

Personal Dignity in the Terminally Ill from the Perspective of Caregivers: A Survey among Trained Volunteers and Physicians

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Abstract

Background: Although dignity is increasingly considered a goal of palliative care, little research has evaluated the understanding of dignity at the end of life from a caregiver's perspective.

Objective: The study objective was to investigate and compare the views of trained volunteers and SCEN physicians on maintaining dignity for patients reaching the end of life.

Design: The study is a survey questionnaire study.

Subjects: Subjects were two groups of caregivers involved in care for dying patients: trained volunteers ($n=236$) and end-of-life consultants (SCEN physicians; $n=427$).

Measurements: Measurement was done via the Dutch version of the 22-item Patient Dignity Inventory on symptoms and experiences that have been shown to influence the sense of dignity in terminally ill patients. Respondents were asked to rate on a five-point scale the extent to which they considered the items as influential on dignity in terminally ill patients, and as problematic in practice in maintaining dignity for patients in the last phase of life.

Results: Overall, volunteers indicated items more frequently as influential to dignity and as problematic in maintaining dignity at the end of life, compared to SCEN physicians. Volunteers gave significantly higher ratings than SCEN physicians to most of the social items, and to half of the psychological and existential items.

Conclusions: It seems that SCEN physicians consider the physical aspects of suffering to be most influential and problematic in practice in preserving dignity, while volunteers think psychosocial aspects are most important in preserving dignity at the end of life. These findings suggest that the role and responsibilities of caregivers involved in care for terminally ill patients affect the factors that they think influence dignity.

Introduction

THE INTEREST IN DIGNITY at the end of life has significantly increased in the past decade. This is probably due to the fact that empirical research has shown that loss of dignity is an important concern for patients at the end of life.¹⁻³

Dignity is important to 92% of the Dutch general public when asked what they consider as important in their dying phase.⁴ In addition, loss of dignity is one of the most common reasons to formulate an advance directive⁵ and one of the most frequently mentioned reasons for requesting euthanasia or physician-assisted suicide in the Netherlands.^{2,6}

Maintaining dignity has been considered one of the main goals of palliative care.⁷⁻¹⁰ A variety of studies identified

factors and themes that may have an impact on the sense of dignity at the end of life.¹¹⁻¹⁶ Chochinov and colleagues performed a qualitative study focusing on how dying cancer patients understand and define dignity, and developed an empirical model of dignity to understand how patients face an advancing terminal illness.¹⁷ From the themes and subthemes of this model, a list of 22 items concerning symptoms and experiences that influence the sense of dignity of terminally ill patients was developed.¹⁸ These 22 items formed the PDI prototype which was later revised into the 25-item Patient Dignity Inventory (PDI).¹⁹ Although it is important to understand how patients understand dignity at the end of life, terminally ill patients are often not able to communicate anymore about their preferences for end-of-life care and what

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supports their personal sense of dignity. As a consequence, family or caregivers might get involved in a complex decision-making process and might need to set priorities for care. A previous study by Steinhauser and colleagues investigated factors considered important at the end of life by patients, their families, physicians, and other care providers. They found that 95% of the patients agreed that maintaining one's dignity is very important at the end of life, and 99% of the physicians and also 99% of other care providers showed strong agreement with this attribute.²⁰ A clear understanding of how caregivers understand the factors that influence dignity in terminally ill patients can help to improve palliative care. In addition, it is of interest to consider which factors hinder the maintenance of dignity in practice from the view of caregivers experienced in caregiving at end of life. Therefore, the current study explored the understanding of dignity of trained volunteers providing care to dying patients at home or in a hospice and physicians who received training to provide their colleagues with information and expert advice concerning all aspects of euthanasia. The aim of this study is to investigate and compare the views of these two different groups of caregivers who are involved in care for terminally ill patients.

Methods

Study design and population

A written structured questionnaire was distributed amongst two groups of caregivers with experience in caring for terminally ill patients. The first group consisted of trained volunteers providing care to dying patients at home or in a hospice who were members of the National Organisation of Volunteers in Palliative Terminal Care (VPTZ).²¹ Most of the volunteers have personal and professional experience in caregiving at the end of life and all of them are being trained regularly by the VPTZ. Volunteers who attended a congress organized by the VPTZ in the fall of 2006 were asked to complete a written questionnaire including questions on dignity.

The other group consisted of Support and Consultation on Euthanasia (SCEN) physicians who participate in a formal network of trained consultants. Next to their work as practicing physician they provide their colleagues with information and expert advice concerning all aspects of euthanasia.²² The Dutch euthanasia law stipulates that consultation with another physician is required in the case of a euthanasia request; consequently the SCEN physician has to visit the patient and has to judge whether the request for euthanasia is in accordance with the criteria for due care, which means that they assess whether the patient's suffering is unbearable and without prospect of improvement.²³ SCEN physicians provide about seven consultations per year, and mostly for patients receiving home care.²⁴ SCEN physicians receive a short questionnaire that serves as a monitoring device of their activities for the SCEN network of consultants every year. In January 2007 all 497 SCEN physicians were sent a questionnaire including questions on dignity.

Measurement instrument

This study was based on the PDI prototype described in the introduction, including 22 items covering the following domains: physical, psychosocial, social, and existential.¹⁹ The extent to which the respondents thought that the items have

influence on maintaining patients' personal dignity in the last phase of life was rated on a five-point scale (1=not at all; 2=slightly; 3=somewhat; 4=to a large extent; 5=to a very large extent). The PDI items were introduced by the following text:

"The term dignity is often used when talking about the last phase of life. However, little is known about how dignity is understood. Because of your experience in providing care to patients near the end of life, we are very interested in how you understand dignity."

Then the respondents were asked, "Could you please rate (based on your experience) the extent to which you think that the following items (1) influence the sense of personal dignity in patients in the last phase of life? and (2) make it problematic in practice to maintain personal dignity in patients in the last phase of life?"

Analysis

First we examined whether each PDI item was considered influential in personal dignity in terminally ill patients, and second, whether the items were seen as factors that can make it problematic maintaining dignity in practice, by calculating the percentage of volunteers and SCEN physicians who scored 4 or 5 on the five-point scale per item. Differences in rating between volunteers and SCEN physicians were described using a 95% confidence interval. Furthermore, we constructed a top 10 list per caregiver group to show which items were most frequently considered as influential in the sense of personal dignity and which items were most often considered a factor that can make it problematic to preserve dignity in practice.

Results

A total of 236 volunteers completed the questionnaire. No response rate can be given, as there is no precise information about the number of volunteers who attended the congress. The 236 volunteers who completed the questionnaire represent 4% of all members of VPTZ and were a representative sample of all VPTZ volunteers with regard to sex; however, the respondents were somewhat older (mean age 59.5) compared to all volunteer members of the VPTZ (mean age 54.8). Of the SCEN physicians, 427 (86%) responded to the questionnaire.

Factors relevant to a patient's personal dignity

Table 1 shows the percentages of volunteers and SCEN physicians who indicated that the PDI items influence the sense of dignity in patients at the end of life to a (very) large extent. Overall, SCEN physicians gave lower scores to the items than volunteers. All social items, and in particular the items "not being treated with respect or understanding" (58% versus 33%) and "not feeling supported by your community" (43% versus 24%) were significantly more highly scored by volunteers than by SCEN physicians. More than half of the volunteers associated the psychological items "not being able to accept things the way they are" and "feeling depressed or anxious" as aspects that influence the sense of dignity in terminally ill patients, while one third of the SCEN physicians considered those items to be associated with a sense of dignity. In addition, two of the six physical items and half of the

TABLE 1. INFLUENCE OF PHYSICAL, PSYCHOLOGICAL, SOCIAL, AND EXISTENTIAL ASPECTS ON SENSE OF DIGNITY IN TERMINALLY ILL PATIENTS ACCORDING TO TRAINED VOLUNTEERS AND SCEN PHYSICIANS^a

	Trained volunteers		SCEN physicians	
	n=236 ^b		n=427 ^c	
	%	95% CI	%	95% CI
<i>Physical aspects</i>				
Not being able to independently manage bodily functions	69	63–75	67	62–72
Changes in physical appearance ^d	52	45–58	28	24–32
Experiencing distressing symptoms	51	44–58	49	44–54
Not being able to carry out important roles	45	38–51	36	31–41
Not being able to carry out tasks of daily living	42	36–49	34	29–38
Not being able to continue with usual routines ^d	41	34–47	16	12–19
<i>Psychological aspects</i>				
Not being able to accept things the way they are ^d	59	52–65	31	26–35
Not being able to think clearly	54	47–60	55	50–60
Feeling depressed or anxious ^d	51	44–58	29	25–34
Not being able to mentally fight	47	40–53	38	33–43
<i>Social aspects</i>				
Feeling a burden to others ^d	70	64–76	54	50–59
Feeling your privacy has been reduced ^d	58	51–64	44	39–49
Not being treated with respect or understanding ^d	58	52–65	33	29–38
Not feeling supported by your community ^d	43	37–50	24	20–29
<i>Existential aspects</i>				
Feeling you do not have control over your life	66	59–72	62	57–67
No longer feeling like who you were	61	55–68	53	48–58
Not feeling worthwhile or valued ^d	60	53–66	45	41–50
Feeling life no longer has meaning or purpose	53	46–59	44	39–49
Not feeling you made a meaningful or lasting contribution ^d	46	39–52	24	20–29
Thinking how life might end ^d	39	33–46	15	12–19
Uncertainty regarding illness ^d	37	31–44	10	7–13
Not having a meaningful spiritual life	29	22–35	26	22–31

^aPercentage that score 4 (to a large extent) or 5 (to a very large extent) on a scale of 1 to 5.

^bBetween 7 and 33 missing observations per aspect.

^cBetween 18 and 34 missing observations per aspect.

^dSignificant difference between volunteers and SCEN physicians.

existential items were significantly more highly scored by volunteers than by SCEN physicians. The existential item “uncertainty regarding illness” was rated as influential to a sense of dignity by only 10% of the SCEN physicians, while 37% of the volunteers made this association.

Factors problematic in maintaining a patient's dignity

Table 2 shows the percentage of volunteers and SCEN physicians who considered that the presence of the PDI items in patients reaching the end of life make it problematic in practice maintaining dignity. Again, SCEN physicians generally scored lower on the items compared to volunteers. The same items that were significantly more often considered relevant to a patient's sense of dignity by volunteers than by SCEN physicians were significantly more often considered problematic in practice by volunteers, except for the items “changes in physical appearance” and “feeling a burden to others.”

Top 10 PDI items most influential and problematic

Table 3 shows the 10 items most frequently scored as having influence on sense of dignity and the 10 items most

often scored as problematic in maintaining dignity in practice according to volunteers and SCEN physicians.

Volunteers considered eight items influential as well as problematic in practice. However, the item “feeling you do not have control over life” is more often considered influential than problematic in practice (third ranked versus eighth rank); and “feeling your privacy has been reduced” is more often considered problematic in practice than influential on dignity (third ranked versus seventh ranked). SCEN physicians considered nine similar items most frequently as influential as well as problematic in practice. Once more, the ranking of these items differs; for example, “experiencing distressing symptoms” has been more often considered an item that can make it problematic to maintain dignity in practice (first ranked) than it has been considered influential to dignity (ranked sixth).

Six items are considered influential as well as problematic in practice by volunteers and SCEN physicians: “feeling a burden to others,” “not being able to independently manage bodily functions,” “feeling you do not have control over your life,” “not feeling worthwhile or valued,” “feeling your privacy has been reduced,” and “not being able to think clearly.” The top 10 items cover all four domains, the physical, psychological, social, and existential domains. Items representing

TABLE 2. EXTENT TO WHICH PHYSICAL, PSYCHOLOGICAL, SOCIAL, AND EXISTENTIAL ASPECTS ARE IN PRACTICE PROBLEMATIC FOR TERMINALLY ILL PATIENTS MAINTAINING THEIR SENSE OF DIGNITY ACCORDING TO TRAINED VOLUNTEERS AND SCEN PHYSICIANS^a

	<i>Trained volunteers</i>		<i>SCEN physicians</i>	
	n = 236 ^b		n = 427 ^c	
	%	95% CI	%	95% CI
<i>Physical aspects</i>				
Not being able to independently manage bodily functions	58	51–65	56	51–61
Experiencing distressing symptoms	46	38–53	57	42–52
Not being able to carry out tasks of daily living	44	37–51	34	29–39
Not being able to continue with usual routines ^d	35	28–42	18	14–22
Not being able to carry out important roles	33	26–40	27	22–31
Changes in physical appearance	22	18–26	22	18–26
<i>Psychological aspects</i>				
Not being able to think clearly	54	47–61	56	51–61
Not being able to accept things the way they are ^d	51	44–58	35	31–40
Feeling depressed or anxious ^d	46	39–53	33	28–38
Not being able to mentally fight	38	31–45	35	30–39
<i>Social aspects</i>				
Feeling a burden to others	60	53–67	48	43–53
Feeling your privacy has been reduced ^d	56	48–63	39	34–44
Not being treated with respect or understanding ^d	54	47–61	31	27–36
Not feeling supported by your community ^d	43	36–50	20	16–24
<i>Existential aspects</i>				
Not feeling worthwhile or valued ^d	54	46–61	35	30–40
Feeling you do not have control over your life	50	43–57	50	45–55
No longer feeling like who you were	49	42–56	41	36–46
Feeling life no longer has meaning or purpose	40	33–46	45	40–50
Thinking how life might end ^d	36	29–43	15	12–19
Uncertainty regarding illness ^d	34	28–41	13	9–16
Not feeling you made a meaningful or lasting contribution ^d	30	24–37	19	14–23
Not having a meaningful spiritual life	20	14–25	21	17–25

^aRespondents were asked to name the three aspects most problematic in practice.

^bBetween 43 and 62 missing observations per aspect.

^cBetween 37 and 51 missing observations per aspect.

^dSignificant difference between volunteers and SCEN physicians.

the social domain were more often highly ranked in the volunteers' top 10, while items representing the physical domain were more often highly ranked in the SCEN physicians' top 10 items.

An interesting finding is that "not being treated with respect or understanding" is only included in the volunteers' top 10 items, and "experiencing distressing symptoms" is only included in the physicians' top 10.

Discussion

The present study was conducted to gain more insight into views of caregivers involved in caring for terminally ill patients on maintaining personal dignity for patients reaching the end of life. Therefore, we explored how trained volunteers and SCEN physicians considered the influence of the PDI items and the extent to which the items can make it problematic maintaining dignity in practice. Overall, volunteers indicated the items more frequently as influential to dignity and as problematic in practice to maintaining dignity at the end of life compared to SCEN physicians. Volunteers gave significantly higher ratings than SCEN physicians to most of the social items and to half of the psychological and existential items.

An important strength is that our study population consisted of two groups of caregivers that can play a valuable role in caregiving for terminally ill patients. Another strength of the current study is the high response of the SCEN physicians. The volunteers included in the present study have been trained in caregiving at the end of life and might possibly be more involved in their work, as they attended a congress on this topic. This probably made them better able to imagine connections between various factors and the influence on the sense of dignity in patients in the final phase of life, and therefore made them a better group of informants, which enhances the quality of the data. However, we do not know the extent to which the trained volunteers are representative of untrained nonprofessional volunteers with regard to their opinions about factors relevant for dignity. Another limitation of this study is that we do not know the response rate of the volunteers, as there was no exact information about the number of volunteers who attended the congress where the questionnaire was distributed.

The findings of the current study show that the understanding of SCEN physicians differs from that of volunteer caregivers regarding the factors that have been shown to be important to the sense of dignity of terminally ill patients. The

TABLE 3. TOP 10 ITEMS OF INFLUENCE ON AND PROBLEMATIC FOR SENSE OF DIGNITY OF TERMINALLY ILL PATIENTS ACCORDING TO VOLUNTEERS AND SCEN PHYSICIANS

Rank ^a	Volunteers		SCEN physicians	
	<i>Of influence</i>	<i>Problematic in practice</i>	<i>Of influence</i>	<i>Problematic in practice</i>
1.1.4.5.	Feeling a burden to others [So] ^b	Feeling a burden to others [So]	Not being able to independently manage bodily functions [Ph]	Experiencing distressing symptoms [Ph]
2.2.1.2.	Not being able to independently manage bodily functions [Ph]	Not being able to independently manage bodily functions [Ph]	Feeling you do not have control over your life [Ex]	Not being able to independently manage bodily functions [Ph]
3.8.2.4.	Feeling you do not have control over your life [Ex]	Feeling your privacy has been reduced [So]	Not being able to think clearly [Ps]	Not being able to think clearly [Ps]
4.6.7.10.	Not feeling worthwhile or valued [Ex]	Not being treated with respect or understanding [So]	Feeling a burden on others [So]	Feeling you do not have control over your life [Ex]
5.7.-.9.	Not being able to accept things the way they are [Ps]	Not being able to think clearly [Ps]	No longer feeling like who you were [Ex]	Feeling a burden to others [So]
6.4.-.-.	Not being treated with respect or understanding [So]	Not feeling worthwhile or valued [Ex]	Experiencing distressing symptoms [Ph]	Feeling life no longer has meaning or purpose [Ex]
7.3.8.8.	Feeling your privacy has been reduced [So]	Not being able to accept things the way they are [Ps]	Not feeling worthwhile or valued [Ex]	No longer feeling like who you were [Ex]
8.5.3.3.	Not being able to think clearly [Ps]	Feeling you do not have control over your life [Ex]	Feeling your privacy has been reduced [So]	Feeling your privacy has been reduced [So]
9.-.9.6.	Feeling life no longer has meaning or purpose [Ex]	No longer feeling like who you were [Ex]	Feeling life no longer has meaning or purpose [Ex]	Not being able to accept things the way they are [Ps]
10.-.-.-.	Changes in physical appearance [Ph]	Feeling depressed or anxious [Ps]	Not being able to mentally fight [Ps]	Not feeling worthwhile or valued [Ex]

^aThese numbers indicate the rankings of the first item in every row. For example, “feeling a burden to others” (rankings: 1.1.4.5.) has been considered most often of influence as well as problematic by volunteers, and SCEN physicians considered this item the fourth most frequently influential in dignity and the fifth most frequently problematic in maintaining dignity in practice.

^bThe abbreviation between the square brackets refers to the domain that includes the item: [Ph] physical domain, [Ps] psychological domain, [So] social domain, [Ex] existential domain.

items from the social domain, and half of the psychological and existential items, were significantly more highly rated by volunteers than by SCEN physicians. A striking finding is that “experiencing distressing symptoms” was highly ranked by SCEN physicians and not represented in the 10 most highly rated items of the volunteers. On the other hand was the social item “being treated with respect and understanding” highly ranked by volunteers and not represented in the 10 most highly rated items of the SCEN physicians.

It seems that SCEN physicians consider the more physical aspects of suffering as most influential on dignity and also as factors that can make it problematic maintaining dignity in practice, while volunteers think psychosocial aspects are most important to preserve personal dignity at the end of life. An explanation might be that the role of caregiving at the end of life differs between volunteers and SCEN physicians. Volunteers are often more involved in someone’s personal life by providing comfort and support to the patient as well as to his or her family and friends, which might impact how volunteers think about the PDI items with regard to preserving or undermining personal dignity in terminally ill patients. They might possibly be better able to imagine how a situation of terminal illness affects a patient’s life and his or her social environment, and consequently what this means to the sense of personal dignity of a patient. Whereas SCEN physicians are required by the Dutch euthanasia law to assess the patient’s suffering and whether it is unbearable. The SCEN physicians see the people who explicitly request euthanasia, i.e., about 7% of all people who die nonsudden deaths in the Netherlands,²⁵ and judge whether the request is in accordance with criteria for due care. Therefore, SCEN physicians see the more complex medical situations, and in accordance with the study performed by Pasman and colleagues,¹⁹ it seems that physicians focus more on physical suffering. However, as loss of dignity is one of the most frequently mentioned reasons for requesting euthanasia or physician-assisted suicide,^{2,6} it is important that SCEN physicians not only focus on physical symptoms but also pay attention to social, existential, and psychological factors that may influence the sense of dignity.

The findings of the current study are in accordance with what Steinhauer and colleagues found in a study on factors considered important at the end of life among patients, family, and other caregivers.²⁰ They also concluded that physicians tend to focus on physical aspects, whereas the perspective of patients and families regarding the end of life is broader, focusing also on psychosocial aspects and spiritual meaning.²⁰ Comparing our results to the data from a study by Chochinov and colleagues focusing on the perspective of terminally ill cancer patients shows that patients more frequently (strongly) agreed that each item relates to a sense of dignity compared to how volunteers and SCEN physicians rated the items.¹⁸ Chochinov and colleagues found that the following two social items were the highest-ranked items by patients: “feeling a burden to others” and “not being treated with respect or understanding.” Our study found that SCEN physicians did not much relate to dignity at the end of life, “not being treated with respect or understanding” in particular. “Experiencing distressing symptoms” was the second to last item considered influential for dignity in Chochinov’s study and not included in the top 10 of the volunteers in the current study; for SCEN physicians the item was most frequently considered problematic in maintaining dignity in

practice. This gives some interesting insights into how dignity at the end of life is understood differently from different perspectives. In order to provide patient-centered care focusing on patients’ needs and wishes, it is important to make caregivers aware of the fact that their understanding may differ from how the patient understands dignity. Therefore, future research should be performed to further explore and better understand these differences.

In conclusion, this study makes an important contribution, since little research has been done to investigate caregivers’ perspective regarding dignity at the end of life. Differences were found in the relative importance of the items according to trained volunteers and SCEN physicians in the Netherlands. We might conclude that volunteers are more likely to associate social factors with a sense of dignity while SCEN physicians are more likely to associate physical factors with a sense of dignity at the end of life. It seems that the role and responsibilities of a caregiver involved in the care of terminally ill patients affect the factors that they think influence dignity. Since dying with dignity has been considered a principle goal of palliative care and the PDI items were developed in accordance to what terminally ill cancer patients perceive influence dignity, the PDI items could help to train people providing palliative care to attend to these factors to promote and maintain dignity in patients at the end of life.

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References

1. Aspinall F, Hughes R, Dunckley M, Addington-Hall J: What is important to measure in the last months and weeks of life? A modified nominal group study. *Int J Nurs Stud* 2006;43(4): 393–403.
2. Jansen-van der Weide MC, Onwuteaka-Philipsen BD, van der Wal G: Granted, undecided, withdrawn, and refused requests for euthanasia and physician-assisted suicide. *Arch Intern Med* 2005;165(15):1698–1704.
3. Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK: A national survey of physician-assisted suicide and euthanasia in the United States. *N Engl J Med* 1998; 338(17):1193–1201.
4. Rietjens JA, van Der Heide A, Onwuteaka-Philipsen BD, van der Maas PJ, van der Wal G: Preferences of the Dutch general public for a good death and associations with attitudes towards end-of-life decision-making. *Palliat Med* 2006;20(7): 685–692.
5. Van der Bruggen J, Rurup ML: “Ik wil dat mijn wil gerespecteerd wordt.” Onderzoek naar de motivatie om een wilsverklaring op te stellen en de verwachtingen van mensen die recent een wilsverklaring hebben opgesteld. Amsterdam: VU University Medical Center, 2006.
6. Haverkate I, Onwuteaka-Philipsen BD, van Der Heide A, Kostense PJ, van der WG, Der Maas PJ: Refused and granted requests for euthanasia and assisted suicide in the Netherlands: Interview study with structured questionnaire. *BMJ* 2000;321(7265):865–866.

7. Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M: Dignity therapy: A novel psychotherapeutic intervention for patients near the end of life. *J Clin Oncol* 2005;23(24):5520–5525.
8. Geyman JP: Dying and death of a family member. *J Fam Pract* 1983;17(1):125–134.
9. McClement SE, Chochinov HM, Hack TF, Kristjanson LJ, Harlos M: Dignity-conserving care: Application of research findings to practice. *Int J Palliat Nurs* 2004;10(4):173–179.
10. Turner K, Chye R, Aggarwal G, Philip J, Skeels A, Lickiss JN: Dignity in dying: A preliminary study of patients in the last three days of life. *J Palliat Care* 1996;12(2):7–13.
11. Baillie L: Patient dignity in an acute hospital setting: A case study. *Int J Nurs Stud* 2009;46:23–36.
12. Enes SP: An exploration of dignity in palliative care. *Palliat Med* 2003;17:263–269.
13. Franklin LL, Ternstedt BM, Nordenfelt L: Views on dignity of elderly nursing home residents. *Nurs Ethics* 2006;13:130–146.
14. Hall S, Longhurst S, Higginson I: Living and dying with dignity: A qualitative study of the views of older people in nursing homes. *Age Ageing* 2009;38:411–416.
15. Matiti MR, Trorey GM: Patients' expectations of the maintenance of their dignity. *J Clin Nurs* 2008;17:2709–2717.
16. Pleschberger S: Dignity and the challenge of dying in nursing homes: The residents' view. *Age Ageing* 2007;36:197–202.
17. Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M: Dignity in the terminally ill: A developing empirical model. *Soc Sci Med* 2002;54(3):433–443.
18. Chochinov HM, Kristjanson LJ, Hack TF, Hassard T, McClement S, Harlos M: Dignity in the terminally ill: Revisited. *J Palliat Med* 2006;9(3):666–672.
19. Chochinov HM, Hassard T, McClement S, Hack T, Kristjanson LJ, Harlos M, et al.: The patient dignity inventory: A novel way of measuring dignity-related distress in palliative care. *J Pain Symptom Manage* 2008;36(6):559–571.
20. Steinhilber KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA: Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000;284:2476–2482.
21. VPTZ: www.vptz.nl/. (Last accessed June 27, 2011.)
22. Van Wesemael Y, Cohen J, Onwuteaka-Philipsen BD, Bilsen J, Deliens L: Establishing specialized health services for professional consultation in euthanasia: experiences in the Netherlands and Belgium. *BMC Health Serv Res*. 2009;9:220.
23. Euthanasia Review Committees. Annual Report 2011. DVC the Hague 2012.
24. Onwuteaka-Philipsen BD, Buiting HM, Pasman HRW, Rurup ML, Willems DL: Evaluatie van SCEN: Wat is goede steun en consultatie? Amsterdam: VUMC, 2010.
25. Onwuteaka-Philipsen BD, Rurup ML, Pasman HR, van Der HA: The last phase of life: Who requests and who receives euthanasia or physician-assisted suicide? *Med Care* 2010; 48(7):596–603.
26. Pasman HR, Rurup ML, Willems DL, Onwuteaka-Philipsen BD: Concept of unbearable suffering in context of ungranted requests for euthanasia: Qualitative interviews with patients and physicians. *BMJ* 2009;339:b4362.

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