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Résumé

Comment les résidents en fin de vie perçoivent-ils le respect et la bienveillance dans les centres d'accueil pour personnes âgées

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Bien que le respect et la bienveillance soient les principes de base de la pratique infirmière, on ne sait pas très bien comment les résidents en fin de vie perçoivent ces marques d'attention dans les centres d'accueil pour personnes âgées. Le but de la présente étude est d'examiner si les familles ont le sentiment que la personne qui leur est chère a été traitée avec respect et bienveillance dans le dernier mois de sa vie en centre d'accueil. Une enquête rétrospective a été menée auprès de 208 personnes ayant perdu un proche dans 21 centres d'accueil situés dans une ville du centre du Canada. La majorité des participants a indiqué que le résident avait toujours été traité avec respect ou bienveillance. Toutefois, des différences significatives sont apparues, et toutes les familles ne croyaient pas que leur être cher avait toujours été traité avec respect ou bienveillance. Les écarts de pratique apparents dans les soins sont inquiétants et indiquent que l'on doit prendre des mesures pour y remédier.

Mots clés : respect, bienveillance, centre d'accueil pour personnes âgées, fin de vie

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How Respect and Kindness Are Experienced at the End of Life by Nursing Home Residents

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Respect and kindness are core principles of nursing practice, yet little is known about how they are experienced by nursing home (NH) residents at the end of life. The aim of this study was to examine the factors associated with being treated with respect and kindness in the last month of life as an NH resident. A retrospective survey of 208 bereaved family members was conducted in 21 NHs located in a city in central Canada. The majority of participants indicated that the resident had always been treated with respect or kindness. However, significant differences emerged, with not all family members believing that their loved one had always been treated with respect or kindness. The apparent lapses in care practices are troubling and indicate that steps must be taken to address them.

Keywords: respect, kindness, nursing home, end-of-life, older adults

Introduction

Treating nursing home (NH) residents with respect and kindness is a fundamental principle of nursing practice. Respect is a moral obligation to others, and it guides all nursing actions (Browne, 1993). Respect acknowledges the uniqueness of each individual NH resident encountered by nurses in their daily practice. Similarly, kindness derives from knowing the resident first as a person and through expressions of interest and concern (Green, 1995). Both respect and kindness develop through bonding with another human being and are demonstrated by approaching a resident as an equal and by listening to and "being there" for the resident (McGee, 1994; Rousseau, 2001). Considering the vulnerability that is experienced as one approaches the end of life, the provision of care based on the values of respect and kindness is more important than ever at this time. Indeed, research demonstrates that older adults and family caregivers view being treated with respect and kindness by health-care providers as a vital component of end-of-life care (Chochinov et al., 2002; Gardner & Kramer, 2009). Even though treating patients with respect is a primary ethical value (Canadian Nurses Association, 2008) and a critical marker of excellence in nursing practice, little is known about how the concepts of respect and kindness are experienced by those living in an NH at the end of life and by their families.

Literature Review

Excellent care at the end of life presupposes impeccable assessment and treatment of pain and other distressing symptoms; attention to emotional, spiritual, and existential distress; and incorporation of resident and family preferences into the plan of care. For most individuals facing the end of life, having control over their final days, dying in a place of their choosing, and being treated with dignity and respect are central concerns (Chochinov et al., 2002; Steinhauser et al., 2000; Vig, Davenport, & Pearlman, 2002). However, research suggests that quality end-of-life care is often lacking in NHs, resulting in residents dying with their symptoms poorly managed, their psychological or spiritual needs neglected, and their families feeling dissatisfied with the care provided (Teno, Kabumoto, Wetle, Roy, & Mor, 2004; Thompson, Menec, Chochinov, & McClement, 2008; Wetle, Shield, Teno, Miller, & Welch, 2005). It is not clear whether or not the failure to adequately meet these care needs translates into a feeling that one is not being respected or treated with kindness. The literature exploring the concept of dignity indicates that the care tenor (e.g., how a health-care provider interacts with the patient), the continuity of self (e.g., a health-care provider's knowing who the patient is as a person), and symptom distress significantly affect the sense of dignity in those with a life-limiting illness (Chochinov et al., 2002). Respect and kindness are behaviours that are intimately related to the experience of dignity. Therefore, failure to meet the dignity-related needs of residents nearing the end of life may compromise their integrity and cause them to feel disrespected.

To provide high-quality care at the end of life, nurses must be attuned to the needs of residents and families and possess the competence and interpersonal skills needed to proficiently deliver holistic care. Research examining expert palliative nursing care indicates that qualities such as kindness, warmth, compassion, and genuineness are key characteristics of an expert palliative care nurse as identified by patients and by nurses themselves (Johnston & Smith, 2006). These characteristics are echoed in the literature examining caring behaviours demonstrated by nurses. Expressive behaviours and interpersonal processes such as establishing trust, listening to the patient, treating patients with respect, and showing patients compassion and kindness, in addition to demonstrating technical competence, are consistently identified by patients and nurses as central to caring (Papastavrou, Efstathiou, & Charalambous, 2011; Radwin, Farquhar, Knowles, & Virchick, 2005; Smith & Sullivan, 1997).

Few studies have examined how family members assess nurses' demonstrations of caring in the NH environment and the corresponding nursing behaviours associated with caring. However, studies examining family members' assessments of a good death in long-term care have consistently identified the importance of staff empathy, a positive attitude towards caring for those who are dying, promotion of dignity and respect, and collaborative relationships in the delivery of high-quality care, all of which correspond to key caring behaviours (Gardner & Kramer, 2009; Munn & Zimmerman, 2006; Vohra, Brazil, Hanna, & Abelson, 2004). Little information is available on the impact of patient or family demographic variables such as age, gender, or patient diagnosis on the assessment of the perception of caring. The dearth of research in this area and the empirical knowledge required to better understand and predict family members' perceptions and reactions suggest a need to determine whether these perceptions are influenced by variables such as participant gender. The literature certainly indicates that gender, religious belief, frequency of visitation, and family functioning influence satisfaction assessments (Fakhoury, McCarthy, & Addington-Hall, 1996; Howell & Brazil, 2005; Kristjanson, Sloan, Dudgeon, & Adaskin, 1996). Thus it is reasonable to suggest that these factors also operate when kindness and respect are being evaluated. In order to redress this gap, the current study explored the impact of both resident and family member characteristics on perceptions of respect and kindness.

With an increase in the illness acuity, level of cognitive impairment, and frailty of older adults being admitted to NHs, these facilities cannot escape the responsibility of providing end-of-life care to a growing cohort of residents with highly complex care needs. Understanding who is most vulnerable to receiving poor-quality care at the end of life and, more specifically, who is not being treated with respect and kindness, may be one way to uncover patterns of care amenable to improvement. The overarching purpose of this study was to examine the factors associated with NH residents being treated with respect and kindness in the last month of life, as perceived by family informants. For the study, a family informant was defined as the individual self-identified as most involved in the care of the resident in the last month of life. The project was driven by three questions: *How prevalent is treatment with respect and kindness in the NH? How do resident, family, facility, and process of care variables correlate to being shown respect or kindness? Which factors are the most helpful in explaining variation in respect and kindness at the end of life in NH residents?*

Methods and Procedures

This article reports findings from a secondary analysis of data collected as part of a mixed-methods study with bereaved family members examining satisfaction with end-of-life care provided in an NH. Part of the study has been published previously (Thompson et al., 2008). Family participants, identified as the primary contact of residents who either died in an NH or had been transferred to hospital and subsequently died there, were recruited from 21 NHs located in a city in central Canada between May 2006 and December 2008. Family members were eligible to participate if they were 18 years of age or older, were conversant in English, and had been involved in the care of an NH resident who died within the preceding 12 months. Although the research literature suggests that bereaved individuals suffer no distress participating in surveys as soon as 2 weeks after a death (Casarett, Crowley, & Hirschman, 2003), the study solicited persons whose relative had died within the preceding 12 months in order to cause the least possible distress and to minimize recall bias. All potential participants who met these eligibility criteria were mailed a letter from the NH facility on behalf of the researchers. The letter invited those wishing to participate in the study to phone a research nurse and indicate their interest in taking part. Participant eligibility was confirmed during this initial contact. Approval by the University of Manitoba research ethics board and access to the individual NHs were secured prior to commencement of the study.

Measures

The module developed for evaluating NH care in the After-Death Bereaved Family Member Interview (Teno, 2004) was the main instrument used to collect data for the study. The After-Death Interview measures whether the care provided met the needs and expectations of family members and also provides a measure of family members' overall satisfaction with care. Developed on the conceptual model of patient-focused, family-centred medical care, this tool assesses quality of care in seven domains: attending to the family's information needs, advance care planning, individualized care, coordinated care, attending to the emotional and spiritual needs of the family, ensuring the physical comfort and emotional support of the resident, and an overall measure of the quality of end-of-life care. The tool has been validated through retrospective telephone surveys of family members of patients who died in hospice, NH, and hospital settings (Teno, Clarridge, Casey, Edgman-Levitan, & Fowler, 2001). Due to the use of skip patterns in the questionnaire, the questions in several of the domains are answered by a very small number of respondents. This affected the Cronbach's alphas in the current sample: inform and promote shared decision-making (0.69), encourage advance care planning (0.62), focus on the individual (0.79), support self-efficacy of the family (0.68), provide coordinated care (0.38), and attend to the emotional and spiritual needs of the family (0.37). As the After-Death Interview has little content regarding contact and communication with nurses and nursing assistants, respondents were asked additional questions exploring the communication of information by nurses and nursing assistants. The Cronbach's alpha for this domain was 0.70.

Five questions from the Nursing Facility Family Satisfaction Questionnaire, developed by Castle (2004), were added to evaluate the NH environment. This series of questions, comprised of 10-point Likert scales, ask respondents to rate how "home like" the facility was, how clean it was, the temperature of the resident's room, if they were able to make the resident's room "home like," and how private the room was. The reliability and validity of the instrument has been established, with Cronbach's alphas for the domains ranging from 0.77 to 0.86 (Castle, 2004).

The responses to the After-Death Interview questions are measured through a variety of response categories, including (a) ratings on a scale of 0 to 10; (b) four-point scales ranging from *always* to *never*; (c) three-point scales (e.g., receiving *less than was needed, more than was needed,* or *just the right amount* of care); and *yes/no* response options. For the purposes of our analysis, all were dichotomized to describe quality care (e.g., the right amount) versus less-than-desirable care.

The main outcomes of interest, respect and kindness, were assessed using two questions: *In that last month, how often was [the resident] treated with respect by those who were taking care of [him/her]? In that last month, how often was [the resident] treated with kindness by those who were taking care of [him/her]?* Responses to these questions were coded on a four-point scale (*always, usually, sometimes, never*).

The survey also gathered resident and family demographic information such as age, gender, medical diagnosis of the resident, presence of Alzheimer's disease or dementia, religious affiliation, length of time in NH, visitation patterns, and participant's relationship to resident.

Procedures

As the After-Death Interview is personalized (e.g., the name of the resident is inserted into the questions), it is read to participants rather than being self-administered. Thus the survey was conducted by a research nurse either by phone or face-to-face, as arranged with the family informant at a mutually convenient time and location. The majority of the interviews were conducted by telephone (n = 182) rather than face-to-face in the participant's home (n = 26). The average interview lasted 52 minutes (range = 20–120 minutes; *SD* = 18 minutes) and took place 7 months after the death of the resident (range = 2–16 months). Verbal consent was obtained from participants interviewed by telephone and written consent from those seen in person.

Data Analysis

Participants who reported that the resident was *sometimes, usually,* or *never* treated with respect or kindness were compared to those who reported that the resident was *always* treated with respect or kindness. Descriptive statistics were used to describe the demographic characteristics of the sample. Chi-square tests were calculated to compare those participants reporting positive experiences (i.e., *always* treated with respect or kindness) to those reporting less desirable experiences. To examine the dimensions that were uniquely associated with reports of being treated with respect or kindness, we performed multivariate regression analyses, using a stepped approach, entering those variables found to be significantly associated at $p < .05$ in bivariate analyses into the model. In this approach, the first phase of model-building consisted of entering significant resident and family demographic variables, including diagnoses and gender. A stepwise procedure was used to select model variables, with $p < .05$ considered statistically significant. In the second phase, those variables related to the resident's death, such as place of death, hospital transfers, and expectations of care, were added into the resulting model from step one. Statistically significant variables were retained in the model. In the final phase of analysis, variables related to the process of care, such as communication, and provision of emotional support were entered into the previous model. Analyses were performed using SPSS version 18.

Results

Sample Characteristics – Decedents and Respondents

A total of 922 letters were mailed to potential respondents. Of those who were mailed a letter, 208 contacted the researchers and were interviewed, for a response rate of 22.6%. Reminder letters were sent during the first year of data collection, but this failed to improve the response rate. Thus a decision was made to discontinue this practice during subsequent recruitment. Provincial privacy laws precluded the collection of specific information regarding non-responders. However, the profile of the respondents is comparable in terms of age, gender, length of stay, and prevalence of dementia to those of samples used in a number of studies examining family satisfaction with NH care (Teno et al., 2004; Vohra et al., 2004; Wetle et al., 2005) in addition to information available on the

NH population in the province of Manitoba (Doupe et al., 2006; Menec, Nowicki, Blandford, & Veselyuk, 2009).

A post-hoc power analysis was conducted using GPower statistical software (Faul & Erdfelder, 1992), to ensure that the sample size was sufficient to permit both precise estimation of predictive strength and a substantial degree of power in determining significance in multiple regression analyses. A sample size of 208 would permit the use of 10 predictor variables in the model and would result in an 88% power of detecting a significant model, assuming a type 1 error rate of 0.05.

Exploring the characteristics of the residents who died, nearly 60% (*n* = 124) were female and the mean age was 87.5 years. A total of 121 (58.5%) were reported to have had either dementia or Alzheimer's disease. The residents were diagnosed with an average of 4.8 medical conditions (range = 0–13). The average length of stay in the NH was 31.9 months (range = 2 weeks–180 months). The majority of residents died in the NH (*n* = 188; 90.4%), the remainder in hospital (*n* = 20; 9.6%). Of the 208 decedents, 64 (40.8%) had been transferred to hospital in the last month of life.

The participating family members had a mean age of 62.5 years and 146 (70.2%) were female; 157 (75.5%) were the adult children of residents; 92 (44.5%) reported having visited the resident two to five times per week, with 73 (35.3%) reporting daily visits and 42 (20.3%) other visitation patterns.

Table 1 shows the distribution of scores on the respect and kindness items. No participants indicated that the resident had *never* been treated with respect or kindness. Of those reporting less-than-desirable care, 33 (16.1%) reported that the resident had *sometimes* or *usually* been treated with respect and 43 (17.4%) that the resident had *sometimes* or *usually* been treated with kindness. The majority of respondents reported that the resident had *always* been treated with respect (82.7%) or kindness (78.8%) in the last month of life. Though respect and kindness are highly correlated ($r = .78, p = .01$), the decision was made to examine them as unique variables in order to explore their conceptual overlap and distinctiveness.

Table 1 ***Distribution of Respect and Kindness Scores***

	Always		**Usually**		**Sometimes**		**Never**	
	n	**%**	***n***	**%**	***n***	**%**	***n***	**%**
Respect (*N* = 205)	172	82.7	27	13.0	6	2.9	0	0.0
Kindness (*N* = 207)	164	78.8	36	17.3	7	3.4	0	0.0

Table 2 ***Univariate Analysis of Respect and Kindness***

Variable	**Respect**				**Kindness**			
	Always %	**Not Always %**	X^2	p	**Always %**	**Not Always %**	X^2	p
Death in NH	86.5	13.5	9.40	.006**	81.8	18.2	7.90	.009**
Died in place wanted to	88.9	11.1	4.40	.04*	85.0	15.0	4.60	.03*
Not transferred to hospital in last month of life	86.8	13.2	3.17	.11	85.2	14.8	4.40	.03*
Death a surprise to family member	86.4	13.6	2.75	.14	71.9	28.1	2.39	.13
Palliative care program involved	84.6	15.4	.019	1.00	84.6	15.4	0.28	.74
NH not-for-profit	84.5	15.5	0.18	.66	80.8	19.2	0.91	.33
NH not religiously affiliated	84.7	15.3	0.19	.69	79.4	20.6	0.006	1.00
Nurse never provided confusing information	89.9	11.0	17.68	.00***	84.8	15.2	15.70	.00***
Nurse provided right amount of information	89.4	10.6	19.70	.00***	85.9	14.1	22.40	.00***
Nurse listened to concerns about care of resident	86.5	13.5	19.10	.00***	82.9	17.1	26.50	.00***
Nurse responded to concerns about care of resident	88.8	11.2	34.30	.00***	84.5	15.5	29.50	.00***

Family was kept informed about resident	93.8	6.3	33.60	.00***	88.9	11.1	26.16	.00***
Staff knew medical history of resident	88.7	11.3	25.80	.00***	83.2	16.8	16.00	.00***
Family/resident input in decision-making	87.2	12.8	25.88	.00***	81.1	18.9	2.29	.16
Resident had specific wishes for end-of-life care	83.7	16.3	.045	.83	79.6	20.4	0.009	1.00
Discussed end-of-life wishes with staff	81.8	18.2	.28	.67	80.5	19.5	0.46	.57
Care provided consistent with wishes	84.9	15.1	.39	.67	84.9	15.1	3.07	.08
Resident had advance care plan	82.9	17.1	.41	.61	77.7	22.3	1.57	.24
NH respected advance care plan	84.4	15.6	.84	.31	79.3	20.7	0.25	.64
Personal care needs addressed	95.6	4.4	41.13	.00***	91.4	8.6	37.25	.00***
Enough staff to help with activities of daily living	95.2	4.8	50.18	.00***	87.8	12.2	27.94	.00***
Enough staff to help with medications	90.3	9.7	44.31	.00***	84.7	15.3	27.04	.00***
No concerns about care when family not present	92.0	8.0	7.91	.005**	86.9	13.5	4.74	.03*
NH staff talked about how it might feel after death of loved one	97.3	2.7	6.08	.01**	94.6	5.4	6.35	.01**
Providing right amount of support with feelings about resident's death	90.5	9.5	21.78	.00***	85.3	14.7	15.6	.00***

(continued)

Table 2 *(cont'd)*

Variable	**Respect**				**Kindness**			
	Always %	**Not Always %**	**X^2**	**p**	**Always %**	**Not Always %**	**X^2**	**p**
Expectations of end-of-life care met	90.1	9.9	24.90	.00***	84.8	15.2	12.1	.001***
Staff talked to family about their spiritual needs	90.0	10.0	3.47	.07*	82.9	17.1	.97	.37
Staff provided information on who to turn to if feeling stressed	91.1	8.9	1.98	.24	82.6	17.4	.33	.68
No pain in last month of life	87.5	12.5	.87	.40	81.3	18.8	.22	.71
No difficulty breathing in last month of life	86.5	13.5	.53	.55	80.2	19.8	.06	.86
No anxiety or sadness in last month of life	87.0	13.0	1.98	.18	81.7	18.3	1.00	.32
Experienced no other symptoms at end of life	88.9	11.1	9.72	.003**	82.4	17.6	3.32	.84
Diagnosed with dementia	85.0	15.0	.29	.70	82.6	17.4	2.2	.16
Less than 5 medical conditions	87.0	13.0	2.62	.12	81.8	18.2	1.5	.29
Male family participant	91.9	8.1	4.30	.04*	83.9	16.1	1.160	.35

* $p < .05$ ** $p < .01$ *** $p < .001$

Differences in Respect and Kindness

Significant differences emerged in the experiences of family members. Some felt that the resident had always been treated with respect or kindness and others felt the resident had not, as reported in Table 2. Characteristics of the resident's death, such as occurring outside the facility, occurring in a place that was "home" to the resident, or transfer to hospital in the last month of life, impacted on whether the family member believed that the resident was treated with respect/kindness. The only variable related to the NH environment that was significantly related to the perception of being treated with respect or kindness was the score on the Nursing Facility Family Satisfaction Questionnaire assessing the long-term-care environment (respect: $t(191) = 5.44$, $p = .000$; kindness: $t(193) = 4.54$, $p = .000$).

Communication between the family and staff also played a significant part in perceptions about whether the resident was treated with respect/kindness. Receiving clear information, receiving the right amount of information on the care and condition of the resident, and being kept up-to-date about the condition of the resident significantly influenced perceptions about respect/kindness. The family and/or the resident having played an active role in decision-making resulted in a feeling that the resident had been treated with respect more often than when decisions had been made without input from either the family or the resident. This relationship was not significant for kindness. No variables related to advance care planning, such as having an advance care plan, discussing wishes related to end-of-life care, or feeling that NH staff respected an advance care plan, were significantly related to feelings of being treated with respect/kindness.

Ensuring that the resident received intimate care, such as bathing, dressing, and feeding, and having adequate staff to deliver this care, impacted on family perceptions of whether the resident was treated with respect/kindness. Similarly, when there were staff available to provide the resident with their requisite medications, respect/kindness was more likely to be perceived. Family members who voiced concerns about the care being provided when they were not present were more likely to report lack of respect/kindness.

Attention to the emotional well-being of family members also affected their assessments of respect/kindness. When family members reported that NH staff talked to them about how they might feel after the death of their loved one, when they believed that they had been provided with the right amount of support in dealing with their feelings about the impending death, and when their expectations around end-of-

Table 3 ***Multiple Regression Analysis of Respect Score on Significant Univariate Variables***

Variable	**B**	**SE B**	β
(Constant)	.490	.26	
Died in NH	-.16	.08	-.14
Died in place wanted to	-.04	.05	-.06
Long-term-care environment score	-.002	.004	-.04
Staff knew medical history of resident	.212	.10	.16*
Decisions made without family/resident input	.036	.11	.02
Personal care needs addressed	.246	.06	.32***
Family kept informed of resident's condition	.131	.06	.16*
Nurse never provided confusing information	.111	.09	.103
Nurse provided enough information	.225	.08	.23**
Nurse listened to concerns about care of resident	.236	.19	.14
Nurse responded to concerns	.128	.18	.09
Family had concerns about care when not present	.041	.134	.03
Enough staff to help with activities of daily living	.166	.07	.20
Enough staff to help with medications	.032	.10	.03
Staff provided emotional support to family	.165	.078	.15*
Staff talked about how family might feel after the death	.082	.06	.09
Care provided was what was expected	.011	.07	.01
Resident had other symptoms at end of life	.045	.05	.06
Family member gender	-.009	.05	-.01

* $p < .05$ ** $p < .01$ *** $p < .001$

Table 4 ***Multiple Regression Analysis of Kindness Score on Significant Univariate Variables***

Variable	**B**	**SE B**	β
(Constant)	.737	.410	
Died in NH	–.186	.11	–.18
Died in place wanted to	.070	.08	.09
No hospital transfer in last month of life	.088	.08	.12
Long-term environment score	–.006	.007	–.09
Staff knew medical history of resident	.230	.13	.19
Personal care needs addressed	.205	.06	.24***
Family kept informed of resident's condition	.199	.07	.23**
Nurse never provided confusing information	.228	.07	.21**
Nurse provided enough information	.081	.09	.07
Nurse listened to concerns about care of resident	–.129	.24	.07
Nurse responded to concerns about care of resident	–.398	.21	.29
Family had concern about care when not present	.343	.22	.22
Enough staff to help with activities of daily living	.034	.11	.04
Enough staff to help with medications	.136	.15	.11
Staff provided emotional support to family	.223	.08	.20**
Staff talked about how family might feel after the death	.040	.09	.03
Care provided was what was expected	.108	.11	.11

* $p < .05$ ** $p < .01$ *** $p < .001$

life care were met, family members more likely to indicate that the resident had been treated with respect/kindness.

Finally, differences in the assessment of respect/kindness emerged based on the medical profile of the resident, the symptoms experienced in the last month of life, and the demographic characteristics of the resident and the family member (Table 2).

Predictors of Respect and Kindness

Multiple regression analysis was performed to further examine the relationship between respect/kindness and the variables found to be significant in the univariate analyses. As noted in Table 3, a significant model of respect ($F = 31.01, p = .000, R^2 = .56$) emerged, accounting for 56% of the variation in respect, with independent contributions from the following: staff knowing the medical history of the resident in order to provide care, staff addressing the personal care needs of the resident, family members being kept up to date and informed about the care and condition of the resident, the family receiving the right amount of information about the care of the resident, and family members being provided emotional support by the staff.

Table 4 reports the significant model for kindness ($F = 17.75, p = .000, R^2 = .47$), which accounts for 47% of the variance in kindness, with the following variables entering into the model: addressing the personal care needs of the resident, family members being kept up to date and informed about the care and condition of the resident, being provided clear and concise information by the nurse regarding the care of the resident, and family members feeling they are provided with emotional support by the staff.

Discussion

This study is, to the best of our knowledge, among the first to describe, from the perspective of family informants, how respect and kindness are experienced by NH residents at the end of life. Slightly more than 82% and 78% of respondents indicated that the resident was always treated with respect and kindness. There is no benchmark against which to measure our results and to determine whether our findings are similar to others. Ideally, 100% of persons in care at the end of life will feel they are treated with respect and kindness. However, our results suggest that there are instances when this is not so. Although respect and kindness are highly correlated and many factors associated with one or the other are similar, there are situations in which they are different. It appears that the place of death influences a family member's assessment of whether the resident has been shown respect and kindness. A home death has been identified as a hallmark of a good death and as a goal for most individuals (Gardner & Kramer, 2009; Stajduhar, Allan, Cohen, & Heyland, 2008). In this study, when the death occurred in the NH — the resident's "home" — respect and kindness were more likely to be reported by the family. Family members of residents who did not consider the NH their home and would have wanted to die elsewhere (most frequently identified as their last place of residence before being admitted to the NH) were more likely to report respect and kindness as lacking. It may be that when death occurred outside the NH, or when the resident did not consider the NH "home," either care failed to meet the family's expectations or the family harboured guilt about NH placement. Thus, it may be not that NH staff failed to respect or treat the resident with kindness, but, rather, that the family member's assessment of the resident's treatment by staff was tainted, because of the family's projecting its feelings of having betrayed the resident by placing them in an NH.

Transfer to a hospital in the last month of life also affects a family's perception about whether the resident was treated with kindness, but not their assessment of respect. Families describe an NH resident's transfer to hospital as something they wish to avoid (Wilson & Daley, 1999), yet the literature tells us that between 30% and 60% of NH residents are hospitalized at least once in their last 6 months of life (Menec et al., 2009; Ramroth, Specht-Leible, Konig, & Brenner, 2006). It may be that family members perceive this transfer as burdensome and stressful for the resident and wish the medical care could have been provided in the NH.

It is not surprising that communication, information-sharing, and meeting residents' personal care needs were key factors influencing family members' feelings about whether respect and kindness were shown. These factors were also identified in a study with cardiac patients and their spouses, which found that attention to needs, empathy, provision of information, dignity, care, recognition of individuality, and autonomy were central to the manifestation of respect (Dickert & Kass, 2009). Respect is conveyed by care providers' body language and verbal language; by listening with interest, providing clear information, and asking the family questions that help to uncover the resident's true nature (Browne, 1993; Jonasson, Liss, Westerlind, & Bertero, 2010). As found in the regression analyses, respect is driven by having intimate knowledge of a resident's medical history — that is, knowing something about the individual. Research into aspects of dignity has found that, like respect, dignity is augmented when care providers "know" the resident (Chochinov, 2004). To show kindness is to be caring, considerate, and attentive to residents' needs (Whitbread, 2008). Given that knowing the resident plays such a large role in kindness and respect, exploring ways to promote resident-centred care is essential. Constructing life stories is one way for health-care providers to begin to know the resident as a person, with his or her unique values and needs (Whitbread, 2008). Dignity therapy in particular may be a mechanism for bolstering one's sense of purpose and meaning, and thus one's dignity (Chochinov et al., in press; Thompson & Chochinov, 2008).

Family members reported that receiving emotional support and talking with a health-care provider about how they might feel after the death of their loved one played a role in their assessment of whether the resident was shown respect and kindness. A tenet of palliative care is that the patient and family are the unit of care (World Health Organization, 2010), and responding to the psychosocial needs of family members is an important part of providing quality end-of-life care. Research has shown that there is a synchronicity between resident and family experiences, particularly in the instance of witnessed suffering (Spichiger, 2009). For example, one study found a direct correlation between patients' quality of life before death and the quality of life of bereaved family members (Wright et al., 2008). The study also found that bereaved caregivers experienced poorer quality of life, more regret, and greater risk of developing a major depressive disorder when there were no end-of-life conversations between physicians and the patient or when aggressive interventions were used. In most instances the suffering of family members was proportionate to that of the patient.

In our study, certain demographic characteristics of residents and family participants were significantly related to the perception of whether the resident had been shown respect/kindness. For example, if, during the last week of life, the resident experienced distressing symptoms such as restlessness, agitation, or confusion, family members perceived the person as not being treated with respect. Competently treating these troubling symptoms and relieving distress can be a challenge for health-care providers working in an NH, who often feel helpless to manage such symptoms (Hall, Schroder, & Weaver, 2002; Hanson et al., 2008; Travis, Conway, Daly, & Larsen, 2001). Being witness to a loved one suffering from these symptoms near the end of life is particularly distressing and may cause one to feel dissatisfied with the care being provided. It is interesting to note that male relatives were more likely than female relatives to indicate that the resident was not always treated with respect; no research examining the impact of gender on assessments of respect could be found to corroborate this finding.

Implications for Research, Education, and Practice

The findings of this study have implications for future research, education, and practice. Future research could further examine and explore respect and kindness as they are experienced at the end of life from the perspective of NH residents. Though the perspective of family members is valuable, understanding the congruence between family and resident assessment of respect and kindness will help to distinguish between family perceptions that may be tainted by guilt over placement and the care that is actually delivered. Family members indicated that hospital transfers affected their assessment of whether the resident was treated with kindness; further research with family members could explore factors that influence this perception. Research examining the perspectives of hospital staff caring for transferred NH residents is also warranted, and could provide insight regarding the environment and care ethos into which residents are being placed. Future work could further explore the ways in which nursing communication and the timing of information delivery influence the assessment of respect and kindness in end-of-life care.

With respect to practice and education, it is essential that nurses working in the NH environment develop empathetic relationships with residents and their family caregivers, built on a foundation of respect and kindness. The most significant predictors of sensing respect and kindness in this context were nursing communication behaviours. This requires the development of educational initiatives to help nurses feel comfortable and confident in delivering difficult information about the care and condition of the resident at life's end. As staff consistently identify the provision of emotional support to families as a challenge, ongoing educational initiatives in this realm are also important. Finally, unrelieved symptom distress affects family members' perception of the care being provided. It is essential that NH staff be kept current in their knowledge regarding the detection and treatment of the restlessness and agitation that can occur at the end of life. It is critical that opportunities for ongoing education in palliative care symptom management be provided.

Limitations

These findings must be placed in the context of the study's limitations. The cross-sectional nature of the study precluded assessment of casual relationships. We therefore cannot conclude whether a lack of respect or kindness drove some of the relationships we noted between the variables examined, or vice versa. It may be that what this study has identified are the constituents of kindness and respect. In this regard, the factors identified in the regression models may constitute elements of being kind or respectful towards residents and their families. For example, to be kind or respectful is to anticipate the information that a family needs and to communicate it proactively.

Surveys of bereaved family members are an important tool for assessing quality of care at the end of life. However, previous research indicates that emotions such as grief, guilt, burden, or stress can shape assessments of care, and thus evaluations may reflect the mood or needs of the proxy respondent (Hinton, 1996; McPherson & Addington-Hall, 2003). Therefore, it may be that assessments of respect or kindness are influenced by respondents' wish that their loved one had indeed always been shown this level of caring.

An additional limitation is that the After-Death Interview may not capture the full range of roles that nurses and nursing assistants play in the NH, and thereby omit scenarios that could influence perceptions about respect and kindness. One area that was obviously lacking in the survey was contact and communication with nursing staff. The researchers took steps to remedy this situation by adding a series of questions to address this fundamental area. The low Cronbach's alpha for many of the domains in the After-Death Interview precluded the calculation of domain and problem scores, as suggested by the tool developers. To overcome this limitation, the decision was made to analyze the responses to the individual questions making up the domains.

The non-probability sampling approach and the low response rate by eligible participants could have resulted in a skewed sample, with those who experienced extremes in care perhaps being more willing to participate than those for whom care was "uneventful." However, given the variability across the scores on the After-Death Interview, this does not appear to be the case.

Finally, the use of secondary analysis is not without methodological concerns. The use of secondary data analyses presents researchers with challenges related to how the original data were collected, the sampling procedures used, the relevance of the original data to the questions currently being posed, and shortcomings in the original measurement tools (Clarke & Cossette, 2000). These challenges were largely overcome in this study due to the fact that the original data set was collected by the first author (GT) for her doctoral studies, and she therefore has intimate knowledge of its strengths and limitations.

Conclusion

To be treated with respect and kindness by health-care providers, especially at the end of life, is a fundamental right of all nursing home residents. The finding that there may be instances when respect and kindness are not being shown is troubling, and steps must be taken to correct such lapses in care. Educational initiatives in NHs need to discuss the concepts of respect and kindness and ways to promote respectful behaviour. Due to the paucity of research in this area, further studies of how respect and kindness are experienced by NH residents and families as the end of life draws near are warranted. We must always remember, however, that being human is the only requisite for receiving respect and kindness, both of which are essential to the preservation of one's dignity.

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