

Examining family meetings at end of life: The model of practice in a hospice inpatient unit

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(RECEIVED June 25, 2014; ACCEPTED August 30, 2014)

ABSTRACT

Objective: Our purpose was to rigorously examine the nature of family meetings as conducted in an inpatient hospice care unit in order to generate an inductive theoretical model.

Method: In this two-phase project, we first interviewed eight members of the interdisciplinary care team who participated in multiple family meetings each week. Interview questions explored why and how they conducted family meetings. Using an observation template created from these interview data, we subsequently conducted ethnographic observations during family meetings. Using the methods of grounded theory, our findings were synthesized into a theoretical model depicting the structure and process of formal family meetings within this setting.

Results: The core of the family meeting was characterized by cognitive and affective elements aimed at supporting the family and facilitating quality care by clarifying the past, easing the present, and protecting the future. This inductive model was subsequently found to be highly aligned with a sense of coherence, an important influence on coping, and adaptation to the stress of a life-limiting illness.

Significance of Results: Provider communication with family members is particularly critical during advanced illness and end-of-life care. The National Consensus Project clinical practice guidelines for quality palliative care list regular family meetings among the recommended practices for excellent communication during end-of-life care, but do not provide specific guidance on how and when to provide such meetings. Our findings provide a theoretical model that can inform the design of a family meeting to address family members' needs for meaningful and contextualized information, validation of their important contributions to care, and preparation for the patient's death.

KEYWORDS: Family meeting, Grounded theory, Hospice care, Inpatient care, Structured communication

INTRODUCTION

Provider communication with family members is particularly sensitive and important during advanced illness and end-of-life care. Family members of a dying patient often have significant unmet needs, a number of which can be addressed through timely and high-quality communication with providers

(Hannon et al. 2012; Gallagher & Krawczyk, 2013). Families rely on good communication with providers for emotional support and as a source of medical information to enable informed healthcare decisions (Royak-Schaler et al., 2006).

Inadequate communication during the time of approaching death results in harmful consequences for family members as well as for patients. In addition to confusion and distress during the patient's phase of dying, inadequate pre-death communication puts patients and families at risk for additional adverse experiences. Family surrogates' decisions may

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be based on inadequate or misleading information, and patient goals and preferences may not be honored (McLeod-Sordjan, 2014). In addition, when surviving family members are unprepared for a patient's death, they are placed at greater risk for damaging physical and psychological health consequences in bereavement (Kim et al., 2013). Given that caregivers' cognitive, affective, and behavioral preparedness for the death of a patient are primarily dependent on communication with providers, the quality of communication preceding a death can have persistent and pervasive effects (Hebert et al., 2009). Furthermore, a lack of preparedness for the death aborts an opportunity for patient and family to address end-of-life developmental tasks (Byock, 1996; Waldrop & Meeker, 2014).

The clinical practice guidelines for quality palliative care (National Consensus Project, 2013) list regular family meetings among the recommended practices for excellent communication and preparation during end-of-life care but do not provide specific guidance on how and when to provide such meetings. Palliative care experts have created clinical guidelines and recommendations to assist clinicians in conducting family meetings (Hudson et al., 2008; Weissman et al., 2010a; 2010b) as well as an information sheet for patients and families (Moneymaker, 2005). Family meetings in palliative care settings are common, yet diverse. They are widely used, though not yet well studied, in palliative care.

Although family meetings have been studied rigorously in intensive care settings (Curtis et al., 2001; 2002; Lautrette et al., 2007; Radwany et al., 2009; Billings, 2011), investigation of their use in palliative care is more recent. Early evidence indicates that family meetings in palliative care settings are effective in reducing unmet needs of family members (Hudson et al., 2009; Hannon et al., 2012). Thus, family meetings are a promising approach for addressing families' information and support needs. The purpose of our study was to advance our understanding of a family meeting intervention targeted to assist family members of a dying patient. Because clinical evidence of the value of family meetings in the hospice inpatient setting is compelling, our research team wanted to rigorously examine these formal family meetings and to describe them theoretically in order to advance the evidence base for best care. Thus, our objective was to examine systematically and describe theoretically the process of family meetings as conducted in an inpatient hospice care unit.

METHODS

In this two-phase project, we first interviewed members of the professional interdisciplinary care team to

learn why and how they conducted formal family meetings. During the second phase, we conducted ethnographic observations as nonparticipant observers during some 25 family meetings. The study was approved by the university's institutional review board for the protection of human subjects and by the hospice agency's research review board.

Setting/Sample/Data Collection

Phase 1

The study was conducted in collaboration with a 22-bed hospice inpatient care unit that is part of a large multicomponent hospice and home care organization serving one county in western New York State. At the time of the study, the average daily census for the hospice organization was 584, including patients in home care, inpatient units, dedicated hospital beds, and nursing homes. Those staff members who worked only in the inpatient unit and who regularly participated in family meetings were invited to participate in the study. Email invitations were extended to two nurse managers, six physicians, and two social workers. Though chaplains often attended family meetings when the focus was one of their patients, they were assigned to provide care in both the inpatient and home care settings and thus were not part of the team routinely conducting the family meetings. If a team member did not respond to the initial email invitation, one follow-up message was sent.

Semistructured interviews were conducted with a total of eight members of the interdisciplinary team (nursing, social work, and medicine) during their work hours. Following documentation of informed consent, interviews were audiotaped. Interviews were conducted in a private room within the inpatient unit. The interview questions were designed to elicit the professional's understanding of and experience with family meetings conducted within the unit. Questions addressed the purposes and indicators of the need for a meeting, structure, content, and process elements. Interviews averaged 32 minutes in length.

Phase 2

Phase 2 consisted of ethnographic observations of a convenience sample of 25 family meetings. Family members were informed about the study by the social worker who was scheduling and coordinating the meeting. With the family's permission, the researcher met with them prior to the meeting to provide information about the study and invite participation. Those family members agreeing to participate provided written informed consent for the researcher(s)

to sit in on the meeting. The researcher sat away from the table in order to observe unobtrusively. Family members were informed that the researcher would make notes about events in the meeting, but not about the specific contents of their story, the patient's illness, or any identifying information.

Data Analysis

The phase 1 provider interviews were audiotaped and transcribed verbatim. Following verification of the transcripts, data were analyzed using the constant comparative methods of grounded theory (Charmaz, 2006). Analysis began with open coding, followed by development of conceptual categories and identification of the properties of the major categories. To strengthen rigor, the data analysis was conducted independently by each of the three researchers, with regular collaborative discussions to achieve consensus. We generated a preliminary theoretical model elucidating the structure and process of the formal family meeting from the perspective of the providers. We developed a meeting observation template based on the codes identified during analysis of the provider interviews.

During phase 2, the template was utilized to support rigorous and consistent ethnographic observation of family meetings (Charmaz, 2006; Birks & Mills, 2011). The template facilitated noting which

features reported by providers were actually in evidence during the meeting and included open space in which the researchers recorded field notes. The first six meetings were each observed by two researchers, and the observation templates were compared, confirming strong interrater reliability.

Frequencies were calculated for various elements characterizing the structure and process of each meeting. Table 1 lists the elements observed using the template and their frequency of occurrence in the 25 observed meetings. Using further constant comparative analysis, the elements identified during observation of family meetings and the field notes taken during the meetings were analyzed in relationship to the major categories of the emerging model (Glaser, 1978).

RESULTS

Study Sample

Phase 1

Eight professionals participated in phase 1 interviews. The sample was comprised of two social workers, four physicians, and two nurses. All except one were female. Participants ranged in age from 35 to 62 years (mean = 47.8), and their years of hospice experience ranged from 3.5 to 19 years (mean = 8.4).

Table 1. Elements of the Family Meeting ($N = 25$)

Element	Frequency	Percent (%)
Structure		
Teleconference in use	2	8%
Meeting opens with introductions	23	92%
Physician leaves the meeting	12	48%
Meeting ends with identifying next steps needed	14	56%
A summary of the meeting provided	6	24%
Process		
<i>Clarifying the Past</i>		
Ask family about patient-related events prior to admission	23	92%
Physician explains medical events since admission	21	84%
Family informs about patient's personhood	21	84%
Provide information about patient's prognosis	19	76%
<i>Easing the Present</i>		
Physician updates about current medical condition	22	88%
Provide information about symptom management	21	84%
Validate care family has been providing	17	68%
Family expresses grief	15	60%
Conflict occurs between family members	1	4%
Conflict occurs between family and staff	1	4%
Ask family about their own physical/emotional well-being	5	20%
Provide information about dying process	15	60%
<i>Protecting the Future</i>		
Provide information about alternative care settings	15	60%
Provide information about what to expect	22	88%
Provide family opportunity to ask questions	22	88%

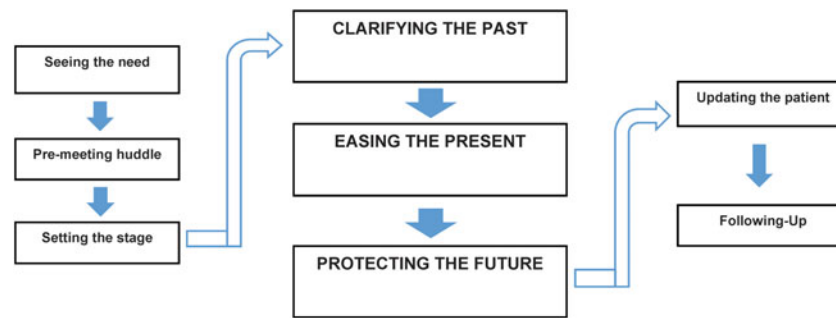


Fig. 1. (Color online) Model of family meeting process.

The mean length of service in their professional role was 18.3 years. The number of healthcare providers at each observed meeting ranged from 2 to 7, with 4 being most common (11 meetings).

Phase 2

Some 88 family members participated in the 25 observed family meetings. The number of family members attending each meeting ranged from 1 to 9, with the modal numbers being 2 and 4 (six meetings each). The role relationships of the family members attending the meeting were diverse; an adult child of the patient was present 80% of the time and a spouse participated in 28% of observed meetings. The meetings we observed ranged in length from 19 to 61 minutes, with a mean length of 42 minutes.

Findings from provider interviews and ethnographic observation of the family meetings were highly consistent. Findings were synthesized to yield the following description of the structure and process of the formal family meeting in the hospice inpatient unit where the study was conducted.

Pre- and post-meeting activities are reported based on provider interviews and discussions witnessed during the meetings. The core phases of the meeting process (clarifying the past, easing the present, and protecting the future) are described from nonparticipant observations and supported by quotations from the provider interviews (see Figure 1). In Table 1, the list of elements from the observation template was reorganized following all data analysis to show the alignment of the meeting activities with the core processes as revealed in the theoretical model.

Pre-Meeting Activities

Seeing the Need

Formal family meetings were not conducted with every family who had a patient receiving care in the unit. Providers described situations warranting a formal meeting, such as a family's especially high need for information or emotional support, family

distress related to medication use, or presence of conflict. Any member of the team could recommend a family meeting, or a family member could also request a meeting. This would most commonly occur among families who had learned about the process from other patients' families.

Once the need for a meeting was recognized, deliberate preparations ensued. The social worker assigned to the patient and family assumed responsibility for coordinating the schedule and attendees. The social worker initially contacted the person identified in the medical record as the primary caregiver. That person was encouraged to invite all involved family members. If the social worker was aware that other family members needed to be present, she would contact them as well:

(...) unless we feel there's a specific need to involve more people than just the primary caregiver, which usually has something to do with a family conflict that we are aware is going on, and we need to try to use the meeting as a way to get people who don't really get along to be on the same page with the patient. [Provider 1 (PR1)]

Pre-Meeting Huddle

Meetings in this setting were always multidisciplinary. Immediately prior to a family meeting, providers engaged in a brief pre-meeting huddle during which they confirmed the primary purpose of the meeting. This typically meant making sure each team member agreed on whether the patient was likely to die soon, and thus would continue being cared for in the unit, or whether a care transition back to home care or to a nursing home was indicated. Confirming a shared understanding among team members helped assure that a consistent message was conveyed to family members.

Setting the Stage

The environment and structure for the formal family meetings were very consistent. The meeting was

always conducted in a private family room and behind closed doors. Providers and family members were seated around a table. When family members were geographically distant, they could participate via telephone. In those cases, a speaker phone was placed at the center of the table and the distant participant was included in the discussion. Family meetings in the setting we studied relied upon the presence of professionals representing multiple disciplines. Given the multifaceted nature of family members' questions and needs, the providers we interviewed believed the presence of multiple disciplines was essential. In the observed meetings, representatives of medicine, nursing, and social work were always present.

The social worker opened the meeting by requesting introductions around the table. Each meeting participant gave their name and role, whether professional or family. The social worker reiterated the purpose of the meeting. Of note, meetings in this setting did not include the patient. Providers expressed strong feelings on this point. They believed that it was important for family members to have the opportunity to express feelings and concerns, as well as ask questions, without needing to be cautious about the patient's feelings. Providers reported that only if patients strongly insisted on being included in the family meeting were they allowed to do so. Patients were not present at any of the observed meetings during this study. Several providers reported that on those occasions, when they had conducted a family meeting with the patient present, they commonly needed a follow-up meeting with only the family members in order to address family concerns:

This is a family support meeting, and the underlying purpose to have a meeting without the patient is so that the family can be open and honest and not have to be reserved or dancing around issues with the patient right there. We have done them where the patient insists on being part of the meeting, and we may have a pre- or a post-meeting with the family that the patient isn't aware of. [PR1]

Analysis revealed that during the meeting providers endeavored to support the family and facilitate optimal care for the patient by pursuing three core objectives, described here as clarifying the past, easing the present, and protecting the future.

Core of the Meeting

Clarifying the Past

The first phase of the meeting, clarifying the past, involved the bidirectional exchange of information about events prior to the patient's admission to the unit. Providers elicited the family's understanding

of how things had been going prior to admission, as well as their expectations going forward. Also, during this phase, it was common for family members to provide information that served to convey to the providers a deeper understanding of the personhood of the patient.

One of the important functions of the family meeting was to resolve discrepant perceptions regarding the patient's status. When staff had a very different idea of the illness phase and prognosis than family members did, there was an attempt to bring perceptions into better alignment. As described by one nurse,

I think the most helpful thing is (. . .) "Tell us what was happening before the patient came in," and a lot of it is just for us to be able to listen and get a sense of where they're coming from or what they're thinking. You can really tell if they're on board and are understanding, or if they're just way off the mark from where we are thinking the patient is. That helps us know where to start. Then I think it's really helpful to hear what their expectations were for the patient when they came here. Again, if it's completely different from what we're thinking is realistic or could happen, that just helps us know what our starting point should be for the meeting. That's probably the most important thing. If we assume they know everything and then we start way over here, and they're not even near there yet, then the meeting's not going to really be effective in helping them understand what's happening. [PR6]

Often in this conversation, family members retrospectively identified problems they had not noticed or understood previously. Providers explained the medical context and meaning of symptoms. For example, if the patient was admitted suffering from delirium, reviewing what had been going on at home would typically identify progressive sleep disturbance. Having a representative from the home care team there could be extremely helpful in assisting the family to remember what had been going on at home and to put the pieces together in a meaningful way. For family members, changes that were nearly imperceptible on a day-to-day basis would be clarified and placed in the context of illness progression. As reported by one physician, "Recalibrating or reframing the events is very, very, very important so that they can understand that they really haven't been eating for three months very well. They can't walk anymore, and that that's dying" (PR5).

Easing the Present

Once a shared understanding of past events was addressed, the second phase of the family meeting

process moved to the goal of easing the present. Information was provided about the patient's current medical condition, ongoing interventions, and response to care. The phase of easing the present included providing full and accurate information about the meaning of patient behavior and symptoms, as well as information about how the unit functions. More than a few people perceived hospice care as euthanasia, and a lack of understanding of symptoms and treatment sometimes left family members with the perception that the patient was being over-medicated and, especially, oversedated. As one social worker explained,

I have been asked, point blank: "When are you going to give her the shot?" What shot? There are still a lot of people, and this is especially in the minority community, that really, truly believe that we "put people to sleep" here. Because their knowledge of this is people come here and they die, so their [understanding of] cause and effect is pretty direct, not seeing the other piece of it. [PR2]

One aspect of easing the present was providing validation to the family for the care they had been rendering, and an attempt to shortcircuit any caregivers' guilt at moving to inpatient care. Providers emphasized to family members that progression of symptoms led to the transfer, not lack of care. Indeed, providers regularly reinforced the important contribution of family to the patient's well-being:

We always use the phrase "family is the best medicine" (. . .) Letting them know how important their role is and them being there at this point, and just helping them understand what they can do, because I think a lot of people feel really helpless. [PR6]

Thus, an important facet of easing the present was to allay family fears, what one physician called "barriers to the bedside" (PR5). Providers sought to demystify dying, so that family members would not be afraid to be present with the patient, talking and touching, and maintaining their relational connection.

Another way in which providers attempted to ease the situation for family members was to acknowledge and normalize conflicted emotions. By giving voice to the frequently experienced contradictory emotions of wanting the dying to be over and not wanting to lose the family member, providers attempted to ease guilt and lessen emotional distress. One physician remarked that for family members at the meetings, "We're 'prophylacting' a lot of unnecessary suffering" (PR5). Providers were observed to listen attentively, and to tailor the pace and depth of information

delivery to family response. Part of how the family meeting served to ease the present was by giving family members a safe place and invitation to recognize what was happening and to allow themselves to experience the difficult emotions the situation was engendering.

Another important strategy for easing the present for family members of patients receiving care in the unit was to directly address conflict between staff and family or conflict within a family, in order to prevent such conflicts from having a negative impact on the patient. Providers readily acknowledged that they were not going to solve complex family issues, and held the more modest but pressing goal of assuring good care for the patient:

There's always a family dynamic. If it's a bad family dynamic, it generally will get worse during a time like this because it's a time of crisis. We kind of go in as the neutral party. If we know that it's kind of this camp against this camp, we'll set the groundwork when we start the meeting. [We'll say], "This is an opportunity for everybody to speak. We need you to respect each other and let one person talk at a time. We're the neutral ground. We're not here to take sides. We're just here on behalf of the patient. That's who we're here to take care of." [PR6]

Protecting the Future

The third process addressed in the family meeting was that of protecting the future. Preparing the family for what was likely to be coming next and sidestepping preventable difficulties were included in this phase. In order to protect the future, providers employed strategies that included helping family members concretely plan for the next phase, whether that was return to home care with enhanced support, transfer to a skilled nursing facility, or the anticipated death of the patient. Particularly if the death of the patient was expected within a short period of time, providers attempted to ensure family preparedness:

A very big part of our job is planning on where people go from here (. . .) [Care here] is whatever the person needs according to acuity. So the planning piece after the education, after the feelings are out, it's that next step of where do we go, even if that next step is "Have you planned the funeral?" [PR2]

Another strategy, designed to ease the present but especially to protect the future and the family's well-being during bereavement, was to emphasize the distinction between the illness with its symptom manifestations and the personhood of the dying

patient. As described by one professional, “Confusion should be explained. The horrible loss of dignity, that needs to be explained, and illness needs to be separated from personhood almost. That’s really important” (PR5).

Providers created an atmosphere within the family meeting that conveyed their commitment to fulfilling family needs regardless of the time required. Protecting the future included allowing time for all of the family’s questions and concerns to be addressed:

We usually end by asking them, “Do you have any other questions or any other concerns that you wanted to talk about, or any other questions for us?” We kind of let them end it, I guess. Let us know when they’ve had their questions answered.

Post-Meeting Activities

Updating the Patient

After providers had allowed as much time as the family needed for questions and discussion, the meeting ended. Regardless of the patient’s level of awareness, at least one team member went to the bedside to update the patient, to report on the family meeting and any decisions emerging from it. Sometimes a family member and team member updated the patient together, according to the family’s preference.

Following Up

After a family meeting, any decisions made during the meeting were implemented. For example, the social worker might meet with the primary caregiver to begin a Medicaid application in preparation for placement in skilled nursing care. Providers continued to assess family needs, and additional meetings would be scheduled if indicated.

DISCUSSION

We endeavored to inductively generate a theoretical description of the family meeting intervention as practiced in one hospice inpatient unit. Based on qualitative interviews with professionals who regularly conducted family meetings and ethnographic observations of the 25 meetings, we developed a model depicting the structure and process of the family meeting in this setting. The core of the family meeting was characterized by consistent cognitive and affective elements that sought to support the family and facilitate high-quality care of the patient by clarifying the past, easing the present, and protecting the future.

Our findings must be considered within the limitations of our study. We investigated the family meeting in only one setting. Providers in this large, well-resourced hospice organization had been conducting family meetings for many years, and the approach had evolved over that time in ways that the providers believed enhanced its value and effectiveness. We studied a convenience sample of consenting family members. It is likely that families with greater unmet needs or with higher levels of conflict would be less likely to consent to the researchers’ involvement. Meetings where conflict was high could look quite different from those that we observed, so this is an important area for future investigation.

The clinicians with whom we partnered strongly believed from their experience that family members benefited from the formal family meetings they regularly conducted. What this study has begun to reveal are facets of the theoretical underpinnings for their success. By assessing the family’s needs related to understanding the patient’s illness, the meaning of symptoms and observed signs, and the likely course the illness is taking, professional staff can offer information and explanations tailored to ease family members’ immediate distress. Similarly, providers can offer concrete assistance to help family members better respond to patients’ needs as well as their own by, for example, validating the importance of their presence and allaying fears that create barriers at the bedside. And finally, a discussion that helps family members separate illness from personhood and recognizes the importance of their presence and care to the well-being of the patient can help family members create meaning that can support them during the inpatient stay and well into their future bereavement.

We found it surprising that specifically asking family members about their own physical and emotional well-being occurred only 20% of the time during the observed meetings (see [Table 1](#)). It may be that this concern was implicit in the entire process of a formal family meeting, and was also conveyed by the protected setting and open-ended timeframe. Providers did not conclude the meeting without assuring that the family members in attendance had no further questions or concerns at that time. It is also possible that a direct query would help elicit information needed to most effectively support family members. Further study could explore whether directly asking the family how they were faring, as individuals and as a family unit, could have positive effects for the family that would not otherwise occur.

Consistent with the philosophical commitments of and guidelines for the delivery of palliative care (World Health Organization, 2007; National Consensus Project, 2013), providers in the study setting

placed great value on the multidisciplinary nature of family meetings for meeting diverse needs. While this approach is similar to that described by some researchers in critical care (Billings, 2011; Shannon et al., 2011; Fisher & Ridley, 2012), it contrasts with physician-led ICU family meetings that focus on the withdrawal of life-sustaining treatment (Curtis et al., 2002; Psirides & Sturland, 2009). The differential effect of having several disciplines present is an important area for continued research, particularly in light of the need for cost-effective healthcare interventions.

Many organizations and providers considering routine implementation of formal family meetings may object that the open-ended timeframe is too costly. However, the clinical experience of the providers we interviewed was that the return on investment was high for this proactive strategy to assist families. Providers observed that immediate improvements in family well-being were common. They noted that, subsequent to a family meeting, calls to the staff went down markedly. Lowered family member distress can also be expected to improve patient comfort and well-being and facilitate adaptation during bereavement (Witt-Sherman, 1998; Akiyama et al., 2010).

In terms of end-of-life communication, the formality and seriousness of the family meeting as conducted in our study setting likely conveyed to family that their needs were noted and taken seriously. Because the environment for the meeting was protected from interruption, family could focus their attention fully on the information being provided to them—in contrast to quick consultations at the bedside or in the corridor. Additional research is needed to identify both immediate and long-term family outcomes related to the family meeting.

In our inductively developed model, the core processes identified during family meetings (clarifying the past, easing the present, and protecting the future) appear to be congruent with the three primary constructs that constitute a sense of coherence (Antonovsky, 1979). Sense of coherence influences coping and adaptation to stressful circumstances, such as that of responding to a family member's life-limiting illness. According to sense of coherence theory, *comprehensibility* is the perception that the challenge is understood. *Manageability* is the perception that sufficient resources are available for coping; and *meaningfulness* is the belief that these challenges and demands are worthy of investment and engagement (Antonovsky, 1979). Providers' intentions (as reported in the provider interviews) and the content of provider communications (as observed during family meetings) were targeted to increase the comprehensibility for family members of what was happening with the ill patient—to explain patient

symptoms and behaviors as part of the physiological and psychological changes occurring in the advanced illness and that come with approaching death. Contextualizing of family members' experiences and observations continued during the phase of *easing the present*. This phase also emphasized the continuing importance of the family's contribution to care and the practical things they could do at the bedside, thus enhancing the manageability of their situation during the inpatient stay. Protecting the future involved helping the family become prepared for what was ahead, but was also targeted at maintaining a focus on the personhood of the dying patient, thus underscoring the meaningfulness of this important phase of both life and the relationship. Further confirmation and understanding of this apparent consistency with sense of coherence theory awaits additional study, including evaluation of family member responses and outcomes related to the family meeting. Such theoretical corroboration would strengthen the foundation for systematizing and testing the family meeting as an evidence-based intervention.

CONCLUSION

Multidisciplinary family meetings are an important strategy for assisting families during the patient's care in an inpatient hospice unit. The family meeting can serve to address family members' needs for meaningful and contextualized information, validation of their important contributions to care, and preparation for the patient's death. Both qualitative and quantitative assessment of family members' responses to the family meeting and further theoretical development are needed. This knowledge can guide both researchers and clinicians in conceptualizing and designing interventions to assist family caregivers.

ACKNOWLEDGMENTS

The authors gratefully acknowledge the support and engagement of the Center for Hospice and Palliative Care, Cheektowaga, New York. Funding for our study was generously provided by the Patricia H. Garman Behavioral Health Nursing Endowment Fund, School of Nursing, University at Buffalo, the State University of New York.

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