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“I want to go home”: How location at death influences caregiver well-being in bereavement

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Abstract

Objectives. Goal concordant or congruent care involves having expressed wishes upheld. Yet, the preferred location for end-of-life care may be unaddressed. Caregiver–patient congruence between preferred and actual locations of care may influence the quality of life in bereavement. The study aimed to explore how the congruence between caregiver–patient preferred and actual locations of death influenced well-being in bereavement.

Methods. Mixed methods were employed. In-depth in-person interviews were conducted with 108 bereaved caregivers of a hospice patient about 4 months after the death. An interview guide was used to collect quantitative and qualitative data: demographics, decision-making, Core Bereavement Items (CBI), Health Related Quality of Life, and perspectives on the end-of-life experiences. Data were analyzed with a convergent mixed methods one-phase process.

Results. Patient preference–actual location congruence occurred for 53%; caregiver preference–actual location congruence occurred for 74%; caregiver–patient preference and location of death occurred for 48%. Participants who reported some type of incongruence demonstrated higher levels of distress, including more days of being physically and emotionally unwell and more intense bereavement symptoms. The Acute Separation subscale and CBI total scores demonstrated significant differences for participants who experienced incongruence compared with those who did not. Preference location congruence themes emerged: (1) caregiver–patient location congruence, (2) caregiver–patient location incongruence, and (3) location informed bereavement.

Conclusions. Congruence between a dying person’s preferred and actual locations at death has been considered good care. There has been little focus on the reciprocity between caregiver–patient wishes. Discussing preferences about the place of end-stage care may not make location congruence possible, but it can foster shared understanding and support for caregivers’ sense of coherence and well-being in bereavement.

Background

Respecting choice and upholding the wishes of people with serious illnesses are core contemporary principles of good care at life’s end (Dahlin, 2013; Institute of Medicine, 2014). Care that is goal concordant or congruent involves both having expressed wishes upheld and no unwanted procedures (Sanders et al., 2018). The preferred location for end-of-life care is an important wish that may be overlooked and unaddressed. Moreover, poor congruence has been found to occur between caregiver and patient preferences for place of death (Shin et al., 2015). Increasing a shared awareness of caregiver–patient preferences about the location of end-of-life care requires knowledge of the prognosis, expectations of illness progression, advance planning, and exploration of family caregivers’ feelings about the dying person’s preferences. The potential for people with serious illnesses to achieve congruence with their family caregivers on preferred place of death depends on caregivers’ recognition and endorsement of the dying person’s preferences and ensuring that supporting dying at home does not become unmanageable (Tang et al., 2010).

Rates of congruence between caregiver–patient preferred and actual locations at death have been found to vary widely (Burge et al., 2015). Factors that influence place of death include individual preference, cultural beliefs, access to care, age, cause of death, social support, race, and ethnicity (Centers for Disease Control/National Center for Health Statistics, 2010). Recent worldwide surveys have indicated that although most people would prefer to be at home while dying, in reality, many cannot be (Gruneir et al., 2007; Fischer et al., 2013; Hinoshita et al., 2015). Some hospitalizations may be necessary and unavoidable (Burge et al., 2015). The wish to die at home can introduce an extraordinary burden for family caregivers; however, both terminally ill patients and their caregivers may reconsider this wish or promise in light of changes in caregiving needs, and preferences may change with the progression of the illness (Tang et al., 2010; Sanders et al., 2018). Some bereaved caregivers have been found to describe an institutional death to be a better place for end-of-life care (Thomas et al., 2014).

Congruence between patient–caregiver preferences for the location of care may contribute to a greater sense of coherence about end-of-life experiences. Antonovsky's (1979) theoretical model of salutogenesis [health (*saluto*) and genesis (*origins*)] focuses on coherence across the health-disease continuum. Salutogenesis asks, "What are the factors pushing this person toward (*disease*) or toward (*health*)?" [Antonovsky, 1979, p. 37]. Antonovsky posits that life experiences help shape one's sense of coherence, which help one mobilize resources to cope with stressors and manage tension successfully (Mittelmark and Bauer, 2017). The Sense of Coherence is informed by the *comprehensibility* or understanding of a situation; the *manageability* or available resources (physical, emotional, and psychosocial) to cope; and the *meaningfulness* or the extent to which the situation makes sense (Antonovsky, 1979). This model offers a conceptual framework with organizing principles (Padgett, 2017), which underscore the need for dyadic shared decision-making and its potential to improve caregiver health in bereavement. The salutogenic model can be a tool for enhancing quality of life (Eriksson and Lindstrom, 2007).

Advance care planning has most often been associated with the receipt of goal-concordant care; understanding the goals of care may also improve caregiver bereavement adjustment, which has been found to begin before death (Schulz et al., 2008; Garrido and Prigerson, 2014; Sanders et al., 2018). Yet, more is known about factors that improve quality of life for the caregiver–patient dyad before death (Sanders et al., 2018). When home death becomes an intolerable burden for family caregivers, it may affect quality of life in bereavement (Tang et al., 2010). The overall purpose of the study was to explore how the nature and quality of advance care planning influenced caregiver–patient experiences near death and in early bereavement. Specifically, the study aimed to explore how the congruence between caregiver–patient preferred and actual locations of death influenced caregiver well-being in bereavement.

Methods

Design

The study employed an exploratory, concurrent mixed methods design (QUAL+QUAN) where both qualitative and quantitative data were collected within the same interview (Miles et al., 2014). Mixed methods were chosen to use quantitative data to explore how the alignment of preferences and location influenced bereavement. Data were collected from bereaved caregivers at three time periods (4, 10, and 16 months) following the death (Teddlie and Tashakkori, 2009; Padgett, 2017; Creswell and Creswell, 2018). The participating hospice is freestanding and the only provider of hospice services for the county, with an average daily census of 434. Although hospice services are provided in nursing homes and in a 20-bed inpatient unit, the majority of care is provided in home settings.

The use of mixed methods facilitated the *triangulation* or comparisons across data types to deepen the understanding of the experience (e.g. decisions about the location of care); *complementarity* or the enhancement or clarification of meaning (e.g. upholding another's wishes); and *expansion* or the broadened theoretical understanding that comes from juxtaposing qualitative and quantitative perspectives (e.g. the comprehensibility, manageability, and meaningfulness of the experiences) (Greene et al., 1989; Padgett, 2017).

This paper presents Time 1 (4 months post death) results of interviews with 108 bereaved caregivers. Bereaved caregivers provide a proxy for the patient's experience at life's end and valuable accounts of their own perspectives (Germain et al., 2016). The project was developed in collaboration with the Research Department and Bereavement Services Program at Hospice Buffalo in Buffalo, NY. The study was approved by the University at Buffalo Institutional Review Board.

Recruitment

An introductory letter explaining the purpose of the study was included in all information packets that were sent to all ($N = 325$) bereaved caregivers who became eligible for bereavement services following a death during the study's recruitment phase from July–December, 2015. Contact information for the identified primary caregivers of all patients who had died within the recruitment period was generated by the Bereavement Services Program and sent to the principal investigator on a secure server. Letters inviting participation and response forms were mailed 3 months after the death. The response rate was 41%. Despite favorable responses from 133, interviews were unable to be scheduled with all due to extenuating situations (e.g. caregiver health and relocation) yielding the final sample of 108.

Procedures

Time 1 interviews were conducted about 4 months following the death to maximize recall of events and decision-making without intrusion during early stages of acute grief (George, 2002). An interview guide was developed that included forced-choice questions with Yes/No or categorical answers and open-ended questions. Interviews were scheduled at a time and location of the participant's choosing and conducted in homes, local coffee shops, libraries, or by telephone. Interviews lasted 45–120 min were audiotaped with permission and professionally transcribed. Supermarket gift cards ($10) were given to thank bereaved caregivers for their participation.

Quantitative data

Demographic data included age, race, education, religious preference, and the relationship between caregiver and patient. Participants were asked about patients' specific wishes for end-of-life care and if they had any form of an advance directive. New York State residents can have one or more advance directives including a Health Care Proxy, Living Will, New York State Medical Orders for Life Sustaining Treatment (MOLST), and Do Not Resuscitate order. Advance directives are not mutually exclusive and some people have more than one.

Participants were asked about both preferred and actual locations of death, including (1) Where did the patient die?, (2) Where did the patient want to be at the end of life?, and (3) Where did you want the patient to be at the end of life? Location response choices included home (whose?), hospital, nursing home, hospice inpatient unit, and other. These questions were utilized for the purpose of reporting location preferences and to group the data by the presence or absence of the alignment of preferences and the location of death to explore the influence on bereavement.

The Core Bereavement Items (CBI) scale involves 17 multiple-choice items that assess the presence and frequency of grief symptoms (range = 0–51). The CBI consists of three subscales: Thoughts and Images (Range = 0–21), Acute Separation (Range = 0–15), and Grief (Range = 0–15). An example question is: Do you experience images of the events surrounding (his/her) death: continuously; quite a bit of the time; a little bit of the time; or never (Burnett et al., 1997).

The Centers Disease Control's Healthy Days Measure (HRQOL-14) was used to assess self-reported health: (1) Would you say that in general your health is (excellent, very good, good, poor)?; (2) Thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?; (3) For how many of the past 30 days was your emotional health not good?; and (4) During the past 30 days, for about how many days did poor physical or emotional health keep you from doing your usual activities, such as your daily routine, work or things you do for fun?

Qualitative data

Open-ended questions were developed to elicit participants' narratives about their experiences and perspectives near the death. Example open-ended questions included (1) Please describe how the illness unfolded and (2) Please tell me about the time leading up to his/her death. Participants' descriptions of the end-of-life experiences illuminated the complexity of dynamics between preferred and actual locations at the end of life. The quantitative questions about preferred and actual place of death also generated qualitative data about the end-of-life dynamics.

Analysis

Data were analyzed using a convergent one-phase design. The mixed methods data analysis involved merging, connecting, and embedding the two types of data. *Merging* involved juxtaposing and interweaving quantitative and qualitative findings. *Connecting* involved the quantitative data informing the qualitative analysis in a temporal sequence. *Embedding* or nesting involved subordinating the qualitative data within groups created by the quantitative data, providing *in vivo* information (Creswell and Plano Clarke, 2011). The analysis was inductive and involved a search for broad patterns with interpretation through the lens of the Sense of Coherence framework (Creswell and Creswell, 2018).

Quantitative data were entered into SPSS v.21. Descriptive statistics (frequency, mean, and range) were calculated for demographic and scaled questions. Preferred and actual locations of death responses were re-coded as four categorical variables to facilitate the comparison of different groups within the sample.

The four variables were:

(1) the alignment of patient's preference with the actual location of death,
(2) the alignment of caregiver's preference with the actual location of death,
(3) the alignment of patient's preference with caregiver's preference,
(4) both patient's preference and caregiver's preference align with the actual location of death.

Participants' responses were assigned a valence of congruent or incongruent on each of the four variables. Next, the four variables were collapsed into two: *Congruent* was defined as both the patient's and caregiver's preferences aligned with the actual location of death. *Incongruent* was defined as some type of misalignment; either the patient's and the caregiver's preferences were misaligned, or one or both did not align with the actual location at death. This variable combined the existence of incongruence between patient and caregiver preferences with the actual location to reflect the presence of any form of misalignment.

Independent sample *t*-Tests were conducted to compare the means for participants' responses that were in the congruent and incongruent groups along the continuous dependent variables. Specifically, caregiver outcomes (e.g. CBI and HRQOL-14 total and subscale scores) were compared for those who experienced congruence and those who experienced some form of incongruence between preferred and actual locations at death.

Interview tapes were transcribed and entered into Atlas ti v.9 for data management and coding. The qualitative data analysis process was iterative and involved two cycles of coding. First cycle coding was used to summarize segments of the data and involved *a priori* or *systematic coding* or the examination of narrative data using a start list of concept-driven codes (Miles et al., 2014). Each code represented the stem of questions from the interview instrument. Example codes included patients' preferred location and caregivers' preferred location. *Provisional coding* involved the revision and modification of codes to reflect the emerging themes that illuminated the illness trajectories and end-of-life experiences. Response patterns emerged, specifically associated with congruence between caregiver–patient desires with the actual location of death. Next, the technique of embedded mixing was employed to create participant groups by the presence or absence of congruence in location preferences (Padgett, 2017). Using the quantitative data, participant transcripts were grouped into document families by whether preferred and actual locations were congruent or if there was some form of incongruence or misalignment:

(1) caregiver–patient location congruence was defined as the actual location of death aligned with patients' and caregivers' preferences;
(2) caregiver–patient location incongruence was defined as when there was some type of misalignment between patient's or caregiver's preferences (or both) and the actual location of death;

The document families were further explored for how alignment or the lack thereof influenced bereavement.

(3) location informed bereavement which was defined as how the presence or lack of congruence between preferred and actual locations at death informed the experience of bereavement.

Pattern codes (inferential and explanatory) were used to illuminate the "bigger picture" (e.g. tension, reciprocity, and responsibility; Miles et al., 2014). Second cycle coding was used to explore the document families (congruent and incongruent). Finally, *selective coding* was used to define and specify the nature of the experiences related to the presence of congruence or incongruence in location preferences (Padgett, 2017), illuminating the concepts (manageability, meaningfulness, and comprehensibility) that create a sense of coherence.

Results

Patients ranged in age from 43 to 101, and the M_{age} at the time of death was 79.6 years (SD = 12.8). Caregivers ranged in age from

32 to 88, and the M_{age} was 61.5 years (SD = 10.3). Patients' length of hospice care ranged from less than 1 h to 912 days and the M_{LOS} was 76 days. Half of the hospice admission diagnoses were cancer [$N = 54$ (50%)]. Other diagnoses are presented in Table 1. The patient population was 60% female and 71.3% of the caregivers were female. The sample was largely White [$N = 94$ (87%) of the patients and $N = 92$ (85%) of the caregivers].

Caregivers reported that 90 (83%) of the patients had specific wishes for end-of-life care and 93 (86%) had some form of the advance directive. Home death was preferred by 69% of patients and 55% of caregivers. Participants reported that there was congruence between patients' preferred and actual locations of death for $N = 57$ (53%). When there was congruence between the caregivers' preferred and actual locations of death for $N = 80$ (74%), congruence existed between caregivers' and patients' preferred locations for $N = 57$ (53%) situations. When there was a patient–caregiver agreement on preferences, death occurred in the preferred location of death for $N = 52$ (48%) (Table 2).

Caregivers who reported that either (1) patient and caregiver had different preferences or (2) the actual location of death was not aligned with either or both a patient's or caregiver's preference were considered to have experienced incongruence. Caregivers who experienced some type of incongruence demonstrated higher levels of distress in bereavement than those for whom patient and caregiver preferences aligned with the actual location of death. When incongruence had occurred, caregivers reported 6.28 days/month of poor physical compared with 5.63 when there was congruence. When there was incongruence caregivers experienced 10.21 days of poor emotional health compared with 4.3 when there was caregiver–patient congruence ($p < 0.05$) demonstrating statistical significance. Caregivers who reported some type of incongruence demonstrated more intense bereavement symptoms. Symptoms of Acute Separation were 7.1 when there was incongruence compared with 5.50 when there was congruence ($p < 0.5$) demonstrating statistical significance, as did the overall CBI score which was 20.14 when there was incongruence compared with 16.86 when there was congruence ($p < 1.0$) (Table 3).

Preference location congruence

Three themes illuminated caregivers' experiences with the congruence between preferred and actual locations at the end of a patient's life: (1) caregiver–patient location congruence, (2) caregiver–patient location incongruence, and (3) location informed bereavement.

Caregiver–patient location congruence

Caregiver–patient location congruence occurred when caregivers and patients preferred the same location for death and that became the actual location of the death. Caregiver–patient congruence resulted from shared knowledge and awareness of what each preferred as death neared and death occurred in the preferred location. Caregiver–patient congruence was accompanied by physical and social elements of comfort. This participant illustrates a situation that unfolded as preferred:

> It was exactly the way she wanted it. She was home, in bed, she had seen all her family, and she had two of her four children with her at the time. We are all so happy for her because she was so lucky, we were so lucky because that's exactly what she wanted … we should all be so lucky. How can you feel that about somebody who dies, lives a long good life, stays at home, surrounded with the family, I mean geez.

Caregiver–patient location congruence was also a function of an enduring relationship with shared values and good communication, and manageable care needs that contributed to the meaningfulness of the experience as described:

> I said to him, 'You will go to a nursing home over my dead body' because I knew he didn't want it. Those last 3–4 weeks I was up around the clock. I might lay down, get a 20-minute nap or something but I would sit by his bed and hold his hand for hours at a time.

Caregiver–patient location congruence was not always easy and often involved managing some fast-breaking challenges. This participant described her own difficulty in managing the challenges of end-of-life care at home and the synergy between her decision and her husband's response:

> It was hard for him to go here [at home]. It was ok because that's what he wanted. That's pretty much all that mattered to me … wherever he wanted. When he got noncommunicative, he was just kind of grunting and the Hospice nurse came in and she was trying to include him in the conversation and she asked me if it was getting too hard for me … and should we take him and put him in the inpatient unit. He grunted and started getting annoyed…until I told her no. Then he quieted right down. He settled right down when I told her I will keep him here because this is where he wants to go (die).

Caregiver–patient location congruence involved the confluence of resources, both internal and external, to facilitate death at home.

Caregiver–patient location incongruence

Caregiver–patient location incongruence occurred when either the patient's and caregiver's preferences or both did not align with the actual location at death. Many factors influenced caregiver–patient location incongruence. The difficulties of the dying process create uncertainty and limited comprehensibility about whether or not a dying person's preferred location is possible and often contributed to incongruence between preferred and actual locations at death. This participant illustrated challenging physical symptoms and her mother's expressed wish "I want to go home":

> She had ALS so as things progressed it was basically me and my mom's sister, we kind of pretty much did most of the stuff on her. We wanted to try and keep her home as long as possible. I know my mom was terrified of hospitals. So when she went to Hospice she was freaking out. She had been throwing up and wasn't feeling well, so one of the Hospice on-call nurses came to the house. At first my mom didn't want to go but the nurse stayed for a while and then Mom really wasn't feeling well so she finally said ok. As far as did she want it to end there, no.

The burden of the dying process was illustrated as reciprocal, felt by both the caregiver and patient, as care needs increased. Incongruence was often described in the context of resignation as illustrated by this participant:

> It would have been tough at home. I would have loved to have her home. Would you like to do everything? Yes. Realistically, you can't and it's frustrating.

Table 1. Participant demographics

	Patient *N* = 108	Caregiver *n* = 108
Age	M = 79.6 (SD = 12.8)	M = 61.5 (SD = 10.3)
Gender		
Male	43 (40%)	31 (29%)
Female	65 (60%)	77 (71%)
Race/ethnicity		
White, non-Hispanic	94 (87%)	92 (85%)
Black, non-Hispanic	9 (8%)	8 (7%)
Hispanic	2 (2%)	2 (2%)
Asian/Pacific Islander		2 (2%)
Native American		1 (1%)
Unreported	3 (3%)	3 (3%)
Marital status		
Married/partnered	38 (35%)	54 (50%)
Divorced/separated	11 (10%)	11 (10%)
Single	12 (11%)	9 (8%)
Widowed	46 (43%)	34 (32%)
Unreported	1 (1%)	
Religious preference		
Catholic	57 (53%)	53 (49%)
Denom. Christian	25 (23%)	21(19%)
Non-denom. Christian	7 (6%)	9 (8%)
Other	2 (2%)	5 (5%)
No preference	17 (16%)	20 (19%)
Education		
>High school	15 (14%)	3 (3%)
High school diploma	42 (39%)	21 (19%)
Some college or 2 years degree	25 (23%)	23 (21%)
College or graduate degree	14 (13%)	48 (45%)
Unreported	12 (11%)	13 (12%)
Caregiver relationship to care recipient		
Spouse or partner		33 (31%)
Adult child		57 (53%)
Sibling		6 (5%)
Aunt or uncle		6 (5%)
Mother-in-law		2 (2%)
Friend or other		4 (4%)
Patient diagnosis		
Cancer	54 (50%)	
Congestive heart failure	12 (11%)	
Alzheimer's disease	9 (8%)	
Stroke	7 (6.5%)	
COPD/emphysema	6 (5.5%)	
Pneumonia	5 (5%)	
Neurological diseases	3 (3%)	
Renal disease	2 (2%)	
Cirrhosis	2 (2%)	
Other or unknown	8 (7%)	

Participants illustrated fear of the experience and memory of death at home. This participant illustrates the dilemma of manageability that many described:

> It was getting to the point where me and my wife are like … maybe we should bring her to our house. We have a massive bedroom downstairs, master bath right off the living room, where at my parents' she was upstairs. So we're debating this. I'm like, I don't know what I'm going to do if she passes away in our house. Maybe that's selfish. I don't know. You have to think about these things

Caregiver–patient location incongruence both emerged from and contributed to difficulty in end-of-life care.

Location informed bereavement

The location at death and its alignment with preferences informed caregivers' perceptions in bereavement. Caregiving is often a function of a personal relationship and serves as a stage of completion of a relationship. Two participants illustrated gratitude, dedication, meaning, and heartfelt purpose they experienced in helping to uphold the patient's wishes:

> I am glad that he didn't die in the hospital. I will feel forever grateful. That was a God-given gift.
>
> It really wasn't a job it was just something that my heart said I had to do and I did.

When patient–caregiver preferences were aligned with the actual location at death, caregivers expressed satisfaction with and meaningfulness of their accomplishment.

The multiple factors that contributed to caregiver–patient location incongruence also influenced the residual feelings that accompanied bereavement and were expressed as guilt, feeling bad, and anger. This participant described the tension she felt between her husband's desires and her abilities:

> I think he wanted to be here and that's what makes me feel guilty. But I didn't have anybody that could stay here. I was still trying to work. There's a lot that I feel bad about but it was better for him. They are the professionals and I'm not although. He did want to be here and he was as long as he could be.

This participant illustrated her need for help and regrets — speaking through tears,

Table 2. Location of death

Location of death	Where patient died	Patient's preferred location	Caregiver's preferred location
Home[a]	49 (45%)	74 (69%)	59 (55%)
Hospital	6 (6%)	1 (1%)	7 (7%)
Nursing home	11 (10%)	3 (3%)	4 (4%)
Hospice inpatient unit	36 (33%)	13 (12%)	26 (24%)
Other	6 (6%)	5 (5%)	2 (2%)
No preference or unknown		12 (11%)	10 (9%)

[a] Home is own or other's home.

Table 3. Caregiver outcomes: congruence between preference and actual locations of death

Outcomes	Congruent (*N* = 52)	Incongruent[a] (*N* = 56)	*t*	df
Health-Related Quality of Life (days/month)				
Poor physical health	5.63	6.28	−0.32	103
Poor emotional health	4.33	10.21	−3.1**	102
Inactivity	3.52	6.19	−1.4	103
CBI				
Thoughts/Images (0–21)	6.73	7.73	−1.5	101
Acute Separation (0–15)	5.51	7.10	−2.7**	101
Grief (0–15)	4.63	5.62	−1.3	102
Total (0–51)	16.86	20.14	−1.8*	100

[a] Fifty-two percent of the participants reported some type of incongruence about the location of death.
*Significant at $p < 0.10$
**Significant at $p < 0.05$.

> I would have wanted her in our home because that's what she wanted. But it was easier for me at the facility. I had people there.

Despite the fact that her husband died where she wanted him to be, she was left with a sense of incongruence because it was counter to his wishes.

This participant's husband wanted to be at home, she wanted him to be in the hospital, and he died in the hospice inpatient unit. Her words illustrate the intensity of feeling of incongruence both before and after the death:

> I prayed and prayed for help for him and part of that help was to end his suffering and when his suffering was ended because he passed, I wanted to put a knife through my heart because I said, 'I willed his death. I was responsible for his death.' So did I prepare myself for that? I guess in a roundabout way by wanting him to be in a non-suffering state.

Location at death mattered and had emotional meaning to caregivers and patients. Caregivers illustrated a state of heightened awareness and emotional arousal as death neared, which influenced their experiences and sense of coherence in bereavement.

Discussion

Death at home is widely considered the gold standard of care at life's end and consistent with a "good death." Yet, the preferred location for end-stage care is often not part of advance care planning conversations. Moreover, not all deaths are possible to manage at home, and not all caregivers are prepared to care for someone who is dying. Attending to caregivers' experiences is key to the delivery of quality serious illness care. The results of interviews with 108 bereaved caregivers of people who died in hospice care suggest that congruence between caregiver–patient preferred and actual locations of death influenced well-being in bereavement. The study results illuminate the interrelationship between caregivers' perspectives and memories of end-of-life location and experience, highlighting the reciprocity between how patients' experiences affect caregivers.

The study findings build on and contribute to knowledge about the nuances of advanced care planning and its influence in bereavement. A majority (83%) of the caregivers interviewed for this study had specific wishes about care near death. About half (53%) of the patients died in their preferred location, and 74% of the patients died in a location that was preferred by the caregiver. Caregiver–patient preferred and location congruence occurred in 48% of the situations. These results are consistent with other studies that have found the number of people who died at home, as preferred, varied from 38% to 94% (Aoun et al., 2010; Holdsworth and Fisher, 2010; Burge et al., 2015). Moreover, the findings align with studies that have documented less than satisfactory communication with professionals over the course and at the end of a terminal illness (Andreassen et al., 2015; Muders et al., 2015).

Caregivers who reported incongruence between preferred and actual locations at death also reported more frequent days of feeling physically and emotionally unwell and more intense bereavement symptoms. The location at death that is congruent with expressed wishes is likely to shape the bereaved caregivers' experience by mitigating anxiety, depression, trauma, and regret and enhancing trust, peacefulness, and satisfaction with care. Yet, the presence of some incongruence between preferred and actual locations can have an opposite effect (Sanders et al., 2018). It is likely that caregivers' and patients' location preferences change as needs intensify. It seems important to explore the meaning and implications of "I want to go home" for caregiver–patient dyads. Quality of life has been used synonymously with well-being and captures the positive aspects of health and mental health, including coping, resilience, satisfaction, and a salutogenic orientation.

The qualitative data illuminated how experiences near the death were recalled and how they influenced bereavement. When caregiver–patient preferences are in agreement and align with the location of death, it was developed from shared understanding but also from end-of-life circumstances that were manageable and resulted in satisfaction with the patients' dying experience. Incongruence between preferences and the actual location at death emerged from the confluence of multiple factors, including uncertainty about the dying process and what to expect. In some situations, as death neared, symptom exacerbations became difficult and exceeded the caregiver's coping resources. Caregivers have been found to value knowing what to expect as death approaches; thus, educating them about the dying process may improve bereavement adjustment (Sanders et al., 2018). The families of people who are dying are often the primary source of physical and emotional supports on an illness trajectory. Family members are often expected to provide direct care, yet many are unprepared for the intensity of emotional and physical needs as death nears. There is growing recognition of this reciprocal suffering in caregiver–patient dyads. The importance of adopting a dyadic perspective in understanding their stress, adjustment, and interrelated physical, emotional, social, spiritual, and financial needs cannot be overstated (Witt-Sherman, 1998).

Salutogenesis encloses positive aspects of human suffering when it is lived with an internal sense of coherence (Costa Oliveira, 2014) and has been associated with perceived good health and mental health (Suominen and Lindstrom, 2008). The Sense of Coherence concepts of comprehensibility, manageability, and meaningfulness can inform the interpretation of the data. Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred (Puchalski et al., 2009). A lack of association between "sense of burden to other" and the degree of physical dependency suggests that this perception is largely mediated through psychological and existential considerations (Chochinov et al., 2007). The landscape of distress near life's end has tended to focus on physical and to a lesser extent psychological challenges. A better appreciation for the nature of distress is a critical step toward a fuller understanding of the challenges inherent in terminal illness (Chochinov et al., 2009). Understanding of "home" and what that means as death nears, together with perceptions about preferring and honoring preferences about the location at life's end may be critical elements of distress at the end of an illness and inform adaptation in bereavement.

The results of the study suggest some clinical implications. Shared decision-making has been defined as an interpersonal, interdependent process by which patients, caregivers, and healthcare providers collaborate on healthcare decision-making (Legare, 2013). Consideration of how memories of the location of death will leave the bereaved caregiver is important in shared decisions. There are people who do not want to discuss the preferred location of care when dying, and so discussions about other priorities and goals of care, such as spending as much time as possible with family, not burdening those who care for them or being pain free may be more important (Holdsworth and Fisher, 2010; Billingham and Billingham, 2013; Thomas et al., 2014). Caregivers have rated the quality of palliative care to be the highest when the death occurs at home or in a hospice (de Boer et al., 2017). Although the majority expresses the preference for a home death, this wish is not shared by all (Billingham and Billingham, 2013). Preferred–actual location congruence is one indicator of the outcome but not of the quality of the dying process; some people consider an institutional death to be a better place for end-of-life care (Holdsworth and Fisher, 2010).

The study had limitations that are important to note. The sample size was small. Although there was enough power to determine statistical significance, a larger sample might have borne out other differences. The sample was generally homogenous across demographic features, limiting opportunities to ascertain if other factors may have contributed to bereavement outcomes. The sample was drawn from one hospice bereavement program and reflects only one geographic region. Greater diversity could have illuminated further differences. The analysis was focused on the preferred-actual location. The place is a narrow way of looking at preferred-actual experiences, as death nears and congruence likely extends well beyond location to include other issues (e.g. incongruence or conflict between family members' preferences and patient and provider preferences for types of care). Moreover, the location where a person spent the majority of time before death may inform preferences.

Conclusion

Congruence between a dying patient's preferred and actual locations at death has been associated with good quality care. However, there has been little focus on reciprocity and how a patient's desires influence a caregiver's experiences. Family members and caregivers grieve and recall the care occurred on the illness trajectory. Discussing the preferred place of death may not make location congruence possible, but it can foster a shared understanding and support of caregivers' needs before and after death contributing to a sense of coherence. Exploring location preferences at death before the end of life nears may be a proactive means for facilitating well-being in bereavement.

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