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Mixed methods analysis of hospice staff perceptions and shared decision making practices in hospice

Debra Parker Oliver, MSW, PhD* [Ira Kodner Professor of Supportive Care],

Division of Palliative Medicine, Department of Medicine, Washington University in St. Louis, Goldfarb School of Nursing, 4590 Children's Place, Mailstop 90-29-931, St. Louis, MO. 63110

Karla T. Washington, MSW, PhD [Associate Professor],

Division of Palliative Medicine, Department of Medicine, Washington University in St. Louis

Kyle Pitzer, MSSW [Senior Analyst],

Division of Palliative Medicine, Department of Medicine, Washington University in St. Louis

Lori Popejoy, PhD, RN, FAAN [Associate Dean for Innovation and Partnerships, Associate Professor],

Sinclair School of Nursing, University of Missouri

Patrick White, MD [Stokes Family Endowed Chair and chief, Division of Palliative Medicine],

Department of Medicine, Washington University in St. Louis.

Audrey S. Wallace, MD [Radiation Oncology],

St. Louis Veteran Health Administration Medical Center, St. Louis, Missouri

Amy Grimsley, MSN, RN, CCRN-K [PhD Student],

Sinclair School of Nursing, University of Missouri

George Demiris, PhD [Penn Integrates Knowledge University Professor]

*Corresponding Author: oliverd@wustl.edu.

Author Contribution

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Dr Parker Oliver, Dr. Wallace, Kyle Pitzer and Amy Grimsley. The first draft of the manuscript was written by Dr. Parker Oliver and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Conflicts of Interest/Competing Interests

The authors have no relevant financial or non-financial interests to disclose.

Availability of Data and Material

Data is available with a Data Use Agreement

Code Availability

Code is available with a Data Use Agreement

Ethics Approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. This sub study was approved by Washington University, St Louis through a reliance agreement with the University of Missouri.

Consent to Participate

Informed consent to participate was obtained from all individual participants included in the study.

Consent to Publish

Consent to publish deidentified data was obtained from individual participants during consent to participate.

Department of Biobehavioral Health Sciences, School of Nursing, Department of Biostatistics, Epidemiology and Informatics, Perelman School of Medicine, University of Pennsylvania

Abstract

Purpose: Shared decision making has been a long-standing practice in oncology and, despite a lack of research on the subject, is a central part of the philosophical foundation of hospice. This mixed methods study examined the perceptions of staff regarding shared decision making and their use of shared decision elements in hospice interdisciplinary team meetings.

Methods: The revised Leeds Attitude to Concordance scale (LATCon II) was used to measure the attitudes of hospice staff toward shared decision making. Field notes and transcripts of hospice interdisciplinary team meetings that included family caregivers as participants were coded to identify 9 theory-driven shared decision making elements. The results were mixed in a matrix analysis comparing attitudes with practice. Three transcripts demonstrate the variance in the shared decision making process between hospice teams.

Results: Hospice staff reported overall positive views on shared decision making; however, these views differed depending on participants' age and position. The extent to which staff views were aligned with the observed use of shared decision making elements in hospice interdisciplinary team meetings varied.

Conclusion: Policy and practice conditions can make shared decision making challenging during hospice interdisciplinary team meetings despite support for the process by staff.

Keywords

Hospice; Caregiving; Psychosocial; Intervention; Clinical Trial; Decision making

Introduction

As early as 1959, physicians discussed the value of active roles for patients in their own care.¹ Hospice considers patients and their family members as a single unit of care, and their participation in decision making is consistent with the hospice philosophy. Federal regulations require that the assigned clinical staff in hospice agencies meet together as part of an interdisciplinary team (IDT) meeting at least every 14 days to discuss every patient and family, identify their current needs, and review their plan of care.² These meetings are designed to make interdisciplinary decisions based on patient and family needs. Hospice IDT meetings are usually held in offices up to an hour from patients' homes and involve discussions of up to 100 patients, sometimes lasting as long as 3–4 hours.³ Patient and family participation in such meetings is uncommon because patients are seriously ill and often unable to travel, and family members have caregiving demands that make it difficult to leave home. Furthermore, given the short duration of time teams spend discussing each case, patients and families attending IDT meetings would only be engaged with the team for a few minutes if they were to attend in person.⁴ As a result, hospice teams have few opportunities to engage patients or family members in a shared decision making (SDM) process with the entire team. This study is part of a pragmatic randomized clinical trial enabling family

members to actively participate in IDT meetings and the SDM process through telephone and web conferencing.

Studies outside of hospice show that 71% of patients prefer to have a role in decision making.⁵ SDM has shown positive outcomes for participants in non-hospice settings, including reduced anxiety.^{6–11} Research suggests that health care providers can improve family caregivers' anxiety by listening and responding to questions, and by providing information with brochures, videos, and group discussions.¹² Providing information and education supports the caregiving role and has the potential to influence family caregivers' health and satisfaction.¹² Additionally, a recent pilot study found that a more coordinated provision of service, similar to what happens in hospice IDT meetings, helps address caregivers' physical and emotional challenges.¹³ In summary, evidence indicates that providing information and emotional support to family caregivers can enhance SDM, increase knowledge, and reduce anxiety.^{14–16}

Implementing a SDM intervention by integrating decision science into care teams is new to hospice.¹⁷ A report by the Agency for Healthcare Research and Quality (AHRQ) reviewed the research related to decision-making for individuals nearing the end of life. No hospice intervention studies supporting SDM were identified.¹⁸ In the United Kingdom, a study found that, while SDM was recognized, its implementation into practice was limited due to conceptual confusion about the practice, uncertainty in processes, and organizational factors impeding SDM.¹⁹ Likewise, a recent systematic review of interventions to support SDM in palliative care identified inconsistencies in delivery of the interventions and in measurement of their effects.²⁰ Authors of the review concluded that additional interventions to support SDM were needed in palliative care.²⁰

Intervention

Access for Cancer Caregivers to Education and Support for Shared decision making (ACCESS)

The ACCESS intervention is a pragmatic cluster crossover randomized clinical trial in seven hospice agencies across one state. Described in detail elsewhere,²¹ ACCESS allows family members (and patients, if able) to join biweekly hospice IDT meetings where their case is discussed via telephone or web-conferencing. In addition to attending these meetings, ACCESS participants are included in online support and education groups.

At the beginning of the study, hospice staff were trained in a nine-step shared decision-making model in one session.²² As a pragmatic trial, hospice staff were encouraged to include elements from this model in IDT meetings attended by patients and/or family caregivers, but it was not required. The day before the IDT meeting, research staff contact family caregivers, reminding them of the meeting and estimating a time for them to join. On the day of the IDT meeting, research staff connect the patient and/or family caregiver via the web or telephone. A convenience sample of the IDT meetings were audio recorded and transcribed for analysis based upon the time available and convenience of the research staff.

Conceptual Model: Team Practice and Shared Decision Making

A conceptual model of interdisciplinary teamwork inclusive of a shared decision-making process supported the scientific premise that patient and family involvement in the care planning process would improve clinical outcomes and reduce caregivers' anxiety and depression. The model details four components of interdisciplinary teamwork: organizational context, team structure, team processes, and outcomes. Feedback loops between and among all components emphasize their interrelatedness.^{23,24} With regard to ACCESS, the most salient aspect of the organizational context is hospice's overarching philosophy, which explicitly regards patients and family caregivers as key decision-makers. Within that context, ACCESS alters the team structure to formally include patients and family members in IDT meetings. It shifts team processes in IDT meetings by introducing SDM, characterized by the following essential elements: 1) defining a problem, 2) identifying potential solutions, 3) discussing benefits, risks and costs, 4) clarifying patient/family values and preferences, 5) discussing patient/family beliefs regarding their ability to follow through with solutions (self-efficacy), 6) offering a provider recommendation, 7) clarifying patient/family understanding, 8) making a decision, and 9) following up.²² We applied this model to our preliminary work and found evidence that family caregivers' lack of information and emotional strain (anxiety) influenced their interactions with staff members and were barriers to SDM in IDT meetings.²⁵

Study Objectives

The purpose of this study was to explore the relationship between hospice staff attitudes toward and use of SDM in hospice IDT meetings. We asked the following questions : 1) What are hospice staff members' attitudes toward shared decision making? 2) Which elements of SDM are observed in ACCESS IDT meetings inclusive of hospice staff and patients/families? and 3) To what extent is the level of attitudinal support for SDM reflected the use of the SDM elements in hospice IDT meetings?

Methods

Qualitative and quantitative data were collected at the same time and analyzed independently in support of the first two research questions. Following those analyses, the data were mixed using a matrix to answer the third research question. Finally, three transcripts were selected as examples of strong, moderate, and weak use of the SDM elements.

Quantitative Methods

Design—Staff attitudes toward SDM were measured via a convenience sample using an online survey of hospice staff from the seven agencies participating in the ACCESS study. Using REDCap (Research Electronic Data Capture),²⁶ we electronically administered the Leeds Attitude Toward Concordance II Scale (LATCon II) to staff members every year for three years.²⁷ While concordance and SDM are not synonymous terms, the process by which concordance is achieved is nearly identical to the SDM process and, from patients and families' perspectives, SDM and reaching concordance are experienced similarly.²⁸ Thus, for purposes of this study, hospice staff members' attitudes toward concordance (as measured by the LATCII) were used as proxies for attitudes toward SDM.

Participants—Leaders in seven hospice agencies distributed the survey link via email to their staff annually for three years. We were unable to obtain the total number of staff receiving the email opportunity and are thus unable to compute a response rate. To recognize participation, we held a drawing to send one staff member from each agency to the state hospice association conference each year of the study. In cases when a staff member participated in more than one year, only that individual's most recent response was included in our dataset.

Measurement—The LATCon II measures attitudes toward a concept called “concordance,” roughly defined as patients’ informed and active involvement in medical decision making—in other words, SDM.²⁷ The 20 items from the LATCon II have response choices of 0–3 representing the amount of agreement with each statement from strongly disagree to strongly agree. Five items (questions 11, 14, 15, 18, and 20) are reversed scored. The instrument yields a summed score between 0–60 with higher scores representing more positive attitudes toward concordance/SDM. The instrument has excellent test-retest, validity, and reliability properties and measures five factors: 1) attitude toward active involvement of patients in medical consultations, 2) attitude toward equitable (i.e., non-paternalistic) interactions between doctors and patients, 3) belief in the necessity for doctors and patients to find common ground and be in agreement on decisions, 4) the perception of benefits in doctor-patient partnerships, and 5) attitude toward doctor-patient equality and shared control in medical interactions.²⁷

Analysis—A multi-step analysis was conducted to examine the characteristics of the sample, the distribution of individual items and subscales, and the relationship between the LATCon II total score and respondents’ age, years in the profession, and professional position in hospice. The characteristics of the sample examined include respondents’ employing hospice agency, age, gender, race, education, position, and years of experience (see Table 1). The distribution of each individual measure item, as well as computed subscales, were also examined (see Table 2). Lastly, based on the nature of the data and assumptions met, Kendall’s tau-b correlation tests and Kruskal Wallis and Dunn post-hoc tests were utilized to examine the relationship between LATCon II score, age, years of experience, and professional position (i.e., nurse or physician, psychosocial staff (e.g., social worker, chaplain), aide, or administrator or volunteer).

Qualitative Methods

Design—To answer the second research question, we obtained a convenience sample of audiorecordings of four hospice agencies’ ACCESS IDT meetings. Recordings were transcribed for analysis. Research staff observed the meetings, took detailed field notes, and reviewed the transcriptions for accuracy.

Data Analysis—The Framework Method, which applies a structured coding framework developed before reviewing the data, was used to analyze transcripts and field notes. We used pre-established SDM essential elements as codes (presented in the conceptual model above).²⁹ Specific code definitions largely mirrored those articulated in the existing model; however, to better reflect the realities of hospice care, the code *defining a problem* was

applied only to data segments that described the identification of problems or challenges that were unlikely to be associated with the normal dying process.

Trustworthiness in the analysis was assured by co-coding. An oncologist (ASW) and a graduate nurse (AG) reviewed each transcript line-by-line. They coded documented utterances related to one of the SDM elements. Additionally, they made notes with context and reasoning for their decision. The coded data segments were compared, and coding conflicts were resolved through discussion between the coders and the first author (DPO). To further enhance trustworthiness, members of the research team not directly involved in the data analysis reviewed the coded dataset, and research staff who had attended the ACCESS IDT meetings reviewed the findings to ensure their face validity.

Mixed Methods

Design—A mixed methods approach was required to answer the third research question: analyzing the relationship between hospice staff attitudes toward SDM and the actual use of the SDM elements in practice. A mixed methods matrix was created to allow for comparison.

Analysis—Following the qualitative and quantitative analysis above, we computed a level of supportive attitude toward SDM for each LATCon II subscale and a level of use for each SDM element. Mean scores on LATCon II subscales were categorized as reflecting weak, moderately weak, moderately strong, or strong support for SDM based on which quartile of possible scores for each subscale they fell into. For example, possible total scores for Subscale 4 (Perception of benefits in patient-physician partnership) range from 0 to 9. Hospice staff members' mean score for that subscale was 7.2, which falls into the top 25% of possible scores for that subscale. Therefore, we concluded that hospice staff members' support for SDM was strong. Similarly, hospice teams' use of SDM elements was categorized based on the percentage of meetings in which researchers coded the elements' use (range of possible percentages was 0 to 100%). Percentage use of an element that fell into the lowest quartile of possible observed use was labeled weak, and labels of moderately weak, moderately strong, and strong were used to categorize percentage use that fell into the remaining three quartiles. For example, providers were observed making a recommendation in 80% of hospice IDT meetings. Since a percentage of 80% fell into the highest quartile of observed use, we conclude that hospice teams engaged in strong use of this element. Table 4 includes each of these calculations, presented in a matrix to allow for comparisons between expressed attitudes toward SDM (measured with the LATCon II) and observed use of SDM elements in actual IDT meetings.

Finally, three IDT meeting transcripts were selected to illustrate SDM processes. Transcripts were chosen for maximum variance including study year, hospice agency, and transcript length. The most illustrative transcripts for strong use of SDM, moderate use of SDM and weak use of SDM are presented in Table 5.

Results

Quantitative Results

Hospice clinical staff from each site responded to surveys (n=224). The mean age of respondents was 46.7 years (sd = 12.0), and a majority were female (90%) and white (92%) (see Table 1). Forty-one percent of respondents were hospice nurses/physicians, followed by psychosocial staff (e.g., social workers, chaplains) and aides (21.3% each); administrative and volunteer coordinator staff were 16.7%. On average, respondents reported to have been working in their profession for 15 years (sd = 10.7). Staff from all seven hospice agencies were represented.

Table 2 summarizes the responses by question, subscale, and total LATCon II score. Respondents on average reported fairly positive attitudes towards SDM (mean = 42, sd = 6.6). For relationships between age and attitudes toward SDM and years of experience and attitudes toward SDM, we found that age has a weak, significant correlation with attitudes toward SDM ($\tau = .12$, $p = .02$), whereas years of experience does not. This test suggests that respondents who were older had slightly more positive attitudes toward SDM. For the relationship between professional position and attitudes toward SDM, we found a significant difference in means between the groups (KW $\chi^2 = 17.21$, $p = <0.001$), and, upon examining our post-hoc analyses, these differences were between aides and the other three groups. Specifically, aides had significantly less positive attitudes toward SDM than other staff.

Qualitative Results

During 18 months of data collection, 62 care plan discussions during hospice IDT meetings attended by family caregivers of hospice cancer patients were audio-recorded and transcribed (average length \approx 8 minutes); 35 unique family caregivers participated in those discussions (in some instances, multiple care plan discussions were recorded for the same patient/family, and multiple family caregivers per patient were permitted to participate in the meetings).

Of the 62 total discussions, there were 13 (21%) in which no problem was identified, and nurses just gave a basic report to the team with no discussion. Of the 49 discussions in which at least one problem was identified, all nine elements of SDM were observed in only three meetings. The least often observed SDM elements were discussion of risks and benefits for potential solutions and the discussion of patient/family values; each were observed in only 31% of the meetings in which problems were identified.

Mixed Methods Results

Table 4 shows the analysis matrix. As illustrated, the extent to which staff views were aligned with their observed use of shared decision making elements in hospice IDT meetings varied. Of the 45 cells included in the table, 39 (86.7%) showed alignment that varied by one categorical level or less. For example, in each of the five cells in which staff members' attitudes were compared with their use of the "define problem" SDM element, staff attitudes

were either within the same categorical level (e.g., strong use and strong support) or only one categorical level apart (e.g., strong use and moderately strong support).

Table 5 illustrates three discussions that occurred during three different hospice IDT meetings. The first transcript represents a successful SDM discussion. The elements of the SDM process are easily observable: the caregiver is heard, the nurse educates, the final solution is clearly agreed upon by all, caregiver understanding is acknowledged, and the medical director concludes with a follow-up plan.

The second transcript illustrates a discussion in which most of the SDM elements were observed. Nevertheless, there are still communication gaps. For example, when the caregiver describes encouraging the patient not to give up on the pain medication and convincing her to take half a tab, stating it is “better than not doing anything,” no one on the hospice team provided feedback.

In contrast, the third transcript is from a meeting in which many SDM elements were not observed. The meeting facilitator, a nurse supervisor, does not attend to the caregiver, who must ask if anyone is talking to her. While the leader appeared focused on obtaining information from each hospice discipline, they missed a valuable opportunity to properly attend to the caregiver’s chief concern. When it comes time for the chaplain to report, they note that the regular chaplain, scheduled to come once a month, has not been there in the last two weeks. The caregiver notes that their pastor comes every week for communion but is on vacation. There is no follow up to ask if they would like a visit while the pastor is gone. Additionally, when the caregiver discusses having a volunteer and notes that perhaps they could help the patient understand what is going on given his failing memory, they are told that “they’re for companionship.” The volunteer coordinator, and every other team member, miss a chance to address the caregiver’s concern regarding memory. Finally, when the caregiver notes a falling problem, the only response is, “the first couple of days are usually the worst after a fall.”

Discussion

Study of the ACCESS intervention provided the opportunity to see inside hospice IDT meetings and explore the communication and the SDM process. The transcripts show the majority of the meetings involve interdisciplinary participation and discussion of many different kinds of problems. Caregivers were not hesitant to bring up problems and participate.

Similar to a study in the UK on SDM practice, we found that, while there is some consistency between perceptions and practice, there are conceptual issues and organizational challenges that impede the use of SDM elements within the hospice setting.¹⁹ One of the conceptual issues are differences between family caregivers’ and hospice professionals’ definitions of problems. One common example found caregivers noting a patient’s loss of appetite as a problem. Family members of cancer patients come to hospice after experiencing traditional oncology care, where patient symptoms, such as loss of appetite, are defined as problems and plans are implemented to address the issue. However, in the

hospice setting, these same concerns are seen differently. Loss of appetite is an expected sign of disease progression and are not necessarily seen as problems that need to be addressed. Based on their previous experiences, family caregivers may view loss of appetite as a problem needing attention rather than an expected sign of disease progression at the end of life. This situation of misaligned expectations between family caregivers and the hospice team may lead to a misunderstanding when not addressed. During a SDM process, family-identified problems need to be discussed even if the issue is not viewed as a problem by the staff. This first step in the SDM process is an important one in the alignment of goals of care. In addition, we identified numerous instances when family caregivers identified problems, such as the fall noted in Table 5, that were not addressed by the hospice team. In some cases, the concerns were dismissed without further discussion.

We also identified organizational challenges to SDM which may contribute to incomplete SDM processes during ACCESS IDT meetings. Hospice IDT meetings have a very short period of time (e.g., 2–3 minutes) allotted for each patient, so there is little time to address complex problems or help with family caregivers' understanding of clinical issues.^{25,30} Using a comprehensive SDM process is in direct conflict with the time pressure teams experience. Transcripts revealed regulatory pressures on these meetings. All hospice teams had complaints about increased regulatory requirements taking away from the clinical focus, such as increased documentation requirements and increased focus on assuring participation by all disciplines. Additionally, teams have been under increased pressure to justify patient eligibility for services to external auditors; thus, many meetings contain justifications for continued hospice involvement.

Strengths and Limitations

This mixed methods study is the first we are aware of to examine the attitudes and practices of hospice staff with regard to SDM. It is a longitudinal study and explores the IDT meetings across several hospices, helping to improve generalizability of the findings. Finally, the study is theoretically grounded with observable elements identified for SDM practice.

The survey portion of this study was limited by an unknown response rate. Additionally, responses to the survey were unequal, requiring the combining of some staff roles (for example physicians and nurses) for analysis. Finally, it is noteworthy that the LATCon II instrument was not designed for the hospice setting.

Implications for Practice

Given that hospice standards of care and hospice clinicians appreciate SDM with family members, the opportunity to incorporate this in the hospice setting is important. IDT meetings would benefit from an efficient structure that would allow them to reallocate the time spent on cases in which there are no problems to be addressed, to cases that had identified problems that would benefit from collaborative engagement of the hospice IDT and family caregivers. Pre-meeting information from family caregivers, combined with the clinicians' assessments, could improve the IDT processes by allowing for efficient identification of problems and orientation of meeting attendees to problem-solving efforts. Additionally, given the short meeting time available, discussion of some SDM elements,

such as self efficacy, may be better done outside the meeting and between the hospice staff and family during a visit. Improved documentation that facilitates clinical discussion while meeting regulatory requirements would be most welcome by these teams. Hospice agencies invest tremendous resources in staff time and energy into IDT meetings, and the purpose and value of them is noteworthy. Improving their outcomes is an important topic for future work.

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Table 1.

Summary of Characteristics of Hospice Staff

	n	%
Location (n = 216)		
Hospice I	68	31.48
Hospice C	39	18.06
Hospice J	29	13.43
Hospice W	22	10.19
Hospice G	22	10.19
Hospice L	19	8.80
Hospice B	17	7.87
Gender (n = 215)		
Female	193	89.77
Male	22	10.23
Race (n = 210)		
White/Caucasian	193	91.90
Black/AA	14	6.67
Other	3	1.43
Education (n = 216)		
Undergrad degree	72	33.33
Grad degree	71	32.87
Some college/other degree	53	24.54
High School (equivalent)	17	7.87
Position (n = 216)		
Nurses/physicians	88	40.74
Psychosocial staff	46	21.30
Aides	46	21.30
Administration/volunteers	36	16.67
Mean (Standard deviation)		
Age (n=199)	46.67 (12.01)	
Years worked (n = 216)	15.09 (10.74)	

Table 2.

Summary LAT ConII score for Hospice Staff and Subscale Category

Question	N	Mean	SD	
1. Prescribing should take account of patients' expectations of treatment.	204	2.49	0.64	
2. Doctors and patients should agree on a treatment plan that takes into account both of their views.	208	2.50	0.67	
3. Patient involvement in the prescribing process always leads to better outcomes.	206	2.33	0.73	
4. The best use of treatments is when it is what the patient wants and is able to achieve.	207	2.41	0.68	
5. Doctors should try to help patients to make as informed a choice as possible about benefits and risks of alternative treatments.	205	1.73	0.48	
6. During the consultation both the doctor and the patient should state their views about possible treatments.	207	2.64	0.59	
7. Doctors should give patients the opportunity to talk through their thoughts about their illness.	201	1.78	0.46	
8. Doctors should make clear when the benefits of the medicine are uncertain.	202	1.79	0.46	
9. Doctors should be more sensitive to how patients react to the information they give.	205	2.56	0.62	
10. It is always important for doctors to listen to patients' personal understanding of their condition.	202	1.77	0.47	
11. It is sometimes appropriate for the doctor to make treatment decisions without the patient's input.	203	1.28	0.85	
12. The doctor and patient should and common ground on what the problem is and jointly agree on what to do.	203	2.33	0.59	
13. Doctors should encourage patients to express their concerns about medicine taking.	201	2.69	0.50	
14. Taking account of patients' views about medicines is not always necessary for appropriate prescribing.	204	1.07	0.82	
15. The doctor is the expert and the patient's role is to do as the doctor says.	202	0.56	0.68	
16. The consultation between the doctor and the patient should be viewed as negotiation between equals.	201	1.75	0.81	
17. A good treatment decision is made when both the doctor and patient agree on the treatment to use.	201	2.46	0.62	
18. During the doctor-patient consultation the patient's decision is the most important.	205	2.21	0.70	
19. Patients should be able to take on as much responsibility as they wish for their own treatment.	203	2.32	0.65	
20. It is not always necessary for doctors to take account of patients' priorities.	202	0.85	0.78	
Total Score mean	183	42.45	6.59	
Subscales ^a				** Category of SDM Support
Attitude toward active involvement of patients in medical consultations	193	10.48	2.10	Moderately strong
Attitude toward equitable (i.e., non-paternalistic) interactions between doctors and patients	194	8.10	1.63	Moderately strong
Belief in the necessity for doctors and patients to find common ground and be in agreement on decisions	197	9.59	1.65	Strong
Perception of benefits in doctor-patient partnerships	199	7.19	1.67	Strong
Attitude toward doctor-patient equality and shared control in medical interactions	195	7.17	1.38	Moderately strong

^aSubscale 1 includes items 6, 7, 8, 9, 11. Subscale 2 includes items 5, 10, 15, 20. Subscale 3 includes items 1, 2, 13, 14. Subscale 4 includes 3, 4, 17. Subscale 5 includes items 12, 16, 18, 19.

** Category of support scoring for each LATCon II subscale was based on mean subscale score divided by quartile.

Subscale 1 (5 items scored 0 to 3, 15 points possible); 0–3.7 = Weak support for SDM; 3.8–7.5 = Moderately weak support for SDM; 7.6–11.3 = Moderately strong support for SDM; 11.4–15.0 = Strong support for SDM.

Subscale 2, 3, and 5 (4 items scored 0 to 3, 12 points possible per subscale); 0–3.0 = Weak support for SDM; 3.1–6.0 = Moderately weak support for SDM; 6.1–9.0 = Moderately strong support for SDM; 9.1–12 = Strong support for SDM.

Subscale 4 (3 items scored 0 to 3, 9 points possible); 0–2.2 Weak support for SDM; 2.3–4.5 Moderately weak support for SDM; 4.6–6.8 Moderately strong support for SDM; 6.9–9 Strong support for SDM

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Table 3:

Shared Decision Making Elements Observed in IDT Meeting (N=49) and Level of Use Category

	N (%)	*Level of use category
Define the problem	49 (100%)	Strong use
Identify options to address the problem	44 (90%)	Strong use
Discuss benefits and risks of options	15 (31%)	Moderately weak use
Incorporate patient/family values and preferences	15 (31%)	Moderately weak use
Assess family caregiver self-efficacy	25 (51%)	Moderately strong use
Offer provider recommendation	39 (80%)	Strong use
Assess family caregiver understanding	18 (37%)	Moderately weak use
Make a decision	37 (76%)	Strong use
Set a follow-up plan	31 (63%)	Moderately strong use

* **Level of use of SDM element during IDT meetings:** Percent of IDT meetings in which SDM element was observed categorized by quartile; < 25% = Weak use of SDM element; 26%–50% = Moderately weak use of SDM element; 51%–75% = Moderately strong use of SDM element; > 75% = Strong use of SDM element.

Table 4

Analysis Matrix Comparing Category of Support for SDM with Level of Use of the Element of SDM Observed in Practice

		** Category of support for SDM subscale				
		Involvement in medical consultations Mean = 10.5 Moderately strong support for SDM	Equitable interactions Mean = 8.1 Moderately strong support for SDM	Belief in common ground and agreement in decisions Mean = 9.6 Strong support for SDM	Perception of benefits in patient-physician partnership Mean = 7.2 Strong support for SDM	Shared control Mean = 7.2 Moderately strong support for SDM
* Level of use of SDM element during IDT meetings	Define problem 100% <i>Strong use of SDM element</i>	<i>Strong use</i>	<i>Strong use</i>	<i>Strong use</i>	<i>Strong use</i>	<i>Strong use</i>
		Moderately strong support	Moderately strong support	Strong support	Strong support	Moderately strong support
	Identify solutions 90% <i>Strong use of SDM element</i>	<i>Strong use</i>	<i>Strong use</i>	<i>Strong use</i>	<i>Strong use</i>	<i>Strong use</i>
		Moderately strong support	Moderately strong support	Strong support	Strong support	Moderately strong support
	Discuss risks/ benefits 31% <i>Moderately weak use of SDM element</i>	<i>Moderately weak use</i>	<i>Moderately weak use</i>	<i>Moderately weak use</i>	<i>Moderately weak use</i>	<i>Moderately weak use</i>
		Moderately strong support	Moderately strong support	Strong support	Strong support	Moderately strong support
	Incorporate patient/ family values/ preferences 31% <i>Moderately weak use of SDM element</i>	<i>Moderately weak use</i>	<i>Moderately weak use</i>	<i>Moderately weak use</i>	<i>Moderately weak use</i>	<i>Moderately weak use</i>
		Moderately strong support	Moderately strong support	Strong support	Strong support	Moderately strong support
	Assess patient/ family self-efficacy 51% <i>Moderately strong use of SDM element</i>	<i>Moderately strong use</i>	<i>Moderately strong use</i>	<i>Moderately strong use</i>	<i>Moderately strong use</i>	<i>Moderately strong use</i>
		Moderately strong support	Moderately strong support	Strong support	Strong support	Moderately strong support
	Make provider recommendation 80% <i>Strong use of SDM element</i>	<i>Strong use</i>	<i>Strong use</i>	<i>Strong use</i>	<i>Strong use</i>	<i>Strong use</i>
		Moderately strong support	Moderately strong support	Strong support	Strong support	Moderately strong support
	Clarify understanding 37% <i>Moderately weak use of SDM element</i>	<i>Moderately weak use</i>	<i>Moderately weak use</i>	<i>Moderately weak use</i>	<i>Moderately weak use</i>	<i>Moderately weak use</i>
		Moderately strong support	Moderately strong support	Strong support	Strong support	Moderately strong support
	Make a decision 76% <i>Strong use of SDM element</i>	<i>Strong use</i>	<i>Strong use</i>	<i>Strong use</i>	<i>Strong use</i>	<i>Strong use</i>
		Moderately strong support	Moderately strong support	Strong support	Strong support	Moderately strong support
	Follow-up 63% <i>Moderately strong use of SMD element</i>	<i>Moderately strong use</i>	<i>Moderately strong use</i>	<i>Moderately strong use</i>	<i>Moderately strong use</i>	<i>Moderately strong use</i>
		Moderately strong support	Moderately strong support	Strong support	Strong support	Moderately strong support

* **Level of use of SDM element during IDT meetings:** Percent of IDT meetings in which SDM element was observed categorized by quartile; < 25% = Weak use of SDM element; 26%–50% = Moderately weak use of SDM element; 51%–75% = Moderately strong use of SDM element; > 75% = Strong use of SDM element. See Table 2.

** Category of support scoring for each LATCon II subscale was based on mean subscale score divided by quartile.

Subscale 1 (5 items scored 0 to 3, 15 points possible); 0–3.7 = Weak support for SDM; 3.8–7.5 = Moderately weak support for SDM; 7.6–11.3 = Moderately strong support for SDM; 11.4–15.0 = Strong support for SDM.

Subscale 2, 3, and 5 (4 items scored 0 to 3, 12 points possible per subscale); 0–3.0 = Weak support for SDM; 3.1–6.0 = Moderately weak support for SDM; 6.1–9.0 = Moderately strong support for SDM; 9.1–12 = Strong support for SDM.

Subscale 4 (3 items scored 0 to 3, 9 points possible); 0–2.2 Weak support for SDM; 2.3–4.5 Moderately weak support for SDM; 4.6–6.8 Moderately strong support for SDM; 6.9–9 Strong support for SDM

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Table 5:

Comparison of 3 sample transcripts of IDT meetings demonstrating shared decision making

<p>Transcript 1: Discussion in which most (8) SDM elements were observed</p> <p>NURSE – [Patient] is 70 years old. He’s on service for bladder cancer with multiple metastatic areas especially the chest. I haven’t been able to see him or talk to him since you started that ointment.</p> <p>CAREGIVER – He really is having smells by the groin area because he is starting to have lesions but my worry is I smell something. I think it’s like getting infected. Because it’s bleeding and it’s crusted and peeling off and it’s like his skin is being eaten.</p> <p>(Defining the problem)</p> <p>NURSE – On the chest or on the groin?</p> <p>CAREGIVER – On the abdomen the one that has the crusting. The one on the chest, it’s gotten worse, it’s different now it’s like white and big nodules. So, it’s really gotten worse since the last time you saw it and you took picture.</p> <p>NURSE (wound care) – My name is [NURSE], I’m the wound care NURSE. What your describing sounds like it’s uh, the cancer tumors themselves that have presented onto his abdomen, his groin and on his chest. The way that cancer tumors work, the way that they always function is they go towards blood sources</p> <p>CAREGIVER – Uh huh.</p> <p>NURSE (wound care) -So they go through mini-vessels that will feed them for a little while but because they’re uncontrolled tissue, they end up eating through that and that’s when that white tissue starts to form because that’s when that’s technically dead tissue. The smell that you have is called anaerobic bacteria. It’s not an infection. It’s just because there’s no blood supply to the area to fight it off.</p> <p>CAREGIVER – Okay</p> <p>NURSE (wound care) -The cream that we provided has the metronidazole in it that’s supposed to help with some of the odor. Then as it starts to drain more and get rid of that dead tissue, the odor will become less. But we can look at that too. We can always increase the metronidazole in it or we can tweak the cream as we go along.</p> <p>(Identifying solutions, Discussing risks and benefits of treatment)</p> <p>CAREGIVER – Does it have the metronidazole? I think it only has, what do you call it now, the numbing.</p> <p>DOCTOR – The lidocaine.</p> <p>CAREGIVER – I don’t think is has the metronidazole.</p> <p>DOCTOR – If it doesn’t have Flagyl, we can add Flagyl in it.</p> <p>(Provider recommendation)</p> <p>NURSE (wound care) – Okay, they will add metronidazole to it so that it’ll take care of the odor. Okay?</p> <p>CAREGIVER – Okay.</p> <p>(Make decision)</p> <p>NURSE (wound care) -So that’s helpful to know, I thought we had it already in there. So, you should start seeing an improvement. Now are you doing it four times a day?</p> <p>(Assess caregiver self-efficacy)</p> <p>CAREGIVER – It’s four times a day.</p> <p>NURSE (wound care) – As needed, okay. How often are you doing it every day?</p> <p>(Assess understanding)</p> <p>CAREGIVER – At least twice.</p> <p>NURSE (wound care) – Okay.</p> <p>CAREGIVER – But, one time, one day was like three times. Because he was complaining of a lot of pain.</p> <p>DOCTOR– Okay, So, [NURSE] will be following up with you. And if you’ve got any questions or concerns, you know to call, okay?(Follow up)</p> <p>CAREGIVER – Okay, yeah, thank you very much</p>
<p>Transcript 2: Discussion in which most SDM elements were observed but problematic (no decision made and lack of follow-up to caregiver identified problems)</p> <p>NURSE: I was just talking to [DOCTOR], we started [Patient] on some steroids because she was having a lot of shooting pains down her leg, and that was just started yesterday. And last night, she was pretty restless, having night sweats and stuff like that, so [DOCTOR] said that if she was really symptomatic she could either not take it or do like half a tablet. She’s only had 4mg. I suggested running a full fan. (Defining the problem)</p> <p>CAREGIVER: The sweating actually started about an hour after she took it. She kind of started pouring sweat. She was using her little fan during the day, and she has one that goes around her neck, [and] has two little fans that point right at her. I told her that [NURSE] said we can do a ½ a tab. ...hoping that it might help, so she did take a ½ a tab. She’s having a lot of nausea today, and she’s really tired from not sleeping well last night, and she’s feeling nauseous. So yesterday was a pretty good day, except for the sweating. Otherwise she was having a pretty good day. She hardly needed any pain meds. She was very awake and alert, but maybe a tiny bit agitated, but not bad. But today she is just not feeling good. (Identifying solutions)</p> <p>NURSE: Yeah, and we had just started her on 25 mics of fentanyl, which has been really effective, and she doesn’t need it as much [for] breakthrough pain. [CAREGIVER], since you have the whole team here and [DOCTOR], do you have any questions that you would like to ask him?</p> <p>(Assessing family understanding)</p> <p>CAREGIVER: ... I guess I’m just kind of wondering where we are in the progress of things, and it’s so hard to know what the cancer is doing inside her body because you can’t see it.</p> <p>NURSE: I know, that’s a hard question. You just have to keep taking it one day at a time and see how she’s eating and drinking and keep her as comfortable as you can.</p> <p>CAREGIVER: Yeah, she’s definitely resistant to the morphine. She really doesn’t like how it knocks her out and makes her feel. I can get her to take an Oxy [Contin] ... but she’s really resisting that morphine. We did it a couple times, and it just knocked her on her butt, and she just didn’t want it. She didn’t want to take anything the next day, and I had to remind her that the Oxy[Contin] is not bothering her, it’s the morphine that does that. [I’m] just concerned as things progress ... that she’s going to be very resistant to the morphine when she needs it. (incorporating patient/family values and preferences)</p> <p>DOCTOR: She might be better off with the Fentanyl, which is a little smoother without the ups and downs, and I think hanging in there with</p>

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<p>Transcript 1: Discussion in which most (8) SDM elements were observed</p> <p><i>the steroids would be worth another try, both for the nausea, pain, [and] just general energy level. I think it could help in just every regard.</i> (Discussion of risks and benefits) CAREGIVER: <i>Yeah, that's why I ... told her let's not give up on it yet The sleeping part will get better in a few days, and let's do 1/2 a tab. It's better than not doing anything.</i> SOCIAL WORKER: <i>Hi, [CAREGIVER]. It's [Social Worker]. I just wanted to check in and see how you are holding up.</i> <i>(Assess family self-efficacy)</i> CAREGIVER: <i>Um, pretty good. Actually, I started feeling like I was crashing a little bit, so I took the day off work yesterday, and [Patient]'s other caregiver was here, and I just got out of the house and went and did some stuff to basically recharge myself, so that was very helpful.</i> SOCIAL WORKER: <i>Good self-care.</i> CAREGIVER: <i>Yeah, I was like, I'm going to have to do that. I'm going to be useless if I don't, so it was very helpful—exactly what I needed—to do something that felt like normal.</i> CHAPLAIN: <i>This is [Chaplain]. I was there last Wednesday and provided a visit to you and your mother. I just wanted to give you a suggestion: You can always reach out to me and call the office if you need that emotional support via a phone call or even if you want me to come out and, you know, do a visit with you one-on-one—give you some reaffirmation that you are doing everything that you can do. You know, I'm here. The team is here for you. (Provider recommendation and Follow up)</i> CAREGIVER: <i>Okay. Thank you.</i></p>
<p>Transcript 3: Discussion in which many SDM elements were not observed</p> <p>CAREGIVER: <i>[Patient] loses his ambulatory skills and all that stuff. You know, things are getting a little bit harder. He feels like he can still do all these things, and so it's difficult, you know, not to argue with him, you know saying, like he wants to get up and not be late for school. And he has to go, so it's hard to help him understand that he doesn't have to go to school. You know, but in his mind he still thinks he's late.</i> (Defining problem) HOME HEALTH AIDE: <i>He gets seen 3 times a week, and he is a two-person transfer.</i> CAREGIVER: <i>Is somebody talking to me?</i> NURSE: <i>No. She was giving her report that he is seen. Who is next?</i> CAREGIVER: <i>Okay.</i> CHAPLAIN: <i>Hi, [CAREGIVER]. This is the Chaplain. I'm one of the chaplains, but it is someone else who is [Patient]'s chaplain. Looks like he visits at least once a month</i> CAREGIVER: <i>Right</i> CHAPLAIN: <i>And he hasn't made a visit in the last two weeks.</i> CAREGIVER: <i>No, he has not.</i> CHAPLAIN: <i>Okay. But he remains available.</i> CAREGIVER: <i>Okay. I mean, [Patient]'s pastor does come out or his, you know, [Priest] comes out and gives him communion. Typically, every week. He's on vacation right now, but he does come out and give him communion quite a bit.</i> CHAPLAIN: <i>That's good. Okay.</i> VOLUNTEER COORDINATOR: <i>Hi. This is [Volunteer Coordinator] from the Volunteer Department. And currently we have no volunteer assigned to [Patient].</i> CAREGIVER: <i>Yes, and I was thinking about that—that maybe he does need, you know, just someone to come and talk to him and help him understand some of the things. You know, because honestly, every single one of us that are taking care of him, you know, we are, we don't have that outside voice. You know, we're his sisters, you know. Does he really pay attention to us?</i> (Identifying solution) Volunteer Coordinator: <i>Okay.</i> CAREGIVER: <i>And, you know, maybe help him understand what is happening. Because I do think he is forgetting what's going on with him.</i> Volunteer Coordinator: <i>Alright. If we assign a volunteer to him, they're for companionship.</i> CAREGIVER: <i>And that's all it is? Just somebody to talk to?</i> Volunteer Coordinator: <i>Right. They wouldn't be able to do any healthcare discussions. They would just be there to support him.</i> (Assessing caregiver understanding) CAREGIVER: <i>Oh. Well, even with that we could try it. You know, just somebody ... for him to bond with or something.</i> Volunteer Coordinator: <i>Alright. Okay. Alright, I will give that message to Sherry, and she will see what she can do for you then.</i> NURSE: <i>I'm just reading through [another nurse]'s reports here. She's got that he's got some increased confusion.</i> (Defining a problem) CAREGIVER: <i>Yes.</i> NURSE: <i>Yeah. Also he's been having more increased difficulty with walking and balancing, having more trouble like sitting up. (Defining a problem)</i> CAREGIVER: <i>Yes. He cannot hold. He cannot sit in a chair without falling to his right, and if there is any tilt to it at all, he slides out of the chair. He doesn't realize that he's falling over because we have to tell him that, so we try to make sure that if he is in a recliner that he is leaning back so that</i></p>

Transcript 1: Discussion in which most (8) SDM elements were observed

he doesn't have that stress on him. But no, ... he cannot sit up straight ... This past week ... I don't know what he did, but I found him on the floor, and during the night and for two days he had a backache. But I think it was from laying on the floor. Because I don't know how long he was there.

(Defining a problem)

NURSE:

Yeah, the first couple of days are usually the worst after a fall. Okay. Alright. Well if you ever have any questions, you know you can always give us a call. We can answer any questions 24/7, or we can send a nurse out if we need too. (Follow up)

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