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DEATH WITH DIGNITY FROM THE PERSPECTIVE OF THE SURVIVING FAMILY: A SURVEY STUDY AMONG FAMILY CAREGIVERS OF DECEASED OLDER ADULTS

ABSTRACT

Background Death with dignity has been identified as important both to patients and their surviving family. While research results have been published on what patients themselves believe may affect the dignity of their deaths, little is known about what family caregivers consider to be a dignified death. **Aim** (1) To assess the prevalence of death with dignity in older adults from the perspective of family caregivers, (2) to determine factors that diminish dignity during the dying phase according to family caregivers (3) to identify physical, psychosocial and care factors associated with death with dignity. **Design** A survey study with a self-administered questionnaire. **Participants** Family caregivers of 163 deceased older (> 55 years of age) adults ('patients') who had participated in the Longitudinal Aging Study Amsterdam. **Results** Of the family caregivers, 69% reported that their relative had died with dignity. Factors associated with a dignified death in a multivariate regression model were: patients feeling peaceful and ready to die, absence of anxiety and depressive mood, presence of fatigue, and a clear explanation by the physician of treatment options during the final months of life. **Conclusions** The physical and psychosocial condition of the patient in combination with care factors contributed to death with dignity from the perspective of the family caregiver. The patient's state of mind during the last phase of life and clear communication on the part of the physician both seem to be of particular importance.

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INTRODUCTION

Caring for a dying relative and the subsequent death of that family member are considered to be highly stressful experiences for those involved (Hebert et al., 2006). Therefore, it is important to provide the best possible care and support not only to patients but also to family caregivers throughout the palliative phase and into bereavement (WHO, 2000). Research indicates that the quality of the last phase of life and the quality of death can affect the psychological and physical health of family caregivers (Kristjanson et al., 1996; Andershed, 2006). Moreover, negative recollections of the final period can complicate the bereavement process or leave surviving family members with feelings of regret (Kristjanson & Aoun, 2004; Shiozakie et al., 2005).

With regard to death, dying with dignity is of major concern to both patients (Chochinov, 2002; Georges et al., 2006) and their families (Steinhauser et al., 2000a). For 92% of the population of The Netherlands, a 'good' death is synonymous with a dignified death (Rietjens et al., 2006). Also, helping patients to die with dignity is a central tenet in end-of-life care (Östluns et al., 2011). The concept of dignity within the context of patient care and death generally refers to *personal* dignity, a form of dignity which is subjectively experienced and relates to a sense of worthiness, and which can be affected by circumstances or the actions of others (Nordenfelt, 2004; Leget, 2013). Since the concept of dignity is, to a certain extent, subjective, individuals may differ in their understanding of dignity and dying with dignity. Given the subjectivity and complexity of the concept, it is difficult to formulate a clear-cut and generally applicable definition (Thompson & Chochinov, 2008). It is, however, possible to identify common themes that may affect dignity, taking into account that the importance of these themes in their impact on dignity varies from person to person and from one context to another (Chochinov et al., 2002; Van Gennip et al., 2013).

Most studies have focused on which factors patients themselves think may influence the dignity of their death (Chochinov et al., 2002; Pleschberger, 2007; Hall, 2009) and on what healthcare professional see as important with regard to a dignified death (Karlsson et al., 2006; Coenen et al., 2007). However, data on which actual factors had made a death dignified or undignified, viewed from the perspective of the family caregivers of the deceased, is sorely lacking. Research done by Chochinov and colleagues on the effectiveness of their developed 'dignity therapy', aimed at enhancing the dignity of the patient at the end of life, indicates that the therapy helps not only patients to accept death but also their family members (McClement et al., 2007). This study suggests the importance of patients' dignity at the time of death for family caregivers. The way in which an individual died may well determine how well the family cope with this loss, as

well as affect their feelings concerning their own death. Knowing that a loved one has died with dignity can be a tremendous source of comfort.

The present study aims to deepen the insight into the circumstances or factors that make the death of an individual dignified in the experience of close family members. This study identifies factors that contribute to a dignified death in older adults ('patients') from the perspective of their family caregivers. First, the prevalence of death with dignity in patients as defined by family carers was established. Next, we determined which factors family caregivers believed had hindered the patient's dignity during the final stage of life. Additionally, we explored which physical and psycho-social factors in patients, and which care factors were associated with a dignified death.

METHODS

Study design and sample

A survey study was conducted among family caregivers of deceased older adults making use of a self-administered posted questionnaire. The sample recruited for this study consisted of family caregivers of deceased participants in the Longitudinal Aging Study Amsterdam (LASA). The LASA cohort is representative for the older population (>55 years of age) of The Netherlands (Huisman et al., 2011). We selected all family caregivers of the participants in the LASA study who died between 2006 and 2009 and who had given permission to contact a named family caregiver for research purposes. The total number of older adults in the LASA cohort who died within this period was 311. The family caregiver of 27 participants could not be located, setting the total number of family caregivers approached at 284. We sent the family caregivers a letter explaining the research purpose and asked them if they were willing to participate in the study by filling out a questionnaire. Of the caregivers we approached, 168 filled out the questionnaire and returned it (59%), 69 did not respond (25%) and 47 did not wish to participate (17%). Missing observations on the dignity scale (independent variable) further led to the exclusion of five family caregivers ($n = 163$). The data collection took place in 2009 and 2010, and the interval between the time of death of the patient and participation in this study varied from 0.5 years to a maximum of 3.5 years. Comparing our sample of 163 with all deaths in the Netherlands aged 55 and over in the year 2008 regarding sex and age showed that the distribution of sex was comparable (LASA sample: 50%, Dutch population: 47%) and that in our sample people under 81 years of age were somewhat overrepresented (LASA sample 35%, Dutch population 45%) (Statistics Netherlands).

The study protocol was approved by the Medical Ethics Committee of the VU University Medical Center, Amsterdam, The Netherlands.

Measurement

A standard questionnaire measuring factors related to dignity at death from a caregiver's perspective was not available. A team of experienced researchers familiar with end of life research developed a questionnaire based on studies investigating the perspective of family caregivers on the broader concept of "a good death" (Steinhauser et al., 2000a; Steinhauser et al., 2000b; Andershed, 2006; Heyland et al., 2006) and on studies investigating the aspects patients found important with regard to dying with dignity (Chochinov et al, 2002; Pleschberger, 2007; Hall, 2009). To check for face validity of the questionnaire, a pilot study was carried out among 6 family caregivers of deceased older adults. After filling out the questionnaire, they were asked in a face-to-face interview if they found parts of the questionnaire unclear or difficult to answer. On the basis of their feedback, final adjustments were made.

The first aim of the questionnaire was to determine whether caregivers found the death of their family member dignified or not. Because we were interested in whether the death of the family member had been dignified in the eyes of the family caregiver and the factors relating to this perception, we did not offer a formal definition or description of a 'dignified death'. Rather, caregivers were asked: "In your opinion, to what extent did your relative die with dignity?" (rated as 1, very undignified; 2, undignified; 3, not dignified/not undignified; 4, dignified; 5, very dignified). We were thus able to divide the participants into two groups – a 'death-with-dignity' group and a 'death-without-dignity' group – for subsequent analysis. Next, family caregivers were asked if, according to them, factors diminishing dignity had been observed: "Please indicate the factors below that may have diminished the dignity of the death of your relative". The factors listed were based on the work of Chochinov (Chochinov et al., 2002) (see Table 2 for factors).

A second objective of the questionnaire was to explore whether certain circumstances or factors could be associated with a dignified death. Four types of factors were included: physical, personal, relational, and care factors. A variety of physical factors was measured: a) presence of 5 somatic symptoms during the last three months of life (rated as 1, not present; 2, somewhat present; 3, very present); b) how many good days the patient had during the final week before death; c) duration of the cognitive capacity to make one's own care decisions (rated as 1, not capable for more than a month before death to 8, capable until death) and d) functional ability, indicating the patient's ability to perform five activities (e.g. (un)dress oneself) during the last three months of life (rated as 1, not possible to 5, yes without difficulty).

With regard to personal and relational factors, family caregivers were asked to indicate on a 3-point scale if psychosocial complaints had been observed during the last three months of the life of the patient. Four items were included, referring to the way in which the patient had coped with approaching death (3-point scale). Having been able to say good-bye to friends and loved ones was rated on a 4-point scale. Finally, a number of care items were included: place of death and whether this had been in accordance with the patient's wishes; three items evaluating the care the patient had received: care in general according with patient's wishes (3-point scale); a clear explanation by the physician of treatment options during the last phase of illness (forced choice), and patient's satisfaction with the contact with the physician (scale of one to five: 1, very satisfied to 5, very unsatisfied).

Statistical Analysis

Based on the scores on the dignity scale (ranking 1 to 5), two groups were defined for subsequent analysis: a 'death-with-dignity' group (scoring ≥ 4) and a 'death-without-dignity' group (scoring ≤ 3). Because we were interested in what *does* constitute a dignified death, we placed the neutral category (3, not dignified/not undignified) within the 'death-without-dignity' group. As a control measure for this decision, we repeated the entire statistical analysis without the neutral group and found similar results in terms of statistical significance. Next, we analysed what factors family caregivers believed had an effect on the dignity of the patient's death.

In a subsequent analysis, we investigated which physical, personal, relational and care factors were significantly associated with death with dignity. We dichotomized all categorical dependent variables. With 3-point scaled items, value 1 was attributed to the high scores ('very present'/'yes') and value 0 to the lower scores ('somewhat present' and 'not present'/'more or less' and 'no'). Differences were tested using Pearson chi-square tests and t-tests where appropriate.

A logistic regression was conducted to investigate which factors were independently associated with dignity in a multivariate analysis, using a forward selection procedure. Due to the sample size only a limited number of variables could be entered into the analysis. Each variable that significantly differentiated between groups was manually entered one at a time and Nagelkerke's R^2 was calculated, starting with the one with the highest R^2 . The variable contributing most to the model was kept in the model, followed by a subsequent round of entering each variable one at a time. This procedure was repeated until there were no more variables contributing significantly to the model (4 factors in total, $p < .05$).

RESULTS

Characteristics of the patients

The family caregivers of 113 patients (69%) reported that the patients had died with dignity, whereas the family caregivers of 50 patients (31%) reported that death was not dignified. With regard to gender, marital status, religion, educational level and place of residence of the patient three months before death, both groups were comparable (Table 1). However, the two groups differed significantly with regard to age at the time of death, with 70% of the patients in the ‘death-with-dignity’ group dying at the age of 80 or over, compared to 52% in the ‘death-without-dignity’ group. Cancer was the most common cause of death among patients in the ‘death-with-dignity’ group, while heart attacks or cardiovascular disease were the most common cause of death among those in the ‘death-without-dignity’ group. The second most common cause of death among patients in the ‘death-with-dignity’ group was old age (24% versus 10% in the ‘death-without-dignity’ group). Death among the patients in the ‘death-without-dignity’ group was significantly more often the result of other causes, e.g. complications following an accident or surgery, or cause of death unknown (14% versus 4% in the ‘death-with-dignity’ group). The relationship of the family caregiver to the patient was comparable in both groups, with the majority being an adult child of the patient (83%). Other types of relationships were: spouse/partner (7%), sibling or relative (5%) or friend (6%), (not in Table).

Table 1. Characteristics of the deceased in the ‘death-with-dignity’ and ‘death-without-dignity’ group (rounded %)

		DWD ^a n=113		DWOD n=50	
		%	Rank	%	Rank
Gender	male	49		52	
Age at death	> 80	71*		52*	
	57 - 80	29		48	
Cause of death	Cancer	26	1	20	2
	old age	24*	2	10*	5
	heart disease/attack	13	3	22	1
	COPD/pneumonia	11	4	8	6
	Stroke	9	5	12	4
	Dementia	5	6	12	4
	organs	5	6	2	7
	other ^b	4*	7	14*	3

Tabel 1 continued

		DWD ^a n=113	DWOD n=50
		%	%
Marital status	married	44	44
	single/divorced	9	8
	widowed	46	48
Educational level Attained	low	62	60
	medium	28	26
	high	10	14
Religion	yes	64	62
Place of residence 3 months before death	home	52	56
	care home	26	24
	nursing home	18	18
	hospital	1	-
	elsewhere	4	-

^a DWD= 'death-with-dignity' group, DWOD= 'death-without-dignity' group

^b complications following accident or surgery, and cause unknown.

*Significant differences between groups ($p < .05$).

Factors that diminished patients' dignity while approaching death according to family caregivers

Table 2 presents the factors that, according to the family caregiver, were observed and were believed to have threatened the patient's sense of dignity during the final stage of life. The presence of all but one of the factors was reported equally in both groups; only 'unable to think clearly' was reported significantly more often by the caregivers in the 'death-without-dignity' group (46% versus 23%). Among the family caregivers in the 'death-with-dignity' group, 40% indicated that none of the factors that could be a threat to dignity was observed (versus 18% in the 'death-without-dignity' group). The total number of factors reported that diminished dignity was significantly higher for caregivers in the 'death-without-dignity' group (mean=1.94) than for the 'death-with-dignity' group (mean=1.37).

Table 2. Factors diminishing dignity during the dying phase according to family carer in the 'death-with dignity' and 'death-without-dignity' group (rounded %)

	DWD <i>n</i> =113	DWOD <i>n</i> =49 ^a
Unable to think clearly	23**	46**
Sense of having no control	23	34
Incapable of own bodily care	21	28
Unable to accept things as they are	18	22
Unable to fulfil daily activities	17	20
Sense of being a burden to others	15	16
Sense that life is meaningless	12	8
Physicians did not sufficiently consider wishes	8	4
Not being treated with understanding	4	8
Different reason ^b	7	16
None of the above	40**	18**
Total number of factors mentioned (<i>means</i>)	1.37*	1.94*

^a Missing case=1.

^b Open-ended question. Answers given: sudden/unexpected death, not ready to die, not able to say goodbye, death could have been prevented, dependency on machines to stay alive, refused request for euthanasia, incontinence, pain, breathlessness, fear, placed in care home.

* Significantly different between groups ($p < .05$).

**Significantly different between groups ($p < .01$).

Factors associated with a dignified death

Physical Factors. More family caregivers in the 'death-with-dignity' group reported that their relative had suffered fatigue during the final 3 months of their life (50%) than was reported by the caregivers of patients whose death was not dignified (24%) (Table 3). More of them had also enjoyed good days in the final week before death (53% in the 'death-with-dignity' group versus 32% in the 'death-without-dignity' group), and more of them remained mentally capable of making their own care decisions until at least one week before death (69% 'death-with-dignity' group versus 52% in the 'death-without-dignity' group). Pain and other symptoms, forgetfulness, shortness of breath, incontinence and functional ability did not significantly differ between the two groups.

Table 3. Illness related variables in the 'death-with-dignity' and 'death-without-dignity' group (rounded %)

	DWD <i>n</i> =113	DWOD <i>n</i> =50	OR (IC)	<i>p</i> value
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Physical symptoms during 3 months preceding death				
Pain and other symptoms	21	20	1.13 (0.49-2.59)	.776
Fatigue	50	24	3.14 (1.48-6.65)	.002*
Forgetfulness	21	22	0.98 (0.44-2.19)	.957
Shortness of breath	13	6	2.31 (0.63-8.43)	.195
Incontinence	49	34	1.94 (0.97-3.89)	.059
Mentally capable of making own care decisions until at least one week before death (versus until less than one week before death)				
	69	52	2.06 (1.02-4.16)	.041*
Number of good days during final week ^a 2 to 7 good days (versus none/1 good day)				
	53	32	2.75 (1.35-5.60)	.005*
Functional ability during 3 months preceding death ^b (<i>means</i> ^c)				
	10.07	10.6	0.93 (0.82-1.06)	.263

* Significant difference between groups

^a Missing cases: 5.5 % of the total *n*.

^b Missing cases: 7% of the total *n*.

^c A sum score was calculated, with scores ranging from 'unable to perform any of the activities of daily life' (minimum score=5) to 'able to perform all activities without difficulty' (maximum score=25).

Personal, Relational and Care Factors. According to the family caregiver, patients whose death had not been dignified were reported significantly more often to have been anxious and/or depressed during the final 3 months of their life (24%), and less able to accept things as they were (30%), compared to patients with a dignified death (6% and 12%, respectively) (Table 4). Of those with a dignified death, 50% had been aware of their impending death. For patients whose death was not dignified, this percentage was significantly lower (20%). Also, patients whose death was considered dignified were more consciously active in making final arrangements before death than those whose death was not dignified (57% versus 24%), and more of them had been capable of finalizing their affairs before death than those whose deaths were not dignified (42% versus 24%). As reported by family caregivers, patients with a dignified death had felt ready to die in 68% of the cases (versus 8% in the 'death-without-dignity' group). Finally, according to family caregivers, significantly more patients with a dignified death had expressed a death wish in the very last days before death (29% versus 8%).

With regard to the relational variables, significantly more patients whose death was without dignity felt lonely during the final three months of their lives according to their family caregiver (22%) compared to those with a dignified death (10%). Both groups did

not differ significantly from each other in perceived sense of burden or loss of interest in others. Among those with a dignified death, 74% had been able to say good-bye to their loved ones versus 38% with a not dignified death.

Care in general had been in accordance with the patient's wishes for the majority of patients who had died with dignity (81%). This was significantly lower for those with a not dignified death (42%). Treatment choices had been clearly explained more often by the physician among patients with a dignified death (71% versus 32% in the 'death-without-dignity' group) and patients with a dignified death had died significantly more often at home or in a residential care home (48%) compared to those with a not dignified death (32%).

Table 4. Personal, rational and care variables for the 'death-with-dignity' and 'death-without-dignity' group (rounded %)

	DWD n=113	DWOD n=50	OR (CI)	p value
Variables personal				
Anxiety/depressed mood	6	24	0.21 (0.08-0.57)	.001*
Unable to accept things as they are	12	30	0.34 (0.15-0.77)	.008*
Peaceful and ready to die	68	8	27.07 (8.99-81.53)	.000*
Aware of death nearing	50	20	4.15 (1.89-9.10)	.000*
Consciously active in making final arrangements before death	57	24	4.14 (1.96-8.74)	.000*
Capable of finalizing affairs before death	42	24	2.26 (1.07-4.77)	.031*
Death wish 3 days before death ^a	29	8	4.23 (1.41-13.06)	.006*
Variables relational				
Loneliness	10	22	0.40 (0.16-0.99)	.043*
Feeling like a burden	10	12	0.89 (0.31-2.52)	.825
Loss of interest in others	15	20	0.71 (0.30-1.68)	.433
Said good-bye	74	38	2.97 (1.30-6.77)	.000*
Variables care				
Care in general according with patient's wishes	81	42	5.52 (2.65-11.48)	.000*
Place of death home/residential care (versus elsewhere)	48	32	2.01 (1.00-4.06)	.049*
Place of death according to patient's wish	35	16	2.93 (0.95-8.99)	.069
Clear explanation by physician of treatment choices ^b	71	32	4.81 (2.23-10.36)	.001*
Satisfied with contact with physician	71	50	2.00 (0.98-4.10)	.056

* Significant difference between groups. ^a Missing cases: 11% of the total n. ^b Missing cases: 9% of the total n.

Multivariate analysis

Table 5 presents the factors associated with death with dignity in the final regression model. Patients who had died with dignity were more likely to have felt peaceful and ready to die (odds ratio (OR) =21.42) and they were less likely to be depressed or anxious (OR =0.11). They were more likely to have suffered fatigue during the last three months of life (OR =2.99). Also, receiving a clear explanation from their physician concerning treatment choices during the final phase of illness substantially increased the likelihood of a death with dignity (OR =3.08) as experienced by family caregivers.

Table 5. Factors associated with dignity during final stages of life. Multivariate logistic regression; reference group 'death-without-dignity' (odds ratio and 95% confidence interval) n= 138^a

Variables	OR (CI)	p value
Peaceful and ready to die	21.42 (5.78-79.44)	.000
Anxiety/depressed mood	0.11 (0.02-0.56)	.008
Fatigue	2.99 (1.04-8.59)	.043
Clear explanation of treatment options	3.08 (1.12-8.44)	.029

$R^2 = .39$ (Cox & Snell), $.55$ (Nagelkerke). Model $\chi^2 (4) = 67.20$ $p < .01$.

^a The number of respondents for this analysis was 138 (84.7% of the sample) due to missing values.

DISCUSSION

This study has explored factors that appear to make the death of older adults dignified from the perspective of their family caregivers. According to the majority of family caregivers, their deceased relative (patient) had died with dignity (69%). Yet, more than half of the family caregivers who believed that their relative did die with dignity also indicated that some dignity diminishing factors, such as the patient's sense of having no control over his situation or being incapable of personal body care, had been present (Table 2). This may indicate that, overall, dignity at death is not easily lost. Factors associated with a dignified death in a multivariate logistic regression model, were: patients feeling peaceful and ready to die, absence of anxiety and depressed mood, suffering fatigue, and a clear explanation by the physician of treatment choices at the end of life.

Physical symptoms such as pain, shortness of breath, and incontinence and reduced functional ability are often cited as relating to quality of life (Albers et al., 2010a; Albers et al., 2010b). These symptoms were, however, not found to be significantly related to dignity during the final stages of life in our study, suggesting that dignity is a separate concept from quality of life. While symptoms causing physical discomfort may reduce the perceived quality of life, they do not necessarily interfere with the patient's dignity at the end of life as perceived by the family carer. There is one exception: our study suggests

that fatigue relates to a dignified death. However, surprisingly suffering fatigue during the period prior to death actually seems to enhance the dignity of death in the experience of family caregivers, while it is generally found to reduce the quality of life (Blinderman, et al., 2009; Albers et al., 2010b).

From our study it appears that two aspects or circumstances affect whether a family caregiver experiences the death of the patient as dignified or not dignified. The first aspect refers to the age at which, and the causes from which the patient dies. First of all, when patients die at an old age (>80 years), it is more likely that the death is considered dignified from a caregiver's perspective. Secondly, death caused by cancer or old age, and death following a period of fatigue are associated with a dignified death. Sudden deaths (i.e. due to a heart attack), deaths due to unknown causes, or deaths as the result of complications following an accident or surgery are more likely to be experienced by family caregivers as not dignified. These findings may indicate that if death is an expected outcome, family caregivers are more inclined to experience the death as dignified than when the death has been sudden. This may also help to explain why family caregivers associate the presence of fatigue in patients with dignity at death. Fatigue may be seen as a signal to the family caregiver that the patient is worn out, tired of struggling against illness, and that death would be a welcome relief that enables the patient to die with dignity. Hebert and Schulz found that the amount of pain the patient experienced prior to death was positively associated with preparedness for death in family caregivers (Herbert and Schulz, 2006). The same may be true for fatigue, thus helping the family to anticipate and accept the patient's death.

The second aspect relates to the manner in which, and the circumstances under which, the patient dies. The state of mind of the patient during the last few weeks before death seems of special importance to the dignity of death from the perspective of the family caregiver. Firstly, for patients who had trouble thinking clearly at the end of life, more family caregivers perceived the death of their relative as not dignified than dignified. Cognitive decline is also identified by physicians and trained volunteers involved in palliative care as one of the most influential factors affecting dignity at the end of life (Albers et al., 2013), as well as being cited as such by both individuals with good and poor health status (Albers et al., 2012). Secondly, the psychological well-being of the patient during the final stage of life affects whether the death was dignified from the perspective of family caregivers. Awareness in the patient that death is nearing, being in a peaceful state of mind and ready to die, having a death wish three days before death, accepting things as they are, not feeling anxious or depressed, and having had the opportunity to say good-bye to loved ones all contribute to a death that was dignified according to the family caregiver. In addition to this, end-of-life care appeared to contribute positively to perceived dignity at the time of death when treatment choices had been clearly explained,

when care was in accordance with the patient's wishes, and when the patient died at home.

While the aspects pertaining to age at death and cause of death are difficult to control, the way in which the patient dies can, at least to some extent, be influenced. The results of our study indicate that clear and honest communication on the part of the physician during the final stages of life can help the family caregiver to experience the death of the patient as dignified, especially by guiding patients and their family caregivers through the process of dying through clear communication on what to expect with regard to treatment, and by helping the patient to feel peaceful and ready to die.

Methodological considerations

This study investigated factors that are important to dying with dignity for older adults, as viewed from the perspective of family caregivers, based on a representative cohort of older people living in the Netherlands. However, comparing our sample we found that while it was comparable to deceased Dutch people of age 55 and over with regard to sex, it proportionally had less people of over 80 years of age. Since we found that age is positively related to death with dignity according to family caregivers, it might be that the 69% of older people with a dignified death might be an underestimation. The underrepresentation of people over 80 years of age is not likely to have influenced the analysis of factors associated to death with dignity. A limitation is that the study was retrospective with an interval varying from a few months to three years between the actual time of death of the patient and participation in this study, and thus a certain amount of recall bias may be present. However, research suggests that family caregivers remember the circumstances surrounding the death of their relative rather accurately (Klinkenberg et al., 2003). Lastly, although we intended to investigate death with dignity from the perspective of the caregiver, it is possible that the caregiver responded to the questions on dying with dignity with the patient in mind.

CONCLUSION

For most of the family caregivers studied, the death of their family member had been with dignity. This study suggests that for a dignified death, in the perception of family caregivers, attending to the psychosocial well-being of the patient is at least as critical as addressing physiological concerns. Given the importance, for both patients and their caregivers, of closure at the end of life, characterised by a sense of peace and preparedness for death, healthcare professionals should provide clear and honest information regarding the patient's limited life expectancy or imminent death. This allows

the patient and his family to prepare for death, and thus contributes to both the patient's and the family's sense of peace and death with dignity.

Clear communication between the attending physician, the patient and family regarding the patient's wishes in terms of treatment and end-of-life care appears to enhance the likelihood of a dignified death as perceived by family caregivers. Such communication can make the final phase of life more comprehensible and foster a greater sense of control for both the patient and the family caregiver during confusing times. Existing research indicates that unpreparedness for the death of a loved one can intensify and prolong the bereavement process by increasing the risk of depression, anxiety, and complicated grief in family caregivers (Herbert & Schulz, 2006). Raising the awareness amongst healthcare professionals treating dying patients that preparedness to die is an integral aspect of a dignified death – both to patients and the surviving family – is important, especially since research has shown that many physicians still find it difficult to address the topic of dying and struggle with the decision of when, i.e. at what point in time, to broach the subject (Cherlin et al., 2005; Wenrich et al., 2010). The present study indicates how important a timely discussion of the patient's death can be.

Overall, this study indicates that the psychological well-being of the dying individual, especially one who is neither depressed nor anxious but ready to face death, is a key factor among family caregivers in determining that their loved one has died with dignity. This underscores the necessity of providing not only physical relief but also mental guidance and support. The 'dignity therapy' developed by Chochinov and colleagues may prove to be an invaluable aid in situations where the dying individual has trouble achieving closure (Chochinov et al., 2005).

This study is to our knowledge the first to identify factors influencing the concept of the dignity of death from the perspective of the surviving family caregivers. Gaining insight into the factors involved in the concept of 'death-with-dignity' is important: whether family caregivers perceive the death of their family member as dignified or not may very well affect their acceptance of the death and their experience of the bereavement process. Further research into this subject is required, focusing on different groups of caregivers (i.e. in different relationships to the deceased) and on different groups of deceased individuals (e.g. different age groups or individuals with specific illnesses).

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