

Original Article

Does Health Status Affect Perceptions of Factors Influencing Dignity at the End of Life?

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Abstract

Context. More people are surviving into old age, and chronic diseases tend to become more common with age. Ill health and disability can lead to concerns about loss of personal dignity.

Objectives. To investigate whether health status affects the perceptions of factors influencing personal dignity at the end of life, and the relationship between those perceptions and sociodemographic characteristics.

Methods. A subsample ($n = 2282$) of a large advance directives cohort study was used. Three different health status groups (good, moderate, and poor) were defined based on the Euroqol-5D and a question on whether they had an illness. For each health status group, we calculated the percentage of respondents who indicated the extent to which the items of the Patient Dignity Inventory would influence their dignity as (very) large. Logistic regression analyses were used to investigate the associations between the perceptions of factors influencing personal dignity and sociodemographics.

Results. The percentage of respondents who indicated the factors as having a (very) large influence on dignity at the end of life were not significantly different for the three health status groups, except for three physical items on symptoms, roles, and routines. Those items were significantly more influential on dignity for people with a poor health status. Gender, old age, having a partner, and having a belief or religion that is important to one's life were associated with an understanding of factors influential to dignity.

Conclusion. Health status seems only to affect the perceptions of physical factors maintaining dignity at the end of life. This might suggest that the understanding of dignity will not substantially change as health status changes and

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Key Words

End of life, palliative care, advance care planning, dignity

Introduction

The European population is aging, with increasingly more people who suffer and die from serious chronic diseases, such as cancer, cerebrovascular disease, heart disease, and dementia.¹ As the average life expectancy has increased in the past decades² and chronic diseases tend to become more common with age, people not only live longer but also live a relatively longer period of life with chronic diseases. An Irish study found that 23% of people older than 65 years had a disability and that this percentage increased to 65% for those older than 80 years.³ These findings are in accordance with the “expansion of morbidity hypothesis,” which states that mortality reductions will increase the years with morbidity and related disability.^{4–6}

Ill health and disability can lead to concerns about the loss of personal dignity. Loss or decline in dignity as a result of chronic disease is frequently referred to in end-of-life care. Accordingly, several studies have shown that loss of dignity is closely related to a patient’s wishes for death.^{7–10} In addition, it has been found that a concern about the loss of dignity was one of the most common reasons to formulate an advance directive in The Netherlands.¹¹

A variety of studies identified factors and themes that may have an impact on patients’ sense of dignity.^{12–17} Chochinov and colleagues¹⁸ demonstrated that the care for terminally ill patients should focus on a broad range of physical, psychological, social, and spiritual/existential issues to promote a patient’s sense of dignity. Furthermore, several studies concluded that dignity should be the focus of care at the end of life.^{19–21} Therefore, considering whether people think their dignity will be undermined if they are maintained in a certain condition or if their treatment is continued under certain circumstances is important for planning adequate care in life-limiting illness. A lack of understanding of a person’s

wishes about future care might result in a loss of dignity and additional distress for relatives and health care professionals. As conserving dignity can be considered a goal of palliative care, it might be helpful to get a better understanding of what dignity means to people and whether peoples’ perceptions of the importance of dignity at the end of life is affected by health status. A concern that is mentioned by several authors is that patients might change their minds about future treatment preferences when confronted with the actual situation or as their health status changes.^{22–24} Therefore, this study aimed to investigate whether health status affects the perceptions of factors influencing personal dignity at the end of life. In addition, we explored the association between the perception of factors influencing personal dignity at the end of life and several sociodemographic characteristics.

Methods

Design and Study Population

The data for this study were collected within the framework of a Dutch Advance Directives Cohort Study, a major ongoing longitudinal study that aims to describe how advance directives are involved in end-of-life decisions in The Netherlands. The design of the Advance Directives Cohort Study is described in detail by Van Wijmen and colleagues.²⁵ The study was approved by the Medical Ethics Review Committee of the VU University Medical Center before the start of the cohort study in 2005. The cohort comprised people with one or more of the most common standard advance directives in The Netherlands: 4496 people who had one or more advance directives (the advance euthanasia directive, refusal of treatment document, and/or appointment of a health care representative) formulated by the NVVE (Right to Die-NL), and 1261 people who had a wish to live statement (stating the

wish to receive adequate care directed at quality of life and explicitly against euthanasia) provided by the Dutch Patient Association. A written structured questionnaire is sent to the cohort every one and a half years. This study is based on the second data-collection cycle for which the data were collected in the spring of 2007. The response rate in the second data-collection cycle was 88% and 90% for the NVVE members and the members of the Dutch Patients Association, respectively (Fig. 1). To analyze the construct of dignity and to assess the content validity of the Patient Dignity Inventory (PDI) prototype, we randomly split the cohort into two subsamples; one received a questionnaire including an open-ended question concerning factors relevant to dignity and the other received a questionnaire including the PDI.²⁶ The present study focuses on a subsample of the PDI cohort that completed more than 15 of all 22 items ($n = 2282$).

Measurement Instrument

The questionnaire included questions on background characteristics and self-perceived

health status, and also included a question that asked the respondents whether they had an illness such as rheumatism, asthma, heart disease, or multiple sclerosis. The Euroqol-5D (EQ-5D)²⁷ was included to measure whether there were no, some, or severe limitations on the following five dimensions: mobility, self-care, activities of daily living, pain/discomfort, and anxiety/depression. In addition, the questionnaire contained the PDI prototype, including 22 items on symptoms and experiences.^{18,26} The PDI prototype preceded the 25-item PDI.²⁸ Respondents were asked to rate the extent to which they thought that these items would influence their sense of dignity during the last phase of life on a five-point scale (1 = not at all; 2 = slightly; 3 = somewhat; 4 = to a large extent; 5 = to a very large extent).

Analyses

We defined the health status groups using the EQ-5D items combined with the question on whether the respondents had an illness. The reason for defining the health status groups in this way is that the illness-related

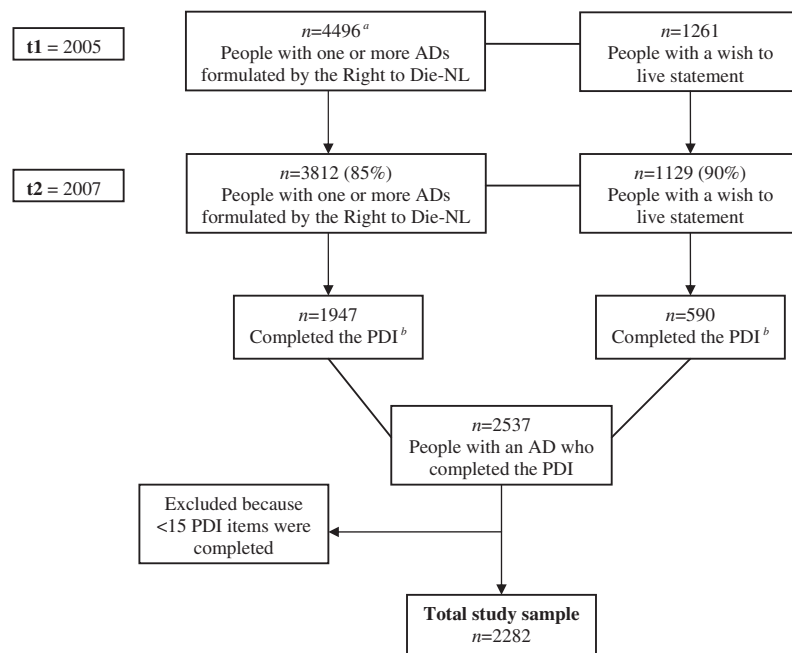


Fig. 1. Flow chart of recruitment and response rates. PDI = Patient Dignity Inventory; ^aThis number refers to people who had drawn up an advance directive (AD) through the Right to Die-NL; people who requested and had not (yet) formulated an AD were not included in this number ($n = 1065$). ^bA randomly selected half of the cohort received a questionnaire that included the PDI; the other half of the cohort received a questionnaire that included an open-ended question on dignity. Therefore, 1865 and 539 people, members of the Right to Die-NL and people with a wish to live statement, respectively, were excluded from this study.

concerns such as dependence and symptom distress may influence personal dignity at the end of life²⁹ rather than the illness itself or the type of illness. First, the good health status group comprised patients who had no illness or impairment regarding mobility, self-care, activities of daily living, pain/discomfort, and anxiety/depression. Second, patients in the moderate health status group indicated that they had an illness and/or were somewhat impaired in at least one of the EQ-5D items. The last group, the poor health status group, comprised patients who indicated that they were severely impaired in at least one of the EQ-5D items. Descriptive statistics were used to describe the characteristics of the respondents. We dichotomized the five response categories of the PDI items by combining response options 1 to 3 (1 = not at all; 2 = slightly; 3 = somewhat) and response options 4 and 5 (4 = to a large extent; 5 = to a very large extent). Percentages of people who indicated that the items could influence sense of dignity to a large or very large extent (rated a 4 or 5 on the five-point scale) were presented for the three different health status groups. Logistic regression analyses were performed to determine if there was a relationship between considering the PDI items as influential to dignity in the last phase of life and health status. We controlled for the factors that were significantly different over the health status groups. To explore if there were any other factors associated with the perceived importance of the PDI items, a backward multiple logistic regression (removal at $P < 0.05$) was performed and odds ratios were calculated. The following factors were entered in the analysis: sex, age, having a partner, living at home, religion, and self-reported health status. The independent variables have been dichotomized for this analysis. Then separate logistic regression models were fitted for each item of the PDI. All analyses were performed using SPSS 14.0 (SPSS Inc., Chicago, IL).

The present study focused only on the people who completed at least 15 of the 22 PDI items, which was 90% of the subsample of the cohort who received the questionnaire including the PDI. Although the excluded people were most comparable with the moderate health status group regarding sociodemographic characteristics, 13% would have been included in

the poor health status group. The main difference was that 54% of the people excluded from this study indicated that they had a belief or religion that they considered important in their lives compared with 37%, 35%, and 43% of people in the good, moderate, and poor health status groups, respectively.

Results

Table 1 presents the characteristics of the respondents. The majority of the respondents had a moderate or good health status. People with a poor health status were more likely to be women (71%) and older (mean age 71 years) compared with people with a good health status (59% of women, mean age 61 years). In addition, people with a poor health status less frequently had a partner, and their place of residence was more frequently a nursing home or care home. People with a moderate or poor health status suffered most often from rheumatoid arthritis, heart disease, and depression, followed by asthma or chronic obstructive pulmonary disease and cancer. Respectively, 26% and 77% of people with a moderate and poor health status assessed their personal health as less than good.

Table 2 shows the percentages of people with a good, moderate, and poor health status who considered the items as influencing personal dignity at the end of life to a (very) large extent. The percentages of people in each health status group who indicated the items as influential to dignity were not significantly different, except for three items in the physical domain: "not being able to continue with usual routines," "experiencing distressing symptoms," and "not being able to carry out important roles." These items were considered significantly more often as important to dignity by people with a moderate and poor health status compared with people with a good health status, after controlling for gender, age, residence, and having a partner.

Table 3 shows the determinants of considering the items as having a large influence on personal dignity in the last phase of life. Female respondents were more likely than male respondents to rate the items as important except for the physical items. Respondents younger than 80 years had a higher chance

Table 1
 Characteristics of People With an Advance Directive per Health Status Group

Characteristics	Good Health Status, <i>n</i> = 719	Moderate Health Status, <i>n</i> = 1433	Poor Health Status, <i>n</i> = 130
Sex, female (%) ^a	59	61	71
Age, mean (SD) [range] ^a	61 (14) [17–91]	61 (12) [25–98]	71 (15) [36–93]
Having a partner (%) ^a	73	58	45
Residence (%) ^a			
At home	98	92	76
Institution (e.g., nursing home, care home)	—	2	12
Other (e.g., sheltered accommodation)	2	6	12
Having a belief/religion considered as important in one's life	37	35	43
Diseases (%) ^a			
Rheumatoid arthritis	—	30	35
Heart disease	—	21	25
Depression	—	6	18
Asthma/COPD	—	11	13
Cancer	—	8	10
Diabetes	—	11	15
Stroke	—	4	11
Multiple sclerosis	—	—	5
Dementia	—	—	2
Self-reported health status (%) ^a			
Very good	40	12	3
Good	59	62	20
Less than good	1	26	77

^aSignificantly different across the health status groups ($P < 0.05$).

of considering the items as influential to sense of dignity at the end of life. Not having a partner was associated with a higher score on all physical PDI items. People who had a belief or religion that was important in their lives were generally less likely to think that the items influence sense of dignity at the end of life. Self-reported health status assessed as “less than good” was significantly associated with two physical PDI items: “experiencing distressing symptoms” and “not being able to carry out important roles.”

Discussion

Limited differences were found when comparing how people in good health and people with a poor health status perceive factors important in maintaining dignity nearing the end of life. Three physical items were significantly more often considered as influential to dignity by people with a poor health status. Self-reported health also was not found to be an important determinant except for perceptions on two physical items on symptoms and roles. Gender, old age, having a partner, and having a belief or religion that is important to one's life were shown to be the most

important determinants regarding the perceptions of factors influential to dignity.

Strengths and Limitations

An important strength of this study is that this is a large-scale study. Therefore, it was possible to subdivide the cohort into three different health status groups. Another strength is that this was the first study that investigated and compared the views on maintaining dignity at the end of life of people with a good health status and people with a poor health status. The study population comprised people with an advance directive, which may be considered a strength because we believe that the quality of the data is enhanced by the fact that the respondents are likely to have thought deeply about end-of-life issues and their life values. However, it also might be argued that this limits the generalizability of the results to other populations. Furthermore, a limitation is that this study did not directly examine whether the perceptions of maintaining dignity at the end of life remain stable over time. The current study was cross-sectional and compared the factors among persons with good, moderate, and poor health status. Longitudinal research is needed to investigate

Table 2
Aspects Considered Relevant for a Sense of Dignity at the End of Life per Health Status Groups

Aspects	Good Health Status (%) (n = 719)	Moderate Health Status (%) (n = 1433)	Poor Health Status (%) (n = 130)
Physical			
Not being able to independently manage bodily functions	63	67	60
Not being able to carry out tasks of daily living	49	52	51
Not being able to continue with usual routines ^a	36	44	47
Experiencing distressing symptoms ^a	32	38	45
Not being able to carry out important roles ^a	25	27	41
Changes in physical appearance	12	14	17
Psychological			
Not being able to think clearly	68	69	64
Not being able to mentally fight ^b	59	61	64
Feeling depressed or anxious	50	49	50
Not being able to accept things the way they are	40	44	50
Social			
Feeling a burden to others	65	70	67
Not being treated with respect or understanding	51	55	50
Feeling your privacy has been reduced	43	48	47
Not feeling supported by your community	44	44	43
Existential			
Feeling you do not have control over your life	59	61	62
No longer feeling like who you were	55	56	60
Feeling life no longer has meaning or purpose	51	53	55
Not feeling worthwhile or valued	41	44	44
Uncertainty regarding illness	30	32	36
Not having a meaningful spiritual life	33	36	33
Not feeling you made a meaningful or lasting contribution	21	23	30

^aSignificant difference among the health status groups after controlling for sex, age, having a partner and living at home ($P < 0.05$).

^b606 missing cases for this item because it was not included in the questionnaire that was sent to the people who were members of the Dutch Patient Association.

the individual stability of the perceptions of factors influencing personal dignity.

The Influence of Health Status on Perceptions of Personal Dignity at the End of Life

Perceptions of the psychological, social, and existential factors influencing dignity at the end of life seem not to be affected by health status. However, health status seems to have an effect on the perceptions of physical factors that would influence dignity in the last phase of life. The results of the current study imply that people with a poor health status are significantly more likely to perceive distressing symptoms, the ability to continue with usual routines, and the ability to carry out important roles as more important than those with a good health status. This would suggest that healthy people tend to underestimate the physical aspects that were found to be influential to dignity at the end of life. The results also suggest that people do not change their minds about the importance of psychological, social, and existential factors when their health status

changes. Therefore, several authors^{16–18} may overestimate the extent to which patients change their minds about life values and preferences for care when confronted with a serious illness or over the course of an illness trajectory regarding the psychological, social, and existential factors influencing dignity at the end of life.

The Influence of Sociodemographic Factors on Perceptions of Personal Dignity at the End of Life

Sociodemographic characteristics seem to have more influence on how people understand maintaining dignity than health status does. First, it seems that old age (older than 80 years) makes people think that the PDI items do not have much influence on maintaining dignity at the end of life. This may be explained by the idea that older people found meaning to, and acceptance of, their lives, making them less anxious about dying than younger people and less worried about maintaining dignity at the end of life.^{30,31} Women

Table 3
Importance of the PDI Items for a Sense of Dignity at the End of Life^a (Odds Ratios)

Aspects	Female Sex	Age <80	Not Having a Partner	Living at Home	Having a Belief/Religion Important in One's Life	Self-Reported Health Status (Less than Good)
Physical						
Not being able to independently manage bodily functions	—	1.5	1.3	—	0.33	—
Not being able to carry out tasks of daily living	0.78	1.3	1.2	—	0.38	—
Not being able to continue with usual routines	—	—	1.5	—	0.52	—
Experiencing distressing symptoms	—	1.4	1.7	—	—	1.5
Not being able to carry out important roles	—	—	1.3	—	0.67	1.5
Changes in physical appearance	1.4	—	1.5	—	1.3	—
Psychological						
Not being able to think clearly	1.3	1.3	—	—	0.50	—
Not being able to mentally fight ^b	1.5	1.4	1.2	1.4	0.66	—
Feeling depressed or anxious	1.3	1.5	—	—	0.86	—
Not being able to accept things the way they are	1.3	—	—	—	0.73	—
Social						
Feeling a burden to others	1.7	—	1.2	—	0.44	—
Not being treated with respect or understanding	1.9	1.5	—	—	1.2	—
Feeling your privacy has been reduced	2.0	1.3	1.3	—	0.71	—
Not feeling supported by your community	2.0	1.3	0.82	—	1.2	—
Existential						
Feeling you do not have control over your life	1.2	1.4	—	—	0.39	—
No longer feeling like who you were	1.3	—	—	—	0.75	—
Feeling life no longer has meaning or purpose	1.3	1.4	—	0.66	0.48	—
Not feeling worthwhile or valued	1.7	1.3	—	—	—	—
Uncertainty regarding illness	1.4	—	1.3	—	1.3	—
Not having a meaningful spiritual life	—	—	1.3	—	1.5	—
Not feeling you made a meaningful or lasting contribution	—	—	1.2	—	—	—

— = the item was entered in the regression but was not significant and consequently eliminated by the stepwise procedure.

^aSeparate logistic regression models were fitted for each PDI item. Odds ratios are presented in the table when significantly different ($P \leq 0.05$) from the null value.

^b606 missing cases for this item because it was not included in the questionnaire that was sent to the people who were members of the Dutch Patient Association.

are more likely to consider items as important to maintaining dignity, especially the social and psychological items. This finding is in line with a study on health-related quality of life in cardiac patients in which it was shown that social support is an important determinant of quality of life among women,³² and another qualitative study that found that women more specifically described psychological and social issues as challenges in living with an ostomy than men who survived colorectal cancer.³³ Not having a partner is an important determinant, which is not unexpected as a partner is often close by to give support. Overall, people who consider religion important in their lives are less likely to believe that the PDI items

have any influence on maintaining dignity at the end of life. This finding could be attributed to the common religious belief that no one but God has the authority to determine life and death, and accordingly, religious people believe that they cannot influence their situation and their dignity at the end of life.

In conclusion, health status is not as much associated with different perceptions of factors influencing dignity at the end of life, except for the perceptions of physical factors. Sociodemographic characteristics such as gender, religion, age, and having a partner are more associated with people's perceptions of factors that influence personal dignity at the end of life than health status or self-reported health.

Our findings might suggest that the understanding of dignity will not substantially change as health status changes. This would imply that the perceptions of factors influencing someone's sense of personal dignity can already be discussed when the patient is in good health or in an early stage of a disease. In light of advance care planning, this might contribute to adequate patient-centered and dignity conserving care at the end of life. However, further longitudinal research is needed to confirm that people's views on dignity remain stable during the trajectory of illness.

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