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2016

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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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DYNAMICS IN THE SENSE OF DIGNITY OVER THE COURSE OF ILLNESS: A LONGITUDINAL STUDY INTO THE PERSPECTIVES OF SERIOUSLY ILL PATIENTS

ABSTRACT

Background Loss of personal dignity in patients with a serious and progressive disease is associated with psychological suffering and loss of the will to live. Preservation of a sense of dignity in the seriously ill should therefore be a primary concern throughout the illness trajectory from diagnosis onward. However, there is currently limited insight into the dynamics of patients' sense of dignity during the progression of illness. **Aim** This longitudinal qualitative study investigates patients' experiences with dignity over time in a diverse patient population (cancer, early-stage dementia and severe chronic illnesses). **Method** Nineteen patients were interviewed annually (max. 4 years). The 56 obtained interviews were analyzed making use of thematic analysis. **Results** Three different trajectories over time could be distinguished: a) a Dynamic Equilibrium in which the individual's sense of dignity was temporarily diminished followed by a return to previous levels; b) a Downward Trend in which the sense of dignity was diminished with progression of the disease without a return to previous levels; and, c) Stability in which the sense of dignity remained unaltered despite changes in circumstances. **Conclusion** While there appears to be a small group of patients for whom dignity remains unaffected by their disease experiences, most patients go through difficult times during which they struggle to maintain or regain their sense of dignity in the face of progressive loss. This longitudinal study offers insight into the dynamics behind this and reveals why some patients manage to maintain their dignity while others cannot.

Published as:

Isis E. van Gennip, H. Roeline W. Pasman, Mariska G. Oosterveld-Vlug, Dick L. Willems, Bregje D. Onwuteaka-Philipsen. (2015). Dynamics in the sense of dignity over the course of illness: a longitudinal study into the perspectives of seriously ill patients. International Journal of Nursing Studies, 52, 1694-1704.

INTRODUCTION

Loss of personal dignity in seriously ill patients is associated with psychological suffering (Chochinov et al., 2002) and can contribute to the desire for an accelerated death (Jansen-van der Weide et al., 2005; George et al., 2006; Ganzini et al., 2007). Therefore, preservation of personal dignity in patients should be of primary concern in psychosocial and medical care throughout the illness trajectory. This realization has led to a surge of research aimed at identifying factors that may potentially affect personal dignity in patients (Chochinov et al., 2002; Matiti & Trorey, 2004; Van Gennip et al., 2013), whereby personal dignity is understood as a subjectively experienced type of dignity related to a sense of worthiness (Burns, 2008; Jacobson, 2009a; Östlund et al., 2012). Unlike universal human dignity, which is considered intrinsic to humankind (Kant, 1981), personal dignity is contingent and contextual and can be enhanced or harmed by certain events, such as the acts of others or changes to the body and mind (Pullman 2004). Personal dignity has been investigated in different contexts: within the context of palliative care (e.g. Chochinov et al., 2002 and 2008), care for patients with severe chronic illnesses (e.g. Slettebø et al., 2009; Lohne et al., 2010; Van Gennip et al., 2013), acute care for older people (e.g. Jacelon et al., 2004), care for nursing home residents (e.g. Hall et al., 2005; Franklin et al., 2006; Pleschberger, 2007; Gallagher et al., 2008; Oosterveld-Vlug et al., 2014), and within the context of vulnerable and marginalized individuals or groups (e.g. Jacobson, 2009b). This body of research has indicated that personal dignity is not only influenced by the individual disease experience, but that it is also strongly influenced by social interactions with others and the social practices of others. Thus, personal dignity is influenced both by an internal aspect, which is the worth and self-respect one ascribes to oneself, and an external aspect, which is the perceived worth and value ascribed by others.

While there is now substantial research on the subjective understanding of personal dignity in a diversity of vulnerable groups, these studies generally make use of a cross-sectional design, measuring individual's experiences at only one point in time. However, as Chochinov and colleagues have pointed out, perceptions of dignity might be dynamic and subject to change along with fluctuations in the clinical presentations of illness (Chochinov et al., 2002). Evidence pointing toward the direction that the sense of personal dignity is not fixed comes from a longitudinal qualitative study on nursing home residents (Oosterveld-Vlug et al., 2013). This study shows that from admission onward, residents go through different stages that reflect how dignified they felt. However, comprehensive insight into how the development of disease and progression of symptoms may affect personal dignity over time in patients with a chronic and potential life-threatening illness is presently lacking. Insight into these dynamics is paramount in gaining an understanding of how patients try to maintain their personal dignity in the face of progressive changes and losses, and can help in providing proactive and continued dignity sustaining care to patients throughout the trajectory of the illness.

The aim of the present longitudinal qualitative study was to explore whether and subsequently how the sense of personal dignity in patients changes over time with the progression of the disease. Longitudinal qualitative research is especially suitable for exploring evolving and complex processes related to changing experiences and needs of patients over time (Murray et al., 2009). By conducting serial interviews, we aimed to provide insight into the dynamics of personal dignity and to explore whether personal dignity decreases as the patient's condition worsens and whether personal dignity can be restored again once damaged, and if so, how. We followed patients with a variety of diseases (i.e. cancer, early-stage dementia, and severe chronic illness) throughout their illness, exploring how their sense of personal dignity was affected over time.

METHOD

Recruitment and sampling

The participants for this study were recruited from among the 6824 respondents participating in the Advance Directive Cohort Study (ADC study 2007 - 2011), a study focusing on people who had signed one or more advance directives (i.e. a will-to-live statement, a refusal-of-treatment document, an advance euthanasia directive, and/or a durable power of attorney for health care) (Van Wijmen et al., 2010). Respondents were asked at 18-month intervals to fill in a self-administered written questionnaire containing questions about the patient's health status, end-of-life preferences and advance directives.

During the course of the data collection for the ADC study, we selected respondents with serious illnesses for the present qualitative longitudinal study from 2008 onwards. Following the principles of purposive sampling to cover a wide range of disease types with high prevalence, we included three different patient groups: cancer patients, patients with severe chronic illnesses (e.g. Parkinson's disease and Crohn's disease) and patients with early-stage dementia. In addition, maximum variation was sought for age and educational level. Only individuals who had indicated on the ADC questionnaire that they were willing to participate in an interview study were selected. These 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. The study was approved by the Medical Ethics Committee of the VU University Medical Center. Participants granted their written informed consent before the start of the interview. Our final sample consisted of 19 patients; 9 were male and 10 were female, with an age range of 25-90 years (see table 1). The interviews took place between 2008

and 2013. Patients were interviewed at one-year intervals, but in some cases, where the patients health rapidly declined, the interviews took place sooner.

Table 1. Characteristics of patients and number of interviews conducted

P.	Sex	Age range*	Illness	Marital status	Education level	Number of interviews
1	M	65-84	Myelofibrosis, tinnitus, heart disease, PNH	Married	Bachelor's degree	4
2	F	65-84	Dementia (Alzheimer's disease)	Residentia I home	Primary school	3 ^a
3	F	45-64	Dementia (Pick's disease)	Divorced	Vocational education	3 ^b
4	M	65-84	Dementia (non-specified)	Married	Master's degree	3 ^c
5	F	25-44	HIV, hepatitis C	Partner	Vocational education	4
6	F	45-65	Spastic tetraplegia	Partner, living alone	Vocational education	2 ^c
7	M	65-84	Crohn's disease, heart failure, bladder cancer	Widow	Academic degree	3 ^b
8	F	65-84	Rheumatism, sciatica, Parkinson's disease, heart failure	Single	Primary school	2 ^b
9	F	65-84	Malignant melanoma	Married	Basic professional training	3 ^d
10	M	≥ 85	Thrombosis, colon partly removed after cancer	Married	Bachelor's degree	4
11	F	65-84	Balance disorder, lung problems after cancer	Divorced	Vocational education	3 ^e
12	F	45-65	Diabetes mellitus, ME (myalgic encephalomyelitis), asthma	Single	Basic professional training	4
13	M	25-44	Crohn's disease	Partner, living alone	Basic professional training	4
14	M	65-84	Lung cancer, metastases	Married	Bachelor's degree	2 ^b
15	F	45-64	Throat cancer, thyroid cancer and skin cancer	Partner, living alone	Vocational education	2 ^b
P.	Sex	Age	Illness	Marital	Education	Number of

		range*		status	level	interviews
16	F	45-64	Brain tumor	Married	Master's degree	2 ^b
17	M	≥85	Dementia (Alzheimer's disease)	Married	Master's degree	3 ^a
18	M	65-84	Dementia (Pick's disease)	Married	Basic professional training	3 ^a
19	M	65-84	Dementia (non- specified)	Married	Master's degree	2 ^f

* Age at the time of the first interview

^a Too demented to be interviewed again (n=3)

^b Deceased within the data collection period (n=6)

^c Withdrew from study (n=2)

^d Cured (n=1)

^e No longer able to participate (n=1)

^f Could not be located (n=1)

Data collection

The in-depth interviews, lasting from 60 to 120 minutes, were carried out in the patients' homes. The interviews consisted of open-ended questions and were guided by a topic list providing cues. The aim of this study was not to gain an objective understanding of the concept of dignity but to identify the patients' subjective experiences of personal dignity. We encouraged patients to give their personal description of dignity by starting with a broad, open-ended question "What is your personal understanding of 'dignity'?". Patients were also asked: "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 relating to their sense of dignity, and what future concerns patients had with regard to personal dignity and dying with dignity. We followed up on the answers with further questioning. During the follow-up interviews, we repeated the same basic questions; additional questions focused on possible changes and developments in symptoms and disease, and on possible changes in self-perceived dignity. The interviews were performed by the first author and by a second, trained interviewer. All interviews were audio-taped and transcribed verbatim. The transcripts of the interviews then served as data for analysis. The interviews were conducted in Dutch. Quotations used in this article were translated by an experienced translator, fluent in both Dutch and English language.

Data analysis and methodological rigor

The longitudinal analysis reported in this article was based on 56 interviews carried out with 19 participants over a time period of four years. We believe data saturation was reached because similar patterns were found among different individuals and after the

analysis of the majority of interviews no new patterns emerged from the data. Content validity was obtained by making sure that the interviews kept a focus on the core concept of dignity and by checking the relevancy of patients' experiences to their sense of dignity. Furthermore, content validity was enhanced by the longitudinal design which made it possible to further clarify or deepen themes that were discussed in previous interviews, and which enhanced the rapport between interviewer and patients.

We made use of thematic analysis to identify themes within the interviews that were related to personal dignity (Boyatzis, 1998; Braun and Clark, 2006). Data analysis was ongoing throughout the fieldwork which allowed emerging themes and concepts to be further tested and developed in subsequent interviews. We analyzed all transcripts for each respondent as a longitudinal single unit to gain insight into the individual experiences over time. Additionally we used a broad thematic approach to search for similarities and differences between patients (Murray et al., 2009; Thomson & Holland, 2010). During the coding of interviews, special attention was given to text sections in which participants reported changes in symptoms and in their experiences and perception of dignity. We also searched for implicit changes by reading all interviews with each patient as a narrative. Summaries containing the most important themes were written for each patient to provide an accessible insight into his/her experiences.

To assure reliability of the coding procedure, several interviews were independently coded by the first and third author and compared for similarities and differences. Differences in coding were resolved by discussion and led to a refinement of the coding list. Inter-subjective reliability was sought throughout the analytic process by extensive discussion within a multidisciplinary research team, consisting of six researchers experienced in qualitative research. Reflection on the data resulted in the discovery of three different trajectories over time. These were characterized as follows: a) a Dynamic Equilibrium in which the patient's sense of dignity temporarily diminished, followed by a return to previous levels; b) a Downward Trend in which the sense of dignity diminished during the progression of the disease without a return to previous levels; and, c) Stability in which the sense of dignity remained unaltered despite changes in the patient's condition or circumstances.

RESULTS

A number of cases representative of each trajectory is presented in our results. A fluctuating sense of dignity (dynamic equilibrium) was observed in the majority of participants. Some participants experienced a decline in their sense of dignity as their

disease progressed (downward trend), and a few patients exhibited a stable sense of dignity over time (stability).

Dynamic Equilibrium

Most of participants stated that as their illness progressed they found themselves confronted by multiple changes and losses, some of which had directly impinged on their sense of dignity. Perhaps most profoundly felt were those losses that resulted in a change to identity and role fulfilment. As the disease advanced, participants were forced to surrender previously held roles such as caretaker or breadwinner, and were placed in a position of dependency. As former potential sources of dignity, such as gainful employment, social prestige, or pride taken in personal achievements vanished, participants were forced to re-evaluate themselves and the meaning of their lives. Most of the participants were quite resourceful in meeting this challenge and were, at some point during the trajectory of their illness, able to reclaim their dignity through various approaches as illustrated below in a selection of cases.

The following case of a middle-aged man with mild dementia is indicative of how participants struggled to maintain a sense of personal dignity when key aspects of identity are threatened as a result of a progressive disease. During the first interview, this participant struggled with the fact that he could no longer lecture to literary clubs as he used to. Giving lectures was an important part of his life and central to his identity, but he had become fearful of losing face and the decline in the quality of his talks had had a negative effect on his sense of dignity:

I: What affects your sense of dignity at this moment? P: That I can do so little, that I'm no longer participating to the full. I still undertake things, I am trying to do as much as I can, to gain knowledge. I participate in two literary clubs, one is French, I have a French library, the other is Italian and I am trying to keep up. Maybe I'm overdoing it, frantically trying to learn new words and so on. I: The "gaps" in your memory as you called them, is that something that diminishes your sense of dignity? P: Yes, because I'm losing face, in my own eyes [...] And I'm also aware that I'm taking a certain risk by giving lectures, that others hear me putting forth an illogical or incoherent argument. (P19)

However, when we interviewed him again one year later he stated that his sense of dignity had improved somewhat. As a result of his deafness (and not of further cognitive degeneration), he was ultimately forced to give up performing intellectually in public, an activity in which he was painfully confronted again and again with the fact that something of his former self had been lost. With the acceptance of his condition came the realization

that being intellectually active as a private activity gave him back his sense of dignity because, in the end, this was what was really meaningful to him:

I: Last time you rated your sense of dignity at 5; this was mainly due to not being able to perform like you use to. Would it be a 5 again? P: I would say it's a bit higher now, more like a 7. I: And why is that? P: Well, I'm hearing less...I'm getting deaf, so a lot escapes me. And that's actually quite peaceful. I: And this helps...? P: Yes, that helps, yes... . That helps because if you have to pick up on everything, put your ear to the ground everywhere, or if you're being asked about all kind of things, or want to stick your nose into everything...I don't have that anymore; I just do a lot on my own. I read a tremendous amount and I tell myself what I read. On every book, I write two, three pages of commentary; that gives me satisfaction, putting my thoughts on paper. And well, in this way I'm still intellectually active and to me that's the most important thing. (P19)

Another participant, a man in his seventies suffering from multiple diseases, also found it hard to deal with the loss of his acquired social status and the degenerative process of aging, as expressed the first time we interviewed him: *"During your life you create an image of being somebody who matters. That image gets destroyed as you age, and that's awful. You want to remain who you are."* (P7). However, two years later his sense of dignity appeared to be released from his previously held social status. Instead, he had found a different source of personal dignity:

"Back then I had these childish ideas that having an academic title is important and things like that... having prestige... being seen with important people. That sort of silly thing. And now other things have become more important to me, I guess. And my status...you see, I never removed that sign on my the door that says "Dr." I'm still a little proud of that. But what I try to do now is to compassionately relate to other people, to get a bit of affection...to show that were glad to see each other, or something like that." (P7)

What also helped patients to maintain or regain their sense of personal dignity was the realization that, in spite of their illness they can still be important to others, although perhaps in a different way. A former gymnastics teacher in his sixties, who was diagnosed with metastatic lung cancer, came to the realization that he could still help children with an autistic disorder like he used to; although his reduced energy levels prevented him from being actively engaged in physical activities with the children, he could still provide guidance:

"I see things somewhat differently now because I've realized that ...apparently I can still mean something to someone else while sitting down. [...] All the things that I used to do for the boys, I am still trying to do them but in a slightly different way. It's just how you...I think that what I meant to the boys, I still have that; I used to do carpentry with them, now I have conversations with them; I had to adjust because I can no longer hold a hammer." (P14, second interview)

Another challenge patients faced is that of becoming increasingly dependent on others, with the awareness that their role and status within the family has changed. This is illustrated by the story of a former builder with myelofibrosis:

"My wife and I have talked about it, about me asking for help...having to accept help. Yeah, I'm a guy, and us guys don't like that, I'm old-fashioned in that sense. So that's a big change for me, that I am now dependent on others. My wife and daughter...they're my support team, they do everything. Things I normally used to do, that every guy normally does, I can't do anymore so she has to do it now. And because she clearly said that it's all worth it to her... because I was scared she would leave me, because yeah, you're in a crisis, you're feeling ill, you have a lot of impairments... and my wife, can she handle all that? Well, we talked about that, got it out in the open. And now I've accepted it, that this is the way it is and that she supports me." (P1 second interview)

During the last interview, three years later, he relates to his situation in more positive terms: *"The relationship with people close to my, my family, has improved since my illness, has become more intense or something like that, and also my children are nearer to me than I ever noticed or felt before."* (P1 fourth interview)

Thus, while confrontations with profound losses and changes had the potential to diminish personal dignity in participants, our findings illustrate that most participants were able to regain their dignity after some time by adjusting their perception and by a re-evaluation of what is valuable in life. With many participants, a shift could be observed from deriving dignity from individual achievement, social admiration and self-assertion to a sense of belonging, being loved by others, and being important to others and being able to give something to others in return.

In most cases, acceptance of the loss of certain capabilities as a result of disease took some time. As diseases tend to fluctuate in their clinical presentation, and in many cases progressively damage physical health, this process of acceptance and adjustment

was an on-going process; with the manifestation of new symptoms, or progression of symptoms, the participants were confronted with further losses. As a result, the sense of dignity in most participants was not fixed but waxed and waned, following the process of adjustment.

Box 1. Casus Dynamic Equilibrium

Mr. B., a former builder, was 68 years old and lived with his wife. He suffered from myelofibrosis, tinnitus and problems with his heart, all of which severely limited his abilities.

First interview

During the first interview Mr. B. revealed that he had attempted suicide because he found it impossible to live with his symptoms, especially the tinnitus, and to be dependent on his wife for everything. He felt unmanly and unworthy. After a course of psychotherapy and expressing his concerns to his wife (who was able to reassure him, telling him that she still loved him and didn't mind taking care of him), he made an effort to come to terms with his altered situation and his perception of himself. Once he accepted his dependency, his sense of dignity improved, and he enjoyed a newfound source of dignity in being able to communicate better with others. He accepted his limitations (e.g. not being able to perform sexually) and he believed he would be able to accept further limitations in the future.

Second interview

Mr. B.'s health had declined further. His blood tests indicated that he may not be a suitable candidate for a bone marrow transplantation, making a blood transfusion the only available option. He was shocked by this news and initially felt resentful. At the time, he was also recovering from pneumonia and felt weak and tired.

In spite of these setbacks, he was able to accept his situation and his sense of dignity rose accordingly. He enjoyed doing the things that were still within his grasp, especially entertaining his 15-month old grandson. This gave him a renewed sense of purpose and made life worth living. Although his condition made it impossible for him and his wife to enjoy their customary annual trip to the Mediterranean, he appreciated the security of being at home where everything he needed was close at hand. His relationship with his loved ones deepened and he became emotionally more sensitive rather than pre-occupied with work as he was in the past.

Third interview

Mr. B.'s health continued to decline. He was extremely tired and managed to stay awake for only a few hours a day. He still tried to remain active, alternating activities with naps during the day. He found it difficult to accept his diminished energy and the fact that he was unable to complete the tasks he had set for himself. Initially, he tried to fight this feeling of fatigue but soon realized it was a lost cause. His spirits sank, and with them his sense of dignity. He worried that his wife would no longer be able to care for him and that soon professional caregivers would be called in to see to his

personal hygiene. This struck him as highly undignified and he dreaded the moment. In addition to this concern, he felt others sometimes displayed a lack of consideration as he did not look ill and this too violated his sense of dignity.

Fourth interview

Mr. B. was diagnosed with an additional disease, PNHS. He received regular blood transfusions, the only remaining medical option. Directly following a transfusion, he felt temporarily better although overall his condition deteriorated. A nurse was called in to help care for him and surprisingly he did not find this as distasteful as he had imagined. Once again, his sense of dignity rose, especially directly following his blood transfusions. His family gave him the strength to carry on and he felt loved and valued. His social world became smaller, but that was fine by him as he had limited energy and his family was what mattered most. Additionally, his ability to do little things when he had the strength, like using the computer, made him feel his life still had dignity and meaning.

Six months after this interview Mr. B. died.

Downward Trend

A few participants felt that their personal dignity had been severely damaged as a result of their illness. Some of them stated at the start of our study that their sense of dignity was low. Subsequently, their sense of dignity did not appear to recover during follow-up interviews. A woman suffering from severe spasms saw death as the only solution in terms of maintaining her sense of dignity:

I: If I would ask you to describe what dignity is in your own words, what would you say? P: Then I would say, to fall asleep in my own bed and not to wake up again. To me that would be the most dignified. (P6)

One year later, her desire for death had become stronger and she was actively planning to end her own life in the near future:

"I couldn't move because of the cold; I was just lying in bed all the time, I couldn't do a thing. And to me, that's not a life. I was in such pain, having so many spasms. And I was completely dependent on the care of others; and there are many sweet people wanting to help me out but I don't want that. And that winter I said OK, this will be my last winter." (P6)

Other participants did experience a fairly high sense of dignity at the beginning of the study, but with the progression of their disease their sense of dignity diminished as was the case with this single woman in her early fifties during the final phase of her life. She said that her sense of dignity had diminished because she started to feel lonely and left out:

"My sense of dignity has diminished slightly because I'm getting weaker. I notice that I get tired, that I am less capable of doing things. But on the other hand, you win some on some points and lose on others. Having said that, I still have the feeling that my sense of dignity has somewhat diminished. Yes, I could try to deny it, but it's a fact. I notice that people are dropping me as a friend because I can no longer participate as I used to. It all takes too long... You know, people don't always feel like taking you along. Of course they deny it, but it's true. At least that's how I see it. You see, I have to live a quiet life. So your circle of friends very gradually becomes smaller and smaller." (P15 second interview)

These participants stated that their illness had come to the point where too much of what they valued was compromised. Pain and fatigue, depression, and being unable to get out of bed and to take care of themselves made them feel they were no longer fully worthy individuals. Also, feeling lonely and helpless led them to conclude that life had become empty and meaningless.

Box 2. Casus Downward Trend

Ms. G. was 49 years old and suffered from severe spasms and chronic pain. Particularly during spastic episodes, Ms. G. found herself severely limited in her actions. She had a partner, and although they did not live together her partner provided assistance where possible, as did her father.

First interview

MS. G. contemplated suicide and was waiting for her partner, who was also severely ill, to die. She felt her life was no longer worth living. She was still able to care for herself, but getting dressed could take as long as an hour and a half, and she once sat on the toilet for a number of hours because she had a spasm attack. In spite of all this, she refused to accept help because she believed that would be thoroughly undignified. She had seen other chronically ill individuals shift their boundaries in order to accept the limitations their illnesses brought about, but she was unwilling to do the same. She had set firm and immovable boundaries for herself; should she become wholly dependent on others for her personal care, she planned to end her life.

Second interview

One year later, Ms. G. was even more strongly convinced that the boundaries of her dignity had been reached. During the previous winter, she had suffered numerous spasms and had become increasingly dependent on others for care. Her father, for example, had to cut her food for her. She refused to be fed, however, and had to wait until her spasms tapered off before she could eat. She also suffered increasing pain and felt drugged by her medication. Travelling by car had become too painful and her world was reduced to her home and garden. Typing emails as a way of maintaining contact with others had become more difficult due to failing eyesight. More and more frequently, she suffered severe spasms that lasted for a number of hours. When she reflected upon herself and her situation, she saw an undignified being; to her, dying in her sleep would be the most dignified and welcome outcome.

Stability

A minority of participants stated that their sense of dignity had remained unaffected by their illness and was completely intact. During the follow-up interviews their perception of their dignity appeared to remain stable; despite changes in the condition of their health or the after-effects, their sense of dignity remained unaltered. A number of these participants held strong religious beliefs and to them 'being created in God's image' implies that human beings will always have dignity:

P: I had to wear diapers for a number of days. While this was rather annoying, my sense of dignity was not affected. I did feel inclined to apologize to the nurses for the trouble I caused, but they invariably answered 'don't worry, that's what we're for'. But I never...you're lying there in your own filth and stench, but I never had the feeling...this is unfamiliar to me. I: You mean it didn't affect your sense of dignity? P: No, as long as I am dignified in the eyes of God. (P10 third interview)

For some individuals, the social position and status they had attained during their career gave them a feeling of dignity for life. For others, bodily changes and diminished capabilities were unrelated to dignity, as is illustrated by the story of a woman diagnosed with a brain tumour:

P: Dignity is unrelated to physical functioning. It's also not related to how drugged I feel. It is completely unrelated. I: So the recent physical changes you experienced do not influence your sense of dignity? P: No. That has to do with adjusting to the discomforts of your body and in this sense it's a rational process, and you can be sad that your body is deteriorating but that's something else. It still is...you still have dignity. (P16 first interview)

"I'm generally good with people but some of them cannot handle it very well, me being ill. That's their problem, not mine. I am not bothered by it. I think my standards of living are excellent and dignified. I have become more dependent, but to me that's an altogether different concept." (P16 second interview)

For these individuals, dignity was unrelated to illness and its after-effects; to them, dignity was related to their upbringing and social status, to their relationship with God, or to the perception that a deteriorating body and a dependency on others are simply unrelated to dignity. Thus, these individuals were able to ward off the possible detrimental effects chronic, progressive illness can have on dignity.

Box 3. Casus Stability

Ms. B. was 55 years old and was diagnosed with a brain tumour. Formerly a personal coach and trainer, she was no longer able to work. Many of her most basic abilities were severely handicapped: her arms trembled and she had difficulty walking. She also suffered from chronic fatigue as a result of medication. She lived with her husband.

First interview

Ms. B.'s sense of dignity was completely intact as she believed dignity resided in the mental and spiritual realm and was unrelated to one's physical condition. To her, the sense of dignity derived from the ability to communicate with others on an equal footing and the ability to maintain reciprocal relationships. In her view, physical symptoms and limitations did not affect dignity; one may become disheartened, but one must learn to accept the situation and cope with it as best one can. Likewise, she believed that being dependent on others was not related to dignity. Factors that were important to dignity, according to her, were staying in touch with what is going on in the world, maintaining an interest in a variety of subjects and taking the initiative in making and maintaining contact with others.

Second interview

One year later, the brain tumour had spread and Ms. B.'s symptoms had worsened. Again, this did not affect her sense of dignity. Her physical deterioration and limited freedom of movement (e.g. no longer being able to use public transportation, physical difficulty with writing) dampened her spirits but as long as she was able to cope with the sense of loss herself, her pride prevented her from seeking professional help. Her sense of dignity remained intact through her relationship with her husband and others who mattered to her, and through her active participation in and enjoyment of the world around her.

Eight months after this interview Ms. B. died.

DISCUSSION

This study examines the dynamics of perceptions of personal dignity over time amongst patients with progressive chronic or life-threatening illnesses. From multiple interviews carried out with each of the patients we studied, it became apparent that three distinct dynamics (Stability, Dynamic Equilibrium, Downward Trend) can be observed with regard to the way patients value their personal dignity as their illness progresses. While a limited number of individuals felt that their personal sense of dignity remained stable and unaffected by disease (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 within this latter group, some patients were able to reclaim their dignity (Dynamic Equilibrium) whilst others were not (Downward Trend). Insight into the dynamics of how and why some patients were able to regain their personal dignity whilst others felt their sense of dignity was lost is crucially important for interventions, especially as the loss of dignity is related to the wish for death and can be as complex and difficult to deal with as disease itself. The present longitudinal study provides a starting point in discovering which factors and processes contribute to the maintenance or loss of a sense of personal dignity amongst patients with progressive chronic or life-threatening illnesses.

Dynamic Equilibrium

The most common pattern observed during our study was one of initial decline in the patient's sense of dignity in response to declining health and capabilities, followed by a return to the previous level of personal dignity (or slightly lower) once the patient was able to accept and adjust to their deteriorating condition. We refer to this pattern of a rebounding sense of personal dignity as dynamic equilibrium.

The cause of decline in personal dignity differed from individual to individual, but overall most patients felt their sense of dignity had been impaired by the transition from being a self-sufficient and autonomous individual to one who is dependent on others as a result of deteriorating health. Furthermore, the loss of certain capabilities as well as physical and emotional changes brought on by the disease challenged patients' self-image and gave rise to concern with regard to the image others had of them.

Severe chronic illness can rob the individual of many of the sources of dignity that were previously available to them. Personal achievements (e.g. in work, as caretaker of their family) and social status – sources that normally provide individuals with a sense of meaning, accomplishment and self-esteem – are no longer readily accessible to many of those who suffer from severe illness. In order to reclaim a sense of dignity, new sources must be found. The first step in this process is the acceptance of loss. In many patients, we witnessed a period of mourning for the loss of physical strength, of capabilities, of independence, and of their former lifestyle and identity. During this period that revolved

around loss, patients generally felt their dignity was impaired. Only after having acknowledged and accepted their altered situation they were open to refocusing on other sources of dignity. The process by which dignity can be restored resembles what has been termed the 'accommodation strategy' in literature on coping and identity. An accommodation strategy can replace the strategy of assimilation (changing the environment in such a way that one's identity can remain intact) when this strategy is no longer workable. The accommodation strategy involves the acknowledgment and acceptance of the fact that due to progressive disease, or aging, one has changed and that one must adjust one's aspirations and self-evaluative standards in order to rebuild one's identity (Brandtstädter and Greve, 1994).

Most patients who participated in our study were able to make the necessary inner adjustments. They could reclaim their sense of dignity through a reorientation of goals and achievements, and 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. Patients eventually came to accept that their world had become smaller. Many patients in our study shifted their focus from their achievements and competencies as a source of worthiness to the social meaning they held for others; instead of seeking status and admiration based on the generally accepted norms and conventions of society, they focused on intimate relationships that fostered well-being and bolstered an immediate sense of dignity. 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. Furthermore, 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 appears to be one of the prerequisites in maintaining dignity as it can forestall the potentially detrimental effects of illness on the individual's sense of dignity.

With the progression of their illness, patients face new challenges and further losses so that the process of adaptation is an on-going one during which the patient's sense of dignity may alter. According to the patients we interviewed there are limitations to what they are willing to accept. For example, many patients stated that conditions such as incontinence, becoming bedridden or cognitive degeneration would severely hamper their sense of dignity; they further expressed concerns about the progression of their disease and its consequences, and feared dying in an undignified state. Nevertheless, we observed that patients did adjust their boundaries as time went on, finding dignity in situations they previously held to be unacceptable.

A temporarily diminished sense of dignity can be considered a normal human reaction to the situation in which the severely, chronically ill find themselves – as part of the process of coming to terms with the numerous losses and life changes disease can

bring about before acceptance, refocusing, and rebuilding identity can begin. Some patients actively involved others in this process. A number of patients talked with their loved ones about the changes in family roles and expressed their concerns about feeling uselessness and no longer of value within the family. Some patients benefitted from professional psychological guidance on the road to acceptance. Other patients were helped by the reassurance they got from discussing possible future scenarios and practical ways of maintaining dignity with physicians or nurses. This suggests that informal and formal caregivers can make a substantial contribution to restoring dignity in patients suffering from severe and chronic illness.

Downward Trend

A number patients in our sample indicated that their personal dignity had been severely impaired as the result of their illness and they believed that their lives had become less dignified, in some cases not even worth living at all. They felt that their quality of life had been compromised, 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. We use the phrase downward trend to refer to the condition marked by a diminished sense of dignity that was not restored to the previous level during the progression of the disease because patients were unable to cope with the changes brought about by their disease. Unlike the patients classified under the Dynamic Equilibrium group discussed earlier, these patients did not 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.

Aside from the assimilation and accommodation strategies mentioned earlier, a third coping strategy is the 'immunized state' (Brandtstädter and Greve, 1994). In deploying this strategy, the individual clings to their 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 described here 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.

Based on our results, a number of factors that may contribute to the feeling that one's dignity has been lost and the subsequent failure to regain it can be cited. Firstly, all of the patients participating in our study who struggled with their sense of dignity 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. Given that many patients believed that meaningful interaction with others is one of the essential prerequisite for maintaining their sense of dignity as stated earlier, the loss of such interaction may very well diminish their sense of dignity, especially toward the end of the illness trajectory as personal achievements become less significant. Furthermore, among those patients who were unable to regain their sense of dignity there was a similarity in living arrangements: although some of these patients did have a partner, they all lived alone. Again, this indicates that 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.

Secondly, becoming heavily dependent on others for the most basic activities, such as eating and getting out of bed, may infringe on the individual's sense of identity, particularly when the individual places a high value on his or her independence and being held in high regard by others. Dignity may be affected by the perception that one is of little value to others, or that one has become an unbearable burden to others, especially when there are few opportunities to reciprocate. For some patients, the inevitable changes in social relationships brought about by the disease were unacceptable.

Thirdly, patients appear to make up the balance between the positive and the negative aspects of their lives. In some cases, especially after a lengthy period of continued illness, the balance tends to shift toward the more negative aspects, leaving patients feeling that their lives are no longer worthwhile. It is important to note that by no means all patients with severe symptomatology who were heavily dependent on others lost their sense of dignity. Additionally, some patients in our study expressed a death wish but still felt dignified.

Stability

Some patients in this study stated that in their view dignity was an inner feeling that remained constant and unaffected throughout their disease. Their sense of dignity was intact and remained stable despite a decline in health and the accompanying loss of capabilities. We termed this third pattern stability in which the patient's sense of dignity remained constant and there was thus no need to recalibrate their sense of dignity after a decline in their health conditions and subsequent changes. Personality characteristics, such as optimism and resilience, may explain why some patients' dignity remained intact and unaltered as the disease advanced.

While for most patients their sense of dignity was influenced by changes to their identity and role fulfilment, patients who reported a stable sense of dignity generally felt that their identity had not been affected by their disease. 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. They were aware that others might view them differently but this did not affect their sense of identity and dignity. This inner focus was also expressed by patients who stated that their dignity could only be affected by the way in which they dealt with their present situation – that is by maintaining emotional and mental strength and remaining self-composed – and not by the effects of the disease or by the views of and treatment by others. For other patients, dignity was grounded in past achievements rather than in present experiences. Their previous social rank (e.g. being appointed to an important post) had given them dignity for life, their sense of identity was anchored in past. Some of the patients in this group were deeply religious. They believe they are God's creatures and their dignity resides in the fact they will maintain their faith in God in spite of what may come. Their concept of individual, personal dignity is thus more closely related to the concept of an unchanging, universal human dignity than is the case amongst patients from the other groups.

Different types of illness

The three trajectories described above were observed across different types of illness, suggesting that the type of illness has little effect on the specific pathways and the dynamics of the sense of personal dignity in patients. A separate 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 & Johnston, 2004). This is in line with the Model of Dignity in Illness which proposes 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) (Van Gennip et al., 2013). 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 surely affect the way the patient copes with changes to identity (Zanetti et al., 1999) and thus how they experience their sense of dignity.

Strengths and weaknesses of the study

To our knowledge, ours is one of the first studies to investigate the ways in which patients' ideas and their sense of dignity may change over time as the illness progresses or

fluctuates. In addition to generating a longitudinal perspective, interviewing patients a number of times had two advantages: it gave us the opportunity to deepen themes that were discussed in previous interviews, and it enhanced the rapport between interviewer and patients, thus fostering an environment of trust that resulted in increased openness from the patients. One of the limitations of the present study is that we chose not to follow up on our patients at the very end of their lives, believing it would be too great a burden for them to be interviewed during their final weeks. Based on this study, we can thus not report on the patients' sense of dignity during the last weeks and days before death, or whether their perceptions had changed. Furthermore, conducting a longitudinal study with participants suffering from a progressive life-threatening disease inevitably means that patients may die, or in the case of dementia, become severely demented before the conclusion of the study.

This is one of the first studies to explore how the sense of dignity in patients changes over time and provides a number of preliminary insights into the underlying dynamics of these changes. However, the study also shows that numerous questions remain that need to be addressed and hypothesis need to be developed that require further testing before we can draw firmer conclusions, particularly with regard to the question as to why some patients manage to regain their sense of dignity over time while others do not. Deeper insight into protective and damaging factors underlying the issues can contribute to a better understanding of situations where dignity is at risk and to the development of effective intervention tactics to assist these patients from both a medical and psychosocial perspective.

CONCLUSION

Our study shows that while there is a small group of patients for whom dignity remains unaffected by their disease experiences, most patients go through difficult times during which they struggle to maintain or regain their sense of dignity in the face of progressive loss. Since the sense of dignity may affect psychological well-being, supporting those patients in their struggle is important. Their dependency on others for reassurance and affirmation may make them especially sensitive to their treatment by others, and it is important to approach them as wholly worthwhile individuals. Additionally, it can be a reassuring thought for patients, family members and caregivers that most patients do manage to make the inner adjustments necessary to maintain or regain a sense of dignity. More attention needs to be paid to those patients whose sense of dignity has been severely diminished by the progression of disease and who are unable to regain their

dignity over a reasonable period of time, sometimes resulting in the desire for a swift death.

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