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Palliative Care Experience in the Last 3 Months of Life: A Quantitative Comparison of Care Provided in Residential Hospices, Hospitals, and the Home From the Perspectives of Bereaved Caregivers

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Abstract

Objective: This study captured the end-of-life care experiences across various settings from bereaved caregivers of individuals who died in residential hospice. **Methods:** A retrospective, observational design using the CaregiverVoice survey with bereaved caregivers of patients in 22 hospices in Ontario, Canada. The survey assessed various dimensions of the patient's care experiences across multiple care settings in the last 3 months of life. **Results:** A total of 1153 caregivers responded to the survey (44% response rate). In addition to hospice care, caregivers reported that 74% of patients received home care, 61% had a hospitalization, 42% received care at a cancer center, and 10% lived in a nursing home. Most caregivers (84%-89%) rated the addressing of each support domain (relief of physical pain, relief of other symptoms, spiritual support, and emotional support) by hospice as either "excellent" or "very good." These proportions were less favorable for home care (40%-47%), cancer center (46%-54%), and hospital (37%-48%). Significantly, better experiences were reported for the last week of life where hospice was considered the main setting of care, opposed to other settings ($P < .0001$ across domains). Overall, across settings pain management tended to be the highest-rated domain and spiritual support the lowest. **Conclusion:** This is one of few quantitative examinations of the care experience of patients who accessed multiple care settings in the last months of life and died in a specialized setting such as residential hospice. These findings emphasize the importance of replicating the hospice approach in institutional and home settings, including greater attention to emotional and spiritual dimensions of care.

Keywords

palliative care, quality, in-patient hospice, hospital, home care, transitions

Introduction

Although most individuals prefer to die at home,[1] this is not always feasible due to the lack of supports in the community and/or the complexity of care required to adequately manage the patient's practical and palliative care needs.[2-4] Most individuals toward the end of life receive care from multiple settings and providers[5] that may include home care nurses, personal support workers, primary care practitioners, as well as hospitals, long-term care facilities (nursing homes), cancer centers, and residential hospices.[6,7] The expansion of community palliative care in the United States, United Kingdom, Canada, and other countries has resulted in about a quarter of patients remaining in their home until death[8-10]; however, many still transition to the hospital in the end when their pain and other symptoms exasperate.[11-14] High need end-of-life patients may also be transferred to a residential hospice, in communities with these facilities.[15]

Residential hospices are free-standing in-patient facilities, dedicated to providing comprehensive palliative care in a home-like setting.[15] In comparison, access to specialized palliative care in the other community and institutional settings, where the majority of individuals die, is often more variable. Barriers to adequately addressing the needs of dying patients in the home include a lack of home care provider expertise, limits on service allocation, fragmentation of multidisciplinary services, and resistance of primary care providers to make home visits.[16-18] In hospital, although care is offered around-the-clock, the traditionally curative approach taken is contrary to

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the goals of palliative care, the beds afford little privacy, and patients are often cared for by a continually rotating staff of generalist providers.[6,19,20]

Given the increasing number of deaths and demand for palliative care,[21] improving the suitability of settings to support patients who are dying is of paramount importance. Despite this, there has been little research that extensively compares the care experience received by patients in varied settings in the last months of life. The objective of this study was to capture the end-of-life care experiences across a wide range of settings, from the perspective of bereaved caregivers of patients who died in residential hospices. We report on the quantitative analysis of responses to the CaregiverVoice survey by these family caregivers. These population-based findings will advance the understanding of the relative strengths and weakness of key care settings for dying patients and their families.

Methods

Study Design and Population

Bereaved caregivers of decedents who died in one of the 22 participating residential hospices in Ontario (out of a total of 30 hospices) were asked to complete the CaregiverVoice survey. This survey assesses various dimensions of the caregiver's perceptions of the patient's care experiences across multiple care settings in the last 3 months of life. Care specifically in the last week of life and the circumstances surrounding death are also assessed.[22]

Data collection occurred between January 2015 and December 2016. An inclusion criterion for survey participation was the ability of the caregiver to read and write English. This study received approval by the Hamilton Health Sciences/McMaster University research ethics review board, Hamilton, Ontario, Canada.

CaregiverVoice Survey

The CaregiverVoice survey contains 62 items and takes approximately 20 minutes to complete.[23] The survey can be completed on paper or online. Both versions contain skip logic so that caregivers only respond to items relevant to the types/places of care the patient received. For each specified setting of care in the last 3 months of life, satisfaction with 4 main domains of support: relief of physical pain, relief of other symptoms, spiritual support, and emotional support, as well as overall care, are assessed on a 5-point scale (1 = excellent, 2 = very good, 3 = good, 4 = fair, and 5 = poor).

The survey is based on the VOICES instrument (Views of Informal Carers—Evaluation of Services) used in the National Survey of Bereaved People in England[24] and has been modified and further validated for use by palliative care services in Canada.[22] The CaregiverVoice survey's internal consistency for domains-of-support items range from $\alpha = .81$ to .93, depending on the care setting assessed. Concurrent validity was evidenced against the gold standard FAMCARE scale ($r_s = 0.66$, $P < .001$), which is one of the most widely used end-of-life satisfaction questionnaires.[25] The survey has been shown to be useful for helping to measure and assess quality of palliative care at end of life.[22,26]

Palliative Care in Ontario

Hospice care in Canada refers to care provided in a residential hospice (ie, a home-like facility), unlike in the United States where "hospice" more loosely denotes specialized palliative care in any setting.[15,27] In Ontario, there are approximately 30 residential hospices; most of that have 8 to 10 beds each.[28] Care and accommodations in these facilities are provided at no cost to the patient. The average length of stay in hospice is 19 days and 4% of deaths in Ontario occur in this setting.[28,29] Similar proportions are reported in the United States (4%) and England (6%), with the percentages of residential hospice-based deaths in these countries and Canada having increased considerably in the recent years.[12,28,30]

In Ontario, once admitted to a residential hospice, it is rare for the patient to be transferred to or receive care from another setting. These individuals are often facing imminent death, requiring a greater intensity of palliative care then can be provided effectively at home or even hospital. In comparison, in the aforementioned countries, about 20% of deaths occur at home and about 40% to half in hospital.[8,9,11] Palliative home care and hospital palliative care units are options in some communities in Ontario, but unlike in the United States, access to these specialized services is not nationally or even regionally standardized.[31]

Data Collection

Two approaches were used to identify bereaved caregivers. In starting, hospices used a retroactive approach contacting all caregivers of decedents in the past 6 months. Then from that point forward, hospices used a prospective approach to identify caregivers, with a minimum of 6 weeks after a patient's death before contact was initiated. Hospices approached identified caregivers using a study protocol that stipulated an initial phone contact to introduce the survey and determine if a paper or online version of the survey was preferred. The paper survey or online link was then mailed to the caregiver. This was followed by a reminder letter approximately 2 weeks later.

The platform used for the online survey was LimeSurvey (LimeSurvey Project, Hamburg, Germany), which was hosted on a secure server at McMaster University, Hamilton, Ontario. Responses written on the paper were entered into LimeSurvey by the research team.

Data Analysis

Data were imported into SPSS version 23.0 (IBM Corp, Armonk, New York) for statistical computations. Descriptive statistics were used to summarize caregiver and patient characteristics and perceptions of services used. A Cochran-Armitage

Table 1. Demographics and Characteristics of Deceased Patients.[a]

Patient Characteristics	n	%
Gender (n = 1135)		
Female	590	52.0
Male	545	48.0
Age (n = 1141)		
Under 50	23	2.0
50-69	316	27.7
70-89	669	58.6
90+	133	11.7
Main diagnosis (n = 1143)		
Cancer	920	80.5
Heart disease	48	4.2
Kidney or liver disease	35	3.1
Alzheimer or other neurological diseases	31	2.7
COPD/asthma	26	2.3
Stroke	21	1.8
Other or unknown	62	5.4
Settings/providers of care[b] (n = 1153)		
Palliative care physician MRP	462	40.1
Received home care	856	74.2
Visited emergency department	715	62.0
Stayed in hospital	701	60.8
Received care at cancer center	487	42.2
Had visiting hospice volunteers	177	15.4
Stayed in long-term care home	114	9.9

Abbreviations: COPD, chronic obstructive pulmonary disease; MRP, most responsible physician.

[a] n = 1153.

[b] Used in the last 3 months of life.

test for trend in categorical ordinal data was used to compare hospice versus other settings' ratings for care in the last week of the patient's life. All tests were 2-sided, and a *P* value of .05 or less was considered statistically significant.

Results

A total of 1153 caregivers responded to the survey, from 2604 approached (44% response rate). Characteristics of the patients represented are presented in Table 1. Among these patients, 52% were women and 70% were 70 years or older. Most patients (81%) had cancer as their main diagnosis. The caregiver respondents tended to be younger than the patients (32% were 70 years or older) and were more often women (69%). Most caregivers were either the patient's spouse (51%) or son/daughter (31%).

In the last 3 months of life, prior to hospice admission, caregivers reported that 74% of patients received home care, 61% stayed in hospital, 42% received care at a cancer center, and 10% lived in a long-term care (nursing home) facility (Table 1). Forty percent indicated that the patient's most responsible physician (MRP) was a palliative care doctor (24% indicated a primary care physician as MRP). The most common referral source for the hospice admissions was home care (54%), followed by hospital (23%). The majority (80%) of patients were in hospice for less than a month before death, with 39% of the total having a stay of 1 week or less.

Comparison of Care by Setting in the Last 3 Months of Life

Figures 1 and 2 present caregiver ratings of the 4 domains of support (ie, relief of physical pain, relief of other symptoms, spiritual support, and emotional support) and overall, for each of the settings of care used by the patient in the last 3 months of life. Nearly, all caregivers (84%-89%) regarded the addressing of each of these domains by hospice as either "excellent" or "very good." In comparison, support in other settings tended to less favorable, with home care (40%-47%), MRP (54%-63%), cancer center (46%-54%), and hospital (37%-48%) receiving lower proportions of either "excellent" or "very good" ratings by the domain. Furthermore, for care provided in the home, cancer center, or hospital, about 20% to 30% of caregivers stated this was either "poor" or "fair" across the domains. Regardless of care setting, pain management tended to be the highest-rated domain and spiritual support the lowest.

Overall, the majority (89%) of caregivers rated hospice care as "excellent," with lower proportions for home care (39%), MRP (52%), cancer center (42%), and hospital (33%). Few rated any of these services as "poor" overall, with the exception of hospital (9%). About 10% of caregivers rated the nonhospice care settings as "fair."

Hospice Versus Other Main Setting in the Last Week of Life

Most of the caregivers (80%) indicated that hospice was the main setting of the patient's care in the last week of life, that is, where they spent most of this time, whereas 10% reported this to be the home and 8% a hospital. The hospice main setting group reported a significantly better experience compared to the main other setting group on (1) there being enough help available to meet the patient's personal care needs, (2) there being enough help with nursing care, (3) the bed area and surrounding environment having adequate privacy, and (4) each of the 4 domains of support being addressed ($P < .0001$ for all values; Table 2).

Continuity of Care

Among the caregivers of patients who received home care in the last 3 months of life, 57% said that these providers definitely worked well together, 36% "to some extent," and 7% "not at all." In terms of transitions between all settings of care 54% of caregivers stated that these "always" went smoothly, 32% "most of the time," and 14% "sometimes" or "rarely." Most (74%) of the worst transitions reported involved those either to or from the hospital.

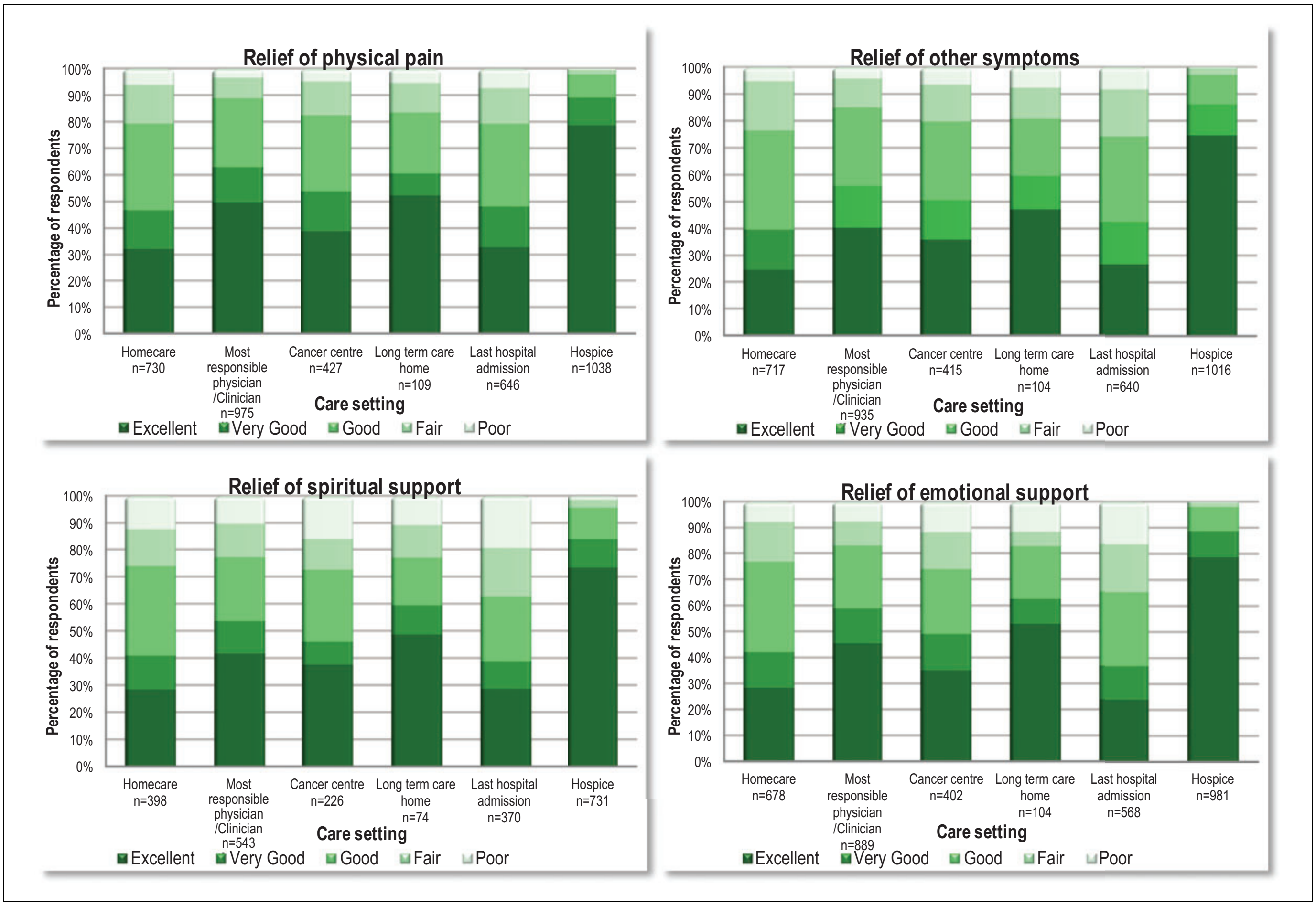

Figure 1. Ratings of domains of support by care in respective care setting (last 3 months of life).

Figure 2. Overall rating of care in respective care setting (last 3 months of life).

Advance Care Planning and Bereavement Support

Just over half (56%) of the caregivers reported that the patient definitely had the opportunity to discuss advance care planning with health-care providers, with 31% stating that this opportunity was provided "to some extent," and 10% "not at all." Caregivers were slightly less inclined to indicate that the health-care providers helped them in knowing what to expect/how to prepare for the patient's death, in affirming "definitely" (49%), "to some extent" (39%), or "not at all" (12%). In regard to bereavement support, most caregivers reported that either they received these services (41%) or that they were aware of them but not interested (43%); 7% would have liked to use these services but were not aware they existed.

Discussion

Our survey of bereaved caregivers of deceased patients is the first to explore the care experience in a population-based sample of patients from residential hospices in Canada. Our findings demonstrate the feasibility of collecting caregiver-reported experiences across multiple end-of-life care settings using one survey.

We found substantial differences in the perceived quality of care provided in hospice, compared to other care settings experienced. Specifically, whereas about 85% of caregivers indicated a highly favorable experience in hospice, this proportion dropped dramatically to around 50% for the MRP and lower for

Table 2. Caregiver Ratings of Professional Help Received and Domains of Support Addressed in the Last Week of Life by Main Setting of Care Identified.

Aspect of Care	Hospice Main Setting of Care in the Last Week of Life	n	Excellent		Very Good		Good		Fair		Poor		Cochran-Armitage Test Value[a]
			Frequency	%	Frequency	%	Frequency	%	Frequency	%	Frequency	%	
Professional Help Received													
Enough help available to meet his/her personal care needs	No	219	109	49.8	69	31.5	8	3.7	25	11.4	8	3.7	121.3
	Yes	881	692	78.5	169	19.2	7	0.8	12	1.4	1	0.1	
Enough help with nursing care	No	218	113	51.8	71	32.6	8	3.7	20	9.2	6	2.8	129.1
	Yes	886	725	81.8	151	17.0	2	0.2	7	0.8	1	0.1	
Bed area and surrounding environment had adequate privacy	No	215	134	62.3	65	30.2	3	1.4	7	3.3	6	2.8	128.3
	Yes	891	808	90.7	81	9.1	1	0.1	1	0.1	0	0.0	
Domains of Support													
Relief of physical pain	No	215	122	56.7	24	11.2	46	21.4	16	7.4	7	3.3	64.0
	Yes	868	681	78.5	91	10.5	77	8.9	13	1.5	6	0.7	
Relief of other symptoms	No	206	105	51.0	26	12.6	47	22.8	19	9.2	9	4.4	64.4
	Yes	840	620	73.8	98	11.7	102	12.1	12	1.4	8	1.0	
Spiritual support	No	117	65	55.6	10	8.5	20	17.1	11	9.4	11	9.4	31.2
	Yes	614	453	73.8	56	9.1	75	12.2	21	3.4	9	1.5	
Emotional support	No	187	106	56.7	20	10.7	34	18.2	18	9.6	9	4.8	64.7
	Yes	808	637	78.8	70	8.7	86	10.6	11	1.4	4	0.5	

[a] $P < .0001$ for all values.

care in the home, cancer center, and hospital. The most positively regarded attribute of care across the settings tended to be relief of physical pain, with the caregivers being less satisfied with the attention given to spiritual and emotional needs, particularly in hospital.

Perceptions of support in the last week of life were also significantly better for caregivers who indicated hospice to be the main setting of care during that time, compared to other settings. Furthermore, although many caregivers reported good continuity of care between settings, the biggest issue was seen as the transition to and from hospital. This is perhaps reflective of a perceived lack of timely response from health professionals to the patient's changing care needs. Similarly, our previous qualitative study of the residential hospice experience found the greatest point of dissatisfaction with this care was that the admission to the service was felt to have occurred too late.[15] Although some patients may not have needed to stay in a hospice until the very end of their life, for others the lack of an available bed meant remaining for days or weeks with insufficient care while the intensity of their illness and the demand on family caregivers escalated. Whether patients who require hospice care are admitted to these facilities is often a matter of timing; a fifth of patients referred to hospice in Ontario die while on a waiting list.[29] A feasible solution is not only for greater access to holistic specialized palliative care through expansion of hospice spaces but also for the provision of these services in the home, hospital, and long-term care facilities. Ideally, patients' wishes to die at home can be actualized when reasonable, understanding that this is not always the best option for effective end-of-life support.

Most studies of palliative care at end-of-life focus on a single intervention or setting of care. Studies that include multiple settings, usually only differentiate by home care and hospital care or do not disaggregate findings by specific setting type. Two multisite-specific surveys that examined satisfaction with care at the end of life from the perspective of bereaved caregivers are the National Survey of Bereaved People (VOICES) in England and the Family Evaluation of Hospice Care (FEHC) survey in the United States.[24,32] These surveys found positive differences in ratings of care in hospice compared to other settings, similar to our study. In the 2015 VOICES study (n = 21 300), 76% of caregivers rated hospice care as "excellent" (as opposed to "good", "fair", or "poor") compared to 43% in the home and 41% in hospital.[24] This difference was less dramatic in the FEHC data (2008-2013, n = 1611), where 88% of caregivers of patients who died in an in-patient hospice unit rated care as "excellent" (5-point scale) compared to 73% of those who died in home hospice care.[33] Higher satisfaction with home care in the FEHC study may be because the patients in the home received hospice-like services. Among both VOICES and FEHC caregivers, one of the main determinants for higher satisfaction with hospice care was the extent and personable nature of communication, including information providing.[33,34] Effective communication, along with expertise, respectful and compassionate care, and trust and confidence in providers, has similarly been identified by reviews to be the care elements that end-of-life patients and their families rank as being most crucial, and hence, instrumental to a quality care experience.[35-37]

The relative nature of individuals' ratings of care services, depending on their past and current experiences, is an important consideration when interpreting health-care satisfaction scores. Frankly, people may think that they received good care because of limited experiences with which to compare; therefore possessing low expectations. In a prior study using the CaregiverVoice survey with a home care cohort in Ontario, where only 18% of the patients accessed or died in hospice (58% died at home and 21% in hospital), 6% and 13% of caregivers rated home care and hospital care, respectively, in the last 3 months of life as "fair" or "poor."[22] In comparison, in the present study, the proportion of "fair" or "poor" ratings of these settings was higher, 14% for home care and 22% for hospital care. These findings demonstrate that care in an enhanced setting such as hospice may raise the level by which all care is judged, and that studies that compare all major settings/providers of care the individual used, potentially give a truer measure of care quality than those that only inquire about a single setting or provider. Indeed, survey measures of care at the end of life are prone to ceiling effects and are not always reflective of service constraints.[38-41]

There are limitations to this study that require consideration, one of which is that we did not directly assess the perspectives of patients. Nonetheless, past studies have found bereaved caregivers to be an adequate proxy for patient reported outcomes and such follow-back surveys have the benefit of capturing critical perceptions of care provided near and at death.[42] Although we obtained a reasonable response rate for a palliative care survey,[24,32] the perspectives included may represent more extreme positive and negative experiences, compared to those of the nonrespondents. The survey was only available in English, thus non-English speaking patients are probably underrepresented. We did not control for variably in length of hospice stay or the intensity of care provided in the other settings used, which may have impacted the perception of each care setting used. We also lack clinical data that could explain later hospice initiation and response variance. Furthermore, approximately 8 hospices in Ontario did not participate in the study. Most of these hospices are different from those included in being more newly established, having a specific disease focus, for example, AIDS, or having a Francophone patient population; patients who died in these settings may have had different experiences than we found. Finally, differences in patient experience between care settings would be expected to be less in countries with more consistent access to specialized palliative care in the home or hospital, such as in the United States where 46% of the population die under the care of the Medicare hospice benefit, often in their homes.[12,43]

In conclusion, based on this multisetting study, it is evident that the perceived quality of palliative care available in the home, hospital, and other key places of care greatly falls below the standard set by the residential hospices examined. Unfortunately, space limitations mean that only a small proportion of the dying population will ever be admitted to a hospice. Rather, these findings point to the importance of emulating the hospice approach to care in other institutional and community settings, including expert pain management and practical care, but also ensuring patient and family psychological/spiritual well-being and partnership in the care process. We believe our findings are applicable to other countries, where patients die in both hospice-like settings that offer specialized palliative care and in settings where these supports are less consistently available.[6,44,45] Finally, the findings highlight the importance of relative assessments to identify gaps in care quality across care settings, in capturing a more absolute measure of the patient experience.

Authors' Note

The study was approved by Hamilton Health Sciences/McMaster University research ethics review board, Ontario, Canada.

Declaration of Conflicting Interests

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