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Question asking by family caregivers in hospice interdisciplinary team meetings

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Abstract

This paper reports findings from a pilot study that enabled family caregivers to use videophone technology to participate in hospice interdisciplinary team meetings. The goal of the study was to ascertain which issues were important to caregivers and the hospice team. A qualitative content analysis of video-recorded team meetings between team members and caregivers was conducted. In a sample of 12 caregivers in 36 discussions, caregivers asked a total of 137 questions, with the majority as Yes/No questions (45.5%) mainly used to seek clarification (19.7%). Hospice staff asked 396 questions, with the majority of questions consisting of Yes/No questions (66.6%) mainly used to ask about the overall condition of the patient (17.2%). Data from this study suggest that when given the opportunity to participate in hospice team meetings caregivers will ask questions of hospice staff. Additionally, in light of prior research, this study's findings suggest that caregivers may have questions that go unaddressed, specifically in regards to pain and medication.

Keywords

caregivers; end-of-life care; communication

Over the last decade, hospice services have increased 162%, and more than 1.3 million terminally ill patients and family members receive hospice services each year (National

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Hospice and Palliative Care Organization, 2008). The philosophy underlying hospice care requires that services be provided in a manner that is consistent with the values, cultures, beliefs, and lifestyles of patients and their family members (Egan, 1998). Additionally, hospice advocates treatment of both the patient and family as one unit of care, evidenced by a focus on care not only during the dying process but with follow-up for bereavement services (Connor, Egan, Kwilosz, Larson, & Reese, 2002). This commitment necessitates the active involvement of patients and families in developing and executing the hospice plan of care (Connor et al., 2002); however, research has found that care recipients rarely participate in hospice interdisciplinary team (IDT) meetings during which care planning occurs (AUTHOR). This lack of involvement limits the abilities of patients and their loved ones to voice concerns, ask questions, and collaborate with the team as a whole.

This paper reports findings from a research project designed to overcome barriers to family involvement in care planning by allowing caregivers of hospice patients to participate in IDT meetings. Using videophone technology, patients and family members were empowered to join hospice IDT meetings as the need for them to travel to the agency office and/or arrange for alternate care for the patient in their absence were removed (NCI R21 CA120179: Patient and Family Participation in Hospice Interdisciplinary Teams) (AUTHOR). Routinely involving caregivers in IDT meetings represents a significant divergence from normal operating procedures (AUTHOR). While both hospice staff members and caregivers were trained on the use of videophone technology prior to the study, they were not provided with a definitive script for the interaction. It was unknown what questions, if any, caregivers would ask the hospice professionals and vice versa. As a result, this analysis was undertaken to systematically explore the types of questions asked by family caregivers and hospice staff during IDT meetings in order to identify which issue(s) were of importance to care providers and care recipients. Specifically, we addressed the following questions: (1) What basic types of questions are asked by family caregivers and hospice staff during IDT conferences? (2) What is the content of those questions? (3) What is the difference in type and content of questions asked by staff and family caregivers?

Method

IDT meetings between caregivers and the hospice team were video-recorded thus making it possible to use a qualitative approach to investigate verbatim data. A content analytic approach, which focuses on the occurrence of selected terms in the data, was used to simplify an understanding of content in the data (Schwandt, 2001). In this study a qualitative content analysis was used to explore caregiver concern and collaboration with hospice staff as facilitated by question-asking. A summative content analysis was conducted which entailed counting and comparison of content followed by interpretation of the context (Hsieh & Shannon, 2005). The purpose of the summative content analysis approach is not to infer meaning, but to explore the usage. A summative approach goes beyond counting words and/or phrases to include the process of interpreting the content. The focus is on discovering the meanings of the words/phrase, and thus in this study we coded the questions and interpreted the content of the questions between the two parties. This approach allows for interpretation of the context associated with the word/phrase.

Setting and sample

The project consisted of video-recorded conferences ($n=36$) between hospice interdisciplinary teams ($n=4$) and caregivers ($n=12$) of hospice patients. The project was part of a larger intervention study examining patient and family participation in hospice team meetings. The inclusion criteria for the patients and family members required: 1) enrollment as a home or nursing home hospice caregiver, 2) adult, 3) access to a standard phone line, 4) without functional hearing loss, and 5) cognitively able to consent. All patients and family

members meeting these criteria were invited to participate in the study. Overall, 45% of referrals consented for a visit to learn more about the study (Parker Oliver et al., In Review).

A maximum-variation sampling design was used to purposefully select a wide range of cases from video-recordings of team meetings with caregivers. This type of sampling is used to capture the broadest set of information and experiences within the data, and includes typical, deviant, and critical cases (Kuper, Lingard, & Levinson, 2008). Criteria for selection to assure maximum variance included caregivers who had attended at least one hospice team meeting with one of the four teams in the study (range 1 – 8 videophone conferences), variance in length of stay in hospice program (range 25 days — 172 days, with four patients still on service when the study was completed), and variance in caregiver relationship to patients (40% spouses, 33% adult child, 25% other relationship) (Kuper et al., 2008). This study was approved by the Institutional Review Board at the supporting university.

Data collection

As a part of the larger intervention study which ran from April 2007 — June 2008 a Graduate Research Assistant (GRA) contacted each caregiver and made a home visit to explain the study, obtain written consent and install a videophone. The intervention enabled family members of hospice patients to participate in the team meeting, connecting them virtually using a plain old telephone system (POTS) videophone to the hospice office. Research staff placed one videophone unit in the home of the family which was connected to a compatible unit in the hospice office. The office unit was unique as it could be projected onto a television screen for the view of the entire hospice team. This connection over the regular telephone allowed family members to have a visual image of the team as well as a two way conversation with them. Figure 1 illustrates the technology used in the intervention.

As part of the GRA's visit, family members were trained how to answer a videophone call using the equipment. However, caregivers were not trained on what to do or say during the videophone conference. Caregivers were contacted during the hospice team meeting when their cases were discussed so they could participate via videophone. The average interaction time was 6 minutes and 35 seconds.

Data analysis

Conferences between family caregivers and hospice staff were videotaped, coded and analyzed using the qualitative data analysis package *Nvivo 8* and techniques of content analysis. The coding framework for initial analysis was based on three major classes of question types (Quirk, Greenbaum, Leech, & Svartvik, 1985): Yes/No questions, who, what, where, why, and how (WH) questions, and alternative questions. Yes/No questions were defined as direct questions that elicit an affirmative or negative response. WH questions (e.g. who, what, why, how, etc.) were defined as direct questions that allow for open-ended responses. Alternative questions have a specific intonation pattern that differentiates them from yes/no questions. Alternative questions formulate expectations, such that the reply to the question should be one of the options presented in the question (Quirk et al., 1985). Alternative questions are phrased so that two alternative choices are presented, for example: "Is she comfortable or uncomfortable?"

Data coding involved three steps. First, five percent of the data was used by two researchers who independently coded data into question type categories as asked by either staff or caregivers. Intercooder reliability was compared and was above .90 on all categories. Through a discussion of differences, the two coders derived strict coding criteria for discerning question types and then each independently coded half of the remaining data set. Second, the multidisciplinary research team used a constant comparative method to discern

themes from among all of the questions. Themes were categorized into mutually exhaustive content areas. Finally, question types for both caregivers and staff were coded into these mutually exhaustive content categories.

Results

In a sample of 12 caregivers, the majority of caregivers (84%) were female providing care for home hospice patients (91%). Eighty-three percent of patients in this study had a primary or secondary diagnosis of cancer. Primary patient diagnoses included cancer (50%), heart disease (8%), lung disease (16%), and failure to thrive (16%). The average age of caregivers was 60.5 years and the majority reported having other caregiving responsibilities. Overall, family caregivers of hospice patients asked 137 questions during videophone conferences with hospice staff. The majority of questions asked were Yes/No questions (45.5%), followed by alternative questions (29%) and WH questions (25.5%). The majority of questions were asked by hospice staff, who posed 396 questions, with the greatest majority being Yes/No questions (66.6%), with only a slight difference between alternative questions (16.4%) and WH questions (17%).

Questions were coded a second time to assess the content category of the question as opposed to the question type. Eight prominent categories related to the content of the questions emerged and are summarized in Table 1 with examples. Questions by both caregivers and staff involved issues of: clarification, coordination of care, medication/pain management, overall condition of patient, social small talk/greeting, technical quality issues, prompts, and symptoms. Clarification and coordination of care contained questions that focused on confirming information during the meeting and from previous staff home visits, as well as confirming the logistics of patient visits and each person's responsibilities. Medication/pain management and overall condition of patient were questions about medication, dosages, refills, regimens, and questions characterized by disease progression to determine whether or not death was imminent. Social small talk/greeting and technical quality issues were questions that focused more on the quality of communication as facilitated through technology as well as social pleasantries. Finally, prompt questions were used by the team to solicit information and more conversation, and symptoms were also team-prompted questions about the physical condition of the patient.

A final analysis was done looking at both the question type and the content category of the question by the caregiver and staff (see table 2). Despite technical quality issues and the use of questions as social etiquette (i.e. greetings) family caregivers predominantly asked clarification questions (19.7%), followed by questions about medication/pain management (9.5%). Although the majority of questions asked by family caregivers were Yes/No questions (45.3%), almost half of all questions asked, questions specifically about medication and pain management were predominantly alternative questions (7.3%). For hospice staff, questions were predominantly about the overall condition of the patient (17.2%), which solicited information about the patient's physical status and accounted for more than half of all questions asked, followed by coordination of care (7.3%), which were alternative question types.

Discussion

This analysis highlights direction for future research, and no generalizations should be made as the study is limited by a small sample size and it represents only two hospice programs. Organizational and structural influences that impact communication in IDT meetings were not accounted for in this study. Organizationally, the amount of time available for team members to spend in IDT meetings is often driven by current patient case loads and case

load standards within the organization. The pressure to meet these standards may have impacted the overall time that team members allowed caregivers to talk in the IDT meeting. Structurally, team members have different requirements for patient visits (Centers for Medicare and Medicaid Services, 2008) and team members did not always have the opportunity to visit the patient and caregiver prior to the IDT meeting. As a result IDT meetings with caregivers were sometimes the first time team members were meeting caregivers. For these reasons, the study is limited by a lack of information regarding how much contact caregivers had with individual team members outside of IDT meetings.

The first research question referred to the types of questions asked by family caregivers and hospice staff during IDT meetings. Both caregivers and staff predominantly asked Yes/No questions. Given that this is the most direct question type, it is surmised that the videophone conference provided the opportunity for direct communication about plans of care. Hospice staff in particular used Yes/No questions for more than half of all questions asked which reflects the task-oriented nature of an IDT meeting.

Interestingly, the analysis revealed that hospice staff asked almost three questions to every one question asked by a family caregiver. While we would expect to see hospice staff ask questions during the videophone conference in order to foster collaboration and communication, we would also expect to see caregivers ask a high volume of questions about care and care planning given the anxiety associated with the caregiving role (Keefe et al., 2003). The difference in amount of questions asked may be due to the institutional context of a planned meeting, inherently affording hospice staff the discursive power to ask more questions (Wang, 2006).

The second research question explored the content of the questions asked during IDT meetings. The analysis concluded eight prominent content categories which indicate that several communicative functions are enabled by the videophone conference. Clarification, coordination of care, technical quality, and prompt questions demonstrate the task function of the IDT meeting. Questions with these content areas focused on achieving active involvement and collaboration. On the other hand, questions regarding medication/pain management, patient symptoms, and the patient's overall condition indicate that the emphasis of IDT meetings between staff and caregivers is the patient's physical care, compared to the psychological, social, and spiritual issues of pain care provided by hospice (Mazanec et al., 2002). Lastly, questions concerning social elements of the caregiver's life, including small talk, indicate that there are relational communication goals between hospice staff and family caregivers.

The third research question investigated the difference in type and content category of questions asked by family caregivers and hospice staff. The thematic analysis of questions revealed that family caregivers in this study predominantly asked clarification questions. These questions focused on confirming the logistics of care and suggest that this is the caregiver's priority when talking with hospice staff. This finding is consistent with prior research on caregiver question-asking during end-of-life care which concluded that the majority of family caregiver questions focus on soliciting medical and practical information (Hebert, Schulz, Copeland, & Arnold, 2008). Clarification questions also evidenced active collaboration between the two parties, which is one of the goals of the hospice IDT meeting.

In addition to clarification questions, family caregivers asked questions about medication/pain management, questions that focused on care of the physical pain of the patient. However, only 9.5% of total questions asked were about pain management issues and 77% of questions asked in this content area were alternative question types. While this finding potentially suggests that this need was not actually perceived by caregivers, it raises

interesting questions in light of previous research findings. Research in the linguistics area argues that alternative question asking can display differences in power (Wang, 2006) and recent end-of-life research has revealed that caregivers are reluctant to ask questions during end-of-life care for their loved one (Hebert et al., 2008). It has been surmised that barriers to question asking include not knowing what to ask, fear of being perceived as ignorant, and the perception that healthcare staff were untrustworthy (Hebert et al., 2008). What if family caregivers have concerns about pain management and their role in providing pain management but are hesitant to voice these concerns even when given the opportunity? Future research should explore barriers to question-asking that are specific to pain management and in delivering pain and symptom management.

Hospice staff, on the other hand, had little variance by question type as 2/3 of all questions asked were the Yes/No type. Overall, the predominant focus was on questions that addressed the overall condition of the patient and coordination of care. We would expect to see these two content areas emerge as hospice staff aims to prioritize the logistics of care planning (i.e., coordination), especially as the patient's condition declines and care plans need adjustment. Noticeably, however, question content focused on the physical domain of care, which is contradictory to the holistic approach to hospice care and philosophy. The holistic approach to hospice encompasses the psychosocial aspects at the end-of-life however questions from hospice staff were not aimed at gaining psychosocial information about the patient.

Overall, this study provides insight on the information needs between hospice staff and family caregivers. The study shows that topics relative to patient care focused on coordination of care and clarification of roles, both goals of the IDT meeting. Hospice team members asked more questions than caregivers by engaging in a direct yes/no question approach. Yes/No questions are thus being used successfully to obtain information that focuses on the logistics of day-to-day care. However, this question type does not afford the caregiver the ability to elaborate or extend the topic of discussion, an important aspect when the goal is to solicit information that is needed to develop a comprehensive care plan. More research is needed to ascertain if these conversations are meeting the needs of patients and caregivers and whether or not caregivers have issues that go unaddressed as prior research has suggested. Finally, active question asking by hospice staff and family caregivers during IDT meetings supports the feasibility of the videophone intervention. Future research is needed to connect patient outcomes with caregiver outcomes to explore the impact of this type of communication.

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Figure 1.
The videophone that was used by caregivers is the Beamer Videophone Station (Vialta, Inc., CA) which operates over regular telephone lines (depicted on the left side). Hospice teams used the Beamer TV Videophone Station to display the image on a large TV screen (depicted on the right side).

Table 1

Eight categories developed from questions asked by family caregivers and hospice staff during team meetings

Category	Example from data
Clarification Caregivers and staff question stated information, clarify what was previously said, and clarify what has been done (regarding patient visits and team actions as well as caregiver actions).	Staff: So she wasn't liking that [referring to body position]? Caregiver: But put it at his mouth?
Coordination of Care Caregivers and staff confirm scheduling visits by staff, visit days, number of scheduled visits per week, what is and what is not working at home, and coordination of who is responsible for what and what is needed.	Staff: Do you want me to increase visits to twice a week? Caregiver: We need two witnesses on that?
Medication/Pain Management Caregivers report patient pain and question medication and dosage. Staff discuss other medication options, changes in pain medication and refills, confirms medication regimen and when it's given, and prompts for a report on patient pain.	Staff: How often does he take his pain medicine? Caregiver: How much should I increase his medicine?
Overall Condition of Patient Caregivers ask questions about when death will occur, normalcy of patient symptoms in terms of decline. Staff confirms caregiver acceptance of "end", questions overall condition of patient, confirms equipment needs.	Staff: Is she worse? Is she comfortable? Caregiver: No, you know just wondering how long it's going to be going on, I just can't tell.
Social Small Talk/Greeting Questions referencing the weather, current events, etiquette (e.g., Hi, How are you?)	Staff: When is that graduation? Caregiver: Did everybody have a happy Mother's Day?
Technical Quality Issues Questions about the ability to see and hear each other	Staff: Do you see me? Caregiver: Do you want me to turn that phone on now?
Prompt Team questions whether or not caregiver has any more concerns or questions	Team: What else can we do for you?
Symptoms Team questions about patient's physical symptoms (e.g., headaches, nausea)	Team: How's your mom's headache?

Table 2

Topics of questions by type of question asked by family caregivers and hospice staff during team meetings.
Values are numbers (percentages)

	Questions asked by Caregivers*	Questions asked by Hospice Staff**
Alternative Questions		
Clarification	1 (0.7%)	9 (2.3%)
Coordination of Care	4 (2.9%)	29 (7.3%)
Medication/Pain Management	10 (7.3%)	12 (3%)
Overall condition of patient	3 (2.2%)	6 (1.5%)
Social Small Talk	4 (2.9%)	5 (1.3%)
Technical Quality Issues	18 (13.1%)	4 (1%)
WH Questions		
Clarification	11 (8%)	9 (2.3%)
Coordination of Care	1 (0.7%)	9 (2.3%)
Greeting ("How are you?")	14 (10.2%)	14 (3.5%)
Medication/Pain Management	2 (1.5%)	7 (1.8%)
Overall condition of patient	0 (0%)	27 (6.8%)
Technical Quality Issues	7 (5.1%)	2 (0.5%)
Yes/No Questions		
Clarification	15 (10.9%)	17 (4.3%)
Coordination of Care	13 (9.5%)	49 (12.4%)
Medication/Pain Management	1 (0.7%)	38 (9.6%)
Prompt ("Any questions?")	3 (2.2%)	38 (9.6%)
Social Small Talk	5 (3.6%)	10 (2.5%)
Overall condition of patient	5 (3.6%)	55 (13.9%)
Symptoms	0 (0%)	17 (4.3%)
Other/Miscellaneous	6 (4.4%)	11 (2.8%)
Technical Quality Issues	14 (10.2%)	28 (7.1%)

* Percentage is proportion of total questions asked (n=137).

** Percentage is proportion of total questions asked (n=396).