Bereaved Family Members’ Assessments of the Quality of End-of-Life Care: What is important?

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Abstract / Families of patients are well poised to comment on the end-of-life (EOL) care received by those patients and can provide feedback to care providers and decision makers. To better understand family-member evaluations of the quality of in-patient EOL care, this study draws on qualitative interview data (n=24) to identify core aspects of EOL care that are important for family members. Based on this analysis, a conceptual framework of family members’ assessments of their experiences with EOL health care services is developed. Findings suggest the need to distinguish between perceived substantive or tangible features of received care, interpretations of the causes and symbolic meanings of that care, and personal and affective outcomes. Practitioners are encouraged to reflect on how behaviours and communications may be interpreted by families. Attention also needs to be given to the changes in practice and organizational decision making that can facilitate more positive experiences for families and patients.

Résumé / Les familles sont bien placées pour faire des commentaires sur les soins de fin de vie prodigués aux patients et leurs observations peuvent orienter le personnel soignant et les décideurs. Cette étude, dont l’objectif était de mieux comprendre les évaluations formulées par les familles, s’appuyait sur les données recueillies lors d’interviews qualitatifs (n=24) visant à identifier les aspects essentiels des soins de fin de vie qui importent aux familles. En nous basant sur cette analyse, nous avons élaboré un cadre conceptuel selon l’expérience des familles en regard des soins de fin de vie. Les résultats de notre étude démontrent la nécessité de faire, d’une part, une distinction entre la perception qu’ont les familles de la nature tangible des soins reçus, et d’autre part, la signification symbolique qu’ont accordé aux soins et à leurs conséquences sur le plan personnel et affectif. On encourage les soignants à réfléchir aux répercussions de leur comportement et de leurs interactions avec les familles. On doit également porter une attention spéciale à la nécessité de changer les modes de prise de décisions tant dans la dispensation des soins que dans leur organisation afin que les patients et leur famille en retirent une expérience positive.

INTRODUCTION

End-of-life (EOL) care is an important health and social policy issue in many developed countries. However, in Canada, obtaining high-quality EOL care has been described as “the luck of the draw” for many (1); Canada placed only ninth in the world in a 2010 EOL care ranking (2). Families of patients are well poised to comment on the EOL care received by those patients and can provide feedback to care providers and decision makers that the patients themselves are frequently unable to provide. Assessments of satisfaction reflecting the perspectives and experiences of families can help ensure that EOL health service planning addresses areas that families identify as important for their own well-being and that of the patient (3).

To “identify what constitutes satisfaction at the EOL and the factors that enable its assessment, it is first necessary to ascertain what issues are important” to families (4, p. 336). A qualitative perspective can provide enriched descriptions of the meanings and behaviours that families attribute to aspects of care they identify as important. This study identifies core aspects of EOL care that are important to families (as opposed to examin-
ing levels of satisfaction or causal predictors), and it outlines a conceptual framework of family members’ assessments of their experiences with EOL health care services.

LITERATURE REVIEW
This review focuses on research on family satisfaction with in-patient EOL care, including research with both bereaved and non-bereaved samples. Quantitative measures of family-member satisfaction with EOL care have tended to assess patient care (such as physical care, emotional care, and symptom management); communication and information; care providers’ attitudes, interpersonal skills, and competence; and features of care services (such as individualized, available, responsive, coordinated, and consistent). To a lesser extent, some measures address the practical and emotional support provided directly to families and the ways in which care providers involve or treat family members.

Quantitative research has also identified care perceptions statistically correlated with general satisfaction measures, suggesting that such features may be considered important by families and might be conceptualized theoretically either as predictors or as part of satisfaction. Such care perception correlates also tend to be incorporated into items of comprehensive satisfaction measures, including: patient symptom relief and physical comfort (5-11); emotional and psychosocial support for patient and family (6, 9, 12, 13); clear information and communication, particularly about prognosis and what to expect (5-9, 11-15); care availability and accessibility (6, 7, 10, 14, 16); consistency of provider and contact persons (13, 15); demonstrated respect, relationship, compassion, and sensitivity (8, 9, 11, 14, 17, 18); and families’ feelings of trust and their positive relationships with care providers (6, 8).

There are measures of family satisfaction with EOL care developed in part from inductive qualitative research with families (5, 6, 19-21). However, most satisfaction assessments include some combination of, but rarely distinguish between, satisfaction with direct patient care and professional support provided to family members (for example, as part of the unit of care). Inductive qualitative studies have also identified substantive features of EOL care that are of concern and importance to families, some of which are already encompassed in quantitative measures: patient comfort and symptoms (20, 22); emotional support (20, 23-25); information, education, and communication (23, 24, 26, 27); and competence (22, 24, 28, 29).

Other aspects identified qualitatively as important to families are addressed to a lesser (and more varying) extent within quantitative measures, including: the organization and resourcing of care; service availability and accessibility; equipment; care provider response and time given to the patient (22, 24, 30, 31); and service coordination, consistency, and flexibility (22-24, 31). Facility environments are also important: their locality, size, atmosphere, visiting policies, comfort, privacy, and noise (22, 26, 31). Families appreciate being given a sense of security (29, 32), being relieved of burden (25), and being relieved of having to advocate constantly (20).

Personalized, individualized service is important (24, 26, 27) and can encompass both organizational and interpersonal aspects of care delivery, though the latter are emphasized to a greater extent in quantitative measures. Interpersonal skills identified qualitatively as important to families include providers’ interactional attitude or approach (such as whether they address patient dignity, wishes, and decisions) (20, 22, 24, 26, 30, 33).

Though qualitative research has identified important features, findings are primarily descriptive, with little conceptual development. Furthermore, much quantitative research on family satisfaction is only minimally informed by broader theoretical understandings. Little distinction is made between the process of care delivery and its content or structure (with some exceptions [22, 28, 32]), or between interpersonal, task, and organizational features.

The goal of this study is to identify areas of importance for bereaved-family-member satisfaction with institutional EOL care and to develop a conceptual framework to understand distinctions between elements of care, their interpretation, and subsequent family outcomes. Using retrospective accounts of bereaved caregivers facilitates reflections on the whole care pathway and may involve less of the high stress and vulnerable feelings caregivers often experience during care provision. Conceptual development can inform quantitative satisfaction research and measurement and assist in utilizing research results to improve care.

METHODS
Participants were recruited from a sample of respondents to a larger quantitative study measuring bereaved family members’ perceptions of EOL care quality in four types of in-patient health care settings (34) in one health region in Western Canada. The four settings have extended care units, which provide long-term residential care to people who are unable to remain at home; inten-
sive care units, which provide one-on-one care to critically ill patients; medical care units, which provide less-intensive nursing care for acutely ill patients who do not require surgical interventions; and palliative care units, which offer a wide range of palliative care specialist and nursing services.

Quantitative satisfaction reports had been collected from 388 bereaved family members who completed mailed questionnaires about their perceptions of care in the unit where their relative had died. Eligible participants were those who: had a relative die in the previous three to six months in one of the four settings, were the patient's primary contact person and had been involved enough to be able to comment on care quality, were older than 18, and could speak English. They were excluded if the patient had died of traumatic, unexpected causes or if the patient had been on the unit for less than 48 hours.

Due to unsolicited feedback and comments they received during the survey data collection, and because they wanted to contextualize and explain preliminary survey results, the researchers decided to conduct in-person, qualitative interviews with a sub-sample of respondents. The aim was to understand, with the aid of interpretive description (35), the context of bereaved family members' perceptions of care quality.

Ethics approval was obtained from the University of Victoria and the participating health agency. Letters of invitation to participate in the study were mailed to all survey respondents and potential respondents who had contacted us with concerns. A sampling frame of 46 individuals agreed to be contacted. Participants were purposefully selected to enhance variation. Roughly equal numbers were selected from the four settings; among them were those who reported both positive and negative experiences (a determination made by a co-investigator based on an overall assessment of close-ended and open-ended survey responses), as well as those who reported transitional experiences (for example, a patient who had a negative experience in one unit and was transferred to another unit, where he or she had a positive experience). This yielded a sample of 24 family members.

A trained research assistant conducted in-person qualitative interviews lasting about an hour and a half to two hours at a location convenient for participants (usually their homes). Participants were asked to describe and evaluate their experiences with the EOL care received by the deceased person (for example, "Tell us about your experiences with end-of-life care."); they were also asked to give examples and describe aspects of care that were important to them ("What was important for you about the care provided at this time?"). To supplement this, the research interviewer asked targeted questions that we had generated by consulting participants' survey results in advance. For example, participants were asked to elaborate on scale items for which they had recorded strong dissatisfaction, on contrasts between different items, on responses that departed significantly from norm scores, and on their open-ended survey comments.

The first and second authors conducted data analysis with guidance from the investigative team and input from the research interviewer. Interviews and interviewer debriefing field notes were transcribed verbatim and read multiple times. A preliminary coding scheme, developed from the first five interviews, was applied to analyze remaining interviews and refined as needed. Thematic coding (within NVivo 8) focused on the substantive content of evaluations, including patient care aspects that participants deemed important (that is, statements of satisfaction or dissatisfaction discussed with reference to specific experiences). General assessments (for example, "They were wonderful.") made without elaboration or reference to the component of care informing them were not coded, nor were descriptions unrelated to evaluative or emotive statements. Data within each content category were analyzed in depth (and compared and contrasted), informing a conceptual framework. Participants often recounted their experiences with a range of service providers and did not always restrict their accounts to a defined EOL stage. Because prior experiences with the health care system and various providers are important in evaluating any particular service, data were analyzed across providers and settings.

Issues of rigour were addressed through analytic immersion in the data; an iterative approach to data collection and analysis; the triangulation of quantitative and qualitative data sources; and informal verification (preliminary findings were presented at an educational workshop with palliative care providers, who offered feedback).

FINDINGS

The average age of the participants was 59; 65 percent were female, and 65 percent were married. Most were Caucasian (82 percent of European descent). The majority (56.5 percent) were employed. A total of 56.5 percent were the adult children of the deceased; 34.8 percent were the spouses of the deceased. The average yearly household income was just under $60,000. In all, 35 percent of the patients had died in extended
care, 30 percent in palliative care, and 17 percent in intensive care or acute care units. Patients spent an average of 251 days on the unit (there is a tendency for patients to have long stays in extended care); 37.5 percent of patients died of cancer, and the rest died of various causes (such as cardiac/respiratory disease, pneumonia, dementia, or multiple conditions). The average age of the deceased was 78.4; 48 percent were female.

Components of Family Members’ Assessments of Health Care

Based on our analysis, we developed a conceptual framework of family members’ assessments of their experiences with EOL health care services. It consists of three components: tangible features, interpretive features, and personal and affective features.

Tangible features

Tangible features (perceptions of events and interactions with formal services and providers) that are important to families were grouped into four sub-themes: what is (and is not) done, what is said (and not said), how it is done and how it is said, and care setting.

What is (and is not) done: A core concern was that the patient be cared for — care should be available, accessible, adequate, and appropriate (that is, it should meet the patient’s needs). Particular concerns varied, but participants valued the patient receiving personal care, timely diagnoses, appropriate treatment and medication, symptom management, and psychosocial and emotional support. One participant was dissatisfied that her mother’s depression went unaddressed; another expressed frustration at the difficulty she had securing oxygen. Families appreciated it when staff made exceptions to facility policy (for example, when they let a patient consume alcohol or allowed a dog in the patient’s room), and they noted the “little things” (for example, when staff ensured that a patient’s son could access the facility when it was closed). Another participant recounted how staff members, knowing the patient enjoyed golf, would find tournaments for her to watch on her television. Care that responds to individual patient needs was valued. Mistakes or gaps in care often left families upset or dissatisfied. Lastly, it was also important (though emphasized to a lesser extent) for family needs to be addressed (for example, when staff checked in with families and showed concern for their well-being).

What is said (and not said): Communication and being kept informed was important to families. One participant appreciated receiving information about the patient’s treatment, including being shown X-rays: “I saw what I could see and I asked and I got told. I was never in the dark. Not of what they were doing.” Families valued being told what to expect and what was happening and why (including being consulted and having decisional input); they appreciated it when staff explained who they were, what they were doing, and who the family could speak to about their concerns. One participant emphasized informational needs “because we’re all novices. We don’t know all this stuff. We have other lives that we know about, but we don’t know about the medical system.” A common complaint was not being told what to expect or what was happening. When one family member went to claim the deceased patient’s belongings, he was shocked to learn that he needed the patient’s will; he wished that someone had explained this to him earlier. Conflicting information from different care providers also generated dissatisfaction.

In the absence of direct communication, participants struggled to understand situations based on indirect and non-verbal cues. They recalled being informed of terminal diagnoses and/or imminent deaths indirectly. They were told, “He’s never coming out of here,” “He has taken a turn for the worse,” “We’ll keep him comfortable”; or they would find out that the patient had been moved to a separate, private room.

How it is done and how it is said: The care process (the manner in which care and information are provided) was important to families. Participants described the behaviour and demeanour of care providers and the way in which they communicated with the patient and (to a lesser extent) the family. This included interpersonal interactions but extended to combinations of events, situations, or care provider actions. One participant’s mother had bowel problems related to a hospital-acquired infection, and staff decided she should be moved to another room. Left in the hallway waiting for the new room to be prepared, she needed a toilet urgently; a commode was put in the hallway and several staff “held blankets around her while she sat on the commode.” The participant did not criticize the staff yet did describe it as a distressing experience. This example highlights how particular care delivery situations can impact on family experiences (even if they do not translate into dissatisfaction).

Participants appreciated care provider behaviours and communications that they perceived as comforting (for example, “sweet” not “stern” talk), gentle (in voice and in touch), energetic, “tuned in” and “in the moment,” easygoing, non-judgmental, cheerful and outgoing. Some (but not all) appreciated physical touch (such as hugs or “a
hand on the shoulder"). Families tended to be dissatisfied with behaviours they perceived as condescending, abrasive, overly efficient, phony, and impatient or annoyed (expressed through tone of voice, body language, sighs, or eye rolling). One participant recounted how her husband had tried to remove his tracheotomy tube and a nurse said to her, “It is driving me crazy.” The participant responded, “Driving you crazy? What the hell do you think it’s doing to him?” Family members were disappointed when providers focused exclusively on care tasks without conversing: “They come, they do, and they go.”

Most participants valued behaviours that reflected a personal connection (making eye contact, smiling, having an engaged posture or demeanour, speaking in a “personal” tone, joking and laughing, or “checking in” with the patient and family), in contrast to “aloof” or “detached” behaviours. There was a mostly positive emphasis on staff members interacting socially, asking personal questions, sharing information about their own lives, or using first names. However, there were exceptions — one participant prioritized respect over personal engagement and did not want to be called by her first name.

Other participants spoke positively about staff who showed that they knew and liked the patient, including expressing their grief or condolences after the death. One participant wished that the cancer clinic had followed up after her mother died: “If you’re treating somebody, there is a relationship set up whether you like it or not. And even an acknowledgement either during [the patient’s] dying or even after, just a printed card to say, ‘We’re sorry your mom died. She was a great lady.”

There was an emphasis on asking the patient how he or she was doing. It was important to participants that staff inform and consult them and the patient regarding care, that they spoke to them directly, and that they acknowledged them and their suffering. One participant said that during a review meeting, staff members whispered among themselves, disregarding the patient’s presence. Likewise, it was important that care providers treated family in a welcoming, accepting manner and offered encouraging comments and input.

**Care setting:** Participants valued peaceful, calm environments where there was a low level of noise and commotion and where there were physical comforts (for example, in the form of chairs and adequate space), privacy, and cleanliness. Isolation-room experiences were referred to as “distressing,” “sterile,” impersonal, cold, depressing, or stressful. Participants appreciated quiet, pleasant roommates who (if desired) could interact socially. Aspects such as lighting, location, and amenities (a courtyard, a window view, or a bright and colourful room) were noted. The space should facilitate visiting. One participant described a room by saying, “You can’t sit by the head of the bed where the person is...You can maybe squish in just between the bed and the counter...I have a closet at home bigger.” Cleanliness was important, particularly in relation to concerns about infection (several participants described hospital-acquired illnesses). Food quality was also important and a common subject of criticism: “terrible,” “unpalatable,” “a shame,” “boring,” “a shock,” “everything tasted the same,” “no choice,” “abysmal.”

**Interpretive features**

Participants made two primary (though not mutually exclusive) causal interpretations about tangible care features — one focusing on system or institutional features and the other on individual staff characteristics. At times, these interpretations aligned with attributions of responsibility.

**Interpretations focused on the health care system:** Based on their experiences, some participants believed that the root determinants of care quality were systemic and contextual features of health care and facility organization, policies and staffing, and financial and human resources. One participant recalled how her mother urgently needed procedures on a Friday afternoon after the facility radiologist had left for the weekend. Another participant placed responsibility for long wait times on government: “We need to put health care as a priority instead of the Olympics.” Other participants connected perceived care competence and coordination to staff training, turnover, and documentation.

Systemic interpretations related to a lack of information were also common. One participant emphasized how shift work, job sharing, and staff turnover made it “hard to track somebody down that was going to have some longevity or be involved.” Another noted that numerous specialists and high turnover meant that “You would never get any results unless you hunted somebody down and asked them.”

To a lesser extent, systemic interpretations were connected to the care process. One participant, herself a nurse, referred to the challenges nurses face in connecting with families on busy wards — it’s “so frantic that you don’t have time to...get to that level.” Another participant, speaking about compassion, said that hospital staff members “have so many people to care for at the same time they cannot give their devoted time to one person. So they have to sort of ration out their feelings.”
Interpretations of physical settings at times also focused on system characteristics. One participant wished for fewer beds per room, yet believed that time, efficiency, and staffing limitations were barriers. Other examples included: “Clinical or institutional food — it’s made for high production”; and, “These units are not designed for privacy.”

**Interpretations focused on individual characteristics of care providers:** Alternative care interpretations focused on perceived characteristics and responsibilities of care providers. For instance, participants made inferences about care provider competence and skill based on tangible features of care; they also made inferences about care provider attitudes and compassion based on tangible features. One participant’s relative received certain services when the participant got angry, which led the participant to interpret the problem as stemming from individual attitudes: “The services are there. It’s just that they’re choosing not to...it’s their own laziness that they are not following through for people.” Another participant maintained that staffing shortages are “not the [patient’s] problem,” adding, “If you do not have time to feed him, then go to your supervisor and say you need more time.” In contrast, “friendly” and “compassionate” nurses were described as attentive and responsive to patient needs through care provision: they were “giving everything”; “they were on top of it.” Care providers were also seen as compassionate when they made exceptions to institutional policies or provided care they were not required to provide, did not have time to provide, and could even “get in trouble” for providing.

Unresponsiveness was interpreted as care providers lacking commitment and viewing their work as “just a job.” One participant spoke about staff members who “did the best they could,” inferring that they made this effort because they were committed to their jobs. Another participant said that a care provider taking as much time as necessary to help a patient — even if that meant staying on past the end of a shift — indicated conscientiousness and professionalism.

At times, interpretations of communications with care providers focused on individual characteristics, including compassion or caring, regard for patients as persons, and (particularly regarding conflicting information) competence. One participant described compassion as “when they sit down and they talk to you. They tell you what’s going on”; in contrast, a lack of communication was perceived as “ignoring” and uncaring.

Finally, how staff spoke with families and delivered services informed interpretations related to whether they: cared about the patient; viewed that individual as a person, not just a patient; were comfortable with death; and were in the “right” job. One participant believed that staff assumed her husband was a “scruffy bum” and blamed him for his disease: “It was the ones who looked away; they’d rush in and rush out just as fast with no conversation.” Participants said that they felt appreciation for staff when they took the time to talk, equating this with kindness and compassion. One participant acknowledged the staffing crunch, yet added that staff, though busy, “could have taken more time and listened.”

**Personal and affective features**

The outcomes of care (for example, impacts on feelings, relationships, and roles) significantly affected participants’ evaluations of care, and they are conceptualized as responses to tangible care features and interpretations of those features.

When care was received when it was needed, participants expressed confidence in the care, along with relief and trust. They also felt comfortable leaving the patient: “I trusted [the nurse]... Mom was in good hands that night.” One participant associated perceived competence with relief and gratitude: it “meant I could just deal with being with [Mother]”; and it ensured that the family “got some downtime.” Having patient needs met lightened worry and guilt, and in the following example, it promoted healthy grieving: “We’re not tortured by what could have been or what was...we were just able to move on with the grieving in terms of missing him as a person and not have to get stuck on the dying.”

Perceived inadequate or inappropriate care generated anxiety, as well as feelings of being neglected and of discomfort about leaving the setting: “I was concerned that if we weren’t there, he wasn’t going to get what he needed.” Some participants provided direct care within the institution, one risking his job to do so. Others expressed dissatisfaction because they believed they needed to express anger or ingratiate themselves with staff to ensure adequate treatment for the patient. Several participants believed that medical complications could have been prevented if appropriate care had been offered, and some regretted not advocating more strongly: “If we’d been a little bit more pushy...it might have been better.”

Good communication instilled trust and decreased anxiety and stress. When families could not obtain information they believed was necessary, some felt ignored or forgotten, contributing to their anger and frustration. Others spoke of actively seeking out information, including tracking down and pleading with doctors: “I’m normally not a demanding person, but I was respon-
sible for [the patient]. I had to know what was happening to him in order for me to understand everything." There were lasting impacts. One participant was disturbed that she was never informed about the results of tests related to her husband's liver failure; another was "haunted" by the fact that no doctor explained to her the cause of her husband's death.

When care providers offered personalized care, acknowledgement, and socialization, and when they appeared fond of the patient, participants perceived them to be like friends or family, and they were appreciative. In these circumstances, participants felt cared about and respected as "real" or "normal" persons; they did not feel that their identity was diminished and that they had become just a "number on a piece of paper." One participant had "faith in the system" when care providers appeared to care about the patient; others felt comfortable, less like an inconvenience. Those who were not comfortable may have been frightened to ask for help: "I was forceful, but not as forceful as I wanted to be because I needed that help. So I had to back off at times." One participant felt dismissed as "just" a family member. The participant who spoke of the hallway commode incident described her distress, implying regret: "Should I have insisted and forced the staff...to put my mom into that bathroom to give her the privacy and dignity of using the toilet, days before she passed away?"

Negative physical environments generated unhappiness, stress, anxiety, fear, and confusion for families and patients. Care environment concerns escalated participants' worries about patient well-being. Having a difficult roommate was traumatic for one participant's father: "He said, 'Don't leave me here.' It was a nightmare." Participants were concerned about impacts on the patient (for example, distress, confusion, or iatrogenic conditions). A few believed that patient quarantine caused emotional deterioration and could lead to the patient receiving less care.

Participant assessments of care settings contributed to perceptions of whether the patient was respected or receiving the care he or she deserved. Negative environments generated disappointment: Mom and Dad "deserved privacy for the last few months"; and "It was stressful to see somebody who's had a good life, paid taxes, done their part, and get stuck in a hallway. It hurt." Participants connected positive environments with feeling reassured that, for example, the patient was respected. For them, positive environments promoted calmness and physical and emotional comfort, including not feeling that they were disturbing others.

**DISCUSSION**

The study sample is non-random and not representative in a statistical sense. However, this is consistent with the study objectives: to assess the satisfaction of bereaved family members with institutional EOL care, identify core components, and delineate distinctions between how families experience and evaluate EOL care. Tangible features of these experiences represent perceptions of care events and interactions. It is important for patients and their families to receive appropriate help when needed, to be kept informed, to be treated well, and to be in an appropriate setting. As evidenced by our literature review, this finding is not new. Efforts at systemic and individual levels are necessary. The physical environment, however, tends to be downplayed in quantitative satisfaction research, despite its implications for family experiences.

The confirmed importance of feeling respected and valued directs attention to a patient- and family-centred palliative care approach (33). A desire to be valued, to be treated as a normal person, and to feel secure about one's identity and self-worth has been identified elsewhere (33, 36-39). Both the process and the content of care can contribute to fulfilling this desire (28). Findings also suggest that the care process extends beyond interpersonal interactions to cumulative combinations of events over time.

Perceptions of tangible care features and causal interpretations of care quality should be distinguished. Furthermore, whereas quantitative surveys often assess perceived characteristics of individual professionals, they less often assess perceived system constraints. Many individuals are aware of the complexities of providing high-quality care in the current health care context. However, though acknowledgement of system constraints sometimes shifts attributions away from individual providers (diffusing potential dissatisfaction [40, 41]), it does not always do so. Further research is needed into interpretations of cause and/or responsibility for care quality; these interpretations may influence whether satisfaction is expressed in particular measures.

Awareness of this distinction also suggests that there are aspects of satisfaction (how care is interpreted and received by families) that can only be indirectly or partially addressed by care providers. Furthermore, evaluations of care quality are influenced by the family's overall evaluations of their experiences with the patient's death, over time. Our findings can advance health care providers' and decision-makers' understanding of bereaved families' experiences; the findings can also advance understanding of families' inter-
pretations of their experiences as well as the emotional impacts of these experiences. Our framework emphasizes a move away from more narrow focuses on satisfaction and toward broader family experiences of services on multiple levels, "the meaning and value attached to them, whether they are positive or negative and whether they can be improved" (41, p. 1358).

Patients in one study appreciated it when staff "demonstrated care and concern, evinced by checking up and following through" (38, p. 460). Similarly, in our study, the assumption that "caring for" (performing the tasks of caregiving, responding to need) demonstrates "caring about" (showing affection and regard), identified by critical and feminist gerontologists, is constructed and reproduced in family accounts. This assumption can fuel guilt feelings among paid health care providers if they are unable to effectively "care for" patients and families. Any care provider's ability to convey "caring about" is limited by his or her ability to gather and use individualized knowledge and by the amount of time the provider is given to develop relationships.

Care providers, in their interactions with families, could consider questions such as, "How can I make these family members feel like I care about them and their loved one?" They could also consider which practices and aspects of institutional structures or environments could generate feelings of depersonalization and exclusion (38, 39). In a context of scarce resources and shrinking access to health care services, it may be even more important for care providers to engage in behaviours and communications that convey "caring about." Yet in establishing these interactions, consideration must be given to care providers' boundaries and abilities in order to prevent burnout. Attention should also be focused on making changes to practice and organizational decision making that will facilitate more positive experiences for families and patients.

Our findings extend previous research on family satisfaction with EOL care by: delineating distinctions between the ways different families experience and evaluate EOL care; highlighting the importance of the process and content of care as well as cumulative combinations of events and experiences over time; and pointing to the need for further consideration of the role of cultural interpretations in overall evaluations of EOL care.

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