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Can personal dignity be assessed by others? A survey study comparing nursing home residents' with family members', nurses' and physicians' answers on the MIDAM-LTC

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ABSTRACT

Background: Preserving dignity is an important goal of the care given in nursing homes. Although nursing home residents themselves are the preferred source of information about the factors that influence their dignity, they may not always be able to provide this. In these cases, information must be obtained from proxy informants such as family members or caregiver staff. Knowledge on comparability of proxies' and residents' answers is then important to interpret this information appropriately.
Objectives: To explore the extent to which responses of different types of proxies correspond with nursing home residents' responses when they both assess the resident's personal dignity.
Design: A cross-sectional survey.
Settings: The general medical wards of six nursing homes in the Netherlands.
Participants: Ninety-five nursing home residents, their family members, nurses and elderly care physicians.
Methods: Agreement percentages were calculated between residents' and proxies' answers on the Measurement Instrument for Dignity AMsterdam – for Long Term Care facilities, an instrument consisting of 31 symptoms or experiences for which presence as well as influence on dignity were asked, and a single item score for overall personal dignity.
Results: Proxies generally rated the residents' dignity more negatively on the single item score than residents did themselves. Agreement percentages between residents and the different proxies ranged between 53% and 63% for the single item score, between 68% and 72% for the presence of items and between 68% and 76% for items' influence on dignity. Agreement on items' presence and influence on dignity was highest for physicians and lowest for family. Family members tended to overestimate the presence of items in the resident's life as well as their influence on dignity. They could however best recognize when a resident's dignity was considerably violated, whereas physicians and nurses overlooked this more often. Physicians and nurses were not always aware that certain items were present – especially of care items in which they themselves were involved.

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Conclusion: Reports from proxy-informants cannot simply be substituted for nursing home residents' reports of personal dignity. However, if residents are not able to provide information themselves, there can still be value in proxy response on dignity if results are interpreted in light of the patterns of deviation observed in this study.

What is already known about the topic?

- Nursing home residents are a vulnerable group with regard to loss of personal dignity.
- The MIDAM-LTC can give insight in aspects that influence the personal dignity of an individual nursing home resident, and can as such be a helpful instrument in providing dignity-conserving care.
- Studies exploring proxies' and patients' perceptions on quality of life – a concept related to dignity – reveal that proxies tend to underestimate patients' quality of life.

What this paper adds

- On a numerical rating scale, proxies generally rate nursing home residents' personal dignity lower than residents do themselves.
- Patterns of deviation differ between proxies with regard to the assessment of factors influencing dignity: nurses and physicians tend to overlook factors that considerably violate a nursing home resident's dignity, while family members tend to be over-concerned.
- Proxy assessments cannot replace nursing home residents' reports on dignity but can still be valuable if collecting resident-reported data appears difficult, providing that a combination of different types of proxies is used, and that results are interpreted in light of the patterns of deviation observed in this study.

1. Introduction

Preserving dignity is an important element of nursing care (Anderberg et al., 2007; Griffin-Heslin, 2005; Jacelon et al., 2004). The concept of dignity within the context of care generally refers to personal dignity – a form of dignity which relates to a sense of worthiness, is individualistic and tied to personal goals and social circumstances (Burns, 2008; Leung, 2007; Östlund et al., 2012). It can be distinguished from *basic* dignity, which is the inherent dignity of each human being and can be regarded as a universal and inalienable moral quality (Leget, 2013; Nordenfelt, 2004). *Personal* dignity, however, can be taken away or enhanced by circumstances or acts from others. Loss of personal dignity has been found to be associated with depression, hopelessness, and a desire for death (Chochinov et al., 2002a). It is this type of dignity that is therefore important to understand, assess and preserve in relation to the quality of health care.

To preserve personal dignity, it is essential for caregivers to give care in accordance with values that are important for the individual patient. Several studies have examined which factors can undermine or preserve dignity – from the patient perspective (Chochinov et al., 2002b; Franklin et al., 2006; van Gennip et al., 2013a), the family perspective (van Gennip et al., 2013b; Nåden et al., 2013), and the caregiver's perspective (Calnan et al., 2005; Dwyer et al., 2009; Jakobsen and Sørlie, 2010). Although all of these perspectives consider respect, autonomy and continuity of self as important elements to maintain personal dignity, some studies also revealed differences between their views on dignity and dignified care (Albers et al., 2013; Baillie, 2009; Periyakoil et al., 2009). For example, both patients in a hospital setting and in a nursing home were found to emphasize the importance of receiving social support from fellow patients, relatives and society whereas staff members were not always aware of the beneficial effects of these relational factors, and focussed more on privacy matters (Baillie, 2009; Oosterveld-Vlug et al., 2013a).

The long-term care setting is a situation where preserving dignity is of great significance. In the Netherlands a quarter of all people above 80 years of age reside in a residential care home or nursing home (Statline Database, 2009), and often spend the remainder of their life there. Besides facing threats to dignity arising from functional and/or cognitive decline and being heavily reliant on staff, these patients live in an unfamiliar environment, may feel discarded by society and increasingly lack social networks, making them particularly vulnerable to the loss of personal dignity (Gastmans, 2013; Goddard et al., 2013; Pleschberger, 2007). To gain more insight in the aspects that influence the personal dignity of patients residing in an institution, the recently developed MIDAM-LTC can be a helpful measurement instrument. By asking patients to identify which aspects undermine their dignity, the MIDAM-LTC can be used to better target dignity-conserving care to an individual patient. This 31-item instrument has been found to have good content validity, construct validity and intra-observer agreement in nursing home residents (Oosterveld-Vlug et al., 2014).

It is generally agreed that due to the highly subjective nature of a concept like dignity, any measurement should rely, where possible, on the perception of the individual (e.g. Gerritsen et al., 2007; Thorgrimsen et al., 2003). However, in nursing homes, collecting resident-reported data on dignity can be a challenge – some residents may not be willing or able to report directly on their own dignity because of medical conditions as fatigue, cognitive decline or aphasia. In these cases, proxy informants such as family members or caregiver staff might function as complementary or alternative sources of information on resident's dignity. Literature shows that the use of proxies to assess another person's subjective experiences has inherent difficulties as well. Characteristics of the proxy – such as the nature of the relationship and time spent with