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THE DEVELOPMENT OF A MODEL OF DIGNITY IN ILLNESS BASED ON QUALITATIVE INTERVIEWS WITH SERIOUSLY ILL PATIENTS

ABSTRACT

Background While knowledge on factors affecting personal dignity of patients nearing death is quite substantial, far less is known about how patients living with a serious disease understand dignity. **Objective** To develop a conceptual model of dignity that illuminates the process by which serious illness can undermine patients' dignity, and that is applicable to a wide patient population. **Design** Qualitative interview study. **Participants** 34 Patients with either cancer, early stage dementia, or a severe chronic illness were selected from an extensive cohort study into advance directives. **Method** In-depth interviews were carried out exploring the experiences of seriously ill patients with regard to their personal dignity. The interview transcripts were analyzed using thematic analysis and a conceptual model was constructed based on the resulting themes. **Results** We developed a two-step dignity model of illness. According to this model, illness related conditions do not affect patients' dignity directly but indirectly by affecting the way patients perceive themselves. We identified three components shaping self-perception: (a) the individual self: the subjective experiences and internally held qualities of the patient; (b) the relational self: the self within reciprocal interaction with others; and, (c) the societal self: the self as a social object in the eyes of others. **Conclusions** The merits of the model are two-folded. First, it offers an organizing framework for further research into patients' dignity. Secondly, the model can serve to facilitate care for seriously ill patients in practice by providing insight into illness and dignity at the level of the individual patient where intervention can be effectively targeted.

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INTRODUCTION

During recent decades, medical advancements have taken flight, resulting in numerous forms of life-prolonging intervention and treatment. One of the potential side-effects of this medical progress is that patients with serious illnesses tend to live longer, often in ill-health, and are frequently confronted with the harsh reality of physical deterioration of the body, loss of functional ability and dependency on others. These illness-related conditions may give rise to existential distress and loss of personal dignity (Nordenfelt, 2004; Jacobson, 2007). Patients whose personal dignity has been shattered, frequently feel that they are no longer of any value and that their lives have become meaningless (Chochinov et al., 2002) or even unbearable, sometimes resulting in the desire to terminate life prematurely (Jansen-van der Weide et al., 2005; Georges et al., 2006; Ganzini et al., 2007). It is not surprising that in forms of healthcare focused on a holistic sense of wellbeing and aimed at avoiding either the hastening or the postponing of death, preservation of dignity until the end of life has become a major concern (Jacelon et al., 2004; Griffin-Heslin, 2005).

Research on patients' sense of dignity has primarily focused on the end-of-life stage, investigating how terminal patients in the last months of life understand dignity (e.g. Duarte Enes, 2003; Hack et al., 2004). Based on the experiences of terminal cancer patients, Chochinov and colleagues have developed a "Dignity Conserving Model" in which themes affecting the sense of dignity of terminal patients are specified (Chochinov et al., 2002). The model serves as a basis for "dignity therapy", aimed at enhancing or restoring the sense of dignity in patients nearing death and helping them to achieve closure (Chochinov et al., 2005).

While both dignity conserving care at the end of life and death with dignity are of major importance, living life with dignity from the diagnosis of a serious, chronic illness onward is worthy of attention as well. Receiving the diagnosis of a serious illness is a pivotal experience for most people, one that turns normal life upside down, causing a fundamental shift from being a healthy individual to being a "patient". During the journey through the illness trajectory, concerns about personal dignity may well arise.

The scarce knowledge on how patients perceive dignity comes from a small number of studies among older nursing home residents whose measure of dignity may be at risk due to their dependency on others, their fragile condition, and/or illness (e.g. Pleschberger, 2007; Gallagher et al., 2008; Hall et al., 2009). In addition, a number of Scandinavian studies have investigated how chronic illnesses such as multiple sclerosis and fibromyalgia, characterized by invisible symptoms such as fatigue and pain, have a bearing on the sense of dignity of those affected (Soderberg et al., 1999; Slettebø et al., 2009; Lohne et al., 2010). The knowledge accumulated thus far is rather fragmented and differing terminologies are used.

The aim of our study was to develop a conceptual model of dignity, applicable to a wide patient population, that illuminates the process by which serious illness can undermine the patient's sense of dignity throughout the illness trajectory, from diagnosis onward. To this end, we conducted in-depth interviews with a population of patients suffering from serious illness that was diverse both in terms of type of illness and stage of illness.

METHODS

Context of recruitment for the qualitative study

The seriously ill patients participating in the qualitative study on dignity were recruited from an extensive cohort study into the practices of advance directives (ADs) in the Netherlands (Van Wijmen et al., 2010). An AD is a written statement that reflects the individual's wishes regarding end-of-life care and medical treatment, formulated in advance in anticipation of a future situation in which the individual will no longer be capable of making his or her wishes known. A cohort of 6824 individuals with an AD was recruited through the two organizations that provide most of the common standard ADs in the Netherlands: the Right to Die-NL (NVVE) ($n=5561$) and the Dutch Patient Association (NPV) ($n=1263$). Respondents received a questionnaire every 18 months, with a follow-up of 7.5 years (see van Wijmen et al. for a detailed description).

Sampling

From this cohort, we selected a sample of individuals with serious illnesses for our qualitative study on dignity. We included three different patient groups: patients with cancer, patients with early-stage dementia, and patients with severe chronic illnesses, such as Crohn's disease, HIV and spasticity (see Table 1). Only individuals who had indicated on the AD questionnaire that they were willing to participate in an interview study were selected. Patients were selected by the first and second author, in consultancy with the research team, following the principles of purposive sampling. Maximum variation (Patton, 1990) was obtained by selecting patients in a way that guaranteed variation in type of illness and in phase of illness, thus obtaining variation in the degree of potential threats to dignity (e.g. patients in the final stage of illness and patients with severe chronic illness in a non-critical phase). Also, we selected those cases that seemed of interest to our study based on the answers provided on the dignity scale in the AD questionnaire. For example, we selected patients who were severely ill and functionally impaired but who still rated their dignity as fully intact (on a 10-point scale), as well as patients who, at the other end of the spectrum, had indicated that their dignity had severely diminished since the onset of their illness.

Patients received a letter explaining the content and purpose of the interview study, followed by a phone call one week later to ask whether they were willing to participate in the study. Fifty patients were approached. Sixteen patients were unable to participate or declined. The main reasons for decline were: not feeling well enough either mentally or physically to participate, finding it too confrontational to talk about their illness, having difficulty communicating, or being too cognitively impaired. Our final sample consisted of 34 patients. Twelve patients (mean age=67) had cancer of various types, eight patients (mean age=74) had early-stage dementia, and fourteen patients (mean age=72) had a variety of chronic illnesses. Both sexes were equally represented. Of these patients, 7 had an AD registered with the NPV, and 27 had one or more ADs with the NVVE. The participating patients resided in different geographical regions in the Netherlands, in both rural and urban areas. The interviews took place in 2008 and 2009.

Table 1. Characteristics of the patients

Patient	Sex	Age range	Illness
<i>Patients with cancer (n=12)</i>			
1	Man	≥ 85	Prostate cancer
2	Man	45-64	Multiple myeloma (Kahler's disease)
3	Man	65-84	Multiple myeloma (Kahler's disease)
4	Woman	45-64	Colon cancer
5	Man	65-84	Myelofibrosis
6	Man	65-84	Cancer in stomach
7	Woman	65-84	Skin cancer (malignant melanoma)
8	Man	65-84	Lung cancer, metastases
9	Woman	65-84	Lung cancer and skin cancer
10	Woman	65-84	Lung cancer
11	Woman	45-64	Throat cancer, thyroid and skin cancer
12	Woman	45-64	Brain tumor
<i>Patients with early-stage dementia (n=8)</i>			
13	Woman	65-84	Dementia, non-specified
14	Woman	65-84	Alzheimer's disease
15	Man	65-84	Dementia, non-specified
16	Woman	45-64	Pick's disease (inheritable type)
17	Man	45-64	Alzheimer's disease (with early-onset)
18	Man	65-84	Dementia, non-specified
19	Woman	≥ 85	Dementia, non-specified
Patient	Sex	Age range	Illness
20	Woman	≥ 85	Damage of the brainstem*
<i>Patients with chronic illnesses (n=14)</i>			
21	Woman	25-44	HIV, hepatitis C

22	Woman	45-65	Spasticity (spastic tetraplegia)
23	Man	65-84	Crohn's disease, heart failure (pace-maker)
24	Woman	65-84	Parkinson's disease, depression
25	Woman	65-84	Rheumatism, sciatica, Parkinson's disease, heart failure
26	Man	≥ 85	Thrombosis, colon partly removed after cancer
27	Man	65-84	Diabetes mellitus
28	Man	65-84	Heart defect, depression
29	Woman	65-84	Balance disorder, lung problems after cancer
30	Man	45-65	TIA, depression, memory problems
31	Man	65-84	Diabetes mellitus, Parkinson's disease
32	Man	65-84	Strokes, Parkinson's disease
33	Man	25-44	Crohn's disease
34	Woman	≥ 85	Blindness, arrhythmia

* not diagnosed with dementia, but suffering from cognitive decline as well

Data Collection

The in-depth interviews were carried out in the patients' home. During some of the interviews with patients with early-stage dementia, a familiar individual was present to support the patient and, if necessary, to assist in answering the questions. Duration of the interviews varied between 60 and 120 minutes. The interviews consisted of open-ended questions and were guided by a short list of topics providing cues. We encouraged patients to recall their experiences by starting with the open-ended question: "What is your personal understanding of 'dignity'?" Another question that addressed the topic of dignity was: "At the moment, do you feel dignified and why, or why not?". Other topics addressed in the interviews were whether patients recalled positive and/or negative incidents related to their sense of dignity, and what future concerns patients had with regard to dignity and death with dignity. We followed up on the answers provided by the patients with further questioning. We made sure not to introduce or suggest themes ourselves, but continued with the themes and terms provided by the patients during the interview. Patients differed in their ability to reflect and communicate articulately on the subject. Some patients had well thought out concepts of dignity and spoke with ease, whereas others required a certain degree of encouragement to discuss the topic in terms of their own thoughts and experiences.

The interviews were performed by the first author and by a second, trained interviewer. All interviews were audio-taped and transcribed verbatim. The first author listened to all interviews while reading the transcript in order to gain a sense of the expressive content of the interview as well as to ensure textual accuracy. Additionally, the content of the interviews and the field notes containing impressions and observations were discussed

with the second interviewer. The transcripts of the interviews then served as data for analysis.

Data Analysis

We conducted a thematic analysis to identify themes within the data and to establish meaningful categories, their relation to each other, and to the core concept of "personal dignity" (Boyatzis, 1998; Braun & Clarke, 2006). In the first phase of rudimentary data analysis, the first author thoroughly read the interviews several times to become familiar with the data. A case summary was written on each interview, expressing the essence of the interview with regard to the research question. This phase of analysis provided the authors with a first impression on the content of the interviews and served as preparation for the second phase of systematically coding the data with the aid of Atlas/ti software. Following an open coding procedure (Strauss & Corbin, 1990), key passages in the interviews were coded for identification and classification. Next, we conducted an across-case analysis in which every code was analyzed through a careful exploration of all text fragments associated with the code. This analysis gave us a deeper understanding of the content of the codes and resulted in collating the codes into broader themes. Next, we integrated the themes into a meaningful conceptual framework in response to the research question "how does personal dignity get affected"? Four main categories, capturing all themes, were established taking into account their interrelatedness to each other and to the core concept of personal dignity. These interpretative analyses resulted in the construction of the "model of dignity in illness". In the final phase, the constructed model was validated. The interviews were reread while tracing the narratives of the patients throughout the model for a final evaluation of its accuracy and comprehensiveness.

Rigor

Inter-subjective reliability was sought throughout the analytic process. The interview transcripts, case summaries and evolving code list were discussed by a research team consisting of six experienced qualitative researchers. Also, the development of the categories and the model were extensively discussed, integrating multiple views. Reliability was also enhanced by requesting a member of the research team (M.G.O.V.) to code several of the interviews with the established code list. This revealed a high consensus between the two researchers. Discrepancies led to a more precise definition of some codes and resolved the issue of selective attention. Memo writing kept track of the theoretical insights and considerations. Constant comparison (Glaser & Strauss, 1967) was used to maintain a close connection between the data and codes. The number of

participants was sufficient to obtain saturation; the analysis of the last interviews revealed no significant new insights. Furthermore, we checked to ensure that the categories were representative of the data and captured all of the main topics brought forward in the patients' interviews. Finally, we verified the developed model with the data.

Ethical Considerations

The Medical Ethics Committee of the VU University Medical Center approved the study. Written informed consent was obtained from all patients before the interview started. The transcripts of the interviews were anonymized.

RESULTS

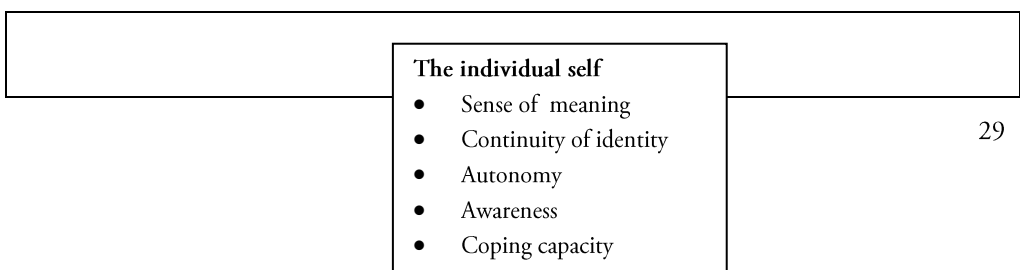
The model

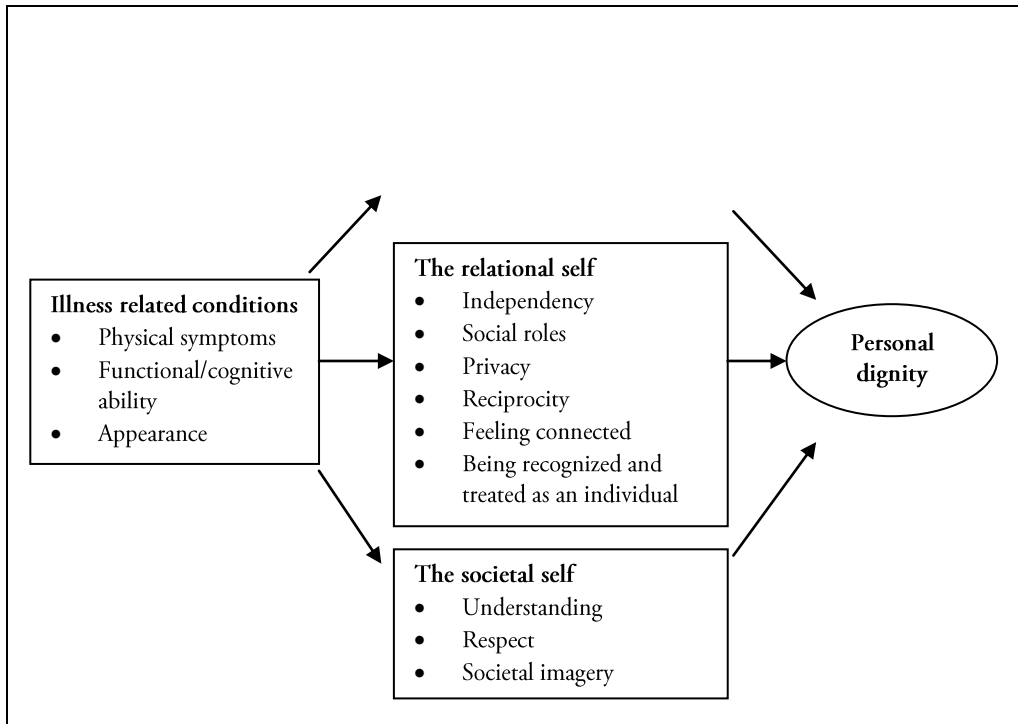
The "model of dignity in illness" illuminates how serious illness may affect the sense of personal dignity of patients. First, we will explain the workings of this model. Subsequently, the themes within the model will be illustrated by quotes from the interviews.

The concept of personal dignity

In the model (Figure 1), dignity is depicted as the result of the presence and interplay between a number of possible factors. The concept of dignity refers to 'personal' or 'subjectively experienced' dignity, a type of dignity that has emerged rather recently. It describes dignity as something that is subjectively experienced by an individual (Nordenfelt, 2004; Leget, 2013). This type of dignity can be distinguished from two other, long-established types of dignity: human dignity, which is considered intrinsic to human kind (Kant, 1981) and which is associated with human rights, and dignity that refers to social position and status (Cicero, 1991), associated with social ranking within society. Personal, or subjectively experienced, dignity relates to existential issues. Loss of personal dignity can diminish one's self-esteem and perceived meaning of life. Serious illness can have a profound negative impact on personal dignity and, as such, the construct of personal dignity is highly relevant within the context of (palliative) care.

Figure 1. Model of Dignity in Illness





The development of the model of dignity in illness

Analyzing the interviews, it became apparent that the sense of personal dignity of seriously ill individuals takes shape within a number of different contexts: in the personal, individual experience of the patient himself, in the relationships the patient has with significant others and healthcare professionals, and in the encounters the patient has with society at large. Thus, in addition to individual experience and perceptions, social aspects are important for the seriously ill patient's sense of dignity. This dual construct of personal dignity – determined on the one hand by personal, inner reflection and on the other by the acts and attitude of others – has been noted in a number of empirical and theoretical studies, leading to the creation of the concept of intrinsic and extrinsic dimensions of personal dignity (e.g. Spiegelberg, 1970; Gallagher et al., 2008; Jacobson, 2009).

The finding that social aspects, as well as individual aspects, are essential to the individual's sense of dignity gave direction to the development of "the model of dignity in illness" proposed here. In the model, three domains of the self are proposed, relating to either the intrinsic or extrinsic dimension: (1) the individual self, relating to the intrinsic dimension, (2) the relational self and (3) the societal self, both related to the extrinsic dimension. 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. The relational self refers to the individual's sense of dignity as formed within dynamic and reciprocal interactions. 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.

Secondly, we investigated the process by which serious illness can affect dignity. Our data suggests that it is not the illness itself that leads to feelings of diminished self-worth. This was the case regardless of type of illness. Rather, changes in the body and mind of the patient as the result of the illness lead to subsequent changes in the patient's personal and social circumstances, which, in turn, can undermine the patient's sense of dignity. This two-staged process is illustrated in the model presented here.

Patient experiences

Below, we give voice to the patients, detailing their experiences of the ways in which illness affected their sense of personal dignity within the different domains of self depicted in the model.

The Individual Self

When asked to define their understanding of dignity, patients associated the term with their own personal identity, with *being* a certain way: they described the kind of person they need to be in order to maintain a sense of dignity and which basic qualities must remain intact in order to achieve this. A patient with Alzheimer's disease expressed it thus: *"There is a little part of yourself, of your very own self, that has to keep functioning, otherwise to me life would be ... awful."* (patient 14). Patients tended to experience a shift in identity during the transition from a healthy, able-bodied individual into a "patient". A number of patients felt their identity was affected by the symptoms of their illness to such an extent that their sense of dignity had, in fact, diminished. For some, the symptoms of their illness limited their activities and former roles to the extent that they no longer felt capable of expressing their true selves, as in the case of an older chronically ill patient who wondered: *"Is this still me?"* (patient 23). Some patients reported that their bodies had become unreliable and even, in some instances, unrecognizable to themselves, as is the case of a middle-aged woman suffering from severe spasms:

"Well, just the fact that it takes me two hours to get into bed. I think that's really terrible, especially since I'm ill and then I see myself...it's like watching myself from above and I see how I'm struggling to get into bed, and I start to shake all

over and then I ask myself what in the world am I doing? I find it all very undignified...". (patient 22)

In addition to the sensation of feeling trapped in a diseased body that prevented the expression of one's true identity, patients reported changes in their behavior as a result of their illness. A man within his fifties suffering from cancer expressed that he was disappointed in how he handled his illness and that he perceived his own behavior as out of character and undesirable:

"My dignity has diminished as I have become more emotional, more unstable and impulsive because of the illness and the medication. Sometimes I think I'm over-reacting and I regret my behavior afterwards. I used to be self-composed, able to handle things..." (patient 2)

Other fundamental qualities that patients cited as a prerequisite for a basic sense of personal dignity were: a sense of autonomy, i.e. being in control of one's situation and one's body and mind, and, secondly, at least a minimal cognitive awareness needed to communicate and express oneself. In addition, patients added that in order for their lives to be dignified, life had to hold meaning and a sense of purpose.

In the face of the challenges brought about by serious illness, many patients exhibited resilience and found ways to adapt to their situation and, hence, shielded their sense of dignity against the potentially detrimental effects of being seriously ill. Dignity was maintained through the following coping strategies: rationalization, humor, spiritual belief, acceptance, compensation and adaptation to one's situation.

The Relational Self

Illness brought about changes in the relationships patients had with significant others in their lives. Individuals who had once been the head of the family or the caretaker, now found themselves in a dependent role. Dependency on others and the inability to fulfill certain social roles was difficult to bear for most patients, and many struggled to accept this new reality.

Being of value to significant others was seen by most patients as crucial to the maintenance of dignity. Almost all patients felt a deep need to be able to make a meaningful contribution to the lives of others. To be able to reciprocate and balance the relationship, for example to be able to provide comfort and wisdom as a counterweight to receiving care, greatly enhanced patients' sense of dignity. Moreover, the feeling of being in a relationship of equality alleviated the sense of being a burden to others. A woman

with early-onset Alzheimer's did not feel her sense of dignity had been lessened by being dependent on the intensive assistance provided by home care workers:

P: With the people from the home care service it's always an exchange. They tell me something, I tell them something, it's... I: Give and take? P: Yes, and it's like a bond, too, and... sometimes they're wrestling with a problem, so tell me all about it. And if you can't help people that way anymore, why do you still exist? (patient 16)

Significant others were capable of contributing to patients' dignity by giving the patient a sense of connectedness and belonging. Also, being included in a social group of family and friends, or with a community, or with those in similar circumstances, and having the ability to participate in shared activities could enhance feelings of acceptance and of normalcy. A relatively young patient with early-onset Alzheimer's disease found that his sense of dignity had grown since joining an Alzheimer's support group:

"I owe that to the Alzheimer's youth group I'm part of, because they treat you with dignity. They don't say "We're going to day treatment", no, they say "We're going to the friend's group". That's a big step in the right direction..." (patient 17)

The fact that others had known the patient as a healthy individual, before the onset of illness, gave patients a sense of continuity of identity with very little sense of shame over their present condition. In answer to the question of what is important in maintaining a sense of dignity, this patient said: *"That they can still see me as the person I once was. Not Mrs. So-and-So, not the patient, no, 'me'."* (patient 16).

Not all patients, however, received sufficient, caring support from their families or social environment. In general, these patients were more troubled about the meaning of their lives and their sense of worth and dignity. Some patients were anxious about becoming a burden to family members and were concerned for their families' welfare.

Patients' dignity was also affected in the social encounters with healthcare professionals. Patients who had been hospitalized for a period of time reported having to face assaults on their sense of dignity during that time. They cited the following as threats to dignity: loss of autonomy, not being informed or taken seriously, general feelings of helpless and powerless, and being powerless to make decisions concerning their own body. This is what a patient with HIV experienced when hospitalized:

P: The first two or three days...that feeling of uncertainty, they just walk right past your bed because they don't have anything to tell you. Just stop for a minute and

say “We’re still doing tests and we’ll let you know as soon as possible”. I: You want them to acknowledge you, to just make contact? P: Exactly. That’s an assurance. You’re already feeling so uncertain just lying there. (patient 21)

This patient continued:

“When you ask for more pain relievers because you just can’t stand it any longer and they tell you can’t have any more, that’s when you really feel...then you think “bastards!” When you get sick, you’re powerless, dependent on others. You just have to submit, you can’t fight it, you just have to go along with it.”

A diminished sense of dignity was noted by some patients who required assistance from others for intimate bodily care. Having to rely on others for intimate bodily care caused shame and was viewed as an invasion of privacy and bodily integrity. An older patient who underwent breast surgery said:

“I never look at my naked body in the mirror any more, that’s how much I hate it. The other day, a very young man came to wash me and I thought “Oh my God, is this really necessary?” I didn’t say anything at the time, but I never want that experience again.” (patient 29)

Sensitive caregiving could help to maintain a sense of dignity in vulnerable situations, i.e. in situations where patients may tend to feel insecure and/or anxious. Patients associated sensitive caregiving with aspects that were the direct opposite of those they associated with the type of caregiving they experienced as an assault on dignity. Being informed about the prognosis of the illness and treatment plans and procedures, being consulted when decisions needed to be made, receiving sufficient attention, not having to wait during times of real need, being recognized and treated as an individual with compassion and respect – all of these were cited as aspects of sensitive caregiving.

The Societal Self

Encounters with others outside the immediate social circle of the patient were often cited as negative experiences that threatened the patient’s sense of dignity. Some patients with overt or external deformations were confronted by insulting remarks about their appearances. For example, patients whose motoric skills were impaired felt that their physical movements were undignified when observed by others. Patients like these tried to maintain appearances and not deviate from the norm. On the other hand, patients with invisible symptoms such as pain, fatigue, or mental decline, stated that, at times, they felt they were not taken seriously by those outside their immediate social circles. This patient

with early-onset Alzheimer's disease described how his dignity was undermined by the reactions of others by which he felt accused of feigning disability:

"You look fine and they can't understand why you're in a mobile scooter, they really can't. People can't understand that you can be sick without looking like it. They don't see anything wrong with me." (patient 17)

A man in his sixties with cancer who suffered from constant fatigue, stated that at times the reactions of others could be "extremely hurtful" and conveyed a lack of understanding and sympathy. Recently, his fatigue caused him to leave a social event early: *"Afterwards, I heard that people said I left early because I wasn't enjoying their company."* (patient 5).

Some conditions made patients prone to stigmatization and potentially to social rejection and/or social isolation. One patient with HIV felt she had to conceal her illness because of general public ignorance with regard to the illness and the social taboo within her small-town community.

Many patients mentioned that to be treated with respect as a worthy individual by others in spite of their illness was important for the preservation of their dignity, as a man with cancer said:

"Dignity is that they treat you with respect; that they talk to you even when you are in a wheelchair, instead of overlooking you." (patient 3)

Patients tried to cope with negative social responses and to re-establish their sense of dignity by adopting an attitude of indifference, or by avoiding the hostile, threatening external world as they perceived it altogether. Many patients stated that they withdrew to their small circle of family and close friends to avoid confrontation with the outside world where they might feel ashamed and judged by the attitudes and responses of others.

Dignity and the self

The stories told by the patients we studied illustrate the ways in which illness can impact the patient's sense of dignity by influencing numerous aspects of the self, both as an autonomous individual and as a social being. What also becomes apparent is that during serious, chronic illness, the patient's sense of self and dignity can be influenced in both positive and negative ways, either bolstering or diminishing the sense of dignity.

In order to gain a better understanding of the aspects and conditions that influence the patient's sense of dignity during serious illness, we can divide these into three domains of self as applied in the model. Looking at those aspects which exert a negative influence on the sense of dignity, we can distinguish the following: (1) at the level

of the individual self: negative ways in which illness factors, conditions and consequences affect the individual self by threatening the patient's sense of identity, meaning, autonomy and awareness; (2) at the level of the relational self: in personal relationships - the inability to fulfill social roles, being dependent, feeling like a burden, and in care relationships - privacy (especially bodily integrity), feelings of powerless, having to submit, not being taken seriously; (3) at the level of the societal self: being stigmatized, stared at, disbelieved, disrespected, judged, standing out or deviate from the norm.

Aspects that have a positive influence on dignity can also be viewed in this way: (1) at the level of the individual self: dignity can be maintained or enhanced by adequate personal coping skills on the part of the patient, e.g. the patient's acceptance of diminished capabilities; (2) at the level of the relational self: in personal relationships - being connected to others, being able to contribute to relationships rather than being a burden, being able to participate in social (family) activities, and in care relationships - respectful, considerate, sensitive caregiving, being properly informed about the illness and treatment, being consulted on important decisions; and (3) at the level of the societal self: receiving respect and recognition as a worthy and competent member of society rather than being seen as a "patient", not being judged negatively based on perceived shortcomings or abnormalities.

DISCUSSION

In this article, a conceptual model of dignity in seriously ill patients has been presented. The model is based on the empirical findings derived from qualitative in-depth interviews among a diverse patient population – in terms of both the type and stage of illness. The model clarifies the relationship between serious illness and the patient's sense of dignity, tracing the various routes from illness to the effects this has on the sense of dignity and highlighting the ways in which serious illness can pose a threat to personal dignity. In doing so, the model specifies how the patient's dignity can be maintained in the face of serious illness.

The merits of the model are two-fold. First, the model offers a broad theoretical framework for further research into a wider, more diverse group of patients than has thus far been available. Secondly, the model can serve to facilitate care for seriously ill patients in practice by providing insight into illness and dignity at the level of the individual patient where intervention can be effectively targeted.

The model has two important implications. First, dignity has an intrinsic and an extrinsic dimension. This duality of the concept of dignity is widely recognized within both empirical and theoretical work on personal dignity (e.g. Jacelon et al., 2004; Nordenfelt,

2004; Jacobson, 2009). It is this extrinsic dimension that sets dignity apart from internally held, psychological feelings, such as pride and self-esteem. We found the extrinsic dimension, the impact of the social world in all its facets, to be of great importance to patients' sense of dignity.

While both our model of dignity during serious illness and the dignity conserving model, based on the study of patients with cancer during the final stage of life, developed by Chochinov and colleagues (Chochinov et al., 2002), recognize the importance of the attitude of care professionals and of social support for the maintenance of patients' dignity, our model extends to include a view of the broader relational and societal domains and provides a detailed description of these.

During the final stage of life, patients tend to withdraw from society, the circle of personal relationships shrinks, and the dependency on care increases. The relational and societal self recede into the background as the individual self takes prominence in the foreground. At an earlier stage in the trajectory, however, patients with a serious illness may still live at home, surrounded by family and friends, and participate in an active social life. The relational and societal self are thus key components in defining their sense of dignity.

Published research findings on the subject of dignity among older and chronically ill individuals substantiates the findings of our study and the model presented here. The importance of the patient's relationships with others for their sense of dignity has been documented in a number of studies. Pleschberger (2007) concluded that the basic prerequisite for the preservation of dignity among nursing home residents was the existence of (dignifying) relationships and encounters, and that residents went to great lengths to avoid jeopardizing these relationships by becoming a burden. According to Franklin et al. (2006), feeling involved and being of value to others gave meaning to the otherwise limited scope of the daily lives of nursing home residents. Baillie (2009) found that for patients in a hospital setting, dignity was enhanced by contact with fellow patients in similar circumstances, and by the establishment and maintenance of good relationships with hospital staff. Remarkably, the staff was largely unaware of the beneficial effects of these relational factors and focused primarily on privacy issues.

A second important implication of the current model 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. This observation is what sets dignity as a construct apart from the concept of 'quality of life' which is more directly determined by the symptoms of illness. That illness effects dignity indirectly is further supported by a quantitative study carried out by Fife and Wright (2000) on the process of stigmatization among patients with HIV/AIDS or cancer. These authors conclude that the overall pattern of their results indicates that both the nature of the illness and the

functional health status of the patient had little direct effect on the patients' self-perception. Rather, the harmful effects of illness manifested themselves indirectly through the stigmas they generated, which, in turn, had a negative impact on the patients' self-perception. Thus, focusing merely on symptom management and medical care seems insufficient to guarantee maintenance of patients' dignity which also appears to be strongly influenced by the psycho-social, and spiritual dimension.

Research on palliative care thus far has focused mainly on the final stages of life and on death with dignity, rather than on living with dignity during a period of prolonged illness. However, the World Health Organization formulated a broader approach to palliative care by stating that it should be initiated as early as possible in the trajectory of any chronic, ultimately fatal illness (WHO, 2002). We believe that research into living with dignity is important for the seriously ill, especially as recent developments in medical science, intervention and treatment can, and indeed tend to, prolong life with illness. More attention should be given to patients' sense of personal dignity throughout the entire trajectory of the disease, from diagnosis onward. Insight into this process may contribute to an understanding of how to guide patients in living the remainder of their lives with dignity. Moreover, early attention to dignity-related concerns may well mitigate future concerns the patient may have and alleviate feelings of anxiety with regard to suffering an undignified death. Prevention of damage to patients' dignity throughout the illness trajectory is paramount; once the patient's sense of dignity has been violated, it can be quite difficult, if not impossible, to regain it during the final, terminal phase. The model developed here indicates that the active involvement of family and friends, an empathic attitude on the part of healthcare professionals, and an educated, enhanced societal awareness can all contribute to bolstering a strong sense of personal dignity in patients with serious illnesses.

Limitations of this study

The model developed here is a preliminary one and requires further testing. Due to the limited size of the sample studied, certain factors (for example, the patients' family situation or their socio-economic background) were not taken into account. Furthermore, our research sample consisted of individuals who had signed an advance directive. Whether patients who have not signed an advance directive understand and experience dignity in the same way, and whether the findings of our study hold true for this population as well, has yet to be examined.

Future longitudinal research in which individual patients are followed throughout the course of their illness may provide insight into the ways in which the patient's sense of dignity may change as the illness progresses. Furthermore, it would be interesting to look deeper into differences between illness groups.

CONCLUSION

Thus far, attention has been primarily given to preserving the dignity of the terminally ill during the final stages of life. However, from diagnose onward, patients undergo tremendous changes to their bodies, minds and their personal and social worlds. Patients must adjust again and again throughout their illness and often feel vulnerable and anxious about what else their illness will bring and, ultimately, about death. High-quality, sensitive professional care and guidance are essential throughout the entire trajectory of illness. Living life with dignity is as important as dying with dignity and could potentially diminish the desire to end life prematurely. This study presents an organizing framework for further research into the dignity of a more general patient group throughout the trajectory of illness.

REFERENCES

- Baillie, L. (2009). Patient dignity in an acute hospital setting: a case study. *International Journal of Nursing Studies*, 46, 23-37.
- Boyatzis, R.E. (1998). *Transforming qualitative information: thematic analysis and code development*. Thousand Oaks, CA: Sage Publications.

- Braun, V., Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Chochinov, H.M., Hack, T.F., McClement, S., Kristjanson, L., Harlos, M. (2002). Dignity in the terminally ill: a developing empirical model. *Social Science & Medicine*, 54, 433-443.
- Chochinov, H.M., Hack, T.F., Hassard, T., Kristjanson, L. J., McClement, S., Harlos, M. (2005). Dignity Therapy: a novel psychotherapeutic intervention for patients near the end of life. *Journal of Clinical Oncology*, 23, 5520-5525.
- Cicero (1991). *On duties*. M.T. Griffin & E.M. Atkins, trans. New York: Cambridge University Press.
- Duarte Enes, S.P. (2003). An exploration of dignity in palliative care. *Palliative Medicine*, 17, 263-269.
- Fife, B.L., Wright, E.R. (2000). The dimensionality of stigma: a comparison of its impact on the self of persons with HIV/AIDS and cancer. *Journal of Health and Social Behavior*, 41, 50-67.
- Franklin, L.L., Ternestedt, B-M., Nordenfelt, L. (2006). Views on dignity of elderly nursing home residents. *Nursing Ethics*, 13, 130-146.
- Gallagher, A., Li, S., Wainwright, P., Jones, I.R., Lee, D. (2008). Dignity in the care of older people – a review of the theoretical and empirical literature. *BMC Nursing*, 7, 11-23.
- Ganzini, L., Goy, E.R., Dobscha, S.K. (2007). Why Oregon patients request assisted death: family members' views. *Journal of General Internal Medicine*, 23, 154-157.
- Georges, J., Onwuteaka-Philipsen, B.D., Van der Heide, A., Van der Wal, G., Van der Maas, P.J. (2006). Requests to forgo potentially life-prolonging treatment and to hasten death in terminally ill cancer patients: a prospective study. *Journal of Pain and Symptom Management*, 31, 100-110.
- Glaser, B.G., Strauss, A.L. (1967). *The discovery of grounded theory: strategies for qualitative research*. Chicago: Aldine Publishing Company.
- Griffin-Heslin, V.L. (2005). An analysis of the concept of dignity. *Accident and Emergency Nursing*, 13, 251-257.
- Hack, T.F., Chochinov, H.M., Hassard, T., Kristjanson, L.J., McClement, S., Harlos, M. (2004). Defining dignity in terminally ill cancer patients: a factor-analytic approach. *Psycho-Oncology*, 13, 700-708.
- Hall, S., Longhurst, S., Higginson, I. (2009). Living and dying with dignity: a qualitative study of the views of older people in nursing homes. *Age and Ageing*, 38, 411-416.

- Jacelon, C.S., Connelly, T.W., Brown, R., Proulx, K., Vo, T. (2004). A concept analysis of dignity for older adults. *Journal of Advanced Nursing*, 48, 76-83.
- Jacobson, N. (2007). Dignity and health: a review. *Social Science & Medicine*, 64, 292-302.
- Jacobson, N. (2009). A taxonomy of dignity: a grounded theory study. *BMC International Health and Human Rights*, 9, 1-9.
- Jansen-van der Weide, M.C., Onwuteaka-Philipsen, B.D., Van der Wal, G. (2005). Granted, undecided, withdrawn and refused requests for euthanasia and physician-assisted suicide. *Archives of Internal Medicine*, 165, 1698-1704.
- Kant, I. (1981). *Grounding for the metaphysic of morals*. J.W. Ellington, trans. Indianapolis, IN: Hackett.
- Leget, C. (2013). Analyzing dignity: a perspective from the ethics of care. *Medical Health Care and Philosophy*, 16, 945-952.
- Lohne, V., Aasgaard, T., Caspari, S., Slettebø, Å., Nåden, D. (2010). The lonely battle for dignity: individuals struggling with multiple sclerosis. *Nursing Ethics*, 17, 301-311.
- Nordenfelt, L. (2004). The varieties of dignity. *Health Care Analysis*, 12, 69-81.
- Patton, M. (1990). *Qualitative evaluation and research methods*. Beverly Hills, CA: Sage.
- Pleschberger, S. (2007). Dignity and the challenge of dying in nursing homes: a residents' view. *Age and Aging*, 36, 197-202.
- Slettebø, Å., Caspari, S., Lohne, T., Aasgaard, T., Nåden, D. (2009). Dignity in the life of people with head injuries. *Journal of Advanced Nursing*, 65, 2426-2433.
- Söderberg, S., Lundman, B., Norberg, A. (1999). Struggling for dignity: the meaning of women's experiences of living with fibromyalgia. *Qualitative Health Research*, 9, 575- 587.
- Spiegelberg, H. (1970). Human dignity: a challenge to contemporary philosophy (p.39-64). In: R. Gotesky & E. Laszlo (Eds.) *Human dignity – this century and the next*. New York: Gordon and Breach Science.
- Strauss, A.L., Corbin, J. (1990). *Basics of qualitative research*. Thousand Oaks, CA: Sage Publications.
- Van Wijmen, M.P.S., Rurup, M.L., Pasman, H.R.W., Kaspers, P.J., Onwuteaka-Philipsen, B.D. (2010). Design of the advanced directive cohort: a study of end-of life decision-making focusing on advance directives. *BMC Public Health*, 10, 166.
- World Health Organization (2002). *National Cancer Control Programs: policies and managerial guidelines*, 2nd ed. Geneva: World Health Organization. <http://www.who.int/cancer/media/en/408.pdf>