Spiritual and Emotional Support of Primary Informal End-of-Life Caregivers in Nova Scotia

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INTRODUCTION

Palliative and end-of-life (EOL) care has been recognized as a priority area for improvement in the Canadian healthcare system for more than a decade, and calls for improvement of palliative and EOL services continue (1, 2). In Canada, EOL care tends to focus on the person who is dying, but it is important to remember that for nonprofessional informal caregivers, usually family and friends, the death of a loved one can be one of life's most stressful events (3).

In previous studies, patients' family members have reported that their experience of EOL caregiving could have been improved by more communication and more emotional and spiritual support (4–8). Despite this, spiritual and emotional support for informal EOL caregivers in Canada is not well characterized in the literature. As part of a large, ongoing, population-based study examining the experience of care at the end of life among adults in Nova Scotia, Canada, this sub-study probed spiritual and emotional support of informal caregivers to help address the information gap. This article examines whether the amount of spiritual and emotional support received by informal EOL caregivers was as much as they desired, and whether differences in receipt of desired support were evident with respect to location of care and characteristics of the decedent and the informal caregiver.

METHODS

Subjects were those people identified as the informant on death certificates of all adults (aged 18 and older) who died in Nova Scotia between June 2009 and October 2010. We refer

to these subjects as “informal caregivers.” We excluded informal caregivers of people who had died of external causes, as well as caregivers associated with deaths that were reported to the research team as sudden and unexpected.

Informal caregivers agreed to participate by replying to a mailed invitation sent from the Vital Statistics Division of Service Nova Scotia and Municipal Relations. They were interviewed via telephone six to ten months after the death of their loved one by means of a Canadian adaptation of the After-Death Bereaved Family Member Interview (9, 10).

The primary outcomes of interest were the determination of whether anyone talked with the informal caregiver about his or her religious or spiritual beliefs during the loved one’s last days of life, whether healthcare professionals involved with the decedent’s care offered emotional support during this time, and whether the support received was as much as desired (the right amount versus less than needed). Covariates of interest included decedent and caregiver characteristics, location of the majority of care in the decedent’s last 30 days of life, and involvement of a specialized palliative care program.

Descriptive statistics were followed by cross-tabulations and Pearson’s chi-squared tests to identify associations between caregiver and decedent characteristics and to determine whether the desired amount of spiritual and emotional support had been provided. Next, crude and multivariate logistic regression analyses were performed to identify the odds of informal caregivers reporting receipt of as much spiritual or emotional support as they wanted. Variables that were significant at a level of $p < 0.1$ in the crude analysis were included in the initial saturated multivariate model, and manual backwards elimination was used to create the most parsimonious model of characteristics related to receiving as much spiritual or emotional care as the informal caregiver desired. The Capital Health Research Ethics Board granted ethics approval for the overall study.

RESULTS

At the time of this sub-study, interviews with 621 eligible informal caregivers had been completed and the response rate to the overall survey was 28 percent. Informal caregivers tended to be female (73.6 percent) with a mean age of 63.2. They were most likely to be the child (51.9 percent) or spouse (35.7 percent) of the decedent. Decedents had tended to die in hospital (55.6 percent) of a neoplasm (40.1 percent) or circulatory system disease (23.3 percent). The majority of care in the last 30 days of life was provided in the home (42.3 percent), in hospital (29.5 percent), or in a long-term care facility (28.2 percent). Almost 44 percent (43.5 percent) received some specialized palliative care; 22 percent lived alone at time of death (Table 1).

Although only 27 percent of informal caregivers reported that someone had spoken to them about their religious or spiritual beliefs during their loved one’s last days, 80.4 percent reported that they had been given as much spiritual support as they wanted. However, significantly fewer informal caregivers who *did not* speak with someone about their religious or spiritual beliefs stated that this was as much support as they desired (82.4 percent) compared to those who *did* have these conversations (96.4 percent, $p < 0.0001$).

Similarly, 27.7 percent of informal caregivers reported having engaged in a conversation with a healthcare professional about how they might feel after their loved one's death, with 78.4 percent indicating that this emotional support was as much as they wanted. A comparison of caregivers who did and did not have these conversations shows that 72 percent of those who were *not* asked about their spirituality and emotions thought that they had received the right amount of emotional support, whereas 98 percent of caregivers who *were* asked considered it the right amount ($p<0.0001$).

Factors associated with the odds of an informal caregiver receiving as much spiritual or emotional support as he or she desired are summarized in Table 2 and Table 3.

DISCUSSION

Although almost 70 percent of caregivers reported that they had not been asked about their spirituality and emotions, most said that they had received as much spiritual and emotional support as they wanted. This suggests that some informal caregivers did not view conversations about these topics as necessary; but others, particularly those who had such interactions, saw this support as desirable.

Support for family members in the pre-bereavement period has been associated with more adaptive coping during bereavement and increased satisfaction with the EOL care the loved one received (7,11). Past research reporting negative health effects associated with caregiving and bereavement and the desire of family members for more spiritual and emotional support provides compelling evidence that the spiritual and emotional care of dying patients' family members is an important aspect of supporting the health and well-being of informal caregivers (4–6, 8).

Similar to a previous American study (12), our Canadian examination found that most informal caregivers are not being asked about their spiritual or emotional needs related to the death of a loved one. Some suggest that in the case of healthcare professionals, this omission may largely be due to their discomfort in raising such questions combined with their uncertainty about their ability to effectively meet the emotional needs of patients or informal caregivers and the lack of time and system supports (13, 14). Alternatively, considering that spirituality and emotions are complicated, personal, and difficult to define, it is possible that healthcare professionals believe they are asking these questions but informal caregivers are not recognizing them as such (14, 15). For instance, in Ontario, self-reported data from family physicians on their palliative care practices for cancer patients indicated that 86.4 percent thought they were providing emotional support (16).

Previous studies have proposed that family, friends, and church communities, rather than healthcare professionals, are important sources of support for bereaved family members (17–19). A recent meta-study of qualitative research that focused on understanding spirituality and the role of spiritual care at the end of life suggests that healthcare providers may be offering support not in the form of a conversation, but through important relational and action-based care, giving respectful, attentive physical care to the dying patient (14). Stajduhar and colleagues echo this in their recent qualitative study: “the assumption that

‘caring for’ (performing tasks of caregiving and responding to need) demonstrates ‘caring about’ (showing affection and regard)...is constructed and reproduced in family accounts” (8, p. 268). Given our finding that informal caregivers who did not receive spiritual or emotional support were less likely to report receiving the right amount, we suggest that healthcare professionals and other care providers be made aware of the value of their conversations and given tools to become more comfortable in dealing with these topics. Clear and helpful steps and phrases that can alleviate their discomfort are available to professional caregivers (20–22).

Common factors associated with a greater likelihood of informal caregivers reporting receipt of as much spiritual and emotional support as they wanted were being male, being of an older age, and having been assisted in caring for the decedent by a specialized palliative care program. In addition, the right amount of spiritual support was associated with the decedent living alone, whereas less support than desired was reported if the majority of the decedent’s last 30 days of life were spent in hospital.

Although it is unclear why, our results pertaining to sex and age are similar to those of an Australia study, in which it was reported that women and younger caregivers (age 65 and under) desired additional spiritual support in caring for a terminally ill family member (23). Australian palliative care services were found not to be a factor (23). In an American investigation, caregivers of critically ill cancer patients who died at home and received home hospice care were less likely to experience emotional distress or prolonged grief than those whose family member had experienced a hospital death (24). It is unclear why caregivers of dying patients who spent most of their last 30 days in hospital instead of their homes were less likely to report receiving the right amount of spiritual support, even though many hospitals provide in-house pastoral programs with support from multi-faith chaplains. However, this may be a reflection of changes in the provision of this service — the onus often falls on the patient or family to explicitly ask for it. When the dying patient remains at home, the informal caregiver is more likely to receive more frequent visits from his or her own spiritual group members. The reasons informal caregivers were more likely to report having received the right amount of spiritual support if the decedent was living alone before death are not known.

With respect to generalizability, baseline characteristics of decedents associated with responding caregivers mirrored those of adult deaths in Nova Scotia (25, 26).

LIMITATIONS

A major limitation of the overall study is the low survey response rate (28 percent). This population-based survey deals with an emotionally difficult subject that many find is too difficult to revisit. The low response rate also reflects the difficulty of contacting the bereaved through a third party. Due to ethical and confidentiality concerns, we left it up to the informal caregivers to contact us after receiving an invitation to participate. It is also probable that many names and addresses listed on the death certificates were not valid, so that invitations did not reach some potential participants.

Recall bias is always a concern; however, the short time between the deaths of the informal caregivers' loved ones and the administration of the survey helped to minimize the problem. Finally, the concepts of spiritual and emotional support are complex, and it is likely that some informal caregivers interpreted these concepts and the support they actually received differently from others. The limited number of response options provided (yes/no; right amount/less than needed) may have constricted many informal caregivers in representing their experience. What one person views as supportive care may not be viewed as such by another. We asked only whether a healthcare professional had offered or talked to the informal caregiver about spiritual or emotional support; we did not ask whether a healthcare professional had given spiritual and emotional support in caring for the patient and the patient's family members.

CONCLUSION

In Nova Scotia, Canada, most informal caregivers report that they were not asked about their spirituality or emotions in the context of the end of their loved one's life. Although the majority reported receiving as much spiritual and emotional support as they wanted, those who did not discuss these topics with a healthcare professional were significantly less likely to report receiving as much support as they desired than those who did have these conversations. We therefore suggest that healthcare professionals and others involved in caring for dying people and their informal caregivers be made aware of how valuable it is for them to offer spiritual and emotional support to informal caregivers and be provided with the tools they need to become more comfortable with this topic.

Future qualitative investigations using focus groups or semi-structured interviews may be beneficial in identifying what informal caregivers perceive as spiritual and emotional support and in determining how healthcare professionals can best supply it.

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Table 1

Demographic Characteristics of Eligible Informal Caregivers and Decedents

Category	Frequency (%)
INFORMAL CAREGIVER	
<i>Sex</i>	
Female	457 (73.6)
Male	164 (26.4)
<i>Age</i>	
Mean (standard deviation)	63.2 (11.3)
Median (range)	61.5 (28–95)
<i>Highest level of education achieved</i>	
Post-secondary	294 (47.3)
Some post-secondary	115 (18.5)
High school graduate	112 (18.0)
Less than high school	99 (15.9)
Missing	1 (0.2)
<i>Self-reported health status</i>	
Excellent	138 (22.2)
Very good	247 (39.8)
Good	156 (25.1)
Fair	61 (9.8)
Poor	18 (2.9)
Missing	1 (0.2)
<i>Relationship of decedent to informal caregiver</i>	
Mother	227 (36.6)
Father	95 (15.3)
Spouse	222 (35.7)
Other relative	73 (11.8)
Friend	4 (0.6)
DECEDENT	
<i>Sex</i>	
Female	335 (54.0)
Male	286 (46.0)
<i>Age</i>	
Mean (standard deviation)	79.3 (12.3)
Median (range)	44 (19–107)
<i>Highest level of education achieved</i>	

Category	Frequency (%)
Post-secondary	150 (24.2)
Some post-secondary	76 (12.3)
High school graduate	97 (15.7)
Less than high school	284 (45.9)
Missing	12 (1.9)
Annual income	
<\$20,000	151 (24.3)
\$20,000–30,000	154 (24.8)
\$30,000–60,000	144 (23.2)
>\$60,000	92 (14.8)
Missing	80 (12.9)
Marital status	
Married	299 (48.2)
Divorced/separated	53 (8.5)
Never married	24 (3.9)
Widowed	245 (39.4)
Living alone on date of death	
Yes	137 (22.1)
No	484 (77.9)
Cause of death	
Neoplasm	249 (40.1)
Circulatory system disease	145 (23.3)
Respiratory system disease	57 (9.2)
Nervous system disease	46 (7.4)
Mental and behavioural disorders	37 (6.0)
Other	87 (14.0)
Location of majority of care in last 30 days	
Home	263 (42.3)
Hospital	183 (29.5)
Long-term care facility	175 (28.2)
Specialized palliative care program involvement	
Yes	270 (43.5)
No	351 (56.5)
Location of death	
Home	129 (20.8)
Hospital	345 (55.6)
Long-term care facility	145 (23.3)
In transit to medical facility	2 (0.3)

Table 2

Odds of Informal Caregivers Having Received as Much Spiritual Support as They Desired during Decedents' Last Days of Life

	Odds ratio (95% confidence intervals)	
Characteristics	Unadjusted	Adjusted
<i>Location of majority of care in last 30 days</i>		
Home	1.0	1.0
Hospital	0.6 (0.3–1.0)	0.5 (0.3–1.0)
Long-term care facility	0.9 (0.5–1.8)	1.1 (0.6–2.1)
INFORMAL CAREGIVER		
<i>Sex</i>		
Female	1.0	1.0
Male	2.4 (1.2–4.7)	2.2 (1.1–4.4)
<i>Age (by 10-year increments)</i>	1.4 (1.1–1.7)	1.4 (1.1–1.8)
<i>Highest level of education achieved</i>		
Post-secondary	1.0	
Some secondary	1.1 (0.6–2.6)	-
High school graduate	1.0 (0.5–2.0)	
Less than high school	0.9 (0.5–1.7)	
<i>Self-reported health status</i>		
Excellent	1.0	
Very good	0.8 (0.4–1.6)	
Good	1.0 (0.4–2.0)	-
Fair	0.4 (0.2–1.0)	
Poor	1.0 (0.2–4.6)	
DECEDENT		
<i>Sex</i>		
Female	1.0	-
Male	0.9 (0.5–1.4)	
<i>Age (by 10-year increments)</i>	1.1 (1.0–1.4)	-
<i>Highest level of education achieved</i>		
Post-secondary	1.0	
Some secondary	1.2 (0.5–2.9)	-
High school graduate	1.0 (0.5–2.1)	
Less than high school	1.0 (0.6–1.8)	
<i>Marital status</i>		

	Odds ratio (95% confidence intervals)	
Characteristics	Unadjusted	Adjusted
Married	1.0	
Divorced/separated	0.6 (0.3–1.3)	-
Never married	1.7 (0.4–7.7)	
Widowed	1.5 (0.9–2.6)	
<i>Relationship to informal caregiver</i>		
Mother	1.0	
Father	0.8 (0.4–1.7)	-
Spouse	1.1 (0.6–1.9)	
Other relative	1.4 (0.6–3.3)	
<i>Cause of death</i>		
Neoplasm	1.0	
Mental and behavioural disorders	0.6 (0.2–1.5)	
Nervous system disease	0.8 (0.3–2.0)	-
Circulatory system disease	0.7 (0.4–1.4)	
Respiratory system disease	0.5 (0.2–1.1)	
Other	0.7 (0.3–1.6)	
<i>Annual income</i>		
<\$20,000	1.0	
\$20,000–30,000	1.3 (0.6–2.4)	
\$30,000–60,000	1.0 (0.5–1.8)	-
>\$60,000	1.7 (0.7–4.1)	
Missing	1.6 (0.7–4.0)	
<i>Decedent living alone prior to death</i>		
No	1.0	1.0
Yes	1.2 (0.7–2.3)	2.1 (1.0–4.1)
<i>Specialized palliative care program</i>		
No	1.0	1.0
Yes	1.8 (1.1–3.0)	1.9(1.1–3.2)

Table 3

Odds of Informal Caregivers Having Received the Right Amount of Emotional Support for Their Feelings about Decedents' Deaths

	Odds ratio (95% confidence intervals)	
Characteristics	Unadjusted	Adjusted
<i>Location of majority of care in last 30 days</i>		
Home	1.0	
Hospital	1.1 (0.7–1.7)	-
Long-term care facility	1.2 (0.8–2.0)	
INFORMAL CAREGIVER		
<i>Sex</i>		
Female	1.0	1.0
Male	2.0 (1.2–3.4)	1.9 (1.1–3.2)
Age (by 10-year increments)	1.6 (1.3–2.0)	1.6 (1.3–1.9)
<i>Highest level of education achieved</i>		
Post-secondary	1.0	
Some secondary	0.8 (0.5–1.3)	-
High school graduate	0.8 (0.5–1.3)	
Less than high school	1.4 (0.7–2.6)	
<i>Self-reported health status</i>		
Excellent	1.0	
Very good	1.0 (0.6–1.6)	
Good	1.1 (0.6–2.0)	-
Fair	1.3 (0.6–2.9)	
Poor	2.1 (0.5–9.7)	
DECEDENT		
<i>Sex</i>		
Female	1.0	-
Male	0.9 (0.6–1.4)	
Age (by 10-year increments)	1.1 (1.0–1.3)	-
<i>Highest level of education achieved</i>		
Post-secondary	1.0	
Some secondary	1.2 (0.6–2.6)	-
High school graduate	0.6 (0.3–1.1)	
Less than high school	1.1 (0.7–1.9)	
<i>Marital status</i>		

	Odds ratio (95% confidence intervals)	
Characteristics	Unadjusted	Adjusted
Married	1.0	
Divorced/separated	0.3 (0.2–0.6)	-
Never married	1.4 (0.4–5.0)	
Widowed	0.8 (0.5–1.3)	
<i>Relationship to informal caregiver</i>		
Mother	1.0	
Father	0.9 (0.5–1.5)	
Spouse	2.0 (1.2–3.2)	-
Other relative	1.1 (0.6–2.0)	
Friend	0.9 (0.1–8.8)	
<i>Cause of death</i>		
Neoplasm	1.0	
Mental and behavioural disorders	0.8 (0.3–1.8)	
Nervous system disease	1.4 (0.6–3.3)	-
Circulatory system disease	1.3 (0.7–2.2)	
Respiratory system disease	0.6 (0.3–1.3)	
Other	1.2 (0.6–2.3)	
<i>Annual income</i>		
<\$20,000	1.0	
\$20,000–30,000	1.1 (0.6–1.9)	
\$30,000–60,000	1.3 (0.7–2.3)	-
>\$60,000	1.2 (0.6–2.4)	
Missing	1.2 (0.6–2.4)	
<i>Decedent living alone prior to death</i>		
No	1.0	-
Yes	0.6 (0.4–0.9)	
<i>Specialized palliative care program</i>		
No	1.0	1.0
Yes	1.8 (1.2–2.7)	1.8 (1.2–2.8)