources to improve their lives. Disconcerting, however, is that the high value our society typically places on characteristics such as independence and autonomy when this leads to the perception of the ill, infirm or elderly as being less worthy. We are, as De Lange points out, responsible, if only to a certain degree, for influencing the other's sense of dignity and should, as a society perhaps review our values and their consequences.

## **IMPLICATIONS AND RECOMMENDATIONS FOR CARE PRACTICE**

This thesis aims to contribute to a further understanding of how patients experience their daily lives while suffering from a severe chronic or life-threatening illness. By maintaining a focus on personal dignity it has explored possible psychological or existential suffering as well as the resilience to preserve a sense of meaning and worth. Listening to the accounts of individual patients about what it is like to live with a serious disease is important for gaining better insight into how to assist patients and their partners throughout the trajectory from diagnose to death. Non-medical issues of patients living at home, such as existential distress, may not be noted by healthcare practitioners. This thesis aims to raise awareness among those involved with seriously ill patients of the patient's inner world, and makes an appeal for a stronger focus on the psycho-social aspects of care, in addition to medical care. Suggestions on how healthcare practitioners and family caregivers can assist those with a serious illness to help them preserve their sense of personal dignity are also given below.

### ***Helping patients to maintain personal dignity***

Others can make a substantial and positive contribution to the coping process through which the patient tries to come to terms with the numerous losses and life changes that disease can bring about, and help them accept changes to their identity and adjust their aspirations. Sharing concerns with family members around issues such as altered roles and feeling useless or like a burden offered some patients relief and eliminated some of their concerns. Some patients benefitted from professional psychological guidance on the road to accepting a new way of life. The Dignity Therapy developed by Chochinov et al. (2005), which is aimed at enhancing or restoring the sense of dignity in patients nearing death and helping them to achieve closure, is one possible means of helping patients further. Some patients responded positively to the reassurance they received from discussing possible future scenarios and practical ways of maintaining dignity with physicians or nurses. This suggests that both informal and formal caregivers can make a substantial contribution to restoring dignity in patients suffering from illness by communicating about concerns and issues pertaining to the patient's sense of dignity. As demonstrated earlier, individuals differ as to which aspects of life and care treatment they value most with regard to their dignity. Communication with patients about their dignity-related concerns is necessary to delivering individualized care, tailored to the specific needs and concerns of the individual patient. Our Model of Dignity in Illness may serve as a useful tool for care professionals who are looking for a practical guide when addressing dignity-related concerns with patients by suggesting possible relevant topics.

Dependency on others is a potential risk factor for the patient's personal sense of dignity. This thesis has demonstrated that dependency is accepted more readily if professional and family caregivers show respect for the patient's sense of agency and autonomy. Caregivers should give patients choices, thoroughly inform them, and take their wishes into account when possible. Additionally, caregivers should recognize that many patients feel a need to reciprocate in order to balance the relationship; they should be given opportunities to do so and thus maintain their sense of dignity. Individuals receiving care should be treated as worthy individuals rather than as impaired and needy patients, individuals who, in their own way, can still give and not just receive.

This thesis has shown that patients suffering from mild to moderate dementia are able to maintain their sense of dignity. Continuing to live at home as long as possible can play an important role. Social withdrawal can be seen as part of a comprehensive coping strategy for those with dementia, aimed at avoiding situations in which they might fail, thus protecting their sense of personal dignity by not exposing themselves to potential humiliation. Some authors have emphasized that staying active and socially involved is important for individuals with dementia and should be stimulated by caregivers to prevent a passive and isolated lifestyle (Harris and Durkin, 2002; Sørensen et al., 2008). While being engaged in meaningful and useful activities was mentioned by our participants as

important in sustaining their personal dignity, at the same time they chose to discontinue certain activities outside the home environment. Caregivers must recognize and respect the positive benefits of social withdrawal in maintaining personal dignity as perceived by the individual, and consider the complexity of this aspect when developing programs for individuals with dementia who require care.

### ***Symptoms of illness and personal dignity***

An important aspect of the Model of Dignity in Illness is that illness symptoms have an indirect effect on patients' sense of dignity, i.e., it is not the illness itself but rather its consequences that may pose a threat to dignity. Thus, while addressing symptoms is highly important from a medical perspective, focusing merely on symptom management and medical care seems insufficient in guaranteeing the maintenance of patients' dignity, influenced as it is by the psycho-social dimension. Thus, social and psychological care may also be required.

Although symptom management plays a major role in palliative care, it is insufficient for ensuring a dignified death. From the perspective of family caregivers, attending to the psycho-social well-being of the patient is at least as critical as addressing physiological concerns with regard to a dignified death. Clear communication between the attending physician, patient, and family regarding the patient's wishes in terms of treatment and end-of-life care appears to enhance the likelihood of a dignified death as perceived by family caregivers. Such communication can make the final phase of life more comprehensible and foster a greater sense of control for both the patient and the family caregiver during turbulent times. Raising awareness among healthcare professionals that preparedness for death is an integral aspect of a dignified death - both to patients and the surviving relatives - is important, especially since research has shown that many physicians still find it difficult to address the topic of dying and struggle with the decision of when to broach the subject (Cherlin et al., 2005; Wenrich et al., 2010).

### ***Changing healthcare policies***

In the Netherlands, major reforms to the healthcare system are currently being carried out. One of the goals, aimed mainly at cost reduction, is to decrease the number of individuals in care facilities by having them to live at home as long as possible. While the main objective of this policy is to lessen the financial burden of institutionalization, it may have other benefits as well. The results of our research show that being at home in one's own environment, surrounded by loved ones, is one of the key factors in sustaining a sense of personal dignity in patients. These benefits, however, can only be realized when certain conditions have been met. Good home care is essential.

In 2013, the Dutch government announced the move away from the welfare state (*verzorgingsstaat*) toward a 'participation society' (*participatie samenleving*) (Troonrede, 2013). One practical aspect of this new society is that citizens of the Netherlands will have to rely more on each other than on state-funded and subsidized care and assistance. As a result of cost cutting measures, the provision of care is shifting from professionals to untrained volunteers and depends on the willingness and ability of family, friends, neighbors and even strangers to fill the gap left by the reduction of professional care workers. Those who require long-term care, among them older individuals and/or those in poor health, are expected to become more self-reliant; first it is assessed what individuals themselves can do and what informal carers can do for them, thereupon it is assessed if professional care is needed.

The introduction of the participation society has a number of consequences for those who are dependent on long-term care and their sense of personal dignity. First of all, as this thesis has shown, the way in which society perceives individuals requiring long-term care can influence their self-perception and feelings of self-worth. Limiting right to professional care and emphasizing the financial costs of healthcare convey the message to care recipients that their needs form a burden for society as a whole to bear. Furthermore, the assumption that (unpaid) long-term care is readily and easily available to patients from within their own circle of family and friends can be seen to contain the hidden message that the patient has perhaps been too lenient on themselves when appealing to the state for care and assistance. Messages like these, implied by the ideology of the participation society, can make patients feel undervalued by society and anxious and insecure about their future. Now that the welfare state has come to an end, concerns may rise implied by the ideology of the participation society about further policies with regard to healthcare and a further degradation of healthcare services. It can make patients feel that their faith is dependent on the good will of society, instead of on a right to care.

Secondly, the new policy has far-reaching consequences for the interpersonal relationships of care recipients. Although the Dutch government makes a strong appeal to its citizens to take responsibility for each other, western society has become a highly individualistic one in which people lead busy lives and where taking care of each other is far from a matter of course. Furthermore, providing informal care can only be organized on a voluntary basis and thus can never be a reliable substitute for daily long-term professional care. While professional care is paid for, informal care must be requested. This means that patients, and older people requiring care, will be forced to appeal to others to volunteer their time and effort. This puts a strain on relationships and can be a humiliating experience for those dependent on care.

In cases where a network of close family and friends is unavailable as a substitute for professional care, patients will have to rely on help from individuals with whom they do not have a close relationship. Being assisted with intimate bodily care can be an embarrassing experience for both parties, as opposed to be helped by a professional who is trained to do the job. As this thesis has shown, patients strive to maintain an appearance of normalcy, and in doing so try to conceal certain things from others. This image falters when others are called in to provide care, allowing them to see through the facade. As has been demonstrated, being dependent on others can diminish one's sense of dignity, especially when there is no opportunity for reciprocation; it can be embarrassing or even painful for patients to request help from people who are not close to them, or to burden family and friends with the responsibility.

Even when a solid social network of family members is in place, relationships between family caregivers and patients may not always be amicable. Our research reveals a generally positive picture, but negative emotions and interactions may well occur because of personal differences, unpleasant or painful incidents from the past, and the like. Also, dependency on the care of informal caregivers can put a strain on relationships when potential caregivers don't have the time, don't live nearby, or lack the resources and/or motivation to provide care. Professional care relations do not have these drawbacks.

It is therefore extremely important from the perspective of maintaining dignity in patients that sufficient professional care is available in cases where a suitable social support network is lacking, or where the patient's sense of personal dignity is severely compromised by having to rely on their social network. Thus, when deciding whether those in need of care can remain at home and what type of professional care is required, not only should the functional capabilities of the care recipient be taken into account, but also the existence or lack thereof of a solid support network. Both the patient and the members of his or her support network must be willing and able to make the care arrangement work in order for it to be a feasible and satisfactory solution.

### ***Society***

This thesis has shown that people with serious chronic or life-threatening illnesses feel that they are often stigmatized and treated without respect, unconsciously or consciously, in a variety of social settings. If we consider all people, regardless of their perceived shortcomings, to be worthy of dignity and respect, we must rethink our views and values with regard to the ill, infirm and elderly and initiate a discourse through various channels ranging from the media to schools and healthcare.

## MAIN CONCLUSIONS

- Personal dignity is not diminished by illness itself but by its consequences, which are partly individual and partly social. The consequences of illness can be influenced, and thus patients' sense of personal dignity can be influenced.
- Symptoms of illness affect the sense of self at three ontological levels: the individual, the relational and the societal level.
- Remaining in the home environment can protect dignity, but only if a strong supportive network is available and adequate professional care is offered. In cases where either or both are lacking, the individual's sense of dignity can be undermined by negative feelings, e.g. feeling like a burden to others, feeling ashamed at having to ask for help from people one does not know well, and feeling isolated and worthless.
- In the case of dementia, the home itself and being among familiar people one trusts help to maintain identity and dignity. Proper support for family home caregivers must be available to make it possible for patients to live at home as long as possible. Sometimes, however, institutionalization is unavoidable. A home-like framework within the institution appears to be a good substitute for the dignity-sustaining care otherwise provided by partners.
- Individuals suffering from severe chronic or life threatening illnesses are often treated without understanding and respect which undermines their sense of personal dignity. Creating social awareness and improving education on this point are important.
- Many aging individuals have a deep fear of dementia before being diagnosed with the disease, or in the early stages; they see dementia as a highly undignified condition. Once the disease has been diagnosed, individuals struggle to maintain their sense of personal identity, but as the disease progresses, many find ways of coping and ultimately do not feel undignified.
- Mental preparedness for death on the part of family caregivers and patients themselves increases the likelihood of a dignified death. Clear communications from physicians and healthcare professionals on treatment options and the nearness of death during the final trajectory, as well as psychological support in finding closure further contribute to death with dignity.

- Maintaining dignity is a process of continuous adaptation. Others can provide valuable support during this process, especially when patients have difficulty coping with the disease experience.
- The manner in which care is provided can have a profound effect, either positive or negative, on the patient's sense of personal dignity, and thus on their overall health and well-being. Caregivers must become aware of the far-reaching impact their care has and treat patients with sensitivity.

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