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A Multimethod Analysis of Shared Decision-Making in Hospice Interdisciplinary Team Meetings Including Family Caregivers

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Abstract

Background—Much of the existing research on shared decision-making in hospice and palliative care focuses on the provider-patient dyad; little is known about shared decision-making that is inclusive of family members of patients with advanced disease.

Aim—We sought to describe shared decision-making as it occurred in hospice interdisciplinary team meetings that included family caregivers as participants using video-conferencing technology.

Design—We conducted a multimethod study in which we used content and thematic analysis techniques to analyze video-recordings of hospice interdisciplinary team meetings ($n = 100$), individual interviews of family caregivers ($n = 73$) and hospice staff members ($n = 78$), and research field notes.

Setting/participants—Participants in the original studies from which data for this analysis were drawn were hospice family caregivers and staff members employed by one of five different community-based hospice agencies located in the Midwestern United States.

Results—Shared decision-making occurred infrequently in hospice interdisciplinary team meetings that included family caregivers. Barriers to shared decision-making included time constraints, communication skill deficits, unaddressed emotional needs, staff absences, and unclear role expectations. The hospice philosophy of care, current trends in health care delivery, the interdisciplinary nature of hospice teams, and the designation of a team leader/facilitator supported shared decision-making.

Conclusions—The involvement of family caregivers in hospice interdisciplinary team meetings using video-conferencing technology creates a useful platform for shared decision-making;

however, steps must be taken to transform family caregivers from meeting attendees to shared decision-makers.

Keywords

hospices; caregivers; family; decision making; patient care team

Introduction

We recently concluded a multi-site longitudinal trial of an intervention that involved the use of video-conferencing technology to facilitate the virtual participation of family caregivers (FCGs) in hospice interdisciplinary team meetings (1, 2). Recruitment for the study was active August 2006-July 2008 and November 2010-April 2014. The goal of the intervention was to improve pain management by providing education and support to FCGs of hospice patients who, per federal regulations in the United States (3), are expected to survive six months or less.

Early evaluation efforts revealed that, in addition to receiving education and support, FCGs in the intervention appreciated feeling part of the care team (4). Many provided suggestions and asked questions during meetings (5, 6), and they commonly voiced appreciation for hospice professionals who involved them in care planning in meaningful ways (4). Hospice staff members voiced similar sentiments, indicating that the intervention provided depth to their understanding of patients' lives and enhanced their ability to collaborate with FCGs when making decisions (5). In short, it appeared that one of the potential benefits of the intervention was that it provided a platform for shared decision-making (SDM).

Shared Decision-Making

SDM is a process wherein a choice is jointly made by a provider and a patient (7) or proxy decision-maker. SDM has been shown to increase the likelihood that services align with patients' and families' preferences and values (8), leading some to label SDM as "the pinnacle of patient-centered care" (9). SDM is supported by a growing body of evidence detailing its benefits, which include increased patient knowledge, more confidence in treatment decisions, and more active patient involvement (10). A number of individuals have identified essential aspects of SDM in clinical encounters (11). Makoul and Clayman (12), for example, identified nine essential elements of SDM, detailed in Table 1. Although SDM has been discussed in health care literature for decades (13), the extent to which it occurs in clinical encounters varies considerably (14, 15).

While research suggests that physicians generally hold a positive view of SDM (15), little is known about other health professionals' SDM-related attitudes and practices (16). In addition, much of the SDM literature focuses on the provider-patient relationship (17). Until recently, little attention was paid to the role of FCGs, who typically assume increasing levels of involvement in decision-making as their family member's illness advances (18). Therefore, given the need to better understand SDM in hospice and the potential of our intervention to facilitate collaborative decision-making processes, we expanded upon existing theoretical frameworks to develop a model of SDM for hospice team meetings.

A Model of Shared Decision-Making for Hospice Team Meetings

The original model underpinning our intervention has been described elsewhere (19). In short, it illustrates how family members' inclusion on health care teams impacts the team's context, structure, and processes which, in turn, affect team outcomes. While SDM is consistent with this model, it was not originally incorporated in an explicit manner. Therefore, we substantially revised the original model, resulting in a framework for SDM in hospice team meetings (see Figure 1). The revised model retains many of the components of the original; however, it also illustrates how individual factors and the communication climate interact to influence the SDM processes at the core of the intervention (20). In addition, it specifies psychological well-being, quality of life, and health as potential outcomes of FCGs' involvement in SDM.

Study Purpose and Research Questions

Equipped with our revised model, we conducted an exploratory descriptive study, the purpose of which was to describe SDM as it occurred in hospice team meetings that used video-conferencing technology to involve FCGs in care planning discussions. We sought to answer the following research questions (RQs): 1) To what extent were the essential elements of SDM present in the meetings? and 2) What were the barriers and facilitators to SDM in the meetings?

Methods

Data Sources and Analysis: RQ1

We conducted a content analysis of video-recordings of the 100 most recent meetings to determine the extent to which the essential elements of SDM were present. All the videos were originally recorded as part of a study that was approved by the University of Missouri Health Sciences Institutional Review Board (MU HSIRB; #1160518). A full description of the original study, including details of participant consent, has been published elsewhere (1). The videos included approximately 12 total hours of content; meetings averaged six minutes and 56 seconds in length. The unit of analysis was one meeting, which was defined as the discussion of one patient's care plan and which occurred as part of a longer meeting during which the care plans for all of the team's patients were discussed. Each meeting included at least one FCG. Only two patients took part in the team meetings (patients are commonly too ill to participate). The number of hospice professionals present varied; minimally, each meeting was attended by a nurse, chaplain, physician, and social worker.

Prior to data analysis, three researchers met to develop a structured tool based on the previously described essential elements of SDM (12). After an initial draft of the tool was developed, we jointly analyzed a subset (10%) of the data, clarifying definitions of the elements in an effort to establish agreement among researchers. Next, we used the tool to guide a content analysis of the remaining data. First, we determined if a meeting included identification of one or more problems. "Problems" were defined as biopsychosocial events that were identified as concerning by FCGs or hospice staff members and for which palliative solutions exist. This excluded clinical events that were considered normal components of the dying experience. For meetings in which at least one problem was

identified, we determined which of the essential elements of SDM were observed in response to the problem(s). When individual researchers were unsure whether an observed behavior fit the definition of a specific element, they reviewed the video with another researcher and arrived at a decision collaboratively. After the full data set had been reviewed, we calculated frequencies for each of the identified elements.

Data Sources and Analysis: RQ2

To identify barriers and facilitators to SDM in hospice team meetings, we conducted a deductive thematic analysis (21) of data from three sources: interviews of FCGs ($n = 73$), interviews of hospice staff members ($n = 78$), and research field notes completed during the recording and analysis of the 100 most recent meetings. All research from which these data were derived was approved by the MU HSIRB (#1057118, #1160518). Interview guides are shown in Figure 2.

After reading field notes and interview transcripts to familiarize ourselves with the content, we identified segments of data that described factors that influenced SDM in the meetings. Then, we labeled the data segments using an initial coding frame that included the following model components: hospice organizational context, team structure, and team processes. After we coded all pertinent data segments, we divided the coded content into one of two broad categories: SDM barriers and SDM facilitators. We then considered all coded data within each category, identifying recurring themes that illustrated specific barriers and facilitators to SDM. To ensure the rigor of our qualitative research procedures, we adhered to guidelines proffered by Whittemore, Chase, and Mandle (22) (see Table 2).

Results

RQ1

Of the 100 team meetings reviewed, 40 included discussion of at least one problem. In total, we identified 51 problems related to a wide range of issues such as patient symptoms, medication side effects, and care coordination. Most problem discussions included identification of possible solutions, provider recommendation(s), a final decision, and a plan for follow-up. Fewer than half included explicit consideration of the risks and benefits associated with proposed solutions, clear incorporation of patient and FCG values, or assessment of the extent to which the FCG understood the information that was discussed. Consideration of caregiver self-efficacy was rare; only one discussion included an explicit, observable assessment of the FCG's self-perceived ability to carry out possible solutions. Frequencies for each of the SDM elements are presented in Table 1.

RQ2

We identified several barriers to SDM, including those associated with the hospice organizational context, team structure, and team processes (see Table 3). In terms of the organizational context, the most commonly cited barrier to SDM was time. Some FCGs described feeling "rushed" and expressed disappointment that the meetings occurred biweekly as opposed to more frequently. One FCG stated, "a lot happens in two weeks" that requires decision-making outside of regularly scheduled meetings. Another indicated that

more time was needed to delve into complex problem-solving, stating that “[the team and I] never really talked long enough [in team meetings].” Several hospice employees expressed frustration with involving FCGs in care planning discussions, as it necessitated additional time in already-lengthy meetings. This led to concerns about the feasibility of engaging in meaningful SDM with all FCGs. One staff member commented, “I’m kind of glad they don’t all want to [join team meetings] because, just realistically, I don’t know how we could pull it off.” Another hypothesized, “if we tried to do it with every patient, I think we’d be in [meetings] all day, some days.”

While most comments about team structure were cited as facilitators of SDM, research field notes indicated that in a few instances the hospice staff members present at the team meeting were not the same individuals who routinely provided care to the patient and family joining the meeting. In those instances, the FCG did not have an existing relationship with the provider(s) participating in the meeting, which could have presented a barrier to SDM. In addition, field notes indicated that at times staff members who were present at the meeting lacked information that was reported to be known by absent team members, presenting another potential barrier to SDM.

Data offered clear support for three team process-related barriers: communication skills, role expectations, and emotional state. Deficits in communication skills, particularly on the part of providers, were identified as barriers to SDM. One FCG expressed dissatisfaction with a hospice employee’s communication during a team meeting, explaining that she felt upset when the staff member “was barking” information at her rather than treating her as an expert member of the team. A hospice team member suggested that SDM in meetings was limited because of her staff colleagues’ communication challenges. She stated, “I think a lot of the staff ... doesn’t know how to handle an interview.” Another stressed the importance of ensuring that FCGs comprehended the concepts and terms discussed during meetings, indicating that caregivers did not always “understand the things [the team was] talking about,” which limited their involvement in decision-making.

Barriers related to role expectations were infrequently mentioned, but were cited as strong influences on SDM. Specifically, “not operat[ing] as part of the team” was mentioned as a barrier. One caregiver explained, “Some [staff members] were sort of independent operators and would arrive and interject an opinion In those cases ... I did not feel like I was part of the decision-making process.” While uncommon, relegating FCGs to the role of “decision receiver” as opposed to regarding them as expert members of the hospice team posed a threat to SDM.

Comments regarding FCGs’ emotional state and the influence that had on SDM were also infrequent; however, a small number of staff interviews and research field notes referenced caregivers whose emotional distress might have best been addressed offline during regular care visits. Some staff members described certain FCGs as especially “needy” and asserted that particularly distressed caregivers could “monopolize everybody’s time” both during and outside of team meetings. When FCGs’ distress shifted the focus away from goal-directed discussions, SDM became more difficult to achieve.

In addition to barriers, we identified several SDM facilitators (see Table 3). In terms of the hospice organizational context, SDM was widely regarded as consistent with broader movements in health care. One hospice employee discussed the growing attention given to “interactive methods” in health care and stated that “[involving FCGs in team meetings] is probably my first real example of [them].” In addition, for some staff members, meetings that included FCGs helped bring to life more abstract elements of the hospice philosophy. FCG involvement in SDM was considered “a perfect way to demonstrate” the hospice philosophy that made FCGs “feel like they really are part of the care plan.”

Several FCGs explained that the structure of the team, which included FCGs and health care professionals from different disciplines, facilitated SDM. One caregiver referred to the decisions that were made in meetings as “group plans.” Another valued the fact that all team members were “on the same page,” while another appreciated “get[ting] input” on decisions from the entire team. Staff members explained that “everyone’s opinion is valid and important” in meetings and that the team is able to “come up with better solutions” and “eliminate a lot of stress” when all members participate.

In terms of SDM facilitators related to team processes, clearly defined role expectations, specifically as they pertained to team leadership, were identified as helpful. Meetings in which a team member facilitated the discussion were described as “thorough”, “focused”, and “organized.” One field note indicated that a designated leader “kept the team moving,” suggesting a potential role for facilitators in addressing time concerns. This connection was further strengthened by our observation that complaints about time were recorded less frequently in field notes completed during meetings with a leader who “control[led] the flow” of information.

Discussion

Team meetings including FCGs routinely involved decision-making. Participants defined problems, proposed solutions, considered provider recommendations, arrived at final decisions, and developed strategies to follow-up on the effectiveness of selected solutions. However, only rarely did meetings include processes that reflected meaningful collaboration with FCGs, such as discussing the risks and benefits of options, explicitly incorporating patient/family values, or assessing FCGs’ understanding and self-efficacy. While it is clear that the potential for SDM with FCGs in meetings exists, it is equally evident that additional measures must be taken to expand the FCG role from meeting attendee to shared decision-maker.

We cannot conclude that the absence of SDM elements was always problematic, however. For example, during one meeting the team discussed a frequently confused patient who resided in an assisted living facility. The patient had recently called 911 and been taken to the hospital for treatment of edema, which could reasonably have been addressed in her facility. To avoid recurrence of an unnecessary trip to the emergency room, the team (including the patient’s daughter, who was a nurse) decided that a sign should be posted in the patient’s room requesting that emergency personnel contact hospice before transporting the patient to the emergency room. While no one formally assessed the caregiver’s

understanding of the discussion, her nursing training likely suggested that she understood basic medical concepts such as edema, and it seems reasonable to assume that she would have understood what was being suggested with regard to posting the sign. In this example, explicit assessment of the caregiver's understanding may well have been unnecessary. It is possible, however, that other absent elements would have benefitted the discussion had they occurred. For example, a discussion of the patient's values might have revealed that she preferred not to display her status as a hospice patient in a place that would be visible to anyone visiting her room, steering the team in the direction of an alternate solution.

Ultimately, researchers should strive to determine if SDM with FCGs in hospice team meetings is associated with important clinical outcomes or patient/family satisfaction. Identifying tangible benefits of SDM would likely bolster support for this approach, which requires additional time and effort on the part of providers. Research of this kind requires appropriate instrumentation. Instruments that have been used to study SDM in other settings should be tested and, if needed, revised in a manner appropriate to the hospice setting and population. Use of (potentially modified) tools that are well-established in other settings, such as the Observing Patient Involvement in Decision Making (OPTION) instrument (23), would allow comparisons among different clinical groups, individual providers, and health care teams.

Study Limitations

A number of study limitations warrant attention. Because researchers met with one another to discuss difficult analytic decisions when analyzing the video-recorded team meetings, we were unable to calculate an inter-rater reliability score for our tool and analytic processes. Future studies would benefit from ensuring that analysts work in isolation from one another, allowing researchers to determine the extent to which they independently selected the same codes for the same units of text (24). In addition, given the absence of SDM elements in most meetings, participants may not have had a good understanding of what SDM should look like in practice, which likely affected their ability to discuss it during interviews. For example, while staff members cited time as a barrier to SDM, they may not have been able to determine whether the additional time was required to engage in SDM or if it was simply due to involving the FCG in the meeting (*e.g.*, troubleshooting technology problems, providing introductions).

Practice Implications

We identified numerous barriers and facilitators to SDM in hospice team meetings including FCGs. The most commonly cited barrier was limited time, consistent with previous research (3, 4). Participant feedback revealed a number of modifications that might improve meeting efficiency. Providing additional emotional support for distressed FCGs outside of regularly scheduled meetings might enhance SDM when the full team is present. In addition, educational materials could be made available to FCGs prior to team meetings, allowing them access to information about key concepts that may be discussed, reducing the amount of time spent educating caregivers and maximizing their ability to participate in SDM in a fully informed manner. Time constraints should also be taken into account as modifications to the intervention are considered, as time may affect which models of SDM are ultimately

incorporated into practice. For example, as opposed to Makoul and Clayman's nine essential elements (12), Legare and Witteman (25) suggest that only three things must occur for SDM to take place: the provider(s) and care recipient must recognize the need for a decision, understand the best available evidence, and take into account the provider's guidance and the care recipient's preferences and values. Given its succinct presentation, this conceptualization of SDM may be more easily translated in hospice and other settings where time is a particularly valuable resource.

Data also suggest that selecting one member of the hospice team to facilitate meetings may enhance SDM, keeping the discussion focused on key issues and concerns. This person could ensure that SDM elements are appropriately incorporated into meetings, based on each patient and family's unique circumstances. This would increase the likelihood that certain rarely-incorporated SDM elements (e.g., assessing caregiver understanding and self-efficacy) would be adequately addressed and avoid any unfounded assumptions regarding FCGs' comprehension or perceived ability to carry out decisions.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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What is already known about this topic?

- Hospice family caregivers often assume increasing levels of involvement in health care decision-making as their family member's illness advances.
- When studied in non-hospice settings, shared decision-making has been found to be associated with increased patient knowledge, more confidence in treatment decisions, and more active patient involvement in care.
- Involving family caregivers in hospice interdisciplinary team meetings may facilitate shared decision-making that incorporates the patient and family perspective to a greater degree than standard practice.

What does this paper add?

- Although the involvement of family caregivers in hospice interdisciplinary team meetings using video-conferencing technology creates a useful platform for shared decision-making, this study demonstrates that steps must be taken to transform family caregivers for meeting attendees to true care partners.
- This study identifies specific barriers to shared decision-making in hospice interdisciplinary team meetings with family caregivers including time constraints, communication skill deficits, unaddressed emotional needs, staff absences, and unclear role expectations.
- This study identifies specific facilitators of shared decision-making in hospice interdisciplinary team meetings with family caregivers including the hospice philosophy of care, current trends in health care delivery, the interdisciplinary nature of hospice teams, and the designation of a team leader/facilitator.

What are the implications of this study for practice, theory, or policy?

- Hospice providers seeking to more fully involve family caregivers in shared decision-making should consider using video-conferencing tools to facilitate caregivers' virtual participation in interdisciplinary team meetings.
- Simply inviting family caregivers to attend hospice interdisciplinary team meetings does not ensure their meaningful involvement in decision-making.
- Hospice providers can facilitate shared decision-making in hospice interdisciplinary team meetings including family caregivers by providing information and emotional support to caregivers outside of the team meeting, by training members of the interdisciplinary team to communicate effectively, and by designating an individual to facilitate team meetings.

Figure 1.

A Model of Shared Decision-Making for Hospice Team Meetings

Family Caregiver Interview Guide

1. How did you feel when participating in the hospice team meetings?
2. In what ways, if any, was the experience of participating in the team meetings beneficial to you?
3. In what ways, if any, could the experience of participating in the team meetings have been improved?
4. If the situation presented itself, would you like to participate again? Why or why not?
5. Would you recommend that other family members of hospice patients participate in their hospice team meetings? Why or why not?

Hospice Staff Member Interview Guide

1. What has it been like to have family members participate in your team meetings?
2. What benefits, if any, have resulted from involving family members in your team meetings?
3. What challenges, if any, were associated with involving family members in your team meetings?
4. Would you recommend that your agency continue to involve family members in team meetings? Why or why not?
5. Would you recommend that other hospice agencies include family members in their team meetings? Why or why not?

Figure 2.
Interview Guides

Table 1**Incorporation of Shared Decision-Making in Hospice Interdisciplinary Team Meetings**

Element of Shared Decision-Making^a	Present in discussion of how many problems (out of 51)	Percentage
Define the problem ^b	51	100.0%
Identify options	32	62.7%
Discuss benefits and risks of options	13	25.5%
Incorporate patient/family values and preferences	15	29.4%
Assess family caregiver self-efficacy ^c	1	2.0%
Offer recommendation (provider)	28	54.9%
Assess family caregiver understanding	25	49.0%
Make a decision	37	72.5%
Develop a plan to follow-up	27	52.9%

^a Elements were drawn from the work of Makoul and Clayman (12).

^b Inclusion criteria required that the discussion include definition of a problem, resulting in 100% incorporation.

^c Family caregiver self-efficacy is defined here as a caregiver's belief in his or her ability to carry out a proposed solution.

Table 2Strategies Used to Enhance Rigor of Qualitative Research Processes^a

Quality Criteria	Definition	Research Strategies
Credibility and Authenticity	The likelihood of generating findings that reflect an accurate and believable interpretation of the data and that capture the experiences of participants from their own perspectives	<ul style="list-style-type: none"> Involved multiple analysts in all study phases Resolved analytic disagreements (e.g., coding differences) via consensus Ensured that all analysts had achieved prolonged engagement in the field (i.e., had multiple years of experience delivering the intervention)
Criticality and Integrity	The degree to which the researchers question study processes and findings, seeking to ensure that all interpretations are valid and grounded in the data	<ul style="list-style-type: none"> Regularly convened research team meetings to review study processes and decisions Maintained detailed records of processes and decisions available for external audit Subjected preliminary findings to independent review by two researchers not involved in data analysis

^aBased on criteria provided by Whittemore, Chase, and Mandle (22)

Table 3**Barriers and Facilitators to Shared Decision-Making in Hospice Interdisciplinary Team Meetings**

Category	Model Component	Theme	Example
Barriers	Hospice Organizational Context	Time constraints	<p>"If we tried to do [the intervention] with every patient, I think we'd be in [team meetings] all day, some days." – Hospice Staff Member</p> <p>From a research field note: "Team had 58 patients to discuss in 2.5 hours. [Medical Director] announced that team meetings must be succinct ... only new concerns/problems [should be discussed]. [Medical Director stated,] 'There is no time for stories or extraneous information.'"</p>
		Absence of familiar and informed team members	<p>From a research field note: "Family's regular case manager was called away today, so the director of clinical services (who appeared to be unknown to [the caregiver]) covered for her."</p> <p>"I had some opportunity ... to establish a relationship [with some members of the hospice team] because they were in and out of the house ... so I felt very comfortable with those folks. But [the Medical Director] just seemed to kind of arrive. And I had no relationship. I had no background. I didn't know where he was coming from ... so that was very difficult." – Family Caregiver</p>
	Team Processes	Communication skill deficits	<p>"I think a lot of the staff ... doesn't know how to handle an interview." – Hospice Staff Member</p> <p>"At the beginning ... it felt like there wasn't a clear direction in terms of ... communicating within an IDT structure with the family member." – Hospice Staff Member</p>
		Unclear role expectations	<p>"Some [staff members] were sort of independent operators and would arrive and interject an opinion It was sort of ... 'top-downish' In those cases ... I did not feel like I was part of the decision-making process." – Family Caregiver</p> <p>"[One challenge was] the person on the other end of the line's expectations ... when you go to the doctor, you're used to it being a ... doctor face-to-face patient visit. [This intervention] is really designed to be driving team meetings. So, [it's a challenge] to not have it become a 'Hey, let's talk to the doctor' type of visit." – Hospice Staff Member</p>
		Emotional distress	<p>In their interviews, some staff members labeled certain family caregivers as especially "needy" and suggested that these individuals "monopolize" time in team meetings and elsewhere.</p> <p>From research field note: "[Family caregiver] appeared very anxious today and was difficult to get off the call. [Team member] eventually had to cut her off."</p>
Facilitators	Hospice Organizational Context	Philosophical congruence	<p>"We always talk about interactive methods in medicine, and [this intervention] is probably my first real example of it." – Hospice Staff Member</p> <p>"[The intervention made family caregivers] feel like they really are part of the care plan." – Hospice Staff Member</p>
	Team Structure	Inclusion of family caregivers on the interdisciplinary team	<p>"There was no ... asking one person and then them talking to the team and finding out if we could do what we wanted to do ... we could find out immediately." – Family Caregiver</p> <p>"Sometimes people get on different wavelengths, and I think [the intervention] helps to eliminate a lot of stress ... because everybody knows what's going on and can talk and work through things and come up with better solutions." – Hospice Staff Member</p>

Category	Model Component	Theme	Example
	Team Processes	Designated leadership during team meetings	<p>Research field notes indicated that meetings in which one individual kept the discussion focused on goal-directed content and ensured the active involvement of key personnel were described as more “thorough”, “focused”, and “organized.”</p> <p>“A designated person to direct traffic became involved and really encouraged efficiency and made it a lot more fun to do.” – Hospice Staff Member</p>