International Journal of Nursing Studies 50 (2013) 1080–1089

Contents lists available at SciVerse ScienceDirect

International Journal of Nursing Studies

journal homepage: www.elsevier.com/ijns

Research paper

The development of a model of dignity in illness based on qualitative interviews with seriously ill patients

Isis E. van Gennip [a,*], H. Roeline W. Pasman [a], Mariska G. Oosterveld-Vlug [a], Dick L. Willems [b], Bregje D. Onwuteaka-Philipsen [a]

[a] Department of Public and Occupational Health, EMGO Institute for Health and Care Research, Expertise Center for Palliative Care, VU University Medical Center, Amsterdam, The Netherlands
[b] Department of General Practice, Section of Medical Ethics, Academic Medical Center, Amsterdam, The Netherlands

ARTICLE INFO

Article history:
Received 14 March 2012
Received in revised form 29 November 2012
Accepted 4 December 2012

Keywords:
Dignity
End-of-life issues
Illness and disease
Model building
Palliative care
Qualitative research

ABSTRACT

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

What is already known about the topic?

- There is quite a substantial amount of knowledge on how patients nearing death understand the concept of dignity, and a comprehensive "Dignity Conserving Model" has been developed based on the experiences of terminal cancer patients in the very last phase of life.

* Corresponding author at: VU University Medical Center, Department of Public and Occupational Health, Van der Boechorststraat 7, 1081 BT Amsterdam, The Netherlands.
E-mail addresses: eol@vumc.nl, i.vangennip@vumc.nl (I.E. van Gennip).

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http://dx.doi.org/10.1016/j.ijnurstu.2012.12.014

- There is some research on how older individuals in nursing homes understand dignity.
- There is some research on how patients with severe chronic diseases understand dignity.

What this paper adds

- Insight into how a broad population of seriously ill patients, suffering from various illnesses, understands personal dignity.
- Insight into patients' dignity in the earlier phases of the illness trajectory, i.e. living with dignity.
- Based on these insights, a "model of dignity in illness" was developed to explain why and how illness can have a detrimental effect on dignity, applicable to a wide patient population.

1. Introduction

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

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

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

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

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

2. Methods

2.1. Context of recruitment for the qualitative study

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

2.2. Sampling

From this cohort, we selected a sample of individuals with serious illnesses for our qualitative study on dignity. We included three different patient groups: patients with cancer, patients with early-stage dementia, and patients with severe chronic illnesses, such as Crohn's disease, HIV and spasticity (see Table 1). Only individuals who had indicated on the AD questionnaire that they were willing to participate in an interview study were selected. Patients were selected by the first and second authors, in consultancy with the research team, following the principles of purposive sampling. Maximum variation (Patton, 1990) was obtained by selecting patients in a way that guaranteed variation in type of illness and in phase of illness, thus obtaining variation in the degree of potential threats to dignity (e.g. patients in the final stage of illness and patients with severe chronic illness in a non-critical phase). Also, we selected those cases that seemed of