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Personal dignity in seriously ill patients

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INTRODUCTION

This thesis reports on research into the ways patients with severe chronic or life-threatening illnesses understand and experience their sense of personal dignity. In this introductory chapter, the aims of the research project are described and a short overview of the methods is provided. Before doing so, usage of the concept of dignity within the context of medicine and healthcare is briefly examined from a theoretical perspective.

CONCEPTS OF DIGNITY: HUMAN DIGNITY AND PERSONAL DIGNITY

The concept of dignity (*dignitas* (Latin), "worthiness") boasts a long philosophical tradition dating back, at least, to Roman and Greek Antiquity, and its meaning has changed along sociocultural and historical lines (Gallagher et al., 2008; Hertogh, 2009; Leget, 2013). In the 20th century, physicians and medical and healthcare researchers began showing an interest in the concept of dignity. The concept they were concerned with was 'human dignity', a notion of dignity that had first gained wide recognition through the Enlightenment philosophy of Immanuel Kant (1724-1804). Kant stated that all human beings possess dignity (*Würde*) by virtue of their rationality. Although the grounds for human dignity have been debated (Malvestiti, 2012), the belief that all humans possess dignity and that this dignity is inalienable has influenced modern thinking since the Second World War.

Human dignity proclaims that all human beings possess inherent worth irrespective of rank, station, or any other contingent quality. They therefore deserve to be treated with respect and are entitled to basic rights, such as the right to self-determination and the right not to be harmed. Thus, human dignity denotes the equal worth of all humans; every human has dignity, therefore any discrimination between persons would be unjustified and immoral on the grounds of dignity. Human dignity is an overarching, fundamental principle that refers, on the one hand, to an *ethical principle* regarding the notions of what it means to be human and how to treat people humanely, stating that the obligation to respect human dignity is a moral absolute, and, on the other hand, to a *juridical principle* that lies at the heart of legislation concerning the basic human rights enshrined in national and international laws and policies, e.g. in the United Nation's *Universal Declaration of Human Rights* (1948).

The concern with human dignity in medicine was triggered by the discovery of the atrocities committed by Nazi physicians working in concentration camps (Burns, 2008).

This discovery, and the sense of shock and horror that accompanied it, resulted in international declarations aimed at securing the consent of the research subject and the provision of research ethic guidelines, such as the Nuremberg Code in 1949, and later, in 1964, the Declaration of Helsinki issued by the World Medical Association which states: "It is the duty of the physician in medical research to protect the life, health, privacy and dignity of human subjects." Subsequently, the debate in medicine and bioethics on human dignity has been propelled further by rapid developments in the fields of genetics and innovations in biotechnology, e.g. human cloning (Andorno, 2013; Leget, 2013).

Over the course of the past decade, human dignity has been increasingly spotlighted in the discussion on good healthcare for patients and other vulnerable, care-dependent individuals such as nursing home residents and those suffering from psychiatric disorders. It has become a key value in care policy and care practice, and has gained political priority, partially due to the attention given by the media, as well as through anecdotal accounts and research reports, to instances of care without dignity for vulnerable groups (Baillie & Gallagher, 2009). The right to care with dignity is now explicitly stated by the international *Code of ethics for nursing*: "inherent in nursing is the respect for human rights, including (...) the right to dignity and being treated with respect." (ICN, 2012).

Thus, 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. It denounces the violation of dignity, e.g. through neglect, abuse and coercion. 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.

The notion of personal dignity, as distinct from human dignity, is a relative new one in the field of medicine and healthcare. It can be understood as a type of dignity that is subjectively experienced and that relates to a sense of worthiness (Pullman, 2004). 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. Unlike human dignity, which is inalienable and a moral absolute, 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 (Pullman, 1999; Nordenfelt, 2004; Jacobson, 2007). Personal dignity is especially vulnerable to the impact of aging and illness because here the individual is subject to profound changes that affect the core of their identity and their relationships to others (Burns, 2008). Which specific occurrences or experiences impact the sense of personal dignity differs from one

individual to another, and the challenges brought on by illness or aging may be faced in a wide variety of ways.

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. Knowledge of the fundamentals of personal dignity is essential for the translation of the imperative of universal dignity into everyday practice. 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.

While this thesis maintains an empirical focus on personal dignity in order to reveal the aspects of care and daily life that impact the individual patient's sense of dignity, it is important to bear in mind that both notions of dignity - the universal and the personal - are intertwined, and that both are essential to good healthcare practice (Leget, 2013; Pols, 2013). The application of the concept of human dignity as a moral guiding principle in healthcare is necessary to avoid an overly individual, subjective and relativistic perspective on care. Maltreatment within care relations or in care facilities may cause personal suffering and violate the personal dignity of those involved, but we cannot consider these incidents simply as subjective perceptions of suffering that need to be addressed at the individual level. Violation of an individual's dignity should not only be viewed as a singular subjective experience open to interpretation, but must also be morally condemnable at a higher level. The notion of universal dignity provides an objective and formal criterion, declaring that society has a moral obligation to provide care that respects the dignity of all patients and others dependent on care. On the other hand, the concept of personal dignity is needed to define how dignity can be protected in the individual patient and to stipulate what is required for the maintenance of dignity.

THEORETICAL AND EMPIRICAL RESEARCH ON PERSONAL DIGNITY

The World Health Organization states that the obligations of healthcare extend beyond providing medical care at the physical level only, and should also facilitate psychological, social and spiritual well-being (WHO, 2002). It is therefore important to understand the broader impact of illness. Maintaining a sense of dignity in patients is essential to the patient's overall sense of well-being (Jacelon et al., 2004; Griffin-Heslin, 2005; Thompson & Chochinov, 2008). Research has shown that the loss of personal dignity is associated with existential distress (Chochinov et al., 2005) and even with the wish to end life prematurely (Jansen-van der Weide et al., 2005; George et al., 2006; Ganzini et al., 2007).

Thus, dignity should be a key component of patient care. Research on personal dignity is gradually emerging. Theoretical studies have contributed to the conceptual clarity of personal dignity, particularly by providing descriptions and taxonomies of personal dignity. Empirical research has contributed to our knowledge of dignity by providing insight into the subjective experiences of patients with regard to their sense of dignity, offering a first-hand, phenomenological perspective of individual subjects.

Taxonomies of personal dignity

Further descriptive categories of personal dignity have been developed by a number of researchers and writers on the subject. Most authors subscribe to the idea that personal dignity is a dual concept, i.e. personal dignity has both an internal and an external component. This is based on the notion that while personal dignity is subjectively felt by an individual, it is not solely a private or individual experience, but also takes shape within interpersonal interactions and always emerges in a social context – that is, the properties that characterize personal dignity depend upon the norms and traditions of a particular society. Different terms have been coined for the intrinsic and external components of dignity: 'self-regarding' and 'other-regarding' dignity (Gallagher, 2004); 'dignity of self' and 'dignity in relation' (Jacobson, 2007 and 2009); 'dignity as an attribute of the self' and 'behavioural dignity' (Jacelon et al., 2004); 'intrapersonal' and 'relational' dignity (Pleschberger, 2007), but the underlying concept is the same. The internal component refers to how an individual values him or herself, whereas the external component refers to the acts, attitude and perception of others as they have a bearing on that individual's sense of dignity. Ultimately, the degree to which an individual values him or herself is affected by "the dignity they see (or fail to see) in the eyes of others" (Jacobson, 2009).

According to psychiatrist Harvey Chochinov (Chochinov et al., 2002) it is this external component that distinguishes personal dignity from conceptually overlapping terms such as pride, self-respect and self-esteem. In a similar fashion, Jacelon et al. (2004) argue that dignity is an attribute of the self, akin to self-esteem or self-worth, but ultimately more than these because in order to feel dignified one needs more than self-worth, especially in relationships with others. Haddock (1996) also notes that, throughout the literature, distinctions are made between "*having* dignity as an aspect of self, and *being treated as if one has* dignity".

The philosopher Lennart Nordenfelt (2004) has proposed a more extensive typology of dignity which also incorporates the thoughts of the classical philosophers. In addition to human dignity, which he refers to as dignity of *Menschenwürde* (echoing Kant), he differentiates three varieties of dignity which are contingent and linked to the individual person: dignity of merit, which depends on social rank and position; dignity of moral stature, which refers to the moral deeds or the virtue of an individual; and dignity of

identity, the modern variety of dignity, which depends on the subject's self-image and which can be influenced by the behavior of others and by changes in the body and the mind. These varieties of dignity have both a subjective and an objective dimension, i.e. dignity can be violated even when an individual is not aware of being treated disrespectfully by another, and disrespectful treatment of a dead body can be considered as undignifying behavior toward the deceased.

Empirical research on personal dignity

In Canada, Chochinov and his colleagues carried out multiple studies on the perception of personal dignity by terminal cancer patients during the final six months of their lives. Based on a qualitative study among 50 cancer patients, Chochinov et al. (2002) developed the "Model of Dignity in the Terminally Ill" which consists of three components: illness-related concerns (i.e. those issues deriving from the illness that relate to one's level of independence and symptom experiences); dignity-conserving repertoire (i.e. the personal approaches that individuals use to maintain their sense of dignity); and social dignity inventory (i.e. environmental factors that influence the quality of an individual's interaction with others). The main focus of this model is on the ability of cancer patients to cope with their illness and the ways in which they try to maintain their sense of dignity. Based on the model, a "dignity therapy" was developed aimed at enhancing or restoring the sense of dignity in patients nearing death and helping them to achieve closure (Chochinov et al., 2005). Additionally, Chochinov and his team developed the Patient Dignity Inventory (PDI), a measuring instrument that can be used by clinicians to detect end-of-life distress (Chochinov et al., 2008).

The personal dignity of nursing home residents is a subject that has also received a good deal of attention and has been mainly researched in Europe (Franklin et al., 2006; Pleschberger, 2007; Hall et al., 2009). In the Netherlands, Oosterveld-Vlug and colleagues have conducted an extensive qualitative study on the factors that enhance or diminish the personal dignity of nursing home residents from the perspective of the residents (Oosterveld-Vlug et al., 2013a and 2014a) and of the nursing home staff (Oosterveld-Vlug et al., 2013b). Among the key factors undermining dignity that were mentioned by the nursing home residents were a low level of autonomy, changes in personal identity, difficulty accepting the situation, requiring assistance with intimate care, having to wait to be helped, being patronized, and feeling written off by society. Conversely, dignity can be protected and maintained through good professional care (e.g. being treated with respect), a supportive social network and adequate coping strategies. Based on this qualitative interview study, the authors developed the Measurement Instrument for Dignity AMsterdam-Long Term Care (MIDAM-LTC) (Oosterveld-Vlug et al., 2014b).

A number of studies have investigated how dignity is experienced by those suffering from illnesses other than cancer. In a quantitative study, Oosterveld-Vlug et al. examined which factors individuals in a poor state of health considered important for their sense of dignity, which has resulted in the Measurement Instrument for Dignity AMsterdam (MIDAM) (Oosterveld-Vlug et al., 2011). Some qualitative studies have been conducted, mainly in Scandinavia, that focus on specific illnesses and the personal sense of dignity of the patients. Lohne, et al. (2010) investigated how individuals suffering from multiple sclerosis experience and understand dignity and violation within a rehabilitation ward. The findings revealed three main themes: (1) 'invisibly captured in fatigue'; (2) 'fighters' law: one who does not ask will not receive'; and (3) 'dignity is humanity'. According to the participants, dignity requires time and is experienced only in a context of empathy and mutual confidence. In a study on patients suffering from head injuries diagnosed as having mild to moderate disability, Slettebø et al. (2009) found that patients experienced their dignity as remaining intact when they were taken seriously, received sufficient, relevant information and were reality-oriented. They experienced their dignity as being violated if they had been neglected or had encountered healthcare personnel who lacked knowledge, were skeptical about what the patient told them, or mistrusted them. The importance of adequate information was stressed.

AIMS AND OBJECTIVES OF THIS THESIS

This thesis addresses three topics: patients' experiences with regard to personal dignity; death with dignity; and, the relation between personal dignity and quality of life.

Patients' experiences with regard to personal dignity

Research on personal dignity of patients thus far has focused mainly on terminal cancer patients during the final stage of life (e.g. Chochinov et al., 2002, 2005, and 2008; Östlund et al., 2011). Empirical studies examining how personal dignity is experienced by patients with diseases other than cancer are scarce. Furthermore, little is known about how patients earlier in a disease trajectory, who mostly are still living at home, understand their personal dignity. The World Health Organization emphasizes that (palliative) care should be initiated as early as possible in the trajectory of any chronic, ultimately fatal illness (WHO, 2002). Preserving the patient's dignity is considered to be a central tenet in care (Jacelon, 2004; Thompson & Chochinov, 2008). Our research therefore aims to provide insight into how personal dignity is experienced in a diverse patient population, both in terms of the type and the stage of illness.

In order to achieve this aim, our first objective was:

- (1) to develop a generic model of personal dignity in illness that illuminates the process by which serious illness can undermine patients' dignity, and that is generic and applicable to a wide patient population.

In addition to cancer, one of the serious illnesses increasingly prevalent in modern western societies is dementia. Older people tend to be fearful of developing dementia (Laforce & McLean, 2005) and perceive dementia as a state of severe suffering and lack of dignity because of the increasing dependency on others and the progressive loss of autonomy and identity (Cohen & Eisdorfer, 1986; Gezondheidsraad, 2002). In the Netherlands and Belgium, this has motivated some to sign an advance directive in which they declare that they wish to forgo treatment or interventions aimed at prolonging life should they exhibit symptoms of dementia (De Boer et al., 2007). Because of the general fear of dementia as an undignified state, it is important to explore how patients afflicted with dementia experience their disease with regard to their personal sense of dignity. Research to date has focused almost exclusively on ways to provide care with dignity to the severely demented living in care facilities. Knowledge is lacking on how individuals in the earlier stages of dementia try to cope with their illness and maintain a sense of dignity.

Our second objective was therefore:

- (2) to explore how patients with mild to moderate dementia experience their personal dignity and which factors play a part in this.

In addition to the above, research on personal dignity among patients from a longitudinal perspective is also lacking and there is limited insight into the dynamics of patients' sense of dignity during the progression of illness. Insight into how the sense of dignity alters over time and in relation to changes in the patient's state of health can improve our understanding of why some patients manage to maintain their sense of dignity while others suffer from a diminished sense of dignity as their health deteriorates.

Our third objective was:

- (3) to explore how patients' experiences of personal dignity change over time with the progression or fluctuation of illness and to establish which mechanisms patients use to maintain or restore their sense of dignity during this process.

Death with dignity from the perspective of family caregivers

The second aim of our research was to improve our understanding of what death with dignity means. Not only do patients fear the loss of dignity during their lifetime as the result of degeneration and progressive loss, they also fear an undignified death (George et al., 2006; Rietjens et al., 2006). One of the main reasons patients fear an undignified death is because of the heavy emotional burden they believe it would place on loved ones and family members. There is, however, a lack of knowledge on the subject of what precisely makes a death dignified or undignified from the perspective of family members of the deceased. Whether the patient dies with dignity may well have a profound bearing on the bereavement process for those left behind. Insight into which factors can make a death dignified in the eyes of family members can help to support and reassure patients and those close to them.

To provide more insight into what makes a death dignified from the perspective of family members of the deceased, the following objective was formulated:

- (4) to investigate which factors affect the dignity of the death of older adults as perceived by family caregivers.

Dignity and quality of life

The third aim of our research was to further explore the relationship between personal dignity and quality of life. Much attention has been given to the quality of life in recent years and the lively debate surrounding this concept has come to include the concept of dignity as well. Although the two concepts are frequently used in conjunction with each other when referring to individuals' well-being, the relationship between them is far from clear and has rarely been the subject of theoretical scrutiny.

Our fifth objective was:

- (5) to investigate the relationship between dignity and quality of life and the assessment of dignity within the quality of life context.

METHODS

Objectives 1 to 3, pertaining to the patient perspective, were addressed by a qualitative study making use of in-depth interviews with patients who suffered either from cancer, mild to moderate dementia, or a chronic illness such as Crohn's disease or HIV. Patients were recruited from an extensive cohort study on advance directives (Van Wijmen et al., 2010). Data collection took place between 2008 and 2012. For the development of the dignity model (objective 1), 34 patients were interviewed. For the study on dementia (objective 2), 14 patients with mild to moderate dementia were interviewed. For the

longitudinal study (objective 3), 19 patients were followed over the course of four years and interviewed at 12-month intervals until the patients died, withdrew from the study, or until the end of the data collection period. A number of patients were interviewed at shorter intervals when their health rapidly declined. In total, 56 interviews were conducted.

The interviews were guided by a topic list providing cues. The interviews focused on how patients understood dignity and what aspects of their lives affected their sense of dignity. During subsequent interviews, the same basic questions were addressed with a specific focus on changes in health status and perceived dignity. Data were analyzed making use of the principles of thematic analysis (Boyatzis, 1998; Braun and Clark, 2006).

For the study on death with dignity as reported by family caregivers (objective 4), a retrospective quantitative study with a self-administered questionnaire was used. 163 Family caregivers of deceased older adults who had participated in the Longitudinal Aging Study Amsterdam (LASA) (Huisman et al., 2011) were recruited. Questions related to the care, health status and social and psychological well-being of the deceased during the last months of life. Data collection took place in 2009 and 2010. The article on the relation between dignity and quality of life and the assessment of dignity (objective 5) is a theoretical article based on a literature study. A detailed description of the research methodology is provided in the individual chapters.

OUTLINE OF THE THESIS

This thesis consists of a collection of articles which have been published in or submitted to international peer reviewed scientific journals. These articles are presented in individual chapters in this thesis in the same form as they were published, which implies that each chapter can be read independently and that there is some overlap in content.

The first three chapters of this thesis present the results of the qualitative interview study. Chapter 2 describes the Model of Dignity in Illness, a generic model which illustrates how illness can affect personal dignity in patients. The model provides a framework for organizing the various factors related to dignity. Chapter 3 reports on how individuals suffering from dementia experience their sense of dignity and which aspects of their lives influence this. Chapter 4 presents the longitudinal study and explores how the patients' sense of personal dignity changes over time with progression of or fluctuation in illness and the mechanisms by which patients try to maintain or regain their dignity. Chapter 5 focuses on what makes a death dignified or undignified from the perspective of close family members. Chapter 6 explores the relationship between quality of life and dignity, and addresses the measurement of dignity in the quality of life research field.

Chapter 7 presents a general discussion in which the main findings are discussed and interpreted. In conclusion, implications for healthcare practice are given.

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