

# What constitutes quality of family experience at the end of life? Perspectives from family members of patients who died in the hospital

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## ABSTRACT

*Objective:* Most palliative care efforts focus on assessing and improving the quality of life and quality of care for patients. Palliative care views the family as the unit of care; therefore, excellent comprehensive palliative care should also address the needs of the family and the caregiver(s). While the recent literature has offered detailed descriptions of caregiving needs in the home setting, it is crucial to describe the needs of family members who provide care for patients with advanced illness in an inpatient setting, where family members serve as the key intermediaries and decision makers. Therefore, we sought to define the relevant aspects of quality of experience for families of hospitalized patients.

*Method:* We convened a series of focus groups to identify the domains important for the quality of experience of dying patients' family members. Participants included bereaved family members of patients who had died at a Veterans Administration (VA) or private academic medical center. We conducted four in-depth follow-up interviews to probe for additional details and validate our interpretation of the focus group findings.

*Results:* Participants ( $n = 14$ ) ranged in age from 46 to 83, with a mean of 62. All were female; 64% were Caucasian, 21% African American, and 14% did not report their ethnicity. Content analysis yielded 64 attributes of quality of family experience constituting eight domains: completion, symptom impact, decision making, preparation, relationship with healthcare providers, affirmation of the whole person, post-death care, and supportive services.

*Significance of results:* Our data have implications for clinical guidance in assisting family members in the inpatient palliative setting, which often includes patient incapacity for communication and decision making. They suggest the importance of developing corresponding methods to assist families with the tasks involved with life completion, being prepared for a crisis and imminent death, and post-death care. Provider communications and relationships are central to the processes of meeting the clinical needs of family members. Our findings should inform the development of measures to assess family experience.

**KEYWORDS:** Palliative care, Caregiving, Quality of life

## INTRODUCTION

Most palliative care efforts focus on assessing and improving quality of life and quality of care for patients. Palliative care views the family as the

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unit of care; therefore, excellent comprehensive palliative care should address family and caregiver needs as well. While recent literature has offered detailed descriptions of the needs involved in home caregiving in palliative care (Funk et al., 2010; Stajduhar et al., 2010), it is crucial to describe family members' needs in the inpatient setting, where they serve as the key intermediaries and decision makers.

Literature reviews describing the experience of home-based caregiver needs have shown the importance of several key areas, including information on practical aspects of care, disease course, consistency of information, and the desire to have communication with providers clarified (Funk et al., 2010; Stajduhar et al., 2010). Lack of preparedness in these areas is associated with increased caregiver anxiety and stress (Funk et al., 2010; Stajduhar et al., 2010). Because caregivers are often required to be at home for extended periods of time, foregoing their usual activities, social support is crucial in combating increased isolation. Many studies within the home setting, including and not including hospice, also describe the need for access to adequate, competent, and continuous support services. In accordance with the above-described needs, most interventions focus on home care caregiver training to increase efficacy in medical management and to enhance emotional coping skills (Funk et al., 2010; Stajduhar et al., 2010).

Despite the extensive reviews of home care research, little is known about what improves caregiver experience in the inpatient setting. This knowledge has its own implications for both intervention and palliative care outcomes assessment. With regard to the former, in the absence of daily, practical bedside demands, which caregiver needs come to the fore and can be best met by hospital staff? Regarding outcomes assessment implications, to date, family members' interview responses often serve as proxies for patient indicators of quality. However, as families constitute the unit of care in palliative care, we must understand what contributes to quality of family experience and therefore what to measure to assess the quality of that experience.

In a previous study, we interviewed seriously ill patients, bereaved family members, physicians, nurses, social workers, chaplains, and hospice volunteers, asking them to reflect on dying persons they had cared for and to identify the important attributes of that experience (Steinhauser et al., 2002; 2004). Participants were sampled from the Durham Veterans Administration Medical Center (VAMC), the Duke University Medical Center, and a community hospice, with groups stratified by role. The study included data describing what was important to providers, families, and patients. Interviewing such a wide range of participants offered the advantage of

multiple role perspectives as well as the cumulative experience from thousands of end-of-life scenarios.

The study produced six domains important at the end of life: completion, symptom impact, relationship with healthcare provider, preparation, decision making, and affirmation of the whole person. These data later became the foundation for an instrument to assess quality of life at the end of life for patients (the QUAL-E questionnaire) (Steinhauser et al., 2002; 2004). In our efforts to develop a companion instrument for family experience, we wanted to conduct additional family-only focus groups that would allow: (1) confirmation or disconfirmation of previous domains and attributes, (2) additional details and new attributes and domains, and (3) probes specific to what is important for families whose loved ones have died in hospital. To assess and measure these needs in an inpatient setting, we sought to define the relevant aspects of quality for families of hospitalized patients. The purpose of the present paper was to describe what families of hospitalized patients consider central to the quality of their experience at the end of life.

## METHODS

### Design

We convened two focus groups to identify the domains important for the quality of experience for family members of dying patients. Discussion in each group was guided by a semistructured interview protocol. Additional probes were employed to gain elaboration of responses to a priori questions as well as themes generated spontaneously by participants (Corbin & Strauss, 1993; Krueger, 1994; Stern, 1985).

### Setting and Participants

Participants were recruited from decedent care records from the Durham VAMC and the Duke University Medical Center, stratified by recruitment site, and consisting of family members of patients who died of chronic disease 6 to 12 months prior. Family members were identified in hospital databases as next of kin and those who had been present in the hospital, and whose loved ones had died of a chronic illness, as opposed to accident or traumatic injury. In addition, they were English speaking, had a telephone (for initial contact), were cognitively able (a Short Portable Mental Status Questionnaire [SPMSQ] score of 7 or higher) (Corbin & Strauss, 1993; Stern, 1985), and lived within 35 miles of Durham, to facilitate ease of travel. We screened medical records to look for instances of family members who demonstrated a lack of ability to communicate.

When calling family members for participation, we confirmed their involvement with medical decision making. Because VA and non-VA institutional settings are distinct in patient and family composition and milieu, separate groups were conducted at each site. All focus groups, led by a trained facilitator, were audiotaped and transcribed. Group members were compensated \$20 for their time.

### Content/Measures

Participants were asked to reflect on the end-of-life experiences and care received by the patient (their loved one) and to comment on what was important, what was most needed, and what constituted quality of experience. When subtopics were not generated spontaneously, we probed specific issues related to their relationship and communication with the healthcare team, the role of location and institutional issues, as well as family and other support. The majority of these topics were generated spontaneously, so that the facilitator probed for more details only when vague language was encountered.

As noted, after analyzing transcripts from each group, we conducted in-depth interviews with two members of each focus group to provide a more fine-grained description of the attributes generated in the larger group discussion.

### Analyses

We conducted a content analysis using open and axial coding techniques (Corbin & Strauss, 1993; Krueger, 1994; Stern, 1985). During open coding, investigators independently read an example of a transcript and analyzed it for common and recurrent themes pertaining to the qualities of a family end-of-life experience. These summaries were then compared for theme agreement and disagreement. One coder (KES) then applied the coding scheme to the remaining transcripts. Throughout the coding process, theme exemplars from all transcripts were reviewed as a check on coding validity. During axial coding, the investigators developed further conceptual domains by describing comparisons between themes and within and between transcripts (Corbin & Strauss, 1993).

In developing our interview protocol for this study, we reexamined the findings from our previous study and its sample, and subsequently developed additional in-depth probes for the present study of only family members. This allowed us to have a general understanding of what was important to family members, based on responses from the first study, and to know where to elicit additional details. We compared attributes and domains listed in both qualitative data collections. Because of theme repetition in the two data samples, we explored the

context of conversations to determine if the second sample attributes provided an extension of a previously identified domain or constituted a new one. This mainly took the form of confirming previous attributes and identifying additional needs of family within an existing domain of experience. In two instances, two new family-centered domains were in fact created.

## RESULTS

The participants in the two focus groups (a total of 14) ranged in age from 46 to 83, with a mean of 62. All were female, 64% were Caucasian and 21% African American, and 14% did not report ethnicity (Table 1). We conducted four in-depth follow-up interviews.

Data from family members' discussions and interviews confirmed the six end-of-life domains identified previously: completion, symptom impact, relationship with healthcare provider, preparation, decision making, and affirmation of the whole person (Steinhauser et al., 2000). Family members generated new attributes for these six domains specific to the hospital setting. They also generated two new domains specific to the quality of family experience: "supportive services" and "post-death care" (Table 2). We offer below the domains and attributes confirmed in our study and provide additional details, illustrative quotations, and discussion about the data novel to the experience of family members of hospitalized patients at the end of life.

**Table 1.** Focus group participant characteristics

	Sample ( <i>n</i> = 14)
Age range	46–83
Mean age	61.8
Gender	
Male	
Female	100%
Ethnicity	
African American	21%
Asian American	0%
White	64%
Other	14% (missing)
Religious affiliation	
Protestant	78%
Roman Catholic	0%
Jewish	0%
Other	14% (missing)
No affiliation	7%
Recruitment source	
VA medical center	50%
University medical center	50%
Community hospice	0%
Some categories do not sum to 100% due to rounding	

**Table 2. Attributes and domains**

Domains and Attributes	Previous Sample 1	Sample 2
Completion		
Spend time together/presence of family	X	X
Meaning making	X	X
Sharing with patients—uniqueness of their life	X	X
Say important things	X	X
Come to peace	X	X
Say goodbye	X	X
Say important things/goodbye even if patient not conscious		X
Symptom impact		
Be free of pain	X	X
Be free of anxiety	X	X
No shortness of breath	X	X
Be kept clean	X	X
Physical touch	X	X
Symptom anticipatory worry	X	X
Concern of current suffering		X
Worry of future suffering		X
Concern that family didn't do all to prevent suffering		X
Concern of putting patient through too much		X
Helplessness in face of suffering		X
Relationship with healthcare system		
Know where to go to get answers	X	X
HCP knows who patient is as a whole person	X	X
Know what to expect from illness	X	X
Participate in/understand decisions about care	X	X
Be kept informed, particularly in crisis	X	X
Staff anticipate family needs		X
Communication clear/no jargon		X
Sensitive to being family of "dying" patient		X
Didn't give up/treat like "dying/ignore"		X
Small touches of comfort—bringing coffee		X
Bend rules		X
Tolerate family emotions, let them have reactions		X
Someone to listen to story—patient's and family's		X
Continuity of care—rotations		X
All floor staff aware of situation		X
Dignity—body care and functions		X
Decision making		
Goals of care clear	X	X
Understand what is happening, what is nature of choices	X	X
Care location choices	X	X
Honesty about situation		X
Family conference, communicate same info to all family members		X

Continued

**Table 2. Continued**

Domains and Attributes	Previous Sample 1	Sample 2
Family conflict		X
Preparation		
Understand physical process of dying	X	X
What to expect about end, not sleeping	X	X
Prepare family emotionally—social worker	X	X
Not regret treatment choices		X
History of illness episodes—compare		X
Prepare family spiritually	X	X
Affirmation of whole person		
Church support—affective and religious visits		X
Family support—emotional and logistical	X	X
Staff support—listening to patient and family stories		X
Supportive services		
A place to stay, sleep		X
Shower		X
Parking, food		X
Allow whole family in room		X
Taught home care		X
Usefulness of hospice volunteers		X
Post-death care		
Respect in caring for body, postmortem		X
Cleaned up		X
Tubes removed before family viewing		X
Prepare family to see body (e.g., eyes and mouth open)		X
Allow time with body		X
Help with decedent care and choices		X
Bereavement services		X
Condolence cards, remembrance service		X
Newsletter, poems, etc.		X

**Completion**

Within the domain of *completion*, families talked about the importance of *spending time together, meaning making, sharing stories, saying important things, coming to peace, and saying goodbye*. Family members described these attributes even in the context of patient nonresponsiveness (either poor communication or even full unconsciousness). Despite the lack of reciprocal communication, families emphasized the relevance of saying goodbye or other important statements toward an overall act of relational completion:

We talked to him constantly. We didn't act like he wasn't listening to us. We let him know who was there and who was coming and going.

Other family members described saying goodbye, even nonverbally:

I didn't walk up and say goodbye, but you know, within my heart (. . .).

### Symptom Impact

Within the *symptom impact* domain, family members confirmed previously identified concerns of *attending to symptoms* to relieve *pain*, *shortness of breath*, *anxiety*, or other presenting symptoms as well as preventing future symptom expression and issues of dignity related to *being kept clean* and *physical touch*. In the present study, these specific symptom concerns were augmented by discussions of more general unease about current and future *suffering*. This sometimes took the form of worry that *the family did not do all they could to prevent suffering* or other times concern about whether *the treatment was worth it*. They often expressed a *sense of helplessness in the face of suffering*:

It was important for him to have immediate care because he was very sick, and it hurt to have to wait and see him suffer. And there wasn't anything I could do to relieve that.

Alternatively, families described a sense of peacefulness, as long as their loved one "wasn't suffering."

### Relationship with Healthcare Provider

Family members spoke most frequently and generated the most attributes within the domain of *relationship with healthcare provider*. Both the previous and current study samples produced attributes of *knowing where to get answers*, *knowing what to expect about the illness*, *having a provider who knows the patient as a whole person*, and *participating in decisions about care*. In the current study, families described a desire to be *kept informed in a crisis*, that healthcare providers *bend the rules* to accommodate family time with the patient and *tolerate families' emotions*, and problems with *unclear communication*, which was often peppered with *medical jargon*:

The doctor did come in and tried to explain to us what it was, but I really wasn't understanding it. It was kind of over my head because we're not doctors.

Additionally, they provided fine-grained detail regarding the need to be sensitive to the family of a "dying" patient, resulting in the need for additional *continuity in care and communication*, the need to *have someone listen to the family's stories*, *anticipate*

*needs*, *offer small touches of comfort*, and *make the whole floor staff aware* of the imminence of death for the family.

### Decision Making

Relatedly, in the domain of **decision making**, family members expressed a need to have clear goals of care, understand the nature of what was happening and the nature of choices, and discuss care location choices. Additionally, families described the importance of honesty about the situation and a desire for meetings to offer all family members the same information:

She [sister] felt like I didn't give him a chance to get better. If they [the medical team] had called a family meeting, then everybody would have gotten the same information at the same time.

### Preparation

**Preparation** included a need to prepare the family emotionally and spiritually (Steinhauser et al., 2008). There was extensive conversation about the need to *better understand the physical process of dying*:

The whole thing about the experience with me was I didn't know he was dying, so it was very hard.

I had been in the room at one point, and the nurse was in there, and I would say, "What's going to happen, how is this going to take place, is his fever going to go so up so high that it's going to kill him, after they take him off the antibiotics?" She just listened to me, and she didn't answer.

### Affirmation of the Whole Person

Our previous study revealed that the domain of affirmation of the whole person entailed feeling as though the patient was known beyond the confines of a disease status and treated with respect and dignity. For the families in the present study, this domain was most often manifested as families described very personal support from *staff*, *family*, and *church members* who acknowledged the individuality of their loved one, and knew the details of a life lived fully:

The chaplain came in and listened to me go on and on about my wonderful husband. Although I know he got tired of listening to me, I told him about his Navy days and his father. He grew up here and his father died in the VA hospital also. So, I went through all that. The nurses, you know, were wonderful.

For families, the affirmation was expressed in the ability to tell stories, participate in life review, and

relay the fullness of life of the family member who in the inpatient setting may have been in a limited or unresponsive state.

Two additional domains were generated by these bereaved family member groups: *supportive services* and *post-death care*.

### Supportive Services

We heard discussions about the importance of needing a place to stay or shower (during extended hospital visits), comments about parking and food, allowing the whole family in the room, and the need for home care training upon discharge and the usefulness of hospice volunteers when under home care:

[The volunteer] would come once a week or whenever we wanted him to. It was great. In fact, he would say, "Leave me some dishes or something to do." He'd tell me all the little things he could do. He would just sit there with [the patient].

### Post-Death Care

Finally, we learned the seminal importance of care for the patient and family after the moment of death. Families expressed the need for *caring for the body postmortem* (such as being cleaned for family to view), *preparing the family to see the body*, *allowing time with the body*, *helping with decedent care and choices*, *condolence cares*, *services of remembrance*, and *newsletters on other bereavement communications*:

They came in and stretched him out and put one pillow under his head and wiped his face. They had already come in a little bit earlier and changed him because he was very particular about his hygiene. (. . .) They had shaved him, bathed him, put him in clean pajamas before he died. After he died, the kind of propped him, and told me I could stay with him as long as I wanted to.

Alternatively, one respondent shared a tormenting memory after no one prepared her to see her husband's body in the morgue. The attendant opened the body bag to reveal the body with mouth and eyes wide open. She said it looked like "he was screaming" when he died.

## DISCUSSION

In palliative care, both patient and family comprise the unit of care. Therefore, to provide comprehensive care, we must have the ability to assess and intervene with regard to the quality of experience for

both patients and families. This need is particularly pertinent when a patient's ability to communicate is diminished due to loss of consciousness, fatigue, or some other symptom burden, and family members serve as intermediaries with healthcare providers. The present study confirmed previous findings regarding the general attributes of quality at the end of life and offered new insights regarding how to improve end-of-life family experience in the inpatient setting, which often includes periods of patient nonresponsiveness. Family members caring for loved ones in the hospital expressed needs distinct from home care settings and required corresponding methods to accomplish life completion, understand symptom expression and burden, communicate with providers, and make treatment choices. Supportive services and post-death care also had a strong influence on overall family experience with end-of-life care and the moment of the death of their loved one.

While we know from extensive prior literature that life completion is important for patients (Funk et al., 2010; Stajduhar et al., 2010), our data show ways that completion is important to family members even in instances where loved ones possess limited or no capacity for verbal or nonverbal interaction. Describing times of patient unconsciousness, family members gave examples of gaining completion by saying important things regarding the meaning of their relationship, loving affirmations, or saying goodbye. This highlights an opportunity for staff to encourage, as some do, family members to engage in tasks of completion and closure, regardless of the patient's cognitive status or ability to interact verbally.

Tasks of completion may arise spontaneously or as prompted by a more formally designed life review narrative intervention, which has shown consistent positive outcomes for geriatric patients as well as for those with chronic illness (Fratorolli, 2006). Dignity therapy offers one modality focused on legacy documents (Chochinov et al., 2005). Our team recently developed specific end-of-life interventions that pair life review with discussing forgiveness and heritage and legacy for patients and caregivers (Steinhauser et al., 2008). The data from the present study emphasize family members benefiting from sharing the loved one's life story or the story of their relationship. In previous work, we called this "concern for the whole person" and affirmed that beneficial support can be delivered in the context of acknowledging the unique stories of patients and families.

Our results also affirm family members' distress about symptom burden and extend the discussion to a more pervasive concern for overall suffering

(see Steinhauser et al., 2001). Most assessment tools measure symptom prevalence, frequency, and severity, all key components to improving quality of care. The current results suggest that, when evaluating a family member's quality of experience, clinicians and researchers must evaluate the extent of perceived suffering and decide which individual factors contribute to a sense of suffering for that particular patient. In addition, the current results point to the role of family education related to end-of-life symptoms that may appear bothersome but are likely not sources of suffering. For example, a patient's open eyes and mouth after death are a common natural physiological response. Or, agonal breathing patterns may alarm family members but are unlikely to reflect the actual sensation of dyspnea.

As expected, the relationship between family members and the healthcare team is an essential element of their perception of the quality of the inpatient stay. In the present study, it was the most often-expressed concern and the one presented in the most detail. In the hospital environment, so laden with uncertainty and crisis, receiving timely information, being updated during crises, and hearing communication in easy-to-understand terminology were described as assisting in ameliorating overall feelings of confusion and helplessness. Even more specifically, family members noted the importance of a healthcare provider's capacity to tolerate families' emotions (Azoulay et al., 2003; Curtis et al., 2002). Recent interventions, particularly within oncology training, are aimed at assisting physicians with skill building to recognize and facilitate patient emotions during serious illness (Back et al., 2007; Koropchak et al., 2006; Skinner et al., 2009). These data suggest the relevance of training for use with family members and nonphysician providers experiencing high levels of patient and family crisis contact.

Beyond emotional responsiveness, these data draw attention more broadly to what family members need from providers to prepare themselves as they move into the active phases of the death of their loved one. First, families requested more practical information regarding the dying process. While hospices and some palliative care programs provide family members with pamphlets about some of the general physical changes that are likely to occur, the family members in our study had not received such material and therefore expressed the need for more real-time information related to the physical idiosyncrasies of their loved one's illness and its likely course of progression. They wanted to know what was normal and what was not, and which physical changes to expect. This was usually related to previously described feelings of uncertainty and helplessness. While the end of life is rife with uncertainty, providers may guide

patients through this process closely, assuring family members that they are doing all that is possible.

Study participants strongly valued the family meeting, when possible, as the preferred modality of information delivery. This strategy reduced relaying of miscommunication and the conflict that arises when information is parceled out to individual family members as it becomes available. This reduction in conflict assisted family members with moving on and grieving rather than being caught up in second guessing choices or blaming other family members for decisions. Family meetings often focused on delivering consistent and practical information to assist with treatment choices; study participants described meetings as an additional opportunity for general emotional caring for the family during illness and preparing them for bereavement. While family meetings are central to most palliative care services, the field is just beginning to include resources from the fields of social work and marriage/family therapy, which base their approach on family systems theory and offer evaluation and therapeutic strategies to assist with challenging family dynamics.

Finally, we saw the emergence of two domains generated only in the family-member groups: **post-death care** and **supportive services**. The majority of training in palliative care is focused up to the point of death, yet the illustrative quotes remind one of the immense importance of the post-death phase of care for the overall experience of family members and their end-of-life memories as they moved through grief and bereavement. With regard to supportive service concerns, many family members traveled significant distances to the hospital and needed assistance in terms of an affordable place to stay, shower, and eat. While these attributes do not fit into our usual quality-of-life model or even the biopsychosocial spiritual model, as noted by Casarett and colleagues (2008), logistical support services are crucial for the overall quality of family experience. Again, this highlights the importance of an interdisciplinary team in addressing the biopsychosocial spiritual needs of patients and family members, some of which are highly logistical. This awareness has been forged in pediatric end-of-life care settings, but is only belatedly being applied to adult caregivers.

## LIMITATIONS

Similar to other studies of caregiving in seriously ill patients, the vast majority of our participants were women. However, by triangulating with previously collected data, which included the responses of males, we were able to mitigate this limitation. While the number of groups in our study was limited to two, the responses were triangulated and confirmed

previous focus group data in which participants responded from the perspective of a professional role in the personal end-of-life experiences and as a member of the family of a beloved patient who had died.

## CONCLUSIONS

A large body of work demonstrates the centrality of the family and caregiving role for those living with chronic disease, mostly among the family members of patients with dementia. More recently, work specific to family members and caregiving in palliative care has emerged in the literature, with a large proportion concentrating on the home caregiving needs of patients and families at the end of life. Our present work contributes to the body of work on family needs at the end of life by addressing their active role in decision making and by emphasizing some unique and unmet needs that arise in the inpatient setting during health crises and in the face of imminent death.

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