Original Article

Author for correspondence:
Véronique Provencher,
School of Rehabilitation, Faculty of Medicine and Health Sciences, Université de Sherbrooke, 3001 12e Avenue Nord, Sherbrooke, QC, Canada J1H 5N4.
E-mail: veronique.provencher@usherbrooke.ca

CAMBRIDGE
UNIVERSITY PRESS

Which has more influence on a family's assessment of the quality of dying of their long-term care resident with dementia: Frequency of symptoms or quality of communication with healthcare team?

Olivia Charest-Drapeau, B.PS.[1], Véronique Provencher, O.T., PH.D.[1,2] (ORCID), Lise Trottier, M.S.C.[1], Guillaume Léonard, PH.D.[1,2], Machelle Wilchesky, PH.D.[3,4], Gina Bravo, PH.D.[1,5] and on behalf of the End-of-Life Care in Dementia Research Group[1]

[1]Research Centre on Aging, CIUSSS de l'Estrie – CHUS, Sherbrooke, QC, Canada; [2]School of Rehabilitation, Faculty of Medicine and Health Sciences, Université de Sherbrooke, Sherbrooke, QC, Canada; [3]Department of Family Medicine and Division of Geriatric Medicine, McGill University, Montreal, QC, Canada; [4]Donald Berman Maimonides Centre for Research in Aging, Montreal, QC, Canada and [5]Department of Community Health Sciences, Faculty of Medicine and Health Sciences, Université de Sherbrooke, Sherbrooke, QC, Canada

Abstract

Objective. Symptoms present at the end of life and the quality of communication with the healthcare team have both been shown to impact family assessments of the quality of dying of their loved one with dementia. However, the relative contributions of these two factors to family assessments have not yet been investigated. To address this knowledge gap, we explored which of these two factors has more influence on family assessments of the quality of dying of long-term care (LTC) residents with dementia. **Method.** This is a secondary analysis of a mortality follow-back study. Ninety-four family members of LTC residents who had died with dementia assessed the quality of dying (*very good* or *not very good*), the frequency of symptoms, and the quality of communication with the healthcare team using a self-administered questionnaire mailed 1 month after the resident's death. Logistic regression analyses were performed to determine the relative contributions of the two independent variables of primary interest (frequency of symptoms and quality of communication) to the families' assessments of the quality of dying. **Results.** Multivariate analyses revealed that the quality of communication with the healthcare team was closely linked to the quality of dying ($p = 0.009$, OR = 1.34, 95% CI = 1.09–1.65), whereas the frequency of symptoms was not ($p = 0.142$, OR = 1.05, 95% CI = 0.98–1.11) after controlling for potential confounders. **Significance of results.** Our findings show that healthcare providers' ability to engage in the end-of-life conversations with families outweighs the frequency of symptoms in family assessments of the quality of dying of their relative with dementia. Enhancing healthcare providers' ability to communicate with families about the end-of-life care could improve families' perceptions of the quality of dying of their relative with dementia and, consequently, ease their grieving process.

Introduction

The number of people living with dementia is expected to grow by approximately 40% in the next decade to reach 75 million individuals worldwide (Alzheimer's Disease International, 2015). The World Health Organization (2020) has ranked dementia as the third leading cause of death in Western countries. Currently, one in three seniors in North America dies with dementia (Canadian Academy of Health Sciences, 2019; Alzheimer's Association, 2020). Although most people living with dementia would prefer to die at home (Wiggins et al., 2019), about two thirds die in long-term care (LTC) facilities (Mitchell et al., 2005; Reyniers et al., 2015). Ensuring optimal quality of dying for LTC residents with dementia is a health priority for many countries (Kane, 2012; Livingston et al., 2017; Estabrooks et al., 2020) and really important to family members (De Roo et al., 2014; Vandervoort et al., 2014; Bolt et al., 2019b).

There is a lack of consistency and clarity in the literature regarding the quality-of-dying construct due, in part, to it being a subjective experience of the person facing the process of dying (Patrick et al., 2001). A systematic review by Hales et al. (2008) identified seven broad dimensions that are consistently reported by patients, families, and healthcare providers

as being central to capturing the quality of dying; these are (1) physical, (2) psychological, (3) social, (4) spiritual and existential experience; (5) the nature of healthcare; (6) life closure and death preparation; and (7) the circumstances of death. Standardized and validated instruments have been used to evaluate the quality of dying in various care settings (Hales et al., 2010; De Roo et al., 2015; Gutiérrez Sánchez et al., 2018), and more specifically at the end of life of people living with dementia (Volicer et al., 2001), reflecting the wide range of measures used to capture this concept. In late-stage dementia, when LTC residents typically lack the ability to communicate, the quality of dying is most often assessed by family members (van Soest-Poortvliet et al., 2011), given their major involvement in healthcare decision-making at the end of their relative's life (Shanley et al., 2017).

Having a high-quality dying experience is universally regarded as a goal at the end of life. Freedom from pain and suffering is considered an important dimension by patients, families, and healthcare practitioners across a wide range of care settings (Steinhauser et al., 2000; Meier et al., 2016; Krikorian et al., 2019). However, studies have shown that nearly half of LTC residents with dementia do not die peacefully, according to family members (De Roo et al., 2014, 2015), an indicator of poor quality dying. Family assessments of the quality of dying relate to symptoms experienced by the resident in the last weeks of life. In a study by De Roo et al. (2015), dying peacefully, as judged by family members, was more prevalent among residents who exhibited less discomfort, restlessness, and choking in the last week of life, as well as less psychological distress (e.g., anxiety, depression, and agitation) in the last month of life. However, according to some studies, many residents with dementia suffer in their last weeks of life (Vandervoort et al., 2013; Pivodic et al., 2018), despite efforts by healthcare providers to minimize suffering and discomfort (Aminoff and Adunsky, 2005; van der Steen, 2010).

The family's perception of the quality of communication with the healthcare team is another factor that has been shown to influence their assessment of the quality of dying (Patrick, 2003; Yamaguchi et al., 2017). For example, Lee et al. (2020) explored the relationship between families' perceptions of end-of-life care in LTC and a good resident death, an indicator of the quality of dying. Their findings suggest that good communication between family members and the healthcare team has an important impact on families' perceptions of a good death. Bolt et al. (2019b) recently explored family caregivers' unpleasant experiences with end-of-life care, specifically involving LTC residents with dementia, and the extent to which these experiences affected their assessments of the quality of dying. In qualitative interviews, family members reported that healthcare professionals often did not inform them about the process of dying or the care provided, which negatively affected their assessments of the quality of dying.

Despite the paucity of research in this area, current studies suggest that symptoms present at the end of life as well as the quality of communication with the healthcare team both impact families' perceptions of the quality of dying of their relative with dementia. However, to our knowledge, no study has yet investigated the relative weights of these two factors in family assessments. Assuming that families' grief might be affected by their experience during the final days of their relative's life (Arruda and Paun, 2016), there is a need to determine which of these two factors has a greater impact on family assessments of the quality of dying of LTC residents with dementia. This knowledge could be used to prioritize interventions most likely to improve the experience for family members visiting a loved one at the end of life and thus ease their grieving process.

This study thus sought to determine the relative contributions of two factors known to influence the quality of dying of LTC residents with dementia — the frequency of symptoms they experience at the end of life and the quality of communication with the healthcare team — to family perceptions of the quality of dying.

Methods

Study design and population

This is a secondary analysis of data collected as part of a mortality follow-back study, which has been described in more detail elsewhere (Bravo et al., 2021). Briefly, the study was conducted within the *Quebec Observatory on End-of-Life Care for People with Dementia*, with prior approval from the Research Ethics Board (REB) of the CIUSSS de l'Estrie — CHUS (reference # MP-22-2016-576). The study aimed to describe LTC residents who had died in the context of dementia, the quality of the care they had received toward the end of life, and the quality of dying. The mortality follow-back study involved 13 LTC facilities in 3 of the largest cities in the province of Quebec, Canada. Following the death of a resident, a designated staff member from each facility was responsible for determining whether the decedent met the following inclusion criteria: (1) had received a clinical diagnosis of dementia, (2) had been admitted to the facility at least 30 days prior to death, (3) had spent at least 15 of the last 30 days of life in the facility, (4) had either died in the facility or spent no more than 3 days before their death in an acute care setting, and (5) had been visited at least once during the week preceding death by a close relative known to the facility. The mortality follow-back study ran from April 2016 to March 2018. A total of 172 eligible residents were enrolled during that period.

Data collection

The data used in this paper came from two sources. The first was the resident's medical chart from which an experienced research assistant extracted demographic and clinical information (e.g., gender, type of dementia, and age at death). The second source was a paper questionnaire mailed to the family member who visited the resident most often during the last week of life according to the designated staff member. The questionnaire was mailed 1 month after the resident's death followed by a thank you/reminder postcard two weeks later. The questionnaire comprised three main sections. The section "Introduction" collected information about the respondents themselves (e.g., gender, relationship to resident, and number of visits in the month preceding death), while the section "Methods" focused on the deceased residents (e.g., persons present at their death). The section "Results" included two standardized tools, i.e., *Symptom Management* (SM) (Volicer et al., 2001) and *Family Perceptions of Physician-Family Caregiver Communication* (FPPFC) (Biola et al., 2007), used to measure respondents' perceptions of the frequency of symptoms experienced by the resident at the end of life and the quality of communication with the healthcare team. Of the 172 residents enrolled in the mortality follow-back study, a designated family member returned the questionnaire for 95 of them for a response rate of 55%. One respondent did not answer the question used to measure the dependent variable (described below). Consequently, the analysis was based on an effective sample size of 94 residents.

Variables and measures

Dependent variable: quality of dying

In the "Results" section of the questionnaire, relatives were asked: "*Today, how would you describe the conditions of your loved one's death?*" Responses were provided on a 4-point Likert scale ranging from *very good* to *very poor*, with the option of checking "*I would rather not give an opinion*". For analysis purposes, we dichotomized the 4-level quality score and modeled *very good* quality of dying as our dependent variable (i.e., as compared with the other rating scores).

Independent variables

The SM scale (Volicer et al., 2001) was used to capture the resident's symptomatology at the end of life. This scale quantifies the frequency of physical or psychological signs of distress (e.g., shortness of breath, agitation, and resistance to care) exhibited by the resident in the month before death. Frequency is quantified on a 6-point Likert scale ranging from 0 (*daily*) to 5 (*never*). Summing ratings on individual items generates a total score ranging from 0 to 45, with higher scores indicating better symptom control. In this sample, Cronbach's alpha was good ($\alpha = 0.74$).

For the same time window, the FPPFC scale (Biola et al., 2007) was used to assess family members' perceptions of the quality of communication with the healthcare team (e.g., family was kept informed, received information about what to expect, and had the opportunity to ask questions) in the month preceding the resident's death. This scale consists of seven items, each scored on a 4-point Likert scale from 0 (*strongly disagree*) to 3 (*strongly agree*). Total scores range from 0 to 21, with higher scores indicating better perceived quality of communication. Internal consistency of the FPPFC was high ($\alpha = 0.93$). In the present study, the word "physician" was replaced by "healthcare team" in all seven items.

Demographic variables included the resident's gender, age at death, type of dementia, and the respondent's age. Other demographic information, such as respondent's gender, relationship to deceased resident, and number of visits to the resident during the last month of life, were used for descriptive purposes and as control variables. These variables have been used as controls in other studies exploring informal caregivers' perceptions of a peaceful (De Roo et al., 2015; Bolt et al., 2019b) or good resident death (Lee et al., 2020). Whether the respondent was present at the time of death was also included as a potential confounder, based on previous findings that this may affect how family members define and assess the quality of end-of-life care and the quality of dying (Granda-Cameron and Houldin, 2012; Beckstrand et al., 2017).

Statistical analyses

Means ± standard errors or absolute frequencies (percentages) were used to describe the characteristics of the deceased residents and relatives. Since the outcome (quality of dying) was binary (*very good* versus *not very good*), logistic regression analyses were performed to investigate its association with the main independent variables (frequency of symptoms and quality of communication with the healthcare team). First, a univariate analysis was performed to estimate the separate effect of each potential predictor. Second, we conducted a multivariate logistic regression analysis to determine the relative contributions of the two main independent variables after controlling for potential confounders (four of the respondents' sociodemographic characteristics). Interpretation was based on an alpha value of 0.05. Results are reported using odds ratios (ORs) and 95% confidence intervals (CIs). All analyses were conducted with IBM SPSS Statistics Version 25 and considered the clustering of residents within facilities.

Results

Description of the sample

Characteristics of the relatives and residents are summarized in Table 1 and compared according to whether the relative rated the quality of dying of the resident as *very good* or not. The majority (73%) of family respondents were female and children of the residents (70%). Just over half of the respondents had visited the deceased resident more than 10 times before their death, and 52% were present at the time of death. The deceased residents were mostly female (67%), and 49% had Alzheimer's disease according to their medical file. The residents' mean age at death was 90 years. Additional demographic information on relatives and residents can be found in Bravo et al. (2021).

As shown in Table 1, none of the characteristics of the relatives or residents were significantly related to the relatives' ratings of the quality of dying, although the ages of the relatives and residents were marginally significant. On the other hand, the two independent variables of primary interest (frequency of symptoms and quality of communication) clearly distinguish between the two subgroups of relatives, with both *p*-values being smaller than 0.001. Relatives who rated the quality of dying of their loved one as *very good* considered both SM and the quality of communication significantly better than those who did not.

Association of the frequency of symptoms and the quality of communication with the quality of dying

Table 2 presents the results from the univariate and multivariate logistic regression analyses. As in Table 1, univariate analysis revealed that the frequency of symptoms (OR: 1.07; 95% CI = 1.03–1.21; $p = 0.005$) and the quality of communication (OR: 1.35; 95% CI = 1.17–1.55; $p = 0.001$) were both associated with the quality of dying. However, when including both independent variables in a single model without further adjustment (multivariate, unadjusted results), the quality of communication was significantly associated with the outcome (OR: 1.31; 95% CI = 1.13–1.51; $p = 0.002$), while the SM was not (OR: 1.04; 95% CI = 0.99–1.10; $p = 0.131$). After adjusting for potential confounding variables, the quality of communication remained significant (OR: 1.34; 95% CI = 1.09–1.65; $p = 0.009$). We also tested the model by including the ages of relatives and residents since these variables were marginally significant between the two subgroups. However, since they did not contribute to the model, these variables were not retained.

Discussion

The aim of this study was to determine the relative effects of the frequency of symptoms experienced at the end of life and the quality of communication with the healthcare team on the quality of dying of LTC residents with dementia as assessed by their families. Our findings, which could help to address current scientific and clinical gaps, suggest that families' perception of the quality of dying is much more associated with the quality of communication

Table 1. Characteristics of the sample and study variables[a]

Variables	Entire sample (n = 94)	Quality of dying		p-value[b]
		Very good (n = 38)	Not very good (n = 56)	
Characteristics of the relatives				
Age (in years; 3 missing)	63.3 ± 1.3	66.7 ± 1.7	60.8 ± 2.2	0.053
Gender (female)	69 (73.4)	26 (68.4)	43 (76.8)	0.190
Relationship to the deceased resident (child)	66 (70.2)	25 (65.8)	41 (73.2)	0.403
Number of visits during the last month of the resident's life (11 visits or more; 1 missing)	49 (52.7)	21 (55.2)	28 (50.9)	0.633
Present at the time of death	49 (52.1)	20 (52.6)	29 (51.8)	0.951
Characteristics of the deceased residents				
Gender (female)	63 (67.0)	22 (57.9)	41 (73.2)	0.309
Age at death (in years)	90.0 ± 0.8	91.6 ±0.8	89.0 ± 1.2	0.055
Type of dementia (21 missing)				0.248
Alzheimer's disease	36 (49.3)	11 (39.3)	25 (55.6)	
Vascular dementia	7 (9.6)	4 (14.3)	3 (6.7)	
Mixed dementia	24 (32.9)	14 (50.0)	10 (22.2)	
Other	6 (8.2)	2 (7.1)	4 (8.9)	
Length of stay in the facility (in years)	3.1 ± 0.4	2.5 ± 0.4	3.5 ± 0.5	0.079
Ability to communicate verbally during the last week of life (very limited or none; 5 missing)	63 (70.8)	26 (72.2)	37 (69.8)	0.943
Frequency of symptoms and quality of communication				
SM (0 to 45; 15 missing)[c]	28.0 ± 1.0	31.6 ± 1.2	25.5 ± 1.0	**0.001**
FPPFC (0 to 21; 3 missing)[d]	16.4 ± 0.5	18.7 ± 0.4	14.9 ± 0.5	**<0.001**

[a]Data reported as mean ± standard error of the mean or frequency with percentage in parentheses.
[b]Derived from a two-sample *t*-test or the χ^2 statistic.
[c]Higher scores reflect a perception of better SM.
[d]Higher scores indicate a greater perceived quality of communication.
The bold values indicates the significance of $p < 0.05$.

they had with the healthcare team than with the frequency of symptoms experienced by the resident.

The importance of good communication between staff and family members at the end of life is in line with results of Lee et al. (2020) who found a significant relationship between this variable and caregivers' perceptions of a good resident death. This result also concurs with a study by Vandervoort et al.

(2014), showing that family members' conversations with professional caregivers about the resident's care preferences at the end of life, based on a written advance care plan, may positively impact their perception of the quality of dying of their loved one with dementia. Family carers of residents with dementia dying in LTC facilities often experience anticipatory grieving at a time when they need to make difficult decisions on behalf of their

Table 2. Associations between the frequency of symptoms, quality of communication, and the quality of dying (n = 78)

	Quality of dying								
	Univariate			Multivariate					
				Unadjusted[a]			Adjusted[b]		
	OR	95% CI	p-value	OR	95% CI	p-value	OR	95% CI	p-value
SM	1.07	1.03–1.12	**0.005**	1.04	0.99–1.10	0.132	1.05	0.98–1.11	0.142
FPPFC	1.35	1.17–1.55	**0.001**	1.31	1.13–1.51	**0.002**	1.34	1.09–1.65	**0.009**

SM, symptom management; FPPFC, Family Perceptions of Physician-Family Caregiver Communication; OR, odds ratio; CI, confidence interval.
[a]Only SM and FPPFC included as independent variables.
[b]Adjusted for four socio-demographic characteristics of the relatives: Gender, relationship to the deceased resident, number of visits during the last month of the resident's life, and present at the time of death.
The bold values indicates the significance of $p < 0.05$.

relative regarding care and treatment near the end of life. Since this situation is unfamiliar to most family members, they feel unprepared, especially when making decisions regarding the end-of-life care (Forbes et al., 2000; Hennings et al., 2010). During this stressful period, family members really feel a need to meet frequently with professional caregivers (Caron et al., 2005). These meetings help families to understand changes in their loved one's condition, answer their questions (Caron et al., 2005), and provide emotional and decision-making support (Forbes et al., 2000; Lopez, 2009), aspects that family caregivers truly value (Bolt et al., 2019a). In their review, Broady et al. (2018) found that greater knowledge of the trajectory of dementia and the resident's condition often helped family carers to accept the imminent loss of their loved one and made them more aware of important aspects surrounding the process of dying. Talking with the healthcare team and being kept informed of the resident's condition may thus give families a better understanding of what to expect at the end of their loved one's life. Open communication, appropriate information, and sufficient attention from the healthcare team may also foster a more peaceful experience for family members (Hennings et al., 2010).

The advanced stages of dementia are characterized by an increase in symptom distress (Mitchell et al., 2009). Pharmacological treatments, such as opioids, anxiolytics, and acetaminophen, are primarily used to reduce pain and make residents more comfortable (Hendriks et al., 2015). Our results confirmed that a low frequency of symptoms had a positive impact on families' perceptions of the quality of dying of their relative, in line with a study by De Roo et al. (2015). However, our findings also suggest that enhancing LTC healthcare providers' abilities to communicate with family caregivers about aspects surrounding the end of life, more than the frequency of symptoms, may improve families' perceptions of the quality of dying of their relative. This conclusion supports the results of Hendriks et al. (2014), suggesting that pharmacological treatments may not improve residents' quality of life in their last week of life. This emphasizes the importance of not neglecting communication while using other approaches, such as pharmacological, because the quality of death could be improved by communicating about the goals of care and decisions regarding the end-of-life treatment.

Since families place a high value on communication, especially in the last month of the resident's life, conversations with healthcare professionals around death and dying should be prioritized. To do this, healthcare providers must be able to establish a relationship of trust with the families. As family carers want to respect their relative's wishes, a relationship in which the values and beliefs of everyone involved are recognized should foster better communication with the healthcare team about treatments offered at the end of life (Caron et al., 2005). A positive and collaborative relationship between families and care teams is also important to support families at these difficult times as well as to build consensus around complex care decisions (Caron et al., 2005; Broady et al., 2018). However, the end-of-life discussions in LTC facilities are rarely initiated by healthcare staff as they do not always know how to start this conversation (Towsley et al., 2015; Morin et al., 2016). Shared decision-making tools have been developed and used to help healthcare professionals who involve patients and family caregivers in end-of-life care conversations and treatment decisions (Giguere et al., 2018; Légaré et al., 2018; Goossens et al., 2020). By increasing the engagement of residents and family carers in care decisions while residents

with dementia are still able to communicate, shared decision-making can lead to better quality decisions that reflect residents' needs and wishes, and provide greater satisfaction for residents, families, and staff (Légaré et al., 2018). Booklets and brochures, including a description of the expected signs and symptoms of dementia, as well as a few questions to prompt further reflection, can help healthcare providers to have a conversation with families about what to expect at the end of life. Such resources have been found to be an acceptable means of transmitting information and activating end-of-life discussions with families (Arcand et al., 2009, 2013; Sussman et al., 2019).

Limitations

This study has some limitations that should be considered. First, the variables included in our analyses were measured cross-sectionally (after the resident's death) rather than longitudinally. This feature of the study design precludes establishing the direction of effects and also raises the possibility of a recall bias. Second, while the percentage of relatives who returned the questionnaire is comparable to that of other studies (Vandervoort et al., 2013; van der Steen et al., 2014; Lee et al., 2020), the relationships between the frequency of symptoms, the quality of communication, and the quality of dying found in this study may differ from those of non-participants. Third, while well-established tools were used to measure the frequency of symptoms and quality of communication (Kiely et al., 2006; van Soest-Poortvliet et al., 2012, 2013), only one item assessed the quality of dying. A multi-item measure of the outcome variable may have generated different results. Fourth, the sample size was relatively small, especially for multivariate analyses, mainly due to missing SM data. For this reason, we chose to restrict statistical adjustments to respondent characteristics identified in previous research as confounders (De Roo et al., 2015; Bolt et al., 2019b; Lee et al., 2020) but did not include resident characteristics in the final model. Residual confounding, therefore, cannot be excluded. Future studies involving larger samples and controlling for wider arrays of covariates are warranted. With larger samples, it would also be possible to identify effect modifiers. Gender, for instance, could influence relatives' perception of the quality of dying of their loved one as female caregivers have reported more emotional distress and higher levels of depressive symptoms due to caregiving than males (Thompson et al., 2004; Xiong et al., 2020). Lastly, for analysis purposes, the nine respondents who checked "*I would rather not give an opinion*" were lumped together with those who rated the quality of dying as *not very good* based on our belief that these relatives were unlikely to have been very satisfied with the dying process of their loved one. To further support this decision, sub-analyzes were carried out to verify that the withdrawal of these nine respondents did not modify the results of the study, which was confirmed.

Conclusion

Although SM has been found to be related to a better quality of dying of residents with dementia in LTC, our study filled a clinical and scientific knowledge gap by highlighting the greater contribution to this outcome of having healthcare providers who engage in end-of-life conversations with families. By keeping family caregivers informed about what to expect at the end of life and by offering sufficient support, healthcare professionals may enhance family carers' perception that their relatives died under good

conditions, which could improve their experience as a caregiver and ease their grieving process. Additional research is required to specifically target aspects of communication that are really important to families caring for a person with dementia dying in LTC. This knowledge could guide the prioritization of interventions most likely to enhance the abilities of healthcare providers to engage in end-of-life conversations with families and thus improve the latters' perception of the quality of dying.

References

Alzheimer's Association (2020) 2020 Alzheimer's disease facts and figures. *Alzheimer's & Dementia* **16**, 391–460. doi:10.1002/alz.12068

Alzheimer's Disease International (2015) World Alzheimer Report 2015. The Global Impact of Dementia. An Analysis of Prevalence, Incidence, Cost and Trends. London.

Aminoff BZ and Adunsky A (2005) Dying dementia patients: Too much suffering, too little palliation. *American Journal of Hospice and Palliative Medicine* **22**, 344–348. doi:10.1177/104990910502200507

Arcand M, Monette J, Monette M, et al. (2009) Educating nursing home staff about the progression of dementia and the comfort care option: Impact on family satisfaction with end-of-life care. *Journal of the American Medical Directors Association* **10**(1), 50–55. doi:10.1016/j.jamda.2008.07.008

Arcand M, Brazil K, Nakanishi M, et al. (2013) Educating families about end-of-life care in advanced dementia: Acceptability of a Canadian family booklet to nurses from Canada, France, and Japan. *International Journal of Palliative Nursing* **19**(2), 67–74. doi:10.12968/ijpn.2013.19.2.67

Arruda EH and Paun O (2016) Dementia caregiver grief and bereavement: An integrative review. *Western Journal of Nursing Research* **39**, 825–851. doi:10.1177/0193945916658881

Beckstrand RL, Hadley KH, Luthy KE, et al. (2017) Critical care nurses' suggestions to improve end-of-life care obstacles. *Dimensions of Critical Care Nursing* **36**, 264–270. doi:10.1097/dcc.0000000000000252

Biola H, Sloane PD, Williams CS, et al. (2007) Physician communication with family caregivers of long-term care residents at the end of life. *Journal of the American Geriatrics Society* **55**, 846–856. doi:10.1111/j.1532-5415.2007.01179.x

Bolt SR, van der Steen J, Schols J, et al. (2019a) What do relatives value most in end-of-life care for people with dementia? *International Journal of Palliative Nursing* **25**, 432–442. doi:10.12968/ijpn.2019.25.9.432

Bolt SR, Verbeek L, Meijers JMM, et al. (2019b) Families' experiences with end-of-life care in nursing homes and associations with dying peacefully with dementia. *Journal of the American Medical Directors Association* **20**, 268–272. doi:10.1016/j.jamda.2018.12.001

Bravo G, Arcand M, Wilchesky M, et al. (2021) The *Quebec Observatory on End-of-Life Care for People with Dementia:* Implementation and preliminary findings. *Canadian Journal on Aging*, doi: 10.1017/S0714980821000659.

Broady TR, Saich F and Hinton T (2018) Caring for a family member or friend with dementia at the end of life: A scoping review and implications for palliative care practice. *Palliative Medicine* **32**(3), 643–656. doi:10.1177/0269216317748844

Canadian Academy of Health Sciences (2019) Improving the Quality of Life and Care of Persons Living with Dementia and their Caregivers. Ottawa (ON): The Expert Panel on Dementia Care in Canada, CAHS.

Caron CD, Griffith J and Arcand M (2005) Decision making at the end of life in dementia: How family caregivers perceive their interactions with health care providers in long-term-care settings. *Journal of Applied Gerontology* **24**(3), 231–247. doi:10.1177/0733464805275766

De Roo ML, van der Steen JT, Galindo Garre F, et al. (2014) When do people with dementia die peacefully? An analysis of data collected prospectively in long-term care settings. *Palliative Medicine* **28**, 210–219. doi:10.1177/0269216313509128

De Roo ML, Albers G, Deliens L, et al. (2015) Physical and psychological distress are related to dying peacefully in residents with dementia in long-term care facilities. *Journal of Pain and Symptom Management* **50**, 1–8. doi:10.1016/j.jpainsymman.2015.02.024

Estabrooks CA, Straus SE, Flood CM, et al. (2020) Restoring trust: COVID-19 and the future of long-term care in Canada. *FACETS* **5**, 651–691. doi:10.1139/facets-2020-0056

Forbes S, Bern-Klug M and Gessert C (2000) End-of-life decision making for nursing home residents with dementia. *Journal of Nursing Scholarship* **32**(3), 251–258. doi:10.1111/j.1547-5069.2000.00251.x

Giguere AMC, Lawani MA, Fortier-Brochu É, et al. (2018) Tailoring and evaluating an intervention to improve shared decision-making among seniors with dementia, their caregivers, and healthcare providers: Study protocol for a randomized controlled trial. *Trials* **19**, 332. doi:10.1186/s13063-018-2697-1

Goossens B, Sevenants A, Declercq A, et al. (2020) Shared decision-making in advance care planning for persons with dementia in nursing homes: A cross-sectional study. *BMC Geriatrics* **20**, 381. doi:10.1186/s12877-020-01797-0

Granda-Cameron C and Houldin A (2012) Concept analysis of good death in terminally ill patients. *American Journal of Hospice and Palliative Medicine* **29**(8), 632–639. doi:10.1177/1049909111434976

Gutiérrez Sánchez D, Pérez Cruzado D and Cuesta-Vargas AI (2018) The quality of dying and death measurement instruments: A systematic psychometric review. *Journal of Advanced Nursing* **74**(8), 1803–1818. doi:10.1111/jan.13687

Hales S, Zimmermann C and Rodin G (2008) The quality of dying and death. *Archives of Internal Medicine* **168**, 912–918. doi:10.1001/archinte.168.9.912

Hales S, Zimmermann C and Rodin G (2010) Review: The quality of dying and death: A systematic review of measures. *Palliative Medicine* **24**(2), 127–144. doi:10.1177/0269216309351783

Hendriks SA, Smalbrugge M, Hertogh CMPM, et al. (2014) Dying with dementia: Symptoms, treatment, and quality of life in the last week of life. *Journal of Pain and Symptom Management* **47**(4), 710–720. doi:10.1016/j.jpainsymman.2013.05.015

Hendriks SA, Smalbrugge M, Galindo-Garre F, et al. (2015) From admission to death: Prevalence and course of pain, agitation, and shortness of breath, and treatment of these symptoms in nursing home residents with dementia. *Journal of the American Medical Directors Association* **16**(6), 475–481. doi:10.1016/j.jamda.2014.12.016

Hennings J, Froggatt K and Keady J (2010) Approaching the end of life and dying with dementia in care homes: The accounts of family carers. *Reviews in Clinical Gerontology* **20**, 114–127. doi:10.1017/s0959259810000092

Kane M (2012). *My Life Until the End: Dying Well with Dementia*. London: Alzheimer's Society. Retrieved from: https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/my_life_until_the_end_dying_well_with_dementia.pdf.

Kiely DK, Volicer L, Teno J, et al. (2006) The validity and reliability of scales for the evaluation of end-of-life care in advanced dementia. *Alzheimer Disease and Associated Disorders* **20**, 176–181. doi:10.1097/00002093-200607000-00009

Krikorian A, Maldonado C and Pastrana T (2019) Patient´s perspectives on the notion of a good death: A systematic review of the literature. *Journal of*

Pain and Symptom Management **59**, 152–164. doi:10.1016/j.jpainsymman.2019.07

Lee E, Sussman T, Kaasalainen S, *et al.* (2020) The relationship between caregivers' perceptions of end-of-life care in long-term care and a good resident death. *Palliative and Supportive Care* **18**, 683–690. doi:10.1017/s1478951520000292

Légaré F, Adekpedjou R, Stacey D, *et al.* (2018) Interventions for increasing the use of shared decision making by healthcare professionals. *Cochrane Database of Systematic Reviews* **7**, CD006732. doi:10.1002/14651858.cd006732.pub

Livingston G, Sommerlad A, Orgeta V, *et al.* (2017) Dementia prevention, intervention, and care. *The Lancet* **390**, 2673–2734. doi:10.1016/s0140-6736(17)31363-6

Lopez RP (2009) Doing what's best: Decisions by families of acutely ill nursing home residents. *Western Journal of Nursing Research* **31**(5), 613–626. doi:10.1177/0193945909332911

Meier EA, Gallegos JV, Thomas LP, *et al.* (2016) Defining a good death (successful dying): Literature review and a call for research and public dialogue. *The American Journal of Geriatric Psychiatry* **24**, 261–271. doi:10.1016/j.jagp.2016.01.135

Mitchell SL, Teno JM, Miller SC, *et al.* (2005) A national study of the location of death for older persons with dementia. *Journal of the American Geriatrics Society* **53**(2), 299–305. doi:10.1111/j.1532-5415.2005.53118.x

Mitchell SL, Teno JM, Kiely DK, *et al.* (2009) The clinical course of advanced dementia. *The New England Journal of Medicine* **361**, 1529–1538. doi:10.1056/NEJMoa0902234

Morin L, Johnell K, Van den Block L, *et al.* (2016) Discussing end-of-life issues in nursing homes: A nationwide study in France. *Age and Ageing* **45**(3), 395–402. doi:10.1093/ageing/afw046

Patrick DL (2003) Measuring and improving the quality of dying and death. *Annals of Internal Medicine* **139**, 410. doi:10.7326/0003-4819-139-5_part_2-200309021-00006

Patrick DL, Engelberg RA and Curtis JR (2001) Evaluating the quality of dying and death. *Journal of Pain and Symptom Management* **22**(3), 717–726. doi:10.1016/s0885-3924(01)00333-5

Pivodic L, Smets T, van den Noortgate N, *et al.* (2018) Quality of dying and quality of end-of-life care of nursing home residents in six countries: An epidemiological study. *Palliative Medicine* **32**, 1584–1595. doi:10.1177/0269216318800610

Reyniers T, Deliens L, Pasman HR, *et al.* (2015) International variation in place of death of older people who died from dementia in 14 European and non-European countries. *Journal of the American Medical Directors Association* **16**, 165–171. doi:10.1016/j.jamda.2014.11.003

Shanley C, Fetherstonhaugh D, McAuliffe L, *et al.* (2017) Providing support to surrogate decision-makers for people living with dementia: Healthcare professional, organisational and community responsibilities. *Health & Social Care in the Community* **25**, 1563–1570. doi:10.1111/hsc.12456

Steinhauser KE, Clipp EC, McNeilly M, *et al.* (2000) In search of a good death: Observations of patients, families, and providers. *Annals of Internal Medicine* **132**, 825–832. doi:10.7326/0003-4819-132-10-200005160-00011

Sussman T, Kaasalainen S, Lee E, *et al.* (2019) Condition-specific pamphlets to improve end-of-life communication in long-term care: Staff perceptions on usability and use. *Journal of the American Medical Directors Association* **20**(3), 262–267. doi:10.1016/j.jamda.2018.11.009

Thompson RL, Lewis SL, Murphy MR, *et al.* (2004) Are there sex differences in emotional and biological responses in spousal caregivers of patients with Alzheimer's disease? *Biological Research For Nursing* **5**, 319–330. doi:10.1177/1099800404263288

Towsley GL, Hirschman KB and Madden C (2015) Conversations about end of life: Perspectives of nursing home residents, family, and staff. *Journal of Palliative Medicine* **18**(5), 421–428. doi:10.1089/jpm.2014.0316

van der Steen JT (2010) Dying with dementia: What we know after more than a decade of research. *Journal of Alzheimer's Disease* **22**, 37–55. doi:10.3233/jad-2010-100744

van der Steen JT, Ribbe MW, Deliens L, *et al.* (2014) Retrospective and prospective data collection compared in the Dutch End of Life in Dementia (DEOLD) study. *Alzheimer Disease & Associated Disorders* **28**, 88–94. doi:10.1097/wad.0b013e318293b380

Vandervoort A, Van den Block L, van der Steen JT, *et al.* (2013) Nursing home residents dying with dementia in Flanders, Belgium: A nationwide postmortem study on clinical characteristics and quality of dying. *Journal of the American Medical Directors Association* **14**, 485–492. doi:10.1016/j.jamda.2013.01.016

Vandervoort A, Houttekier D, Vander Stichele R, *et al.* (2014) Quality of dying in nursing home residents dying with dementia: Does advance care planning matter? A nationwide postmortem study. *PLoS One* **9**(3), e91130. doi:10.1371/journal.pone.0091130

van Soest-Poortvliet MC, van der Steen JT, Zimmerman S, *et al.* (2011) Measuring the quality of dying and quality of care when dying in long-term care settings: A qualitative content analysis of available instruments. *Journal of Pain and Symptom Management* **42**, 852–863. doi:10.1016/j.jpainsymman.2011.02.018

van Soest-Poortvliet MC, van der Steen JT, Zimmerman S, *et al.* (2012) Psychometric properties of instruments to measure the quality of end-of-life care and dying for long-term care residents with dementia. *Quality of Life Research* **21**, 671–684. doi:10.1007/s11136-011-9978-4

van Soest-Poortvliet MC, van der Steen JT, Zimmerman S, *et al.* (2013) Selecting the best instruments to measure quality of end-of-life care and quality of dying in long term care. *Journal of the American Medical Directors Association* **14**, 179–186. doi:10.1016/j.jamda.2012.09.019

Volicer L, Hurley AC and Blasi ZV (2001) Scales for evaluation of end-of-life care in dementia. *Alzheimer Disease and Associated Disorders* **15**, 194–200. doi:10.1097/00002093-200110000-00005

Wiggins N, Droney J, Mohammed K, *et al.* (2019) Understanding the factors associated with patients with dementia achieving their preferred place of death: A retrospective cohort study. *Age and Ageing* **48**, 433–439. doi:10.1093/ageing/afz015

World Health Organization (2020) WHO Reveals Leading Causes of Death and Disability Worldwide: 2000–2019. Retrieved from: https://www.who.int/news/item/09-12-2020-who-reveals-leading-causes-of-death-and-disability-worldwide-2000-2019.

Xiong C, Biscardi M, Astell A, *et al.* (2020) Sex and gender differences in caregiving burden experienced by family caregivers of persons with dementia: A systematic review. *PLoS One* **15**(4), e0231848. doi:10.1371/journal.pone.0231848

Yamaguchi T, Maeda I, Hatano Y, *et al.* (2017) Effects of end-of-life discussions on the mental health of bereaved family members and quality of patient death and care. *Journal of Pain and Symptom Management* **54**, 17–26. doi:10.1016/j.jpainsymman.2017.03