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Personal dignity in seriously ill patients

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SUMMARY

In the introduction of this thesis (**chapter 1**) the various meanings contributed to the concept of 'dignity' within the field of health care are shortly described. A fundamental distinction can be made between universal dignity and personal dignity. The principle of human or universal dignity creates an ethical context fundamental to protecting the well-being of individuals dependent on the care of others. Nevertheless, as a general principle it does not provide clear guidelines for care practitioners on practical matters such as how to foster the individual's sense of dignity or how to deliver dignity-sustaining everyday care. To this end, the concept of personal dignity is much better suited when dealing with the practical application of care. This type of dignity is situated at the subjective, phenomenological level. It is the dignity that we assign to ourselves and that relates to our sense of self-worthiness. Personal dignity is contingent and contextual; it can be enhanced or diminished by external events as the result of the acts or attitude of others and as a result of changes in the subject's body and mind. Patients are vulnerable for losing their personal dignity because of their confrontations with multiple losses and because of their dependency on the care of others. Insight into the type and quality of care, as well as knowledge of which particular life experiences influence the patient's sense of personal dignity are indispensable to care practitioners attempting to understand how they can protect or enhance the patient's sense of personal dignity through caregiving. The present thesis aims to contribute to this body of knowledge by providing insight into the experiences and perceptions of patients with regard to their personal dignity based on in-depth interviews with the patients themselves. Because there was limited knowledge on the understanding of personal dignity of patients with chronic or terminal illness still living at home, the main focus of this study was on this group. Patients were recruited from a cohort study on advance directives (the ADC study). Additionally, this thesis addresses the question what constitutes a dignified death, and how dignity can be meaningfully positioned in the quality of life framework.

The aim of the study presented in **chapter 2** was to develop a conceptual model of personal dignity in illness applicable to a wide patient population. 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. In total, 34 patients with either cancer, mild to moderate dementia or serious chronic illness were interviewed. The model, based on a thematic analysis of these interviews, 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. According to the model of

personal dignity in illness, illness related conditions do not affect patients' dignity directly but indirectly by affecting the way patients perceive and value themselves in three domains: in the domain of (a) the individual self which refers to the individual's internal, private evaluation of himself as an individual and autonomous human being based on his personal experiences and his perception of his worth as an individual; (b) the relational self, referring to the individual's sense of dignity as formed within dynamic and reciprocal interactions; and, (c) the societal self, which refers to the individual as a social object, seen through the eyes of 'the other' through which the social discourse on illness and patients may be manifested. Within each domain of self, various themes or aspects were identified which can be affected by illness and which may have a bearing on an individual's sense of personal dignity.

Chapter 3 examines more closely what having dementia means for one's sense of personal dignity. Dementia is considered by the general public as a disease imposing a serious threat to dignity because it has a bearing on qualities that are generally considered as fundamental for dignity, such as maintaining autonomy, continuity of identity and the ability to communicate sensibly with others. However, there is very limited research on the perspective of those suffering from dementia themselves. The study described in chapter 3 is based on in-depth interviews conducted with 14 individuals with mild to moderate dementia. The interviews were analyzed following a thematic approach. The study indicates clearly that the way others view and treat individuals with dementia has a significant impact on their sense of personal dignity. The intensity with which a decline in personal dignity was experienced depended largely on the social context of the individual. While diminished autonomy and changes to the individual's former identity due to cognitive impairment could lessen a sense of dignity, individuals with mild to moderate dementia were generally able to maintain their dignity within the safe, secluded environment of the home. However, the sense of mastery individuals with mild to moderate dementia were able to maintain within their home environment, with the aid of their partner, often disintegrated in the outside world. Their perceived failure to consistently behave in normative ways evoked feelings of shame and made them aware that part of their former self had been lost. They further reported being confronted by an array of negative reactions. This study shows that beside personal coping with gradual losses due to dementia, the role of others is paramount for a sense of personal dignity in individuals with mild to moderate dementia for it shapes the experiences and the perception individuals with dementia have of themselves.

Chapter 4 presents a longitudinal qualitative study which explored whether, and subsequently how the sense of personal dignity in patients changes over time with the

progression, or fluctuation, of the disease. 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 why some patients are able to maintain or regain their sense of personal dignity, while others seem to lose their sense of dignity, possibly resulting in wish to die. Serial interviews were conducted with 19 patients with either cancer, early-stage dementia or serious chronic disease. Patients were interviewed every year with a maximum of 4 years. In total 56 interviews were obtained. All transcripts for each respondent were analyzed as a longitudinal single unit to gain insight into the individual experiences over time. Additionally a broad thematic approach was used to search for similarities and differences between patients. From this analysis, it became apparent that three distinct dynamics can be distinguished with regard to the way patients value their personal dignity as their illness progresses: 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.

The aim of the study presented in **chapter 5** was to deepen the insight into the circumstances or factors that make the death of an individual dignified in the experience of close family members. Family caregivers of 163 deceased older (> 55 years of age) adults ('patients') who had participated in the Longitudinal Aging Study Amsterdam (LASA), were recruited. These family carers completed a self-administered questionnaire. Of the family caregivers, the majority (69%) reported that their relative had died with dignity. We explored which physical and psycho-social factors in patients, and which care factors were associated with a reported dignified or undignified death by family caregivers. From our study it appears that two aspects or circumstances affect whether a family caregiver experiences the death of the patient as dignified or not dignified. The first aspect refers to the age at which, and the causes from which the patient dies. The results indicate that if death is an expected outcome, family caregivers are more inclined to experience the death as dignified than when the death has been sudden. The second aspect relates to the manner in which, and the circumstances under which the patient dies. The psychological well-being of the patient during the last few weeks before death seems of special importance to the dignity of death from the perspective of the family caregiver. In addition to this, end-of-life care appeared to contribute positively to perceived dignity at the time of death when treatment choices had been clearly explained, when care was in accordance with the patient's wishes, and when the patient died at home. This study suggests that for a dignified death, in the perception of family caregivers, attending to the psychosocial well-being of the patient is at least as critical as addressing

physiological concerns. Furthermore, it is important to provide clear and honest information regarding the patient's limited life expectancy or imminent death. This allows the patient and his family to prepare for death, and thus contributes to both the patient's and the family's sense of peace and death with dignity.

In **chapter 6** it is discussed how personal dignity can be assessed in a meaningful manner within the quality of life research field. It has recently been argued that the concept of dignity should be considered as an integral aspect of the quality of life and should as such be included as a domain in quality of life instruments for long-term care. While the quality of life research field has embraced personal dignity as an important concept within the quality of life framework, limited attention has been given to the already substantial body of research carried out on personal dignity. As a result, in the measurement of personal dignity within the quality of life framework, the complexity of the concept is sometimes ignored in favor of a simple, one-dimensional definition of dignity which may miss essential elements. Quality of life instruments are often used to evaluate quality of care and for policy making. Because preserving the personal dignity in individuals dependent on care is considered a central aim of care, it is vital that dignity is measured in an adequate fashion. The understanding of personal dignity within the quality of life discourse could benefit from incorporating the findings and insights from research in the field of dignity studies. The dignity domain in quality of life instruments needs to be expanded to include more items relevant to dignity. Furthermore, in certain situations it may be beneficial to assess the personal dignity of care recipients more fully by using purpose-built dignity instruments or by conducting face-to-face interviews.

Chapter 7 discusses the principal findings of the studies and their implications for care practice. Also, some methodological drawbacks are addressed, the most important one being that all participants in our study were from Dutch origin. Because views on personal dignity are influenced by cultural belief systems it may very well be that people with different ethnic backgrounds have a different understanding of dignity. Therefore, the results of the study must be interpreted with caution with reference to people living in western society with a different ethnic background.

While the general public is fearsome of disease impairing dignity, especially with reference to dementia, our study has shown that most people are resourceful in finding ways of maintaining their sense of dignity and giving meaning to their lives. We found that patients are capable of recognizing that there are multiple sources of dignity and tapping into these sources to improve their lives. Which themes are relevant and prioritized differs between individuals, but in general it can be stated that the social environment played a important part for patients' sense of dignity. This is also expressed in our model in which

the social takes a prominent place in the form of the relational and societal self. However, a sense of personal dignity also depends on how an individual feels about himself and on how he manages to cope with the disease experience. Regardless of what others say, one may still feel unworthy if one does not live up to one's own expectations. While addressing symptoms is highly important from a medical perspective, focusing merely on symptom management and medical care seems insufficient in guaranteeing the maintenance of patients' dignity, influenced as it is by the psycho-social dimension. Non-medical issues of patients living at home, such as existential distress, may not always be noted by healthcare practitioners. This thesis aims to raise awareness among those involved with seriously ill patients of the patient's inner world, and makes an appeal for a stronger focus on the psycho-social aspects of care, in addition to medical care.