Conversations about the use of life-sustaining treatment in the ICU

By

Kristen E. Pecanac

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The dissertation is approved by the following members of the Final Oral Committee:
Barbara King, Assistant Professor, Nursing
Barbara Bowers, Professor, Nursing
Douglas Maynard, Professor, Sociology
Junko Mori, Professor, Asian Languages & Cultures
Roger Brown, Professor, Nursing
Margaret Schwarze, Associate Professor, Surgery

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Introduction

Introduction

Background & Significance

Life-sustaining treatments—treatments that replace part or more than one part of the body that has ceased functioning (McGee, 2011)—are increasingly being used in intensive care units across the country. Among Medicare beneficiaries, use of intensive care in the last month of life has increased over the last ten years to 30% (Teno et al., 2013). Such care is costly; patients who are admitted to the intensive care unit prior to their death have an average inpatient cost of $24,541 compared to an average cost of $8,548 for patients who are not admitted to the intensive care unit (Angus, et al., 2004). Aside from the economic strain, there is a concern that the use of such treatments may only prolong the quantity of life while not improving the quality of life (and in some instances, even decreasing quality of life). Therefore, decisions often need to be made about the use of certain treatments in certain situations.

It is estimated that less than 5% of patients in the intensive care unit are able to make their own decisions about life-sustaining treatment (Prendergast & Luce, 1997). When a patient is unable to make decisions, the decision becomes the responsibility of a surrogate decision maker. Surrogate decision makers need to make profound decisions, such as whether to withdraw the patient from the ventilator (likely leading to the patient’s death) or to continue mechanical ventilation with a tracheostomy (which could sustain the patient’s current condition indefinitely). Surrogate decision makers struggle with making this decision for many reasons, including not wanting to be responsible for letting the patient die (Schenker et al., 2012). Research focused on surrogate decision makers’ experience in making treatment decisions has highlighted that it is a very stressful and burdensome experience (Wendler & Rid, 2011). The stress has even been likened to post-traumatic stress disorder, as research has shown that stress levels are high immediately after the decision, but remain elevated for at least six months after the decision is made (Tilden, Tolle, Nelson, & Fields, 2001).

While decision making regarding life-sustaining treatment is inherently challenging for surrogate decision makers, experiencing conflict with the healthcare team can exacerbate the difficulty. Conflict in the intensive care unit is exceedingly prevalent. Physicians or surrogate decision makers perceive conflict in about two-thirds of patient cases (Schuster, Hong, Arnold, & White, 2014). Half of surveyed nurses reported experiencing at least one situation of conflict in the previous week worked (Edwards, Throndson, & Girardin, 2012). Perceived conflict with the healthcare team is associated with surrogate decision makers' distress and lower health-related quality of life 90 days after their experience in the intensive care unit (Lemiale et al., 2010). Negative effects of conflict are not limited to surrogate decision makers; clinicians also experience distress, burnout, and decreased quality of patient care from conflict with surrogate decision makers (Danjoux Meth, Lawless, & Hawryluck, 2009).

Communication between clinicians and surrogate decision makers may bring about conflict. Research in primary care has shown that *how* clinicians communicate about treatment can affect how recipients respond to the treatment, including whether they resist the proposed treatment (Stivers, 2005). It is therefore imperative to explore how clinicians communicate about decision-making regarding life-sustaining treatment and how surrogate decision makers respond, including whether they express resistance to certain communication practices. In addition, it is important to consider how nurses communicate with surrogate decision makers, as they have a constant presence at the bedside. In this dissertation, I qualitatively and quantitatively examine communication between clinicians and surrogate decision makers while discussing decision making about life-sustaining treatment, as well as explore nurse-surrogate decision maker communication.

Literature Review

Due to their effect on surrogate decision makers' experience, this review includes literature on conflict, communication, and nurses, as they relate to decision making regarding life-sustaining treatment.

Conflict

The majority of conflicts between surrogate decision makers and the healthcare team occur due to the family's request for more treatment than the healthcare team regards as being valuable to the patient (Breen, Abernethy, Abbott, & Tulsky, 2001). A survey found that 32% of surrogate decision makers would continue to request treatment if the physician indicated a 1% chance of patient survival, while 18% of surrogate decision makers would continue to request treatment if the physician indicated no chance of patient survival, partly due to skepticism in the physicians' ability to prognosticate (Zier et al., 2009). Surrogate decision makers may also resist making a decision regarding life-sustaining treatment altogether. Resisting a decision, such as whether to withdraw the patient from the ventilator or to continue mechanical ventilation with a tracheostomy, increases the risk of patient suffering from continuing treatment that is not medically indicated (Billings & Krakauer, 2011; Oberle & Hughes, 2001). About 90% of surveyed healthcare practitioners believed enhanced communication training for physicians would be an effective and acceptable solution to address the issue of providing non-beneficial treatment (Downar et al., 2015).

Communication

Surrogate decision makers have expressed frustration from lack of communication (Kirchhoff et al., 2002) and have emphasized that they need clinicians to listen and provide communication that is timely, honest, and clear (Norton, Tilden, Tolle, Nelson, & Eggman, 2003). Researchers have explored the communication that occurs during the "family conference", a time when the healthcare team and surrogate decision makers discuss decision making regarding life-sustaining treatment. Two discourse analysis studies showed that the physician needs to present negative evidence of the patient's health status (Barton, Aldridge, Trimble, & Vidovic, 2005) and establish consensus that the patient's status is terminal before surrogate decision makers will discuss decision making (Aldridge & Barton, 2007). An additional four studies showed that high levels of surrogate decision makers' satisfaction is associated with physician use of empathetic statements (Selph, Shiang, Engelberg, Curtis, & White, 2008), high levels of shared decision-making (White, Braddock, Bereknyei, & Curtis, 2007), high proportion of family speech (McDonagh et al., 2004) and assurances that the patient will be comfortable, not suffer, or abandoned before death (Stapleton, Engelberg, Wenrich, Goss, & Curtis, 2006). These findings are important contributions to our understanding of communication in the family conference, but more research is necessary to determine if certain communication practices lead to surrogate decision makers' resistance and potential for conflict.

Nurses

While physician communication appears to be important, nurses are also important to the surrogate decision-making process. Two qualitative studies have shown that nurses can have a positive influence on surrogate decision makers' ability to make a decision for a patient in the intensive care unit. Limerick (2007) found that nurses provided surrogate decision makers valuable information and support during the decision-making process. Long and colleagues (2011) revealed that nurses often clarified information given to surrogate decision makers after the physician left, as one participant stated, after she "felt [the physicians] had just kind of thrown up on me" (p. 209). This phenomenon, of which there has been little empirical investigation, has been termed the “meeting after the meeting.” The meeting after the meeting occurs informally between the nurses and family, and is a time when nurses interpret what was said in the ‘formal’ meeting between the physician and the family (White, 2011). These studies show that nurses appear to be valuable to surrogate decision makers throughout the decision making process, however their communication with surrogate decision makers has not been explored.

Addressing the Gaps

There remain two important gaps in the literature regarding our understanding of communication during decision making regarding life-sustaining treatment. First, no studies have explored how surrogate decision makers respond to clinicians’ conversational practices during the family conference, and whether communication during the family conference could lead to surrogate decision makers’ resistance to engage in decision-making. While studies have explored family satisfaction with communication, it cannot be inferred that high levels of satisfaction are indicative of low levels of resistance. There is also no indication that the conversational practices studied (e.g. empathetic statements) directly contributed to family satisfaction; it may be that other features of the communication contributed to their satisfaction. The analysis of such studies has also primarily focused on the physician communication, ignoring the communication by the surrogate decision makers in the interaction. The surrogate decision makers’ contributions are important to examine because they can help to inform the physician’s communication, as they are contextually oriented. Without surrogate decision makers’ contributions, the analyses are largely incomplete. The details about *how* communication occurs are important for designing interventions to reduce resistance and potential for conflict in these conversations.

A second limitation of current research is the exclusion of nurse-surrogate decision maker communication that occurs after the family conference. It is clear from the literature that surrogate decision makers’ interactions with nurses are important; however, their actual communication has not been captured in previous studies. Therefore, it is not known how these meetings function, what is discussed, and if nurses further communicate about the need for decision making when conflict was present in the family conference.

Specific Aims

To address the gaps presented in the literature, this dissertation presents a mixed-methods study using conversation analysis and event sequence analysis to explore the communication between clinicians and surrogate decision makers.

The specific aims of this study are:

1. To determine how clinicians introduce the need for decision making regarding life-sustaining treatment and how surrogate decision makers respond
2. To determine the transitional probability of certain introductions preceding resistance
3. To explore the nurse-surrogate decision maker communication after the family conference

Thirty-six family conferences, in which decision making regarding life-sustaining treatment is discussed for an intensive care patient, were audio recorded. I first analyzed the communication with conversation analysis to determine how clinicians introduced the need for decision making regarding life-sustaining treatment and how surrogate decision makers subsequently responded (**Aim #1**). I then used event sequence analysis to determine the transitional probability of certain introductions preceding resistance (**Aim #2**). Finally, I used conversation analysis to explore the nurse-surrogate decision maker communication after the family conference (**Aim #3**). The depth of this data will be crucial for identifying directions for effective communication strategies and potentially decreasing conflict during decision making regarding life-sustaining treatment.

Methods

Design, Sampling, and Setting

This study has a cross-sectional design, in which 36 family conferences were audio recorded. Data were collected in two units: a 24-bed neuro-cardiac/medical-surgical intensive care unit and a 12-bed burn unit with capabilities for intensive care unit patients in all 12 beds, at a community hospital in an urban, Midwest city over a 12-month period.

A convenience sampling design was used, with an attempt to recruit all eligible participants involved in a family conference with the following inclusion criteria:

- English-speaking
- 18 years of age or older
- Participating in a family conference of a patient who is intubated

Participants who do not speak English were excluded because the communication process for non-English speakers was expected to be much different with the use of a translator. Participants less than 18 years of age were also excluded because they are not legally able to act as surrogate decision makers or to be clinicians. Patients who are intubated are unable to communicate and participate in decision making due to having an endotracheal tube in their mouth. Therefore, patients were not included as participants because this ensured capturing interactions of surrogate decision making.

Procedure

I identified participants by visiting the units Monday through Friday and asking nurses if they had any patients who were intubated. When a patient was intubated, I contacted the attending physician to describe the study and obtain his/her assent to invite staff and surrogate decision maker participation in the study. The patient's nurse approached the surrogate decision maker with an information sheet about the study to determine if he/she was willing to speak to me. If the surrogate agreed, I discussed the study in detail and answered questions. If interested in participating in the study, I asked the attending physician when the family conference would occur. Consent was obtained from all participants before the family conference.

Data Collection/Instruments

All family conferences occurred in the patient's room or in a private room on the unit. I started audio recording at the beginning of the conversation. If a nurse was present in the family conference, I continued to audio record the conference after the physician had left the room in order to collect data on any potential communication after the family conference.

During the family conferences, I captured the sequence in time of each participant's communication using a hand held computer loaded with the WorkStudy+ program (Quetech Ltd, Canada). I designed the input format on the program so that I had a button for each type of potential participant in the family conference ("nurse," "physician", "family member" etc.). When a person spoke, I touched the corresponding button. The program then documented the time and sequence of each participant's talk in the interaction. This data collection allowed me to match the voice in the audio recording to the type of speaker ("nurse," "physician," etc.) for accurate transcription.

Data regarding the patient's characteristics (age, admitting diagnosis, race) was collected from the medical record by the nurse and documented on a patient information sheet. I collected data on the patients' characteristics and not the surrogate decision makers' characteristics because: 1) surrogate decision makers are often emotional before the family conference, and I felt it would be inappropriate to ask them to do too much, 2) many surrogate decision makers in the feasibility study stated relief that they did not have to give any personal information and fewer may have participated if they needed to give this information.

Of the 36 family conferences, there were 32 patients (patient demographic characteristics are presented in Appendix III). For 4 patients, I audio recorded 2 family conferences. To ensure diversity of conversation, I limited the number of family conferences led by each clinician to 10 family conferences and then no longer recruited participants led by those clinicians in future family conferences. There were 2-26 participants in the family conferences. Participants included physicians, nurses, nurse practitioners, family members and friends of the patient, case managers, chaplains, and ethicists. Further description of the 36 conversations is presented in Appendix II.

Data Management

I personally transcribed all audio recordings verbatim using the transcription method developed for conversation analysis (Hepburn & Bolden, 2013). The transcription notations are found in Appendix IV. I changed names (person or hospital), dates, or other identifiable information in the transcriptions. In order to link the hand held computer information, audio recording, and patient characteristics, I coded each of them, numbered in consecutive order. When I had the same patient (e.g. “01”) for a second conference, I numbered that conference with a letter (“01a”) so that I knew the audio recording and hand held computer data should be linked to patient “01.”

Data Analysis

I used a mixed-methods approach, utilizing conversation analysis and event sequence analysis to analyze the data. I first used conversation analysis to determine how clinicians introduce the need for decision making regarding life-sustaining treatment and how surrogate decision makers respond (**Aim #1)**. Then I conducted event sequence analysis to determine the transitional probability of clinicians' introductions preceding resistance (**Aim #2**). I also used conversation analysis to explore the nurse-surrogate decision maker communication after the family conference (**Aim #3**).

Additional discussion of data analysis is presented in the following chapters:

- Theory and assumptions underlying each method (Chapter 1)
- Description of analysis for each method (Chapter 1)
- Integration of methods (Chapter 1)
- Specific process for analysis for Aim 1 (Chapter 2)
- Specific process for analysis for Aim 2 (Chapter 3)
- Specific process for analysis for Aim 3 (Chapter 4)

Other Notes on Methods

Video recording. Although I could have captured important details of the interactions by video recording these observations, I made the decision not to video record due to concerns of confidentiality and recruiting. The refusal rate to participate in this study was 35.7%; 20 of the 56 eligible family conferences were not audio recorded due a family conference participant declining to participate in the study. I believe the refusal rate would have been higher if I had video recorded the conversations, due to the added intrusiveness of multiple video cameras and potential ability to visually identify participants.

Certificate of Confidentiality. To reduce the legal risk for clinicians, I obtained a Certificate of Confidentiality. With the Certificate, the audio-recordings of the family conference could not be used as evidence in a legal proceeding.

Introduction to 4 manuscripts

These 4 manuscripts represent a cohesive body of work from the dissertation study. A methods paper describes the innovative methodological approach for the study, and three papers describe results for the three specific aims of the study.

- Chapter 1: Combining Conversation Analysis and Event Sequencing to Study Health Communication
    - The first chapter is a methods paper. Combining conversation analysis and event sequencing is an innovative mixed-methods approach to analyzing interaction data. Using this approach could be helpful to further our understanding of how to improve communication in the healthcare setting. I describe both conversation analysis and event sequencing, compare the assumptions behind each method, and demonstrate my approach for combining the methods.
- Chapter 2: Doing Delicacy: Introducing the Need to Make a Decision about the Use of Life-sustaining Treatment
    - Chapter 2 attends to Aim 1 of this study: to determine how clinicians introduce the need for decision making regarding life-sustaining treatment and how surrogate decision makers respond. The focus of this paper is to demonstrate the use of a perspective-display invitation, as part of the perspective-display sequence (PDS), to introduce the need to make a decision about life-sustaining treatment. The surrogate decision makers responded to this invitation by providing their assessment of the patient’s preferences. As a result, clinicians often incorporated this assessment into a decision proposal.

- Chapter 3: Decision Proposals in the Family Conference
    - Chapter 3 attends to Aim 2 of this study: to determine the transitional probability of certain introductions preceding resistance. During analysis of the first aim, it became apparent that there was a difference in how clinicians introduced treatment decisions regarding withdrawing treatment and treatment decisions regarding withholding treatment. In withdrawing treatments, clinicians used the PDS (described above), in which they first asked about the patient's preferences before giving a decision proposal. However, in withholding treatments, clinicians introduced the need to make a decision by directly giving a decision proposal. Therefore, the focus of this paper was to compare different decision proposal formulations and to determine the transitional probability of certain proposals preceding resistance or alignment with the proposal.
- Chapter 4: An Exploration of Nurse-family Communication after a Family Meeting in the ICU.
    - Chapter 4 attends to Aim 3 of this study: to explore the nurse-surrogate decision maker communication after the family conference. This paper focuses on the "meeting after the meeting" between nurses and surrogate decision makers, after the physician leaves the family conference. This is the first paper to explore nurse-surrogate decision maker communication.

Chapter 1

Combining Conversation Analysis and Event Sequencing to Study Health Communication

To be submitted to Research in Nursing and Health

Word limit: 5500 words

There is growing attention to the need to improve communication in healthcare settings. Communication is one of the most frequently identified root causes of sentinel events reviewed by The Joint Commission (The Joint Commission, 2015), and improving the effectiveness of communication among caregivers is a National Patient Safety Goal for hospitals (The Joint Commission, 2016). Communication between clinicians and patients is also important; using clinician-patient communication strategies that improve health outcomes and health care quality is a goal of the Healthy People 2020 initiatives (U.S. Department of Health and Human Services, 2014). In addition, clinician-patient communication is central to shared decision making, a process in which clinicians and patients or the patient's family communicate to define goals of care and make treatment decisions (Kon, Davidson, Morrison, Danis, & White, 2016). Consequently, it is vital to explore how we can improve communication among clinicians as well as communication between clinicians and patients.

Previous research methods used in health communication studies may leave important gaps in our knowledge about how clinicians can best communicate. For example, studies that have explored clinician-surrogate decision makers' communication in the intensive care unit have focused on the relationship between certain aspects of the clinician's communication during the conversation and family satisfaction with the communication after the conversation (McDonagh et al., 2004; Selph, Shiang, Engelberg, Curtis, & White, 2008; Stapleton, Engelberg, Wenrich, Goss, & Curtis, 2006; White, Braddock, Bereknyei, & Curtis, 2007). However, these studies focused only on clinician communication and do not inform our knowledge of the interaction that occurs between clinicians and surrogate decision makers. Investigating the interaction is important because it may provide insight into how surrogate decision makers receive and respond to clinician communication during the conversation. Without analyzing surrogate decision makers’ responses to specific clinician utterances used in the interaction, it is difficult to determine which communication strategies can best assist the surrogate decision-making process.

One way to improve our understanding of healthcare communication is to use an innovative mixed-methods approach with both conversation analysis and event sequencing. Conversation analysis is a theory of interaction with methodological procedures for analyzing interactions, including clinician-patient communication, in disciplines such as sociology and linguistics. Conversation analysts qualitatively study the sequential organization of an interaction and examine how each utterance leads to another utterance in a conversation. Event sequencing, a quantitative method, could also be used to analyze the sequence of utterances as they occur in a conversation. Although either method would be a valuable approach to assess surrogate decision makers’ responses to specific clinician utterances, it is my contention that combining the methods would provide a robust and thorough qualitative analysis along with statistical analysis of important relationships. Studying communication with this mixed-methods approach—using conversation analysis and event sequencing—has not been previously described. The purpose of this paper is to describe conversation analysis and event sequencing and explain how integrating these methods strengthened the design of a study that explored communication between clinicians and surrogate decision makers in the intensive care unit.

Conversation Analysis

Conversation analysis is a theory of interaction with methodological procedures for analyzing interactions. A key assumption in conversation analysis is that interaction is structurally organized (Heritage, 1984). Participants in the interaction bring their competencies of this organization to the conversation, which influences their behavior as well as their interpretation of the behavior of others (Heritage, 1984). Speakers take turns during a conversation and even though there may be multiple participants in the conversation, there are minimal gaps between turns and minimal instances of overlapping talk (Schegloff, 2007). The reason for this outcome is that each participant is bringing their competence of the structure of conversation and following the organization accordingly.

A second assumption of conversation analysis is that contributions to interaction are contextually organized (Heritage, 1984). Context in this usage refers to the actions made by the speakers in the interactions. What a speaker says in a conversation is dependent upon what had just been said in the conversation. Likewise, what a speaker says also determines what will be said next in the conversation. As stated by Heritage (1984), “the context of a next action is repeatedly renewed with every current action” (p. 242). How a speaker interprets what was said informs what they will say next.

As interaction is both structurally and contextually organized, the third assumption is that no detail in the interaction can be “dismissed, a priori, as disorderly, accidental, or irrelevant” (Heritage, 1984, p. 241). The details of how something is said—not just what was said—are critical to the analysis (Hepburn & Bolden, 2013). Therefore, the data for conversation analysis comes from audio or video recordings of naturally occurring interactions to ensure that all of the details of the interaction are captured and retrievable. Other sources of data such as interviews, observational data recorded through field notes or coding schemes, or experiments involving manipulation of behavior, are insufficient for analysis because they lose important details of the interaction. There is a concern that these details may instead be replaced by idealizations of how the interaction occurred instead of how the interaction had actually occurred (Heritage, 1984). By using audio or video recordings of data, the interaction can be played repeatedly as well as transcribed in a way that represents what the interaction sounded like. Transcripts of the data indicate volume changes, pitch changes, and other features of the sounds of the interaction because every detail in the interaction is considered important.

The primary focus of analysis in conversation analysis is sequential organization or “any kind of organization which concerns the relative positioning of utterances or actions” (Schegloff, 2007, p.2). Utterances perform actions, such as requesting, announcing, questioning, etc., often through a single turn of talk (Clayman & Gill, 2012). The action of each utterance cannot be determined in isolation, but is informed by the sequences of actions in the interaction (Clayman & Gill, 2012). Sequences are courses of action implemented through talk (Schegloff, 2007). The analysis is focused on the actions accomplished by the utterances in an interaction, determined by their placement and context in the interaction.

To demonstrate the usefulness of exploring an interaction using conversation analysis, I will use the example of Stivers’ (2005) study of pediatrician-parent discussions of treatment for a child with a viral infection. Stivers (2005) found that when pediatricians discussed treatments (such as cough medicine and fluids), parents responded with minimal resistance; yet when pediatricians discussed not giving antibiotics, parents were more likely to respond with resistance and sometimes even demanded antibiotics. Some physicians provided antibiotics after such parent resistance, even though they are not indicated for a child with a viral infection (Stivers, 2005). In these situations, looking at family satisfaction would not be a useful outcome to assess the communication strategies because it is possible that parents who demanded and received antibiotics would be satisfied with the communication. In addition, the details of how physicians used different introductions to the treatment plan and how the family responded would be lost. Exploring the interaction using conversation analysis can therefore be valuable to improve our understanding of communication in the healthcare setting.

Event Sequencing

Event sequencing is a quantitative method for measuring and analyzing observed behavior. The “events” are the behaviors of interest in an interaction and the “sequence” of the events during the observation is the focus of analysis. There are two key components of event sequencing: 1) Systematic observation, and 2) Capturing the process of behavior and not just outcomes.

In order to measure the events in an observation, the observation needs to be systematic. Researchers need to identify the key constructs of the anticipated events in an observation, determine their research questions, and develop a coding scheme (Bakeman & Quera, 2011). Then, trained observers pilot the coding scheme and achieve reliability in their coding of the events in the observation. This “preplanning,” allows for development of an adequate measuring tool (the coding scheme) so that the observations are systematic (Bakeman & Quera, 2011).

Another important component of event sequencing is that the *process* of events are captured and not just the outcomes. Event sequencing captures the sequence of events as they occur over time in a continuous observation period (Bakeman & Deckner, 2005). Therefore, the contingency of events occurring is important to the analysis, and researchers can ask questions such as “When X occurs, what happens to Y?” (Bakeman & Quera, 2011). From capturing the sequence of events, you can calculate the transitional probability. The transitional probability is the probability of transitioning from one event to another in a sequence (Brown, Pridham, & Brown, 2014). Lag sequential analysis provides even more detail in that it examines not just the responding event (lag 1) after an initial event, but the second responding event (lag 2), third responding event (lag 3), etc. (Chorney, Garcia, Berlin, Bakeman, & Kain, 2010). Event sequencing therefore provides a more detailed analysis than correlational analysis (which only looks at whether two events are related) because there is a focus on how antecedent events can influence subsequent events in a sequence (Chorney et al., 2010).

In the context of health communication, event sequence analysis could be a valuable method to analyze the actions of the utterances said in a conversation as events. Similar to conversation analysis, the sequence of the actions (events) in the interaction could inform us about how a clinician's utterance leads to certain responses from patients, family members or other clinicians. Event sequence analysis additionally allows for the calculation of the transitional probability of one event leading to another in the interaction. Through "expansion," in which quantitative findings can expand on qualitative findings (Fetters, Curry, & Creswell, 2013), event sequence analysis can expand on the findings from conversation analysis by providing strong, statistical evidence of the likelihood of the sequence of events occurring in the interaction.

Combining the Methods

I combined conversation analysis and event sequencing in a study that analyzed communication between clinicians and surrogate decision makers about making a decision regarding life-sustaining treatment in the intensive care unit. I audio recorded, transcribed, and analyzed 36 clinician-surrogate decision maker conversations. Two of the study's specific aims were 1.) To determine how clinicians introduce the need for decision making regarding life-sustaining treatment and how surrogate decision makers respond and 2.) To determine the transitional probability of certain introductions preceding resistance.

Prior to conducting a mixed-methods study, it is imperative to determine whether the assumptions underlying each method are congruent, to allow for integration. Both conversation analysis and event sequencing require the use of naturally occurring data for analysis, and therefore analysis could come from the same data set. In addition, both methods are focused on the sequence of actions (or events) that occur in an interaction. An important assumption of event sequencing is the contingent relationships of events, which is also congruent with conversation analysis' assumption of interactions being contextually oriented. Due to these similar assumptions, these methods could be used together to analyze an interaction.

Another consideration in conducting a mixed-methods study is to determine how to integrate the methods. Sandelowski (2000) provided a variety of templates regarding priority and temporal sequence for integrating multiple methods in a study. Event sequencing requires pre-planning and the use of a coding scheme. For this reason, the integration template for the study was CONVERSATION ANALYSIS>event sequence analysis: conversation analysis was the priority method of analysis conducted prior to the event sequence analysis.

I engaged in a detailed and thorough conversation analysis of sequences from the conversations that involved clinicians introducing the need for decision making regarding life-sustaining treatment and surrogate decision makers responding to those introductions. While there were many actions identified in these sequences, I had narrowed my focus for quantitative data analysis to determining the transitional probability of certain decision proposals preceding surrogate decision makers' resistance to these proposals. Therefore, only clinicians' utterances that had the action of a decision proposal and surrogate decision makers' utterances that had the action of resistance or alignment with the decision proposal that were identified in the conversation analysis became the codes, or events, used for event sequencing (see Figure 1 for an example).

Figure 1: Process of coding from conversation analysis

```
1      M1:   The other thing we: need to address as well, (0.7) um like we
2            talked about this morning, is if his heart were to stop beating
3            [techn]ically:
4      F1:   [Mmmm?]
5      M1:   His code status is not dnr.
6      F1:   Right.
7      M1:   It's full code.
8      F1:   Mm [hmm?]
9      M1:      [Um  ] so if his heart were to stop beating, medically, there
10           would be personnel to go in, start compression:s, potentially
11           shock his heart, do more- (0.7) harm than
12     F1:   Mm hmm?=
13     M1:   =Potential [good]=
14     F1:              [I-  ]
15     M1:   =At this point.
16     F1:   Right. I understand that.
17           (2.5)
18     F2:   Yeah.
19           (0.7)
20     F1:   An:: y- yeah. We're both like no mm mrm. That's e- that's not
21     F2:   It's reached that already.
22     F1:   Yeah. It's not what we want to do.
23     M1:   Okay.
```

Conversation analysis		**Event sequencing codes**
1-5:	The physician starts with a preface that transitions to a different topic. The physician references a previous conversation and then provides an "if" statement. He finishes the phrase with a statement of the patient's current status along with the word "technically" which suggests the status could change.	
6:	The significant other aligns with this statement.	
7:	The physician repeats his previous statement ("Not dnr") in a new formulation ("it's a full code").	
8:	The significant other gives a continuer.	
9-11:	The physician restates the "if" statement and provides a list of actions of what would happen. The physician begins to provide a subjective description of these actions, with "do more harm than-"	
12:	The significant other provides another continuer.	
13-15:	The physician finishes the statement in line 11 with "potential good at this point." which is a judgment that tacitly acts as a **decision proposal** to not do those actions.	Decision proposal
16:	The family member indicates understanding.	
17:	There is a long pause here, which may indicate the physician Is waiting for a more affirmative statement or direction of what that means for how they should proceed.	
18-19:	A friend agrees, followed by a pause.	
20:	The significant other begins to explain their assessment of providing the treatment.	
21:	The friend aligns with the family member's statement.	
22:	The significant other **aligns** with the proposal.	Aligning
23:	The physician closes the sequence.	

Creating the coding scheme from the conversation analysis made the coding scheme robust, because it was developed from the data already analyzed and alleviated concern for choosing codes that may not occur or may not be relevant to the conversation. However, this integration template created a concern for reliability because a key component of event sequencing is piloting the coding scheme among researchers and ensuring consistency in the coding prior to the observation and data collection. In this study, the data was audio-recorded, so the coding scheme could be developed after data collection. In addition, only one person coded the conversations, and consequently it was not necessary to establish reliability among different coders. Another researcher with expertise in conversation analysis assessed the codes and the analysis from which they were derived to ensure validity. As mentioned previously, the codes came directly from the actions identified in the conversation analysis. The intention of integrating these analyses was to engage completely in a conversation analysis, and explore the relationships of crucial sequences quantitatively to add breadth to the data.

Results of Mixed-Methods Analysis

Conversation analysis was used to determine how clinicians introduce the need for decision making regarding life-sustaining treatment and how surrogate decision makers respond. Clinicians tended to introduce a decision-making conversation by using a perspective-display invitation (Pecanac, 2016). A perspective-display invitation is a part of the perspective-display sequence (PDS) that has been previously described in physicians’ presentation of a bad-news diagnosis (Maynard 1991, 1992). In the family conferences, the PDS had the following three components: 1.) The clinician asked the surrogate decision makers to share their assessment of the patient’s preferences, 2.) The surrogate decision makers shared their assessment, 3.) The clinicians incorporated the surrogate decision makers’ assessment into their decision proposal for life-sustaining treatment (Pecanac, 2016). By first asking about the patient, clinicians were able to introduce the need to make a decision in a delicate way. Surrogate decision makers responded with their assessment of the patient’s perspective, which clinicians used to assist in decision-making.

Event sequence analysis was the second method used to determine the transitional probability of certain introductions preceding resistance. The clinician introduction explored in the conversation analysis was the perspective-display invitation, which often led to a decision proposal. Therefore, the focus of the quantitative analysis shifted slightly to determine the transitional probability of certain decision proposals preceding resistance. Proposals that incorporated previously described patient preferences (such as with the use of the PDS described above) had a transitional probability of surrogate decision makers aligning to the proposal of .76 (Pecanac, 2016). In contrast, proposals in which the clinician asserted that the healthcare team was going to do or not do a treatment, had a transitional probability of surrogate decision makers resisting the proposal of .70 (Pecanac, 2016). There were no statistically significant differences of aligning or resisting responses to the proposals between surrogate decision makers of White or African American patients. Overall, surrogate decision makers tended to be more resistive to decision proposals that appeared to be paternalistic than to proposals that incorporated their view of the patient’s preferences.

Discussion

Combining conversation analysis and event sequencing allowed a more thorough story to be told with the data. The pattern of the PDS, in which clinicians introduced the need to make a decision by asking for the surrogate decision makers’ assessment and then used that assessment to make a decision proposal, was an important pattern found in the conversation analysis. The importance of how clinicians provided a decision proposal became evident, and this led to a change in focus of the events analyzed (from decision-making introductions to decision proposals) in the event sequence analysis. The event sequence analysis permitted evaluation of the probabilities of certain proposals preceding resistance or alignment to the proposal as part of the decision-making process. In addition, conversational patterns for different demographic variables, such as race of the patient, could be compared. I effectively combined conversation analysis and event sequence analysis to add to the knowledge of how clinicians discuss decision making regarding life-sustaining treatment.

Researchers could apply this mixed-methods approach to answer other research questions pertaining to healthcare communication. The utterances of interest of the presented study were surrogate decision makers' aligning or resisting responses to clinicians' utterances, due to the high prevalence of perceived conflict between surrogate decision makers and clinicians during the decision-making process (Schuster, Hong, Arnold, & White, 2014). However, it is possible to evaluate any type of utterance in the analysis, such as describing risks of a procedure, demonstrating understanding, acknowledging emotions, etc. There is also the possibility of initiating the conversation analysis without looking for certain utterances but exploring the data with an "unmotivated inquiry" to determine what seems interesting to analyze further (Clayman & Gill, 2012). A benefit of using conversation analysis before event sequence analysis is that something important may be discovered that may not have been previously considered. In the presented study, the variables of the quantitative analysis changed slightly based on the results of the conversation analysis, and researchers should proceed with a degree of flexibility to make changes that will strengthen the value of the quantitative data.

Researchers could use this mixed-methods approach to identify useful conversational practices and design interventions that would improve health communication. Conversation analysis findings have been used for “informal interventions” in which specific conversational practices have been recommended to clinicians in workshops and other educational avenues (Robinson & Heritage, 2014). According to Robinson and Heritage (2014), the next task in designing an intervention based on findings from conversation analysis (CA) is to “examine potential associations between CA derived interactional practices (transformed into variables) with outcomes” (p. 207). By initially designing the study with the intention of using event sequence analysis, one can collect the variables or outcomes of interest needed to examine associations and this next task can be done seamlessly after the conversation analysis. The findings from the event sequence analysis may provide the data necessary to engage in design and pilot testing of an intervention that would improve communication among members of the healthcare team or between clinicians and patients.

I would like to make a comment about conducting a study using conversation analysis. Conversation analysis is a method that requires years of training and practice. Researchers without experience in conversation analysis would need to collaborate with an expert in this methodology. However, this provides a wonderful opportunity to engage with researchers in other disciplines and to expand upon our own theoretical assumptions.

In conclusion, conversation analysis and event sequencing are two methods that can be combined to investigate healthcare communication. Conversation analysis provides a detailed analysis of the interaction between participants in a conversation. When combined with quantitative analysis of the patterns of communication in an interaction, this data will help to inform which communication strategies produce positive outcomes. All participants in a conversation contribute to and help to shape the interaction. Research methods need to reflect this reality of social interaction to enhance understanding and improve healthcare communication.

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Chapter 2

Doing Delicacy: Introducing the Need to Make a Decision about the Use of Life-sustaining Treatment

To be submitted to Health Communication

Page limit: 25 pages

Patients in the intensive care unit (ICU) often require life-sustaining treatments that replace a part or more than one part of the body that has ceased functioning (McGee, 2011). The hope for all patients is that life-sustaining treatments are used temporarily and can be removed once the patient recovers. However, there are times when a patient remains dependent on such treatments and is not expected to recover. In these situations, a decision needs to be made about whether to keep a patient on life-sustaining treatments or to discontinue the treatments, which will presumably lead to the patient's death. In the ICU, surrogate decision makers make most of these decisions, not the patient, due to severity of illness (Prendergast & Luce, 1997). Surrogate decision makers experience distress (Wendler & Rid, 2011) and even symptoms of post-traumatic stress disorder in making these decisions (Tilden, Tolle, Nelson, & Fields, 2001).

Clinicians often meet with surrogate decision makers during a "family conference" to discuss the need for making decisions about life-sustaining treatment. Unlike other medical interactions that begin with the reason for the visit and end with a treatment recommendation (ten Have, 1991), patients discussed in a family conference are often so severely ill that no treatment exits that could improve the patient's condition. Instead, the treatment options available are to perform a procedure that will sustain the patient on life-sustaining treatments indefinitely (potentially with little or no improvement expected) or to discontinue the life-sustaining treatments. Clinicians have the responsibility to not only disclose this bad news, but also engage the surrogate decision makers in choosing which of these difficult options they prefer for the patient during the family conference. Previous discourse analyses of the family conference have shown that the physician needs to present negative evidence of the patient's health status (Barton, Aldridge, Trimble, Vidovic, 2005) and establish consensus that the patient's status is terminal, before surrogate decision makers will discuss decision making

(Aldridge & Barton, 2007). The transition from the delivery of bad news about the patient's condition to the need to make a decision is therefore important for decision-making conversations to occur.

Even though clinicians present treatment options based on the patient's condition, treatment decisions are interactional work. Stivers (2005) found that parents influence pediatricians' treatment decisions, even when not invited to participate in the decision, by accepting or rejecting the proposed treatment. According to an American College of Critical Care Medicine and American Thoracic Society policy statement, clinicians should invite surrogate decision makers to participate in decision making about life-sustaining interventions, in a process known as "shared decision making" (Kon, 2016). Shared decision-making is based on the premise that clinicians have expertise about the treatments and the potential outcomes of each treatment decision, yet surrogate decision makers have expertise about what kind of life the patient would want to have. Clinicians, therefore, are called to work with surrogate decision makers to elicit preferences and collaboratively make a treatment decision. How clinicians begin engaging surrogate decision makers in discussing treatment decisions is unknown. The purpose of this study was to explore how clinicians introduce the need to make a decision about the use of life-sustaining treatment and how surrogate decision makers respond to these introductions.

Data and Method

Data include 36 family conference conversations audio recorded in 2 ICUs in an urban, Midwest community hospital. There were 2-26 people in each conversation. Participants in the family conferences included physicians, nurses, case managers, nurse practitioners, chaplains, ethicists, and family and friends of the patient. To examine cases of surrogate decision making, an inclusion criterion of this study was for all patients to be intubated on a breathing machine and subsequently unable to communicate and participate in the conversations. Additional inclusion criteria were for participants to be at least 18 years old and English speaking. When a family conference was scheduled, participants were recruited to be in the study. Each participant gave verbal consent to have the family conference audio recorded. This study was reviewed and approved by the University of Wisconsin-Madison's Health Sciences Institutional Review Board.

The average age of the patients discussed in the family conferences was 62.7 years old (ranged from 35-89). There were African American (66%) and White (34%) patients. The majority were admitted for an infection, lung condition, cardiac arrest, or neurological condition.

In most conversations (78%) there was no appointed surrogate decision maker (such as a power of attorney for healthcare) and the family members/friends needed to make the decision together, all as "surrogate decision makers" (unless stated otherwise). The audio recordings were transcribed using the conventions of conversation analysis to indicate how the talk was produced in the interaction (Please refer to Appendix IV for explanation of the transcription symbols). All names shown in the transcripts are pseudonyms to protect the participants' identities.

The conversations were analyzed using conversation analysis. We examined the interaction between participants in the conversation by examining their turns of talk. Talk "is better examined with respect to *action* than with respect to *topicality*, more for what it is *doing* than for what it is *about*" (Schegloff, 2007, p. 1). What an utterance "does" in a conversation is perform actions, such as requesting, announcing, questioning, etc. (Clayman & Gill, 2012). Sequences are courses of action in a conversation that get some activity accomplish (Schegloff, 2007). Conversation analysts look for patterns in interactions of how participants in the conversation work together to accomplish activities through certain sequences of actions.

The focus of this analysis was the following activity: introduction and receipt of the need for decision making regarding use of life-sustaining treatment. The decision-making conversations shown in this paper involve decisions about whether to place a tracheostomy, which is a device that allows a patient to remain on a breathing machine indefinitely. This option involves a degree of commitment because a patient may never be able to live without the breathing machine, making the patient bed-bound and needing to reside in a nursing home due to the dependence on others for most if not all personal care activities. The alternative option is to discontinue life-sustaining treatments, including the breathing machine, likely leading to the patient's death.

Analysis

The conversations had different structures of how the decision-making discussion was introduced. In a few conversations, the clinician only alluded to a potential need to have a decision-making discussion in the future, without pursuing this discussion in the current conversation. It seemed as though clinicians only alluded to decision making when more time was needed to determine whether the patient's condition would improve or worsen. An example is Transcript A (M1 is a physician and F3 is the sister-in-law of the patient).

```
A.
M1:   Now if things change (0.7) then we have to re discuss what we do and
      what we don't do, but for right now we'll carry on with everything that
      we're doing and if [something]=
F3:                      [Okay.    ]
M1:   =Comes up we'll-
CM:   °Yeah.°
M1:   We'll treat him.
F3:   [Okay.]
```

In other conferences, surrogate decision makers initiated the decision-making discussion by asking for the plan (often while the physician was discussing the patient's condition, indicating that they already understood the patient’s condition and were eager to know the next step) or by expressing concern that the patient’s condition would not improve or could be permanent. An example is shown in Transcript B (M1 is a physician, F4 is a sister of the patient).

```
B.

F4:   HHHHHH #I have to ask this#
M1:   Mm hmm?
      (3.5)
F4:   #Worse case scenario,#
      (2.2)
F4:   #If he doesn’t wake up in these seventy two hours,#
      (2.2)
F4:   #I know he won’t want to live like this.#
```

Despite these occurrences, the clinician transitioned into talking about decision making in the majority of the conversations. While clinicians used a variety of different mechanisms for the transition—such as introducing the different treatment options or describing considerations for decision making—a common pattern (42%) was the use of a perspective-display invitation, the first turn of the perspective-display sequence. The remaining analysis will describe the use of the perspective-display sequence to introduce the decision-making discussion about life-sustaining treatment.

The Perspective-Display Sequence

The perspective-display sequence (PDS) has been described previously as a device used by clinicians to avoid blatantly telling diagnostic news (Maynard, 1992). The PDS is a series of turns: 1) The clinician’s perspective-display invitation, 2) The recipient’s reply or assessment, and 3) The clinician’s report and assessment, which often incorporates the recipient’s assessment (Maynard, 1991). In this sequence, the clinician first asks the recipients their perspective of the situation (the perspective-display invitation) and when the recipient provides their perspective, the clinician can use this material to "agreeably fit clinical findings and diagnoses" (Maynard, 1991, p. 189) when providing their own assessment or diagnosis. The delivery of a bad news diagnosis is thus an interactional activity, in that the recipient's perspective is co-implicated in the clinician's presentation of the diagnosis (Maynard, 1992).

In the context of initiating the need to make a decision about life-sustaining treatment in family conferences, the turns of the PDS are as follows: 1) Clinician's perspective-display invitation of the patient's perspective, 2) The recipient's reply or assessment, and 3) The clinician's decision proposal, which often incorporates the recipient's assessment. As this corpus is of surrogate decision making, the clinician does not ask for the surrogate decision maker's own perspective, but rather asks for the surrogate decision maker's assessment of the *patient's* perspective for the particular situation. This allows for families and close friends to share their views of what the patient would want in the situation. The clinician can incorporate this perspective into his/her decision proposal about whether to continue or discontinue life-sustaining treatment.

An example of this PDS structure is presented in Transcript C. There are 4 people in this family conference: 2 physicians (M1 & M2) and 2 daughters of the patient (F1 & F2). They had discussed the patient's struggles in managing her chronic lung disease and that she is now on a breathing machine.

C.
M2: Do ↑you kno::w (1.0) her preferences (0.5) of the kind of quality of
life she would want?
F1: Mm ↓mrm.
M2: With the [mini]=
F1: [Sh-]
M2: =Discussions that you've had?
F1: Yes. She wouldn't want a- (1.0) this is no quality of [life. right?]
M2: [Ok. She]
wouldn't want to be on a machine,

```
10  F2: Correct.
11      (0.7)
12  M2: She if she:::: would not want to be >it makes it even more< wouldn’t
13      want to be in a nursing home,
14  F1: I (0.5) trie:::d I been trying to do that,
15  M2: And she would not- (0.7) what do you think.
16  F1: Until last ↑week when [she  ]=
17  M2:                       [Yeah.]
18  F1: =Wasn’t feeling well then the next day she feels okay then she
19      doesn’t,
20  M2: Right.
21  F1: Barb ok k- call family (0.5) services let’s get it- kick back in.
22  M2: The nursing home.
23  F1: Yes.
24  M2: [And she would not-]
25  F1: [Assisted  living  ] yeah.
26  M2: And she would not want that. (0.5) ↑Would she want that? ↓or [not]
27  F2:                                                              [One]
28      day she’d [want]=
29  F1:           [ No.]
30  F2: =It, one day she [wouldn’t.  ]
31  F1:                  [But no, not] to be taken care of laying in a bed
32      no.
33  F2: No.
34  F1: That’s no quality of life.
35  M2: Got it. So- so
36  F1: No
37  M2: Fam- um- (1.0) u::m phys- um- assisted living that’s a different
38      thing you’re still independent but- who doesn’t want a little help
39      here or the:re?
40  F1: Mm hmm.
41  M2: That’s not the issue. We can get to a point where if she’s on a
42      breathing machine and can’t get off it? she’s gonna need twenty four
43      seven, (0.2) lying in a bed kind a thing.
44  F1: Right.
45  M2: Ok? So that’s- we know that extreme. Where it is in the middle,
46      (0.7) we can kind of (0.7) have more discussions in what that (0.7)
47      would be .hhh but what I’m hearing from you based on your discussions
48      with her is (0.7) if she would not be able to be (0.5) able to
49      interact and be s::omewhat independent,(1.2) anything short of that
50      would not be a quality of life °she would have wanted.°
51  F2: [Correct.]
52  F1: [ Right. ]
```

In lines 1-2, the physician delivers the perspective-display invitation, which asks about the patient’s preferences of the kind of quality of life she would want. This is a yes/no question, and daughter 1 initially gives a “no” response (line 3). The physician then adds an increment “with the mini discussions that you’ve had?” (lines 4 & 6). It is possible that including “mini” demonstrates that although they may not have had ‘The Talk,’ a formal discussion to talk about advance directives or future plans, preferences could have been shared in “mini” discussions that they’ve had (notice the physician states that they’ve had mini discussions, instead of asking if they have had such discussions). After this increment, daughter 1 states “yes”, then elaborates by stating “she wouldn’t want a” (line 7). She abandons this utterance to give her assessment, “this is no quality of life, right?” (line 7). The physician proposes a candidate understanding of what the daughter means by “quality of life” by suggesting specific aspects of care that the patient would not want, including being “on a machine” in line 9 (which the daughter agreed with in line 10) and being “in a nursing home” in line 13.

In line 14, daughter 1 begins a story to demonstrate evidence of how the patient feels about going into a nursing home. The physician provides a continuation of the daughter’s story with a possible conclusion of the patient’s perspective, “and she would not” (line 15), however he abandons this conclusion to ask the daughter about the patient’s perspective. In lines 16-21, the daughter continues her story, seemingly from the physician’s contribution “and she would not”, by adding on “until last week” (line 16), at which point she demonstrates that the patient’s reaction changes day-to-day, depending on how she is feeling (lines 16-21). The physician clarifies that this story is still referring to the nursing home in line 22, to which the daughter initially agrees (line 23) and then in line 25 clarifies she is talking about assisted living. In line 26, the physician again tries to relate the story to a conclusion about the patient’s perspective by first stating that the patient “would not want that” but after a brief pause, asks if the patient would want it. Daughter 2 summarizes her view of the patient’s perspective in lines 27-30, connecting it back to the story that the patient’s perspective of the nursing home depended on the day and how she was feeling. In line 31, daughter 1 provides a more specific assessment of what she feels the patient does not want regarding the nursing home by stating "but no not to be taken care of lying in a bed, no." Daughter 2 agrees with this statement (line 33) and daughter 1 reaffirms that "that's no quality of life" for the patient (line 34), returning to the utterance that she initially used in line 7.

In line 35, the physician acknowledges his understanding of the patient's perspective and clarifies assisted living situations and how they do not relate to the patient's current situation (lines 37-41). The physician then describes a hypothetical scenario of the patient's current situation and uses the daughter's language "lying in a bed kind a thing" to put a potential patient outcome into the context of her assessment (lines 41-43). Daughter 1 aligns in line 44 and the physician continues to show his understanding of the daughter's assessment of the patient's preferred quality of life in lines 45-50. The physician is explicit in using the daughters' assessment by prefacing his understanding with "what I'm hearing from you" (line 47). Then he includes "based on your discussions" and "quality of life she would have wanted" which refer back to his perspective-display invitation ("Do you know her preferences of the *kind of quality of life she would want*? With the mini *discussions* that you've had?"). In overlap in lines 51 and 52, each daughter aligns to the physician's assessment, suggestive of an emphatic co-alignment.

The physician continued to discuss the patient's prognosis and poor health, and they decided that the patient would not want to be resuscitated if her heart stopped (not shown). The physician then discussed that the patient may get off of the breathing machine or may need to have a tracheostomy placed to continue supporting the patient on the breathing machine before stating the following:

```
148  M2:  She would still go to a nursing home, still go to a high ↑level
149       nursing home where they're taking care of her twenty [four seven. ]
150  F1:                                                       [And she'd be]
```

```
151          laying in a bed.
152   M2:   And she’d be laying in a bed.
153   F2:   (        )
154   M2:   And we could try to get her off but it’s: not quite easy with her
155         underlying problems.
156   F2:   Ri:ght.
157   M2:   My sense is she would not have <wanted that.>
158   F2:   Correct no.
```

In lines 148-149, the physician describes the situation with components of the conversation previously discussed: he mentions going to a nursing home and described the outcome as “taking care of her twenty four seven.” Daughter 1 interrupts this utterance to show her understanding that “she’d be laying in a bed,” (as the physician had previously described, “twenty four seven lying in a bed kind of a thing” in lines 42-43). The physician repeats this utterance in line 152, and in line 157 states “my sense is she would not have wanted that,” which functions as a decision proposal in that the physician is providing his assessment of what the patient would want, based on the previous conversation. Daughter 2 aligns to this proposal (line 158).

This example shows that the PDS can occupy more than just three turns of perspective-display invitation, surrogate decision maker assessment, and decision proposal. The daughters told a narrative as evidence of the patient’s preferences for quality of life. The physician attempted a few times to assert a candidate version of the surrogate decision makers’ assessment of whether the patient would want to be in a nursing home (line 15 and 26), but backed off to ask the surrogate decision makers and obtain more evidence. Thus, the physician seemed to be working hard to clarify what the surrogate decision makers were saying in order to gain an adequate understanding of the patient’s preferences. He then provided a summary of the patient’s perspective in lines 45-50 and later his proposal for treatment in lines 148-157, which directly incorporated utterances previously used, and situations previously described in the conversation.

Another example of this PDS structure is presented in Transcript D. There are 3 people in the family conference: physician (MD), mother of the patient (F1), and brother of patient (F2). They had just discussed the patient's history of having a progressive illness, and the physician explained that the patient had a "major" infection and subsequently needed to be on many different life-sustaining treatments.

```
D.
1   MD: Um and I- I guess the- the big question is the philosophical question
2       as to how aggressive to be:. It was my understanding, and (0.2) she
3       ↑kinda nodded her head with that but again it's hard when she can't
4       talk, that she didn't want to be on machi:nes
5       (0.7)
6   MD: O:r any artificial things. Can- can you tell me about that what she
7       said [before?]
8   F1:      [  Um   ] whe::n Dr. Sto- Stonestreet?
9       (1.0)
10  F1: Need to see [#uhhhhh#]
11  MD:             [There's-]
12  F1: [Stanstreet.]
13  MD: [Too  many- ] too many na:mes but yeah ((laughs))
14  F1: Stanstreet? [or   whatever   ]
15  MD:             [Yeah Stanstreet.]
16  F1: U:h came in ((coughs))
17      (1.5)
18  F1: She was uh- fairly: coherent, you know and being able to no:d or
19  MD: [ Mm  hmm  ]
20  F1: [Like shake] >something<. <And we asked her if (1.2) we pull the
21      breathing?> the ventilator out? A:nd she was in distress? Would she
22      want it back in and or a tracheotomy?
23  MD: Tracheostomy yes
24  F1: Ostomy?
25  MD: Yeah.
26  F1: And she said no.
27     (1.7)
28  MD: When was that conversation.
((Omitted 13 lines of mother trying to determine the day of conversation))
42  F1: Ummm and it ↑coulda been Friday too but
43  MD: Sure that's okay.
44  F1: ((laughs))
45  MD: But at such time is- she was- pretty clear?
46  F1: Mm hmm?
47  MD: Everybody thought that [ she ]=
48  F1:                        [Yeah.]
49  MD: =Was crystal clear about it.
50  F1: Yeah. He had a bit of an: accent then.
51  MD: Right.
52  F1: She didn't- quite understand it. >Lily said it
53      (1.0)
```

```
54  F1: And she agreed and ↑he was there and then is it Dr. Suishom?
((Ommited 13 lines of mother trying to determine name of doctor))
68  F1: Her if I saw her but >anyway< she- and then once he- uh- him and I
69      confirmed it? He spoke with her. And then she came in (0.7) and u::h
70      restated what was said,
71      (0.7)
72  MD: [Ok]
73  F1:>[Co]rrectly< so that was it.
74  MD: So that seems like a pretty [clear decision]=
75  F1:                             [ ((c o u g h))]
76  MD: =Then [not  to]=
77  F1:       [Mm hmm?]
78  MD: =Do the tracheostomy.
79  F1: No: I think that'd be too much for her.
80  MD: And if we get the tu:be out not to put it back in.
81  F1: Right.
```

The physician introduces the topic, which he describes as a “question” to demonstrate that it will need an answer. In line 3, he prefaces his own understanding of how to answer that question but then provides the evidence he has used for his understanding, which is the patient’s reactions in a prior encounter. He acknowledges the limitations of such evidence, but proceeds to give his assessment “that she didn’t want to be on machines” in line 4. There is a pause in line 5, which is an opportunity for the mother to respond. In line 6 the physician clarifies his understanding to include “or any artificial things,” and then seeks the mother’s assessment of these statements by using a perspective-display invitation in lines 6-7. In this perspective-display invitation, the physician is seeking more evidence about what the patient wants by specifically asking about “what she said before.” The mother responds by starting a story with “when Dr. Stonestreet,” but the upward intonation indicates uncertainty and after the pause in line 9, the mother explains a “need to look” at the board behind her, where all the doctors names are written (lines 10). She continues with the story in line 16 about a prior discussion, and notes that at the time of the discussion the patient was “fairly coherent,” and gives evidence as to why she believed she was coherent in lines 18-20. In the mother’s story (lines 20-22), she uses reported speech of the questions asked in the conversation, including the hypothetical scenario of whether she would want the ventilator back in if they pulled it out, as well as the question about wanting a tracheotomy. The physician repairs her use of tracheotomy by stating tracheostomy in line 23. In line 26, the mother finishes her story by using direct reported speech of her daughter's answer "and she said no." Direct reported speech may be used here to make the claim more robust or give evidence of what the patient had said (Holt & Clift, 2007)

There is a pause in line 27, which may indicate the physician's confusion about this recounted story because if the patient had been on the ventilator at the time of the conversation (this seems to be the case, because the phrases "*if* we pull the breathing, the ventilator *out*", and "would she want it *back in,*" indicate that it was *in* at the time), it would have been physically impossible for her to verbally say no. This may be why the physician probes about the timing of this conversation in line 28. There are a few turns of trying to determine the day (not shown), and the mother continues to express uncertainty about the day on line 42, and the physician alleviates her task of trying to determine the day in line 43. However, he continues to express concern about the evidence presented of what the patient wanted, and seeks confirmation that the patient was "pretty clear" in line 45. The mother acknowledges this in line 46, but the physician elaborates for further evidence of clarity in lines 47-49. The mother demonstrates evidence that the patient was clear by first acknowledging an issue of clarity in line 50 and then providing more details of the story of who-said-what in lines 52-54, which leads to her trying to find the name of another physician involved in the discussion (not shown). She continues the story in lines 68-69, including that the answer was "confirmed" initially by herself and Dr. Stanstreeet. She then shows further evidence of confirmation by another doctor restating what was said in lines 69-73, and states "so that was it" to show the end of the story.

The physician responds in lines 74-78 with his assessment of the story regarding the patient’s perspective, which functions as a decision proposal because it declares a specific treatment decision to not do the tracheostomy. The mother aligns with the decision proposal, elaborating with her own assessment in line 79. The physician continues with another assessment and decision proposal, “and if we get the tube out not to put it back in” (line 80). The mother aligns to this proposal in line 81.

This example of the PDS structure is a bit different from Transcript C because the physician initially gave his own understanding of the patient’s preferences (albeit, tentatively) prior to the perspective-display invitation. However, the introduction to the decision-making conversation is still focused on sharing the patient’s preferences, not on personal opinions of what to do or discussion of specific treatment decisions. The physician provided a more general understanding about what he thought the patient would want, regarding being “on machines” and “any artificial things,” and he asked the mother about “that” in the perspective-display invitation. It was the mother of the patient who then gave evidence of the patient’s perspective of specific treatment decisions (to not place a tracheostomy and to not re-intubate, if necessary) with a narrative account. In this example, the physician worked hard to clarify that the patient’s preferences were indeed clear, not only because he was concerned about the clarity of the patient’s preferences from his own encounter, but also because there was some erroneous information in the mother’s narrative. Once satisfied, the physician then incorporated her specific perspective into his decision proposal.

These examples provide demonstration of the interactional work being done here: the PDS is used to determine the surrogate decision makers’ assessment of the patient’s perspective in order to come to a treatment decision with the surrogate decision makers. After the perspective-display invitation, the surrogate decision makers produced an assessment of the patient's perspective, which often involved a narrative to provide evidence of knowledge of the patient's perspective. The clinicians demonstrated their understanding of that perspective and provided a proposal for specific treatment decisions.

A Closer Look at the Perspective-Display Invitation

It is important to consider the different formulations that the clinicians use for the perspective-display invitation. In Transcript C, the physician changed his initial formulation, "Do you know her preferences of the quality of life she would want?" to include "with the mini discussions that you've had?" in order to help the daughter construct an answer. Including this elicitation of discussions did assist the daughter in providing an assessment. In Transcript D, the physician asked about what the patient has "said before;" this also led to the mother providing an assessment. Asking about previous discussions with the patient was the most common type of perspective-display invitation:

E.
NP: Mrs. Dean just ta um (0.2) get your viewpoint now (0.2) you know him just as well obviously as Jerry, have you ever *discussed* with him what his wishes would be?
F.
M1:   And I wanted to know what- what your thoughts are as people who know her best if you've had any *discussions* with her about what she would want in this situation?
G.
M1:   Ok um did he at any point you know when you became his power of attorney *discuss* with you what he would- you know- did he *discuss* this kind of sit- situations or scenarios and what he would want done for himself?

Mentioning prior discussions with the patient provides discursive resources that the surrogate decision makers can use in constructing the patient's view or perspective, often with a narrative of the prior discussion.

There is one example when asking about discussions with the patient is initially unsuccessful in producing the surrogate decision maker's response of the patient's perspective (Transcript H). In this family conference, there are 8 people: 2 physicians (M1 & M2), nurse (RN), nurse manager (NM), case manager (CM), nurse practitioner (NP), and the patient's sister (F2) and brother (F1). The sister is the appointed surrogate decision maker. They had just discussed the sudden critical illness of the patient, which has led to the patient requiring multiple life-sustaining treatments. The patient has shown some improvement, but it is uncertain to what extent the patient will recover.

```
H.
1  M1: Have you had any discussions uh with Haley about uh these kind of
2      issues?
3  F2: We really haven't.
4  M1: Ok
5  F2: Um which is sur↑prising with all the illnesses that she's had that
6  CM: [Mm hmm]
7  F2: [   I  ] mean we never did and.
8      (0.7)
9  M2: What do you think about her (0.7) personality, let us sa:y when she
10     was eh up and about and healthy:, and you go and visit an- an older
11     u::h uncle or an aunt or cousin a:nd mean- usually this is when- when
12     the discussion comes up oh mean- mean like I remember that with my-
13     with my parents
[[Omitted 14 lines of physician telling story about his parents]]
28  F2: Well I- I'd have to say um we had an aunt,
29  M2: [Mm hmm. yeah]
30  F2: [ That   um  ] was pretty much on life support. and a lot of the
31      relatives would come and say ↑oh you know, she just- she just needs
32      to die.
33  M2: Mm hmm.
34  F2: A:nd Haley got very upset about that. Cause she said when it's time
35      to go, God will take her. (1.0) On the other hand um and- and she's-
36      she's very much a Catholic Christian. um (0.5) it- it bothers her
37      when you know plugs have to be pulled on people.
38  M2: Ok.
```

In this example, we can see that the physician mentions discussions with the patient in his perspective-display invitation in lines 1-2. The sister gives a mitigated disconfirmation over lines 3-7, adding that it is "surprising" which may suggest a realization that a previous conversation could be expected in this circumstance and yet they have not achieved that expectation. In lines 9-13, a different physician provides the surrogate decision maker a hypothetical way to answer the question, first inquiring about the patient's personality and then about previous experiences visiting older family members. This provides context for a discussion with the patient, as the physician adds, "Usually this is when the discussion comes up." After the physician shares his personal family story about an older relative with an illness, the sister is then able to share her own story of an aunt on life support (lines 28-37). In lines 31-32 the sister uses direct reported speech of relatives who would say "oh she just needs to die" to which the sister reported Haley (the patient) saying "when it's time to go, God will take her" (lines 34-35). In line 36, the sister states the patient's religion to reinforce the religious influence of the patient, which may have shaped this perspective. Then the sister gives her assessment of the patient's preference, "It bothers her when you know plugs have to be pulled on people" (lines 36-37), which is presented to show a contrast to the reported speech "when it is time to go, God will take her": the patient believes in God's actions producing the patient's death and not "pulling plugs" on people to produce their death.

In this example, asking the surrogate decision maker about prior discussions about "these kind of issues" did not lead to an assessment of the patient's perspective. However, asking about the patient's personality and prior scenarios of relatives with illnesses assisted the sister in determining her assessment of the patient's perspective because it provided a context for when these discussions might happen. Asking about discussions with the patient may produce the "best" evidence of the patient's perspective; however, when a formal "talk" did not occur, clinicians seem to ask surrogate decision makers to consider features of the patient or "mini" discussions or situations where informal comments may have been shared.

There are also conversations where the clinician seems to produce a perspective-display invitation, yet the surrogate decision makers do not provide their assessment. An example is Transcript I, which includes 8 people in the family conference: 2 physicians (M1 & M2), case manager (CM), nurse (RN), 2 brothers of the patient (F1 & F3), the patient's cousin (F4) and the cousin's wife (F2). Although the cousin was the designated power of attorney for healthcare, he had relinquished those duties to a brother (F1) 2 days prior to this meeting, but during the meeting they decided that they would all be more comfortable making the decision together (all 4 of them ended up signing the consent form for the tracheostomy at the end of the meeting). They discussed that the patient has lung disease and is weak, requiring a breathing machine. The physician has just discussed the possibility of placing a tracheostomy.

I.
M1: If we're all okay with that, we will proceed with that. but be↑fore
we even get there, I wanted to bring up something, .hhh is that what
Mr. James would want. We have to ask ourself this question. you guys
have known him for longer than we did.
F1: Mm [hmm.]
F2: [Mm] [hmm.]
M1: [And] the question here is .hhh e::h- e::h- eh- does:: Mr.
James like to ↑have a tracheostomy like this? and be sup↑ported on the
ventilator for I don't know how long, maybe a week maybe [five days]=
F2: [Mmm hmmm]
M1: =Maybe (0.5) two weeks [maybe-]
F1: [Mm hmm.]
M1: Maybe I don't want to say for the rest of his life [but]
F2: [Yes.]
M1: U::::h- I- nobody can tell [my- my-]=
F1: [Mm hmm?]
M1: =My thoughts that we may be [able]=
F2: [Yeah]
M1: =To get him off the ventilator [once we have the]=
F2: [O :: k a y]
M1: =[Tracheostomy in]
F1: [O k a : y]
M1: But (0.2) people are different, I've-
((sniff))
M1: [Seen people]=
F2: [Mmmm hmmmmm.]
M1: =Who said no I don't like to look like that I don't want to live like
that I don't- I would rather not live if this is the only way I can
[↑live]

```
30  F1: [Mmmm ] [hm.]
31  M1:         [So ] not knowing the patient before [coming]=
32  F2:                                              [Mm hmm]
33  M1: =In to the hospital not [knowing]=
34  F2:                         [Mmmmmmm]
35  M1: =The patient's .hhh personality actually I've never even had a
36      conversation [with Mr. James]=
37  F1:              [Mmm   ri:ght  ]
38  M1: = Because (1.2) mean I only get to see him
39     (1.2)
40  M1: [ In ]=
41  F2: [Yeah]
42  M1: =This [situ ]a[tions]
43  F1:       [Right] [yeah ]
44  F2: That's all.
45  F1: Mm hmm
46  M1:  So- so:: that's why we want to rely on- we like to rely on the
47       families who can [give us]=
48  F1:                   [Mmm hmm]
49  M1:  = A- a- an idea about their personalities and what their wishes were
50       and ↓all those things so
51  F3:  Ok.
52  M1:  Of course if there is a written statement that- that the patient
53       would put uh- out ahead of time, that could act as a guide for us to
54       [work on that]
55  F2:  [  O k a y   ]
56       (2.5)
57  M1:  So that's- that's basically where we- where we ↓are. and mean-
58       [mean]
59  F1:  [°Ok°]
60  M1:  Anything you want to add cause I'm (    )
61  RN:  I don't think so.
```

In line 1, the physician discusses the possible plan to proceed with the tracheostomy, contingent on the premise that all are in agreement with the plan (he includes himself with "we" statements, "we're all okay with that" and "we will proceed with that"). This could be a relevant place for the physician to pause and allow the surrogate decision makers to comment, yet instead he continues in lines 1-2 with a preface of something needing to be done before such a decision could be made. In lines 2-3 there is a first attempt to elicit the surrogate decision makers' assessment, "Is that what Mr. James would want." In line 3 the physician uses another "we" statement to emphasize that this is something everyone needs to consider. In lines 3-4, the physician begins to separate himself from the family by acknowledging that the family has known the patient longer than the healthcare team. This utterance implicitly invites the family to give their assessment, yet a brother and the cousin's wife respond with continuers (line 5 and 6) and the physician asks a more specific question in lines 7-9, "Does Mr. James like to have a tracheostomy like this? And be supported on the ventilator." The physician shows uncertainty with how long the patient will be on the ventilator, ranging from days to the rest of his life, in lines 9-15. He provides reassurance in lines 17-21 that they "may be able to get him off the ventilator once we have the tracheostomy in." After this reassurance, the physician provides reasons why people may not want to have a tracheostomy based on personal experience ("I've seen") in lines 23-29.

A brother provides another continuer in line 30, and the physician continues by again expressing the extent to which he does not know the patient in lines 31-42. This statement could be another implicit perspective-display invitation as it is an opportunity for the surrogate decision makers to give their assessment as people who knew the patient (unlike the physician) but a brother and the cousin's wife just align to these statements in lines 43, 44, and 45. The physician continues by explicitly explaining that they need to rely on families' perspectives (lines 46-50). This could also be hearable as an invitation for the surrogate decision makers to provide their ideas about the patient's personality and wishes; however, a brother responds, "Ok." (line 51). The physician then mentions the possibility of a written statement (line 52-54), which could be hearable as eliciting information of whether there is a written statement, and the cousin's wife responds with "okay" (line 55). After the pause in line 56, the physician seems 'stuck' and asks the nurse for her help in adding to the conversation (line 60).

Transcript I is different from the other transcripts in a few ways. First, the physician discussed the possibility of a tracheostomy prior to asking for the surrogate decision maker's assessment (not shown). However, the presentation of the tracheostomy was more informational than decisional, and the physician moves into the perspective-display invitation (he compresses the transition space) before giving the surrogate decision makers a chance to comment about the tracheostomy or discuss decision-making (Lines 1 & 2: "If we're all okay with that, we will proceed with that. But before we even get there…"). Second, the surrogate decision makers appear to refuse the physician's perspective-display invitations as invitations. Even though they are presented as statements rather than direct questions, they appear to still have the action of requesting information or inviting the surrogate decision makers' assessment. The surrogate decision makers do not respond to these as invitations—they do not share their assessment—but instead respond to them as statements, using continuers such as "mm hmm" and acknowledgment tokens such as "yeah" and "okay." It is unclear if withholding their assessment is intentional or a function of the design of the perspective-display invitation.

After the previous sequence, another physician (M2) asked the surrogate decision makers about the patient's usual mental status and health history and they discussed the patient's health behaviors when he was at home. M1 then redirected the conversation back to the patient's wishes, with another perspective-display invitation:

```
326  M1: So if we go back to ask- to- to ask the same question that I asked
327      before, what are your thoughts his wishes would be. Knowing- you
328      guys known him [for- for- for]
329  F1:                [Hhhhhhhhhhhhh]
330  F4:                        [Well-]
331  M1: For all your [lives so-]
332  F4:              [Me far as] I know about him,
333      (1.5)
334  F4: He may no:t-
335      (2.5)
```

```
336  F4: He might not like that but he would- he will accept it.
337      (1.0)
338  M1: Might not like it but he would [accept it.]
339  F4:                                [He  would ] accept it.
340  M1: °Yeah.° (0.2) °Yeah.°
341  F1: Mmm
342  F4: He sick? He accept it.
343  M1: Okay.
344  F4: Yeah he accept anything that help him.
```

The physician (M1) refers to the "same question that I asked before" (line 326), however he uses a more direct invitation by asking the surrogate decision makers "what are your thoughts his wishes would be" (line 327). After asking this question, he continues in lines 327-331 to acknowledge the reason he is asking, which is that the family has known the patient for "all your lives." The cousin prefaced his assessment using the same language as the physician: "far as I *know* about him" (line 332). After a pause in line 333, an abandoned utterance in line 334, and another long pause in line 335, the cousin produced his assessment "he might not like that but he would- he will accept it" (line 336). The physician repeats the utterance, without showing indication of accepting or rejecting the assessment, and this may function as a way to probe for clarification or more information for the assessment (line 338). The cousin repeats part of the utterance in line 339, and again the physician shows minimal acknowledgment in line 340. A brother makes an acknowledging sound in line 341 and again the cousin repeats his assessment with minimal elaboration of the reason why ("he sick?") in line 342. The physician acknowledges the assessment in line 343, although still minimally, and the cousin provides a bit more elaboration to his assessment in line 344. After this sequence, a brother (F1) tells a narrative that confirms this assessment of the patient's perspective (not shown).

Transcript I provides insight about the formulations of the perspective-display invitation as well as the surrogate decision makers' assessment. When the physician used a more direct question for the perspective-display invitation, a surrogate decision maker provided his assessment of the patient's wishes. This is in contrast to the tacit invitations used in the earlier sequence, which the surrogate decision makers did not respond to as invitations. The perspective-display invitation also asked for thoughts on what the patient's wishes would be, instead of asking about previous discussions (seen in other transcripts). In response to this invitation, the surrogate decision maker provided an assessment without giving a narrative or providing any other evidence for this assessment. It is possible that this lack of evidence led to the physician's minimal responses instead of explicitly acknowledging this assessment and then moving on to discuss treatment based on this perspective.

Also notable about Transcript I are the references to the surrogate decision makers' knowledge of the patient (lines 3-4, lines 46-50). This is a pattern in other perspective-display invitations from this corpus. In example E, the nurse practitioner had previously talked with Jerry, the patient's son, about the patient's wishes. Now she was addressing Mrs. Dean, stating "just to get your viewpoint now, you know him just as well obviously as Jerry" in order to elicit Mrs. Dean's perspective of the patient's wishes. In Transcript F, the physician states she wants to know "what your thoughts are as people who know her best." It is possible that by referring to the surrogate decision makers' knowledge of the patient, the clinicians are providing an account for asking for their assessment. In Transcript I, the physician bluntly states that he does not know the patient, which accounts for asking the surrogate decision makers' assessment of what the patient would want. Reinforcing that the surrogate decision makers have knowledge that the physician does not have may help surrogate decision makers understand the importance of their contributions to the discussion and to the decision making.

Discussion

In this corpus of family conferences, many clinicians introduced the need to make a decision about life-sustaining treatment by using a perspective-display invitation to determine the surrogate decision makers' assessment of the patient's preferences. Using a perspective-display invitation accomplishes a few important tasks for the decision-making conversation. First, asking about the patient orients the surrogates to consider the preferences of the patient (instead of the clinicians or the surrogate decision makers), which is important because the decision is being made on behalf of the patient. Second, asking about the patient is a delicate way to ease into decision making because it allows the surrogate decision makers to share insights into what kind of life the patient would want before the difficult decision is presented. This is in contrast to the possibility of a more abrupt approach of stating that a decision needs to be made, describing the options, and then asking about the patient's preferences. Third, asking for the surrogate decision makers' assessment prior to delivering a decision proposal helps to portray that the clinician is not all-knowing about what is best for the patient but rather is in need of information from the surrogate decision makers to make a proper proposal.

We found that the formulation of the perspective-display invitation seems to be important for surrogate decision makers to provide their assessment of the patient's perspective. Asking about prior discussions the surrogate decision makers have had with the patient seems to be useful for surrogate decision makers to provide their assessment of what the patient would want. Even though this formulation initially did not lead to an assessment of the patient's preferences in Transcript H, the physicians were able to assist the surrogate decision maker by providing more ideas of how to determine the patient's perspective. This example emphasizes the interactional work of these conversations, as the same formulation may not work in every situation; the clinician needs to work with the surrogate decision makers to help them elicit the patient’s perspective.

Perspective-display invitations that were constructed as direct questions instead of tacit invitations also appeared to be useful in enacting surrogate decision makers’ assessments. In Transcript I, the surrogate decision makers resisted the physicians’ tacit invitations. It has been noted that speakers who feel that the second speaker’s turn is an inadequate response work towards correcting the response through repair practices (Sidnell, 2010). Although the physician kept redesigning the invitation in an attempt to elicit a different type of response, he initially kept these invitations tacit, and only attempted a more direct invitation much later in the conversation. However, the use of tacit invitations may show how the physician is managing the delicacy of the question, which may be beneficial in these sensitive conversations. As previously stated, it is important for clinicians to attend to the interaction with surrogate decision makers and adjust their perspective-display invitations as needed.

Clinicians who use the PDS are engaging in shared decision making, which has been identified as a beneficial practice for surrogate decision makers. An intervention study found that when clinicians asked family members questions about who the patient was as a person, family members had fewer symptoms of anxiety, depression, and post-traumatic stress disorder 90 days after the death of the patient (Lautrette et al., 2007). In addition, the facilitated values model has emphasized that clinicians make an explicit “bridge” between stated values and recommended treatments (Scheunemann, Arnold, & White, 2012), which describes the third turn of the PDS—clinicians incorporating the surrogate decision makers’ assessment of the patient’s values into their decision proposal. The PDS practices identified in this study are therefore not surprising. However, the use of the PDS to introduce a decision-making conversation is interesting as it accomplishes not only the practice of shared decision making but also a subtle transition to asking surrogate decision makers to make a difficult treatment decision.

In conclusion, clinicians use the PDS—beginning with a perspective-display invitation—to introduce the need to make a decision about life-sustaining treatment. In doing so, they are “doing delicacy,” by asking about what kind of life the patient would want instead of directly discussing the grim options available. Hearing the surrogate decision makers’ assessment of the patient’s preferences is useful for clinicians to propose an appropriate treatment that aligns with such preferences. Decision making regarding life-sustaining treatment will never be easy, but devices such as the PDS may be useful for clinicians and surrogate decision makers to begin the decision-making discussion.

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Chapter 3

Decision proposals in the family conference

To be submitted to Critical Care Medicine

Word limit: 3000 words

Introduction

Surrogate decision making in the intensive care unit is a difficult process; at least a third of surrogate decision makers experience a negative emotional burden that lasts months or even years (1). While some emotional burden can be expected in these circumstances, surrogate decision makers have expressed frustration with the communication they receive from clinicians (2, 3). Due to the interest in improving communication, many studies have explored the family conference, when clinicians and surrogate decision makers discuss decisions about life-sustaining treatment. A review of this literature has included suggestions for organizing and conducting family conferences, such as acknowledging strong emotions and spending time exploring the family's reactions to what was discussed (4). Curtis and White (5) have also suggested communication practices, such as increasing the proportion of time spent listening to family rather than talking and assuring family that the patient will not suffer. These suggestions can provide general guidance of *what* to say or do, but not *how* to say or do it. It would be helpful for clinicians to know how to discuss important components of the conference, such as how to solicit the surrogate decision makers' understanding of the situation, how to introduce the need to make a decision about life-sustaining treatments, or how to propose a particular treatment decision.

By exploring the conversational practices in the family conference, we can decipher which practices help or hinder the surrogate decision-making process. As we were analyzing data to determine how clinicians introduced the need to make a decision about life-sustaining treatment (6), it became apparent that clinicians communicated differently about decisions to withdraw treatment from decisions to withhold treatment. For decisions to withdraw treatments, clinicians tended to follow a "perspective-display sequence" (7, 8): 1.) The clinician asked the for surrogate decision makers’ assessment of the patient’s preferences (often by inquiring about previous discussions with the patient), 2.) The surrogate decision makers provided their assessment, and 3.) The clinician incorporated this assessment into a decision proposal (6). However, for decisions to withhold treatments, such as CPR, clinicians tended to introduce the need to make a decision by directly proposing a decision for or against the use of a particular treatment.

As described in a shared decision making policy statement, The American College of Critical Care Medicine and American Thoracic Society suggest that clinicians offer to provide a treatment recommendation that takes into account the medical facts, the patient’s values, and the clinician’s judgment of what is medically appropriate (9). It is not yet known if clinicians offer recommendations or decision proposals in this fashion or how surrogate decision makers respond to such recommendations or proposals about life-sustaining treatment decisions. The purpose of this study is two-fold: 1.) To explore how clinicians make decision proposals about different life-sustaining treatments and 2.) To determine if certain decision proposals are more likely to lead to surrogate decision makers’ aligning with or resisting the proposal.

Methods

We audio-recorded 36 family conferences in a 24-bed general ICU and a 12-bed burn ICU at an urban, Midwest community hospital. We included family conferences about an intubated patient, in which all participants were 18 years of age or older and English speaking. We used convenience sampling to sample participants who were engaged in a family conference. When a family conference was scheduled, a member of the research team (KEP) approached each participant about the study and obtained verbal consent prior to audio recording the family conference. There were 20 eligible family conferences that were not audio recorded because a family member, physician, or nurse declined to participate in the study (35.7% refusal rate). This study was reviewed and approved by the UW Health Sciences IRB.

Of the 36 family conferences, there were 32 patients (patient demographic characteristics are presented in Table 1). For 4 patients, we audio-recorded 2 family conferences. To ensure diversity of conversation, we limited the number of family conferences led by each clinician to 10 family conferences. There were 2-26 participants in the family conferences. Participants included physicians, nurses, nurse practitioners, family members and friends of the patient, case managers, chaplains, and ethicists.

Table 1. Description of Patient Characteristics (n=32)

Age

Mean 62.7, Min-max 35-89

Race

66% Black

34% White

Admitting/primary diagnosis

31% Pulmonary issue

28% Infection (non-pneumonia)

19% Cardiac arrest

16% Altered mental status/stroke

3% Burn

3% GI bleed

This was a mixed-methods study; we first analyzed the data using conversation analysis (a qualitative method) and then event sequence analysis (a quantitative method). Conversation analysis is different from other qualitative methods in that the focus of the analysis is how participants interact with each other in the conversation, not just what was said in the conversation (10). Each utterance in the interaction has an action "that can be shown to have been recognized by co-participants as that action by virtue of the practices that produced it" (11). Examples of actions include asking, answering, disagreeing, offering, contesting, etc. (11). The actions of interest in this analysis were the clinician proposing a decision to do or not do a particular treatment and the surrogate decision maker aligning with or resisting the proposal. Actions such as sharing a judgment about the treatment or indicating a treatment plan were included as decision proposals because they are moves to engage in decision making about the treatment.

There were four different decision proposal formulations identified: giving personal recommendation to do or not do the treatment, emphasizing that the treatment wouldn't work or would cause harm, asserting that the healthcare team is going to do or not do the treatment, or incorporating previously described patient preferences into their proposal. The next utterance in the sequence was coded as one of the following actions: a surrogate decision maker response aligning to the proposal, a surrogate decision maker response resisting the proposal, or other. Actions such as changing the subject or remaining silent were considered resisting responses because they are moves to avoid aligning with the proposal. The "other" action included any utterance that followed the proposal that was not resisting or aligning to the proposal. These "other" utterances were not all responses by the surrogate decision makers but were often continuations of the clinician's own turn of talk after making a decision proposal. The analysis was shared with another researcher proficient in conversation analysis to ensure validity of the analysis. These actions identified in the conversation analysis directly served as codes for quantitative analysis (see Table 2).

Table 2. Action codes used for analysis

Code	**Example**
Decision proposal	
Giving personal recommendation to do or not do a treatment	"This is where I would recommend putting a trach in him."
Emphasizing that the treatment wouldn't work or would cause harm	"She's at the point where if her heart stops? Even all the electricity, all the stuff we do, it's not going to get her back."
Asserting that they are going to do or not do the treatment	"If his heart stops, then we just make sure he's comfortable and we don't do anything more."
Incorporating previously described patient preferences into their proposal	"And my guess is based on this and conversation, she would not want that."
Resisting the proposal	
When proposal was to do a treatment	"Well she's very clear about not wanting anything heroic."
When proposal was not to do a treatment	"I would really like to see if we could work with him in terms of taking care of his infections."
Aligning with the proposal	"That's what he wanted, so that's what he wanted, yeah."

The codes were entered into Noldus Observer XT, a software package that allows for coding behavior in observational data (12). The files were converted to Sequential Data Interchange Standard (SDIS; 13) format by the ObsTxtSds program (14) for subsequent analysis in the Generalized Sequential Querier (GSEQ) program. The GSEQ program was designed for analysis of sequential observational data (13), and therefore maintains the sequence of codes. We then calculated the transitional probability, the probability of transitioning from one action to another (15), as well as odds ratios to determine if aligning or resisting is more likely in the presence of a particular proposal than in its absence (13). Proportional difference tests were also calculated to compare transitional probabilities between type of treatment decision and patient race, using an exact two sample proportions binomial test (16).

Results

Due to our interest in comparing the types of decisions discussed, we dichotomized the decisions into two groups: decisions about withdrawing treatments (or placing a tracheostomy) and decisions about withholding treatments (such as CPR, intubation, further escalation of treatments). Not all conversations included decision proposals for both withdrawing and withholding decisions, and in some conversations, there were no decision proposals, even if withdrawing or withholding treatment decisions were discussed. The frequency of decision proposal formulations for both types of decisions is presented in Table 3. When discussing a decision to withhold treatments, clinicians used more proposals that emphasized that the treatment would not work or would cause harm (10 vs. 1). When discussing a decision to withdraw treatments, clinicians used more proposals that incorporated previously described patient preferences (14 vs. 3). Clinicians asked the surrogate decision makers for their assessment of the patient’s previously described preferences or wishes in 18 conversations when discussing withdrawing treatments and in only 2 conversations when discussing withholding treatments (however, they did not always give a proposal or recommendation based on these preferences).

Table 3. Frequency of decision proposal formulations

Proposal formulation	**Withdrawing decision** (n)	**Withholding decision** (n)
Giving personal recommendation to do or not do a treatment	11	7
Emphasizing that the treatment wouldn't work or would cause harm	1	10
Asserting that they are going to do or not do the treatment	3	7
Incorporating previously described patient preferences into their proposal	14	3
Total	29	27

The transitional probabilities of certain proposal formulations bringing about surrogate decision makers' resistance or alignment are presented in Table 4. The transitional probability of a proposal that incorporates the patient's previously described preferences leading to alignment with the proposal was .76. The odds ratio of an aligning response in the presence of this proposal was 28.27 (95% CI 9.71-91.72; p<0.01). The transitional probability of a proposal that asserts the healthcare team is going to do or not do a treatment leading to resistance was .70. The odds ratio of a resisting response in the presence of this proposal was 13.9 (95% CI 3.47-55.66; p<0.01).

Table 4. Transitional probabilities of proposals leading to resisting or aligning response

Proposal Formulation	Response	All Decisions
Giving personal recommendation to do or not do a treatment	Resisting	.22
	Aligning	.22
	Other	.56
		n=18
Emphasizing that the treatment wouldn't work or would cause harm	Resisting	.36
	Aligning	.36
	Other	.27
		n=11
Asserting that they are going to do or not do the treatment	Resisting	.70
	Aligning	.30
	Other	0
		n=10
Incorporating previously described patient preferences into their proposal	Resisting	.12
	Aligning	.76
	Other	.12
		n=17

Although there was a high transitional probability of alignment to proposals that incorporated patient preferences, there were instances where surrogate decision makers resisted these proposals. Surrogate decision makers who resisted the proposals often expressed the need for more time to make the decision or a desire to give the patient "another chance" (shown below). In the example below, the surrogate decision maker had previously described that the patient did not want to be in a nursing home (these wishes, along with concern for quality of life, were also included in an advance directive). The physician incorporated these preferences in his proposal and the surrogate decision maker resisted this proposal:

```
M1:   You know we can do a lot of things to people? But a certain point in
      their life, when they're older, and they have more problems, and their
      wishes are that they don't want all this done? Then I think
      the focus of what we do is not on- maybe curing something?
F1:   Mm hmm?
M1:   But kind of, you know, helping them go through the final process of
      their life with dignity and comfort, instead of kind of struggling on
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the ventilator, and you know being uncomfortable. We kind of have to put yourself in that place, is that what he would really want and I know you don’t want to lose someone and we don’t either? But you kind of have to look what they want. How would they want to react to the situation.

F1: I understand what you’re saying but I still want to give him another chance

There were no statistically significant differences in responses to proposals based on type of treatment decision (Table 5) or by race of the patient (Table 6). However, a notable finding is that surrogate decision makers of White patients had a higher transitional probability of resistance to proposals that emphasized that the treatment wouldn’t work or would cause harm than surrogate decision makers of African American patients (.67 vs. .25). In addition, giving personal recommendations to do or not do a treatment had a higher transitional probability of aligning responses in withholding decisions (.43) and a higher transitional probability of resisting responses in withdrawing decisions (.36). Interestingly, surrogate decision makers of African American patients represented all circumstances of aligning responses in withholding decisions and surrogate decision makers of White patients represented all circumstances of resisting responses and an aligning response in withdrawal decisions. A response other than resisting or aligning had a higher probability for both types of decisions (.55 & .57). Oftentimes this “other” response was the clinician providing an explanation for their recommendation before giving time for the surrogate decision makers to respond to the recommendation. Explanations often referenced an external, third-party agent, such as God or another physician. For example:

NP: I would recommend that we change to a do not resuscitate, which means that we’ll continue to get his breathing as good as it can be to get that tube out and let him have some good time, but if- if God says, the heart stops and we haven’t gotten there yet, then we let him go at that point. And that would be con- we would call that a do not resuscitate.

Table 5. Transitional probabilities by treatment decision

Proposal Formulation	Next Utterance	Withdraw Decision	Withhold Decision	Proportional Difference	p-value (95% CI)
Giving personal recommendation to do or not do a treatment	Resisting	.36	0	0.36	0.10 (-0.12, 0.69)
	Aligning	.09	.43	-0.34	0.17 (-0.73, 0.12)
	Other	.55	.57		
		n=11	n=7		
Emphasizing that the treatment wouldn't work or would cause harm	Resisting	1	.30	0.7	0.39 (-0.36, 0.98)
	Aligning	0	.40	-0.4	0.83 (-0.81, 0.64)
	Other	0	.30		
		n=1	n=10		
Asserting that they are going to do or not do the treatment	Resisting	.67	.71	-0.05	1 (-0.71, 0.53)
	Aligning	.33	.29	0.05	1 (-0.53, 0.71)
	Other	0	0		
		n=3	n=7		
Incorporating previously described patient preferences into their proposal	Resisting	.14	0	0.14	0.83 (-0.52, 0.46)
	Aligning	.79	.67	0.12	1 (-0.35, 0.71)
	Other	.07	.33		
		n=14	n=3		

Table 6. Transitional probabilities by race

Proposal Formulation	Next Utterance	White	African American	Proportional Difference	p-value (95% CI)
Giving personal recommendation to do or not do a treatment	Resisting	.36	0	0.36	0.10 (-0.12, 0.69)
	Aligning	.09	.43	-0.34	0.17 (-0.73, 0.12)
	Other	.55	.57		
		n=11	n=7		
Emphasizing that the treatment wouldn't work or would cause harm	Resisting	.67	.25	0.42	0.31 (-0.28, 0.87)
	Aligning	.33	.38	-0.05	1 (-0.59, 0.62)
	Other	0	.38		
		n=3	n=8		
Asserting that they are going to do or not do the treatment	Resisting	.67	.71	-0.05	1 (-0.71, 0.53)
	Aligning	.33	.29	0.04	1 (-0.53, 0.71)
	Other	0	0		
		n=3	n=7		
Incorporating previously described patient preferences into their proposal	Resisting	0	.17	-0.17	0.50 (-0.49, 0.36)
	Aligning	.80	.75	0.05	0.98 (-0.49, 0.45)
	Other	.20	.08		
		n=5	n=12		

Discussion

Clinicians made decision proposals differently based on the type of treatment decision discussed. Clinicians were more likely to ask the surrogate decision makers their assessment of the patient’s previously described preferences and to provide decision proposals that incorporated such preferences when discussing withdrawing treatments. In comparison, clinicians were more likely to emphasize that the treatment would not work or would cause harm when proposing to withhold treatments. Decision proposals that incorporated the patient’s previously described preferences were more likely to result in surrogate decision makers’ alignment whereas proposals that asserted the healthcare team was going to do or not do a treatment were more likely to result in surrogate decision makers’ resistance. There were no statistically significant differences between resistance and alignment to proposals for type of treatment decision or race of the patient.

The way surrogate decision makers responded to the different decision proposals is not surprising based on what we know about surrogate decision makers’ perceptions of treatment recommendations. White and colleagues (17) found that 42% of surrogate decision makers preferred not to receive a physician recommendation in situations of limiting life support because they felt that it was beyond the role of the physician or that the physician could not know enough about the patient to make a recommendation. However, utilizing a perspective-display sequence by first asking about the patient and then incorporating the patient’s preferences or values into the recommendation or proposal may attend to this concern because the recommendation develops from a shared activity. In other words, the clinician is not taking a dominant role in producing the recommendation or proposal because it is not derived entirely from the clinician’s perspective; it includes the family’s perspective of what the patient would want.

Deflecting complete ownership of the decision proposal seemed to be a common practice. Clinicians who used a personal recommendation formulation (e.g. “I recommend…”) tended to provide an explanation that used an external agent (most commonly, God) for their recommendations. Even though they took personal ownership for the recommendation, this was tempered by appealing to some sort of “higher power” in their explanations for recommending a certain treatment plan. Proposals that emphasized that the treatment would not work were also framed to be more aligned with limitations of the human body than the clinician’s personal views or values of the situation. Clear exceptions to this lack of ownership pattern were proposals in which the clinicians asserted that they were going to do or not do something, which surrogate decision makers often resisted. Clinicians may therefore incorporate outside influences to their proposals—the patient’s wishes, God, limitations of the patient’s body—to avoid the perception of an assertion of a treatment plan and subsequent resistance from the surrogate decision makers.

There may be situations, however, when a more assertive approach may be warranted. There were instances when surrogate decision makers resisted decision proposals that incorporated the patient’s preferences. Scholars have contended that “physicians’ strongest ethical obligation is to ensure that decisions are made in accordance with patients’ values” (17). In circumstances where surrogate decision makers do not appear to be making decisions that are congruent with the patient’s preferences, wishes, or values, it might be acceptable for clinicians to take a more assertive stance.

Clinicians’ decision proposals were different based on the type of treatment decision discussed, which may indicate different perceptions of the need for surrogate decision makers’ level of involvement in the decisions. Surrogate decision makers have expressed a preference for significantly more control over a “value-sensitive” decision about life support, compared with a “technical” decision about choice of antibiotics (18). Clinicians in this study were less likely to ask about patient’s values for decisions about withholding treatments, such as CPR, and instead more likely to use decision proposals that emphasized whether the treatment would work. It is therefore possible that clinicians consider decisions to withhold treatment as more technical than value-sensitive.

There has been some discussion in the literature about surrogate decision makers’ involvement in decisions about CPR when resuscitation is unlikely to provide any benefit, with suggestions to give the surrogate decision makers a choice to defer the decision to clinicians (19) or to inform them that CPR will not be performed and check for dissent to that action (20). This latter suggestion is similar to the decision proposal of asserting that the treatment would not be done, and clinicians might use this approach to avoid the perception of choice and subsequently minimize the potential for disagreement with the plan. However, in this study resistance was high when such assertions were made, as surrogate decision makers still demonstrated an ability to disagree with the assertion and negotiate the decision. Similar resistance was found in a study of treatment recommendations for a child with a viral infection; parent resistance to nonantibiotic treatment decisions demonstrated that these decisions were negotiations that required parent acceptance (21), even though they were not value-sensitive decisions. Further research should explore how surrogate decision makers perceive their role in decisions to withhold treatment compared to decisions to withdraw treatment.

This study has several limitations. The number of decision proposals in the conversations was small, which likely contributed to the lack of statistical significance of the findings. Data were also collected in one hospital. It is possible that the culture of this hospital affected how decision proposals were communicated to surrogate decision makers. In addition, only African

American and White patients were represented in the sample. Responses to decision proposals should be explored with a larger, more diverse, sample.

This study offers insight into how clinicians give decision proposals and how surrogate decision makers' respond to these proposals. There is evidence to suggest that incorporating the patient's previously described preferences into a decision proposal leads to surrogate decision makers' alignment to those proposals. These results strengthen the need for clinicians to engage with surrogate decision makers in shared decision making to determine the best treatment decision for the patient.

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Chapter 4

An Exploration of Nurse-Family Communication after Family Meetings in the ICU

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Word limit: 3000 words

Introduction

Nurses are increasingly being recognized for their key role during end-of-life decision making. According to the American Nurses Association, “Nurses need to remain in the forefront as leaders and advocates for the delivery of dignified and humane end-of-life care. They must be prepared to provide compassionate guidance and support for patients and their families in making quality of life choices throughout the lifespan, especially those pertaining to the end of life” (p. 31).[1] However, nurses have expressed a lack of clarity about how to perform this role as a barrier to participating in surrogate decision-making discussions for a patient in the intensive care unit (ICU).[2-5]

To engage nurses in the surrogate decision-making process, White suggested five roles: educate the family about the role of the surrogate, organize regular meetings between the family and the multidisciplinary team, prepare the family for each multidisciplinary meeting, provide emotional support and ‘nudges’ during the multidisciplinary meeting, and facilitate the “meeting after the meeting.” The” meeting after the meeting” occurs informally between the nurse and family, and is a time when nurses interpret for the family information physicians had just provided in the ‘formal’ meeting between the physician and the family.[6]

The suggested roles specify actions that nurses can own to participate in the surrogate decision-making process, particularly pertaining to the family meeting. Family meetings have been extensively studied to identify how to improve communication with families.[7-,10] However, these studies have excluded the nurse-family communication that occurs after the meeting. Therefore, how nurses communicate with families during these informal conversations is unknown. The purpose of this paper is to explore the nurse-family communication in the meeting after the meeting.

Methods

Thirty-six family meetings were audio-recorded and analyzed using conversation analysis. We conducted recruitment and data collection in a 24-bed general ICU and a 12-bed burn ICU at a community hospital in an urban Midwest city. IRB approval was obtained from the University of Wisconsin-Madison Health Sciences IRB.

When a family meeting was scheduled, a member of the research team recruited participants in the meeting for the study. Participants were eligible if they were English speaking, 18 years of age or older, and involved in a family meeting of a patient who was intubated (making the patient unable to fully participate in the meeting). If any participant did not meet these criteria, the family meeting was not included. We obtained verbal informed consent from all participants prior to audio recording the family meeting. The audio recorder was started at the beginning of each family meeting. If a nurse was present, audio recording continued after the physician had left the room to collect nurse-family communication after the family meeting. The patient's nurse documented the patient's age and race for demographic data.

To accurately identify each voice in the audio recording during transcription, a member of the research team was present during the family meetings with a hand-held computer loaded with the WorkStudy+ program.[11] The input format on the program was designed with a button for each type of participant in the family meeting ("physician", "family member" etc.). When a participant spoke, the corresponding button was pressed. The program documented the sequence of each participant's talk in the interaction, which we referred to during transcription. We transcribed audio recordings using the transcription method developed for conversation analysis.[12]

Data were analyzed using conversation analysis. Conversation analysis is “an approach within the social sciences that aims to describe, analyze and understand talk as a basic and constitutive feature of social life.”[13] In conversation analysis, the focus is not only what is said, but includes the details of how something is said[12], to answer the questions of what is being done and how it is accomplished.[14] Every utterance is doing a particular action, such as asking, answering, disagreeing, offering, etc.[15] After an utterance there is a response, which also performs an action that allows us to see how participants interpret and understand the actions of the previous utterance in the interaction.[15] This method of analysis was especially useful to determine what nurses’ utterances were doing in the meeting after the meeting and how families responded to those utterances.

Results

Nurses were present during 15 family meetings (42%). There were only 2 meetings after the meeting. The patients discussed in both meetings were African Americans in their 50s.

The first example is after a family meeting with 8 people: 3 physicians, a case manager, an ethicist, a nurse, the patient’s daughter, and the patient’s sister. During the meeting, the physicians explained that the patient was experiencing multi-organ failure and this is “one of the last chapters of her life.” The physicians asked the family whether they wanted to continue ventilation with a tracheostomy or withdraw the patient from the ventilator. The family shared their thoughts about both options and expressed uncertainty about the “best” option. The final decision was for the family to talk amongst themselves and then regroup with the healthcare team later. The conversation in Figure 1 took place with the sister (F2), daughter (F1), and nurse (RN) in the room after the meeting.

Figure 1

```
RN:   Do you guys need anything from me at this point?
      (0.5)
F1:   [↑Um]
RN:   [Any] clarifi↑cation of anything, anythi:ng
      (0.7)
      ((door closes))
      (0.7)
RN:   You want [to talk about? any-  ]
F2:            [Just trying to absorb] everything that’s been sai:d
      [that’s all.]
RN:   [Which  is- ] which [ is  ]=
F2:                       [Yeah.]
RN:   =The hardest part. [Everybody::]
F2:                      [ Mm   hmm. ]
      (0.5)
RN:   Jus- lot of people talking, lot of information shared back and forth.
      (1.2)
RN:   .hh Mean if you need clarifi↑cation of anything o:r you know just let
      me kno:w.
F2:   Kay.
      (0.2)
F2:   I [appreci]ate-
RN:     [We can-]
      (1.0)
RN:   We can talk it out.
F2:   All right. Thank you.
RN:   A:l:righty.
      (0.5)
RN:   U:m if you need me, I’m here until three thirty- call me- anytime.
      [Oka::y?]
F2:   [Okay.  ] Thank you [so much.]
RN:                       [And I’ll] grab some more klennex for [you guys.]
F2:                                                             [All right]
      then.
```

In line 1, the nurse offers her assistance, “Do you guys need anything from me at this point?” The daughter starts an utterance with “um” in line 3, but it is in overlap with the nurse attempting a second offer, with a suggestion of how she can help, which is to “clarify anything.” She begins another utterance in line 4 with “anything.” There is no response in line 5, a door closes (likely one last person in the room), and a pause in line 7. Line 8 is produced as a continuation of line 4, with a third offer, “Anything you want to talk about?” The sister interrupts by providing an account for not accepting the offer in lines 9-10. The nurse expands upon the sister’s explanation of “trying to absorb everything” in lines 11 and 13, and the sister acknowledges this in lines 12 and 14. There is a slight pause in line 15, and then the nurse provides an additional account for needing to absorb everything in line 16. There is a pause in line 17. The nurse provides her fourth offer in lines 18-19, repeating the possibility of needing clarification, and adds “just let me know” potentially showing that this offer extends to a later time. The sister acknowledges this in lines 20 and expresses appreciation in line 22. The nurse provides another offer in line 25 with “we can talk it out”, and the sister acknowledges and states “thank you” which can be an attempt to close the conversation. The nurse acknowledges in line 27, then gives a final offer in line 29, as well as provides her availability. She ends the utterance with the understanding check, “okay?” and the sister acknowledges, and upgrades her thank you to “thank you so much” to reinforce closing the conversation. The utterance that the nurse is going to grab Kleenex in line 32 may indicate that the daughter, who is mostly silent during this exchange, is crying or visibly upset.

The second example is after a family meeting with 26 people: 2 physicians, a case manager, a nurse, and 22 family members of the patient (not all could be identified, but there were 2 sons, a daughter, and a sister). During the meeting, the physicians conveyed that the patient was in an irreversible coma, and asked the family whether the patient would want to continue living in that state. There was a lot of tension and yelling between family members and some family members left the room before the meeting was finished. The final decision was for the family to talk amongst themselves and then regroup with the healthcare team later.

Due to the large number of participants in the room constantly coming and going, we do not know who is in the room when the conversation in Figure 2 occurred, but the speakers are a sister (F2), daughter (F1) and nurse (RN). The physician has just shown the daughter and the sister the patient’s CT scans, which indicate a worsening intracerebral bleed. It is possible that the physician is still in the room for the duration of this interaction, however he does not engage in the conversation.

Figure 2

RN: Yeah I’m sorry for you too.
F2: Thank [you.]
RN: [Must] be tough.
(0.5)
RN: #So sorry?#
(2.0)
RN: It’s a h:a:rd conversation come ↓here. ((RN hugs F2))
(3.0)
((cough))
(1.7)
RN: I’ll pray for you.
(0.5)
RN: And I’ll pray for your family after I leave today ( ) ok?
F1: ↑O↓kay.
(1.0) ((RN begins to hug F1)
F1: No I- don’t touch- I know you mean well. [Just touching is just=
RN: [Oh I know you don’t like all=
F1: =[Irritating me.]
RN: =[The touching] gotcha gotcha no problem, I’m sorry.
((door closes))
F1: Thank you [though, I appreciate it.]
RN: [You betcha- I’m a pray] for you. [All of you.]
F1: [All of you] being here.
RN: Your sisters too sure.
(1.5)
RN: #Okay.#
(0.5)
RN: All right.
(1.2)
RN: I’m gonna be back in the room.

In line 1, the nurse offers empathy to the sister. The sister receives this offer with “thank you.” The nurse offers more tokens of empathy in lines 3 and 5, with no response from the family. The nurse offers more empathy in line 7, and the “come here” is referring to the nurse offering the sister a hug. They hug, and there are long pauses in lines 8 and 10, with no verbal response. The nurse offers to pray for the family in line 11 and after a short pause in line 12, expands on praying for the family in line 13, ending with an understanding check, “ok?” The daughter offers minimal response in line 14. In line 15, there is a pause and the nurse goes to hug the daughter. In line 16, the daughter refuses the hug, then provides a palliative “I know you mean well” and an account for the refusal, “just touching is just irritating me.” The nurse interrupts before hearing the explanation, starts with a change of state token “oh” and indicates her understanding of the daughter’s refusal. The nurse then acknowledges and apologizes in line 19. In line 21, the daughter provides another palliative by thanking the nurse, and the nurse aligns and again offers to pray for the family. The daughter expands on her thank you in line 23, whereas the nurse expands upon her offer to pray for the family in line 24. There is no response to this offer, which leads the nurse to start to close the conversation with “okay” in line 26 and “all right” in line 28, without response. The nurse then tells the family where she is going and leaves the room.

These two situations are similar in that the nurse is offering something and the family is refusing that offer. In the first example, the nurse was offering to clarify information and talk about what they discussed in the family meeting. The family, however, refused the offer and minimized their need for assistance from the nurse. Even after multiple attempts to offer her assistance, the family did not accept these offers. In the second example, the nurse is offering empathy, verbally (with very minimal family response) and physically by hugs. The sister hugged back but did not verbally respond, and then the daughter verbally and physically refused the hug, followed by palliatives and an explanation. The nurses in both situations ended the interaction by stating where or when they will be available after they leave the room, possibly to offer assistance if the family needs them later. This may be because in both situations, the family does not seem interested in continuing their interactions with the nurse at that time.

While these were the only examples of the “meeting after the meeting” between nurses and family, there was another interaction when a palliative care nurse practitioner arrived at a family meeting late and stayed and talked with the family after the meeting. Although this was not a nurse-family interaction, it is important to include because similarly to the above examples, the family did not accept the offers of assistance and kept moving to close the conversation. There were 7 people in the family meeting: 2 physicians (M1 & M2), a case manager, a nursing student, a nurse practitioner (NP), the patient’s sister (F1) and the patient’s significant other (F2). During the meeting, the physician emphasized the poor state of the patient’s chronic lung disease, which they expected to continually decline. The healthcare team had been unable to wean the patient from the ventilator, and they asked whether the patient would want to have a tracheostomy or not. The family stated they wanted to proceed with a tracheostomy, but wanted a few more days to give the patient a chance to wean off the ventilator. The conversation in Figure 3 begins when the nurse practitioner first arrived.

Figure 3

M1: Debra you want ta? Anything- I’m leaving.
NP: Um I apologize I’m Debra from palliative care? [and]=
F2: [Okay.]
NP: =I’m- I’m a resource for you too as far as information, I’m .hhh a big
picture person? [And]=
F2: [Okay?]
NP: =So: I can certainly help you if you have questions if there’s
something you don’t understand I’m available to you to kind of explain
that a little bit more in detail so-
F2: Do you have a card?
NP: I do. (0.2) I do yes. So um-
M1: Okay if you don’t mind I will just be
((Omitted lines of M1 leaving))

NP: You know what we look at then is really quality of life. And- you know
qual- life quality is so important to all of us, it’s the reason we get
↑up in the morning and you know if- if there’s no quality in our life
the days can be pretty lo:ng. You know just um- .hhh so and- an- you
know him best? and so <↑you can help> in- in his sted to kind of decide
life quality, you know what was important to him and ↑that’s all gonna
play into your decision as you think about this and look at the whole
big picture is .hhhh you know who- who is Jordan and what would he-
what would he want if he <knew toda:y> what things were gonna look
like. Because that’s what’s hard. >Nobody ever imagined this. You never
imagined, ↑he never imagined he would be in this [position.]
F1: [Right.]
NP: So it’s really hard to know exactly what- what he would do? But you
know certainly knowing him as well as you ↑do you’ll have some insight,
um in working through this as to what he- he would want um (0.7) just
by knowing who he is.
(0.7)
NP: So
(2.0)
NP: Um
(0.7)
F2: Hhhhh
(0.5)
NP: And as I said and you know any of the more technical things? You know
sometimes I can help to break them down a little bit for you? If- if
there’s things that you’re not quite understanding I certainly would be
happy to help with that.
(0.7)
NP: From the- some of the medical things too I should have more- little
more time to do that.
(1.0)
NP: So
F1: Yeh we’re okay for now.

The physician invites the nurse practitioner to talk in line 1, and the nurse practitioner first apologizes for her tardiness, then introduces herself and explains her role in lines 2-5. Then the nurse practitioner offers answering questions and explaining things in more detail in lines 7-9. The significant other asks for a card in line 10, which could be seen as a move to close the current conversation with the nurse practitioner because she is showing interest in contacting the nurse practitioner later. The nurse practitioner might also receive this as a move to close the conversation because she acknowledges that she has a card but does not provide it (she provides it at the end of the conversation) and attempts to continue the conversation with “So um.” A physician stating he had to leave in line 12 interrupts this utterance.

In lines 15-25, the nurse practitioner discusses quality of life and what the patient would want in the situation. The sister responds with “right” in line 26. The nurse practitioner suggests that the family has “some insight” of what the patient would want. There are pauses in lines 31, 33, 35, in between the nurse practitioner’s attempts to continue the conversation with “so” and “um” in lines 32 and 34. These pauses are opportunities for the significant other or sister to take a turn in the conversation, but they do not. The significant other audibly exhales in line 36. Then the nurse practitioner offers her assistance with understanding the “more technical things” in line 38. There is a pause in line 42, and the nurse practitioner expands on this offer in lines 43-44. There is a long pause in line 45, and then the sister refuses the offer in line 47.

Discussion

These findings show that there were very few instances where the nurse was with the family right after the family meeting. When present, the nurse was not well received during this time. Whether the nurse was offering clarification or showing empathy, the family seemed to resist these offers. It does not appear that this occurs only for bedside nurses, as a palliative care nurse practitioner also offered her assistance and the family did not accept this offer at the time.

The time immediately following the family meeting may not be the best time for nurses to engage with families. After receiving information from the physician, likely including bad news, the family may need this time to absorb the news together before they are ready to continue the discussion with the nurse. According to Schaffer and Norlander, it may take time for families to understand and accept the bad news, adding, “It is the nurse who journeys along with them to support the process of coming to terms with their new reality” (p. 46).[16] Nurses may best support families by initially giving them time to be with each other, while also showing that they are available when the family is ready.

A limitation of this study is that, although 36 family meetings were recorded, only 2 meetings between the nurse and the family occurred. The interactions analyzed had different situations and family reactions, yet in each, the family was encouraged to ask questions and the physicians answered these questions. It is possible that families would want to have immediate clarification from nurses in situations where the family does not feel comfortable asking the physician questions or is not satisfied with their answers. Further research is needed to determine circumstances in which families would welcome discussion with the nurse immediately after the family meeting.

Another limitation is that the study only captured nurse-family communication immediately after the family meeting in the same space where the family meeting occurred. This limitation may account for the few nurse-family conversations; more conversations would be expected based on the evidence in the literature that they occur. Nurses have described the importance of their role to reinforce, re-explain, or provide additional information to families after their meeting with the physician.[3, 17, 18] Surrogate decision makers have also described nurses as valuable for clarifying information after the physician had left.[19] It is likely that many of these “meeting after the meeting” conversations take place at the bedside, perhaps long after their meeting with the physician. Further research is needed to explore nurse-family communication at the bedside.

Another reason for the small sample of meetings after the meeting is that nurses attended less than half of the family meetings. These findings are similar to other studies; in a survey, only 24% of nurses reported “often” attending family meetings, and 19% reported “often” participating in family meetings.[4] Many barriers have been identified for the lack of nurse participation, including need for more training,[4] physicians not inviting nurses to attend the meeting nor asking for their perspective,[3,4] nurses feeling undervalued or underempowered,[3] and lack of time due to patient care duties.[2-4] To address some of these barriers, Nelson and colleagues have advocated for work system changes including enculturating physicians and nurses about the importance of nurse participation and planning for coverage of patient care duties during a family meeting.[20] A communication workshop for bedside nurses has also increased nurse confidence and skill with contributing during family meetings and nurses reported feeling empowered to participate in such discussions.[5] Additional interventions that address these barriers will be important for nurses to have a role in surrogate decision making regarding life-sustaining treatment.

In conclusion, nurses who attempted to interact with families immediately after the family meeting were met with resistance. It is possible that families need time to absorb the information and provide each other support. Further research is needed to determine if it may be better for nurses to have the “meeting after the meeting” with families at the bedside, after allowing families such time.

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Discussion

The findings of this dissertation study contribute to our understanding of surrogate decision making regarding life-sustaining treatment. I found that clinicians tend to introduce the need for decision making by initiating a perspective-display sequence: clinicians use a perspective-display invitation to determine surrogate decision makers' assessment of the patient's preferences, surrogate decision makers' provide their assessment of the patient's preferences, and then clinicians incorporate this assessment into their decision proposals about the use of life-sustaining treatments. Using this approach, clinicians are delicately easing into a decision-making conversation because they are not outright telling surrogate decision makers that they need to make a decision. Surrogate decisions makers thus responded with their perception of the patient's preferences, not with resistance to the need to make a decision. Clinicians were also demonstrating shared decision making by constructing their decision proposals with surrogate decision makers' assessments. Surrogate decision makers were more likely to align to proposals that incorporated the patient's preferences. In contrast, surrogate decision makers were more likely to resist proposals where the clinicians asserted they were going to do or not do a treatment.

In addition to these important findings, this was the first study to explore nurse-surrogate decision maker communication after the family conference. There were very few instances where nurses talked with the surrogate decision makers immediately after the family conference. When they did, nurses tried to offer information/clarification or acts of empathy; however, surrogate decision makers refused these offers. In fact, surrogate decision makers often moved to close the conversation or provided some indication that they did not want to continue their interaction with the nurse.

Limitations of this study have been described in previous chapters, but the central limitation was the small sample size of 36 family conferences. If I had more family conferences, it is possible I would have had more decision proposals to include in my event sequence analysis as well as more “meetings after the meeting” to analyze for nurse-surrogate decision makers’ interactions. The initial goal was to have 40 family conferences, which was not only comparable to the sample size of other event sequencing studies (Bakeman & Quera, 2011), but also seemed reasonable based on the speed and success of recruiting 10 family conferences in 5 weeks during my feasibility study.

I was only able to collect data on 36 family conferences in 1 year because I experienced a few unexpected recruiting issues. In the year since I had conducted the feasibility study, there had been tremendous turnover of both nurses and hospitalists. The hospital is structured so that intensivists are never attending physicians but only consulting physicians. The hospitalists are usually the attending physician (unless the patient has an attending from a specialty, such as cardiology, neurology, or surgery, although many of these specialties transfer attending responsibilities to the hospitalist if sufficient time has passed since the patient’s MI, surgery, etc.). Therefore, obtaining buy-in from the hospitalists was critical to the success of this study. Luckily, the director of the hospitalist had not changed, and he distributed information about my study to the hospitalist staff. However, there was still quite a bit of concern from the new hospitalists about who I was, what I was doing, and whether my study was going to cause problems for their relationships with surrogate decision makers; all valid concerns. It took time to gain trust, which delayed my data collection, but I feel my presence on each unit everyday was helpful and eventually many hospitalists became more comfortable with the study.

Another unexpected recruitment issue was the presence of young children in the family conferences. I decided to exclude family conferences with participants less than 18 years old because minors are not legally able to act as surrogate decision makers or able to give consent. I did not feel this would significantly affect my recruiting because there were no children in the family conferences of the feasibility study and I assumed people would not bring their children to such a sensitive and difficult discussion. However, there were many family conferences where children were expected to be present and therefore I could not recruit family members of these conferences. In some instances, everyone consented to be in the study, but then the last participant came with a child and I could not audio record the family conference. I considered changing my inclusion criteria, but I decided not to because I believe that such an experience would be difficult enough for a minor that I did not feel it was appropriate to engage with them about participating in research. I also feel that adding the hassle for the parents to discuss this with their children was more than I could ask them to do. For these reasons, despite not reaching my recruiting goal, I believe this was an appropriate exclusion criterion.

Another potential concern is that those who agreed to participate in this study were more likely to align with clinicians' decision proposals than those who refused to participate. The refusal rate of this study was 35.7%, and it is possible that clinicians or surrogate decision makers who refused to participate did so because of apparent discord with each other, which could have led to more resistance displayed in the family conferences. While possible, some surrogate decision makers who participated in the study expressed frustration with clinicians and their communication, and they disclosed that they wanted to participate because they believed that the communication needed to be improved. In two family conferences, surrogate decision makers described their discontent with clinicians. Therefore, it cannot be assumed that all the surrogate decision makers who participated in the study were satisfied with the communication or the clinicians.

Future Directions

My long-term goal as a researcher is to improve the surrogate decision-making process for life-sustaining treatment decisions in the ICU. If clinicians use the PDS to introduce the need to make a decision and provide a decision proposal, surrogate decision makers may be more likely to align to such proposals and less likely to perceive conflict with clinicians. Therefore, a logical next step would be to design an intervention based on my findings, to promote the use of the PDS. I would like to acknowledge a few concerns I have about the state of the science prior to planning a possible intervention.

Through learning about conversation analysis, I have not only learned how to do this method, but also how to see the world through a different lens. An assumption of conversation analysis is that interaction is structurally organized and individuals bring their competencies of this organization to their interactions (Heritage, 1984). We do not need to think about these competencies however, they are part of our common sense or habits. When we ask people to change their choice of communication in an interventions study, we are asking them to think about their choice of communication. A conversation analyst described his experience of conducting an intervention study: “Many of the interactional behaviors of participants in conversation appear to occur below their level of conscious awareness, and one feature of the intervention approach described here is that it aims to make participants more conscious of these behaviors” (Wilkinson, 2011, p. 42). While asking people to think about what they say is reasonable, let us consider the communication suggestions that are currently in the literature about how to improve communication in family conferences.

There have been many tools and tables developed with the intention to improve communication in family conferences. In an article about “practical guidance” for family conferences, Curtis and White (2008) provided a table of 8 components (such as giving empathetic statements and providing explicit support for the family’s decision), and a description of the VALUE mnemonic (Value family statements, Acknowledge family emotions, Listen to the family, Understand the patient as a person, Elicit family questions). A review of the literature (Lautrette, Ciroldi, Ksibi, Azoulay, 2006) included a table with 30 elements of suggestions for preparing for, planning, and ending the conference, 21 of which are suggestions for communication (such as to provide honest and meaningful information about the prognosis without discouraging hope and to avoid the temptation to give too much detail about pathophysiology as a way to deal with our own discomfort).

While potentially helpful to clinicians, remembering the 8 elements or the 21 suggestions or even the VALUE mnemonic seems overwhelming. Heritage and Robinson (2011) conducted an intervention study in which they had primary care clinicians change just one word: instead of “Are there *any* other concerns you’d like to address during this visit?” they had clinicians say, “Are there *some* other concerns you’d like to address during this visit?” They had issues with clinicians making this change because it felt less “natural,” even though it was only a change of one word (Heritage and Robinson, 2011). By having clinicians attend to multiple communication suggestions, they would be so conscious of what they “needed” to say that they might not really be present in the interaction and responding appropriately to the surrogate decision makers.

In their article, Curtis and White (2008) do caution against the communication becoming too protocolized and robotic, and state that communication needs to be adapted to respond to the needs of the surrogate decision makers. My concern is that the more suggestions clinicians try to incorporate into the family conference, the more they are thinking about their own communication and the less they will be thinking about the surrogate decision makers' communication in the interaction. It is quite possible that this was an issue for the nurses in the meeting after the meeting: they felt it was their "duty" to be there for the family and offer information or empathy, which may be why they kept providing offers even though the family members kept indicating they were not interested.

Despite these concerns, I still think I could incorporate the use of the PDS from my findings into an intervention for a number of reasons:

1) I noticed that clinicians were already using the PDS to introduce the need to make a decision and to make decision proposals. It is considered best practice to ask about patient preferences (Kon et al., 2016), and it is likely that physicians, especially palliative care physicians or intensivists, have already received training to incorporate preferences into treatment recommendations or decision proposals. However, an intervention could still be warranted due to the following observations :
    a. The way that clinicians are incorporating the elicitation of patient preferences into their conversations with the PDS structure, as an approach to introduce decision-making, seems to be beneficial for the conversation.
    b. Clinicians of other specialties who have these conversations (such as nephrologists, cardiologists, and hospitalists, as seen in this sample) may not receive similar training.

   c. Some clinicians used the PDS to introduce the need to make a decision about withdrawing treatment in some circumstances but used a different approach in other, similar circumstances. This discrepancy needs to be explored further to determine if this is an issue of training or not.

2) Surrogate decision makers tended to align to decision proposals that incorporated patient preferences. It is reasonable to assume that this alignment between surrogate decision makers and clinicians would lead to less dissention and conflict. The subsequent negative consequences that surrogate decision makers and clinicians experience from conflict could be reduced. In addition, the incorporation of patient preferences is helpful for treatment decisions to be rooted in what the patient would have wanted.
3) The PDS incorporates many of the communication elements and suggestions from previous studies (see Figure 1). Clinicians who learn how to do the PDS would be simultaneously using other suggested communication strategies, with only needing to remember one 3-turn sequence.

Figure 1: The PDS incorporating components and suggestions for communication in the family conference

Don't let the family feel like they have decided to "pull the plug" on a loved one[2]

Provide honest and meaningful information about the prognosis without discouraging hope[2]

Provide consistent communication from different team members[1]

Acknowledge and address family emotions[1]

Affirm nonabandonment of patient and family[1]

Explain the principle of surrogate decision making to the family[1]

Empathetic statements[1]

Acknowledge strong emotions[2]

Before finishing the discussion about end-of-life care, summarize the major points and ask family members if they have questions (tolerate silences, wait for questions[2]

Use reflection to show empathy and to encourage discussion about the emotion[2]

Family should understand that care is maintained even when treatments are limited; separate life-sustaining treatment from comfort care[2]

Incorporated into PDS

Explore and focus on patient values and treatment preferences[1]

Listen and respond to family members[1]

Provide explicit support for decisions made by the family[1]

Increase proportion of time spent listening to family rather than talking[1]

Find out what the family understands; give them the opportunity to describe the patient's life and medical history[2]

Align the clinicians' and the families' view of what the goals of care should be[2]

Listen to what families have to say[2]

Repeat what patients or families have said as a way to show that clinicians heard them[2]

Don't describe all possible treatment options equally reasonable: make recommendations[2]

Review what the family knows about the patient[2]

Identify areas of uncertainty and disagreement between the family and the team[2]

Introduce everyone to be sure that everyone knows each person's role[2]

Frame the discussion by saying that it is commonly held for severely ill patients[2]

Make the family as comfortable as possible about discussing dying and death[2]

Assure family that the patient will not suffer[1]

Avoid unnecessary technical jargon, use the terms "dying" or "death"[2]

Avoid the temptation to give too much detail about pathophysiology as a way to deal with our own discomfort (unless asked by the family)[2]

Stress the specific palliative treatments that can be offered when the goals of care change from cure to comfort[2]

Tolerate silences that can precede difficult questions or expressions of emotions[2]

[1]Curtis & White (2008); [2]Lautrette, Ciroldi, Ksibi, & Azoulay (2006)

For these reasons, I believe it would be worth designing and pilot testing an intervention to determine the feasibility of teaching the PDS along with clinicians learning the PDS, and whether the PDS can produce positive outcomes, such as reduced conflict and reduced distress among all involved in the surrogate decision-making process.

For nurses, more research is needed regarding their role in the decision-making process, particularly their communication with surrogate decision makers. It might be prudent to explore if nurses have perceived that surrogate decision makers need time after the family conference, which may explain why so few nurses approached them immediately after the conference. In addition, it would be helpful to capture bedside conversations between nurses and surrogate decision makers. Collecting data on nurses' conversations at the bedside would likely be a methodological challenge, but would help to fill a gap in our knowledge of how nurses assist surrogate decision makers in the decision-making process.

Current interest in nurse communication has involved creating a new role: a communication facilitator. Communication facilitators are nurses or social workers trained to improve communication between the ICU team and surrogate decision makers, which have led to reduced length of stay and costs of care for decedents (Curtis et al., 2016). Although these results are positive, this "intermediary" role is already considered a part of the bedside nurse's role as the patient's (or in this circumstance, the family's) advocate (Pecanac & Schwarze, 2016). Many of the tasks of the communication facilitators: meeting with family to understand their concerns and needs, providing the family communication and emotional support, and participating in family conferences (Curtis et al., 2016), should already be tasks of the bedside nurse. However, nurses interviewed about their perception of the communication facilitators expressed enthusiasm because they never had the time to do these task themselves (Howell, Nielsen, Turner, Curtis, & Engelberg, 2014). We need to address systems issues that preclude nurses from doing these tasks already in their domain. Further research should explore whether training all bedside nurses to do these tasks effectively and providing a system that allows them to do these tasks efficiently would be less resource-intensive and more cost-effective than using communication facilitators.

In conclusion, I believe the findings of this study provide an important foundation for future research. As a previous critical care nurse, I have personally been affected by the negative consequences of the surrogate decision-making process, and therefore I am committed to improving this process for all involved. It is my hope that with developing new communication strategies for all clinicians, including nurses, I can bring about positive change.

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Appendix I: Glossary of Terms

Two of these papers will be submitted to journals for critical care practitioners and researchers. Therefore, they include terminology that will be easily recognizable and understandable to the audience of the journals. This section will clarify such terminology for those who do not share this critical care background.

Weaning the patient from the ventilator: Patients are put on ventilators when they are unable to breathe on their own. As soon as possible, health care practitioners want to remove patients from the ventilator and have them breathe on their own again. The process of determining whether a patient would be able to tolerate breathing on his/her own is called “weaning.” Generally, the patient is placed on a lower setting of the ventilator and if the patient is able to tolerate this lower setting, the patient is placed on an even lower setting, until eventually the ventilator is removed. If a patient is unable to wean from the ventilator, this means that the patient is requiring a fair amount of support from the ventilator and not tolerating being placed on a lower setting.

Intubate: The majority of patients are initially placed on the ventilator connected to an endotracheal tube, which is inserted in the patient’s mouth down into the trachea. This action is known as “intubation.” If a decision is made not to put the patient on a ventilator, the patient is considered “DNI” or do not intubate.

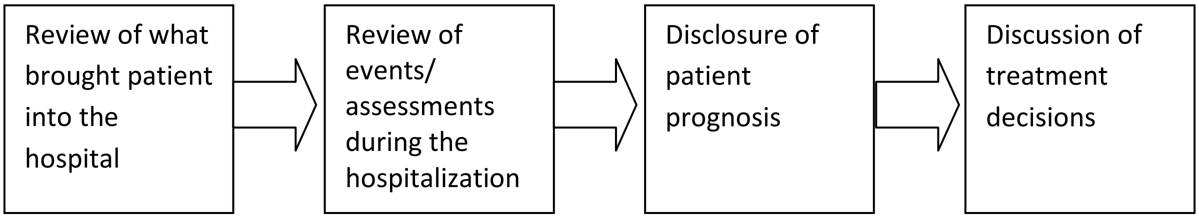
Tracheostomy: Due to the high risk of infection and esophageal scarring, the endotracheal tube inserted during intubation is not used permanently. If a patient has required prolonged ventilation and is unable to wean from the ventilator, the endotracheal tube needs to be removed and the patient will need to be connected to the ventilator with a more permanent option. This permanent option is a tracheostomy, a tube that is inserted directly through the neck into the trachea. A patient can remain on a ventilator with a tracheostomy indefinitely. The concern in placing a tracheostomy is that the patient requires a high-level nursing home and could subsequently remain in their current health state indefinitely (which many times involves very minimal cognition or ability to interact with others).

Terminal extubation/withdrawing the patient from the ventilator: If a patient has required prolonged ventilation and is unable to wean from the ventilator, the family does not have to have a tracheostomy placed. They can instead choose a terminal extubation or to withdraw the patient from the ventilator (these phrases mean the same thing). In a terminal extubation, the patient is taken off of the ventilator (the ventilator is “withdrawn”) with the expectation that the patient will pass away. The focus of care shifts from attempting to cure or manage the patient’s condition to providing the patient comfort at the end of his/her life.

Code status/CPR/DNR: The patient’s code status refers to whether the clinicians would engage in cardiopulmonary resuscitation (CPR) or not. If a decision is made to perform CPR, the patient is considered a “full code.” If a decision is made not to perform CPR, the patient is considered “DNR,” which stands for do not resuscitate.

Appendix II: Overview of Conversations

There were 36 conversations audio recorded and included in this study. Of these 36, there were 32 patient scenarios (2 conversations were audio recorded for 4 patient situations). There were 2-26 people in each conversation. Participants included physicians, nurses, nurse practitioners, family members and friends of the patient, case managers, chaplains, and ethicists. Physicians of multiple specialties (critical care/pulmonology, palliative care, hospitalist, family practice, cardiology, neurology, nephrology) usually introduced discussion of treatment decisions; however, there were times when discussion of treatment decisions was initiated by other members of the healthcare team, such as a nurse practitioner or case manager. The conversations were 5:52-43:42 minutes long. The structure of the 36 conversations tended to occur with the following sequence of events:



Usually the physician reviewed what brought the patient into the hospital and the events during the hospitalization, but there were times when the physician asked the family to share their understanding of these occurrences. After the family provided their perspective, the physician clarified or added important information as needed. The disclosure of patient prognosis may have involved the prognosis to survive, return to their previous health state, or simply that more would be known about the patient’s prognosis after a certain amount of time or certain events occurred. The discussion of treatment decisions included whether to place a tracheostomy, withdraw the patient from all life-sustaining treatments, perform CPR, intubate the patient, perform a life-saving procedure, and escalate treatments.

There were some exceptions to this structure (as described in Chapter 2). In 5 conversations, family members initiated discussion of treatment decisions during review of what brought the patient into the hospital or review of events/assessments during the hospitalization. In 5 conversations, the physician only alluded to the potential need to discuss treatment decisions at a later time, without asking for a decision at that time. However, treatment decisions were at least mentioned in every conversation.

A patient’s written wishes (in an advance directive) were mentioned in 5 conversations. In 7 conversations, a power of attorney was identified. In all other conversations, the family needed to make a decision together.

The outcome of the majority of conversations (22 [61%]) about whether to place a tracheostomy or withdraw the patient from the ventilator was to have the family talk amongst themselves and meet with the physician later. In 8 of these conversations, the delay was due to uncertainty about whether the patient would improve. In 14 of these, the family wanted to have more time to talk with each other and decide. In contrast, all decisions about code status were made during the meeting, with no additional time needed.

Appendix III: Description of Sample

Description of Patient Characteristics (n=32)

Age

Mean 62.7, Min-max 35-89

Race

66% Black

34% White

Admitting/primary diagnosis

31% Pulmonary issue

28% Infection (non-pneumonia)

19% Cardiac arrest

16% Altered mental status/stroke

3% Burn

3% GI bleed

Description of Surrogate Decision Makers

Power of Attorney for Healthcare (n=7)

Daughter/son	2
Sister	1
Niece	1
Cousin	1
Significant Other	1
Friend	1

Appendix IV: Transcription Notations

The following transcription notations are adapted from the following publication: Hepburn, A., & Bolden, G. B. (2013). The conversation analytic approach to transcription. In J. Sidnell & T. Stivers (Eds.),*The handbook of Conversation Analysis* (pp. 57-76). Oxford: Blackwell.

Brackets: overlapping talk

```
M1: Maybe I don’t want to say for the rest of his life [but ]
F2:                                                    [Yes.]
```

Talk that occurs at the same time is shown using brackets, lining up when the overlapping talk started and ended for both speakers.

Equal signs: latching

```
MD: Everybody thought that [ she ]=
F1:                        [Yeah.]
MD: =Was crystal clear about it.
```

Talk that continues with a discernible silence between two turns.

Period: falling intonation

```
 F2: We really haven’t.
```

The turn of talk ends with falling intonation.

Comma: slightly rising intonation

```
 F1: I been trying to do that,
```

The turn of talk ends with slightly rising intonation.

Question mark: strongly rising intonation

```
 M1: Have you had any discussions uh with Haley about uh these kind of
     issues?
```

The turn of talk ends with strongly rising intonation.

Underlying: emphasis

```
 MD: Can- can you tell me about that what she said before?
```

Talk that is underlined indicates some sort of emphasis or stress.

Degree signs: quiet speech

```
 M2: Anything short of that would not be a quality of life °she would have
    wanted.°
```

Talk that is markedly quiet is surrounded by degree signs.

Arrows: rising or falling pitch

```
   M2:  She would still go to a nursing home, still go to a high ↑level
        nursing home where they’re taking care of her twenty four seven.
```

Sharp increases in pitch are marked with an upward arrow; sharp decreases in pitch are marked with a downwards arrow.

Greater-than/less-than symbols: quicker or slower speech

```
 1  F1: Her if I saw her but >anyway<
 2  M2:  My sense is she would not have <wanted that.>
```

Talk that is quicker is marked as shown in example 1 above, with the greater-than/less-than symbols pointed toward the speech, ><. Talk that is slower is marked in example 2 above, with the greater-than/less-than symbols pointed away from the speech, <>.

Colon: stretching of sound

```
   M2: She if she:::: would not want to be
```

Colons are used to indicate stretching of the preceding sound. The more colons that are used, the more stretched the sound is.

Hyphen: speech cut off

```
   F2: She just- she just needs to die.
```

Talk that abruptly stops is marked by a hyphen.

Pound sign: creaky voice

```
   F4: #I know he won’t want to live like this.#
```

Talk that has a creaky quality is surrounded by pound signs. In this study in particular, pound signs also indicate talk that is produced while crying.

Parentheses: unsure of talk

```
   F2:  (         )
```

Talk that is not clear or unintelligible is marked by parentheses .

Double parentheses: description of events

```
   F1: U:h came in ((coughs))
```

Sounds or events that occur in the conversation are surrounded by double parentheses.

Parentheses with numbers: silences

```
   (3.5)
```

Silences are measured in seconds, to the tenth of a second, and are surrounded by parentheses.

Hhh: breathing

1 M1: I wanted to bring up something, .hhh is that what Mr. James would
want.
2 F4: HHHHHH #I have to ask this#

When there is a period before an “h,” it marks an in-breath, as shown in example 1 above. When there is no period before an “h,” it marks an out-breath, as shown in example 2. The more h’s there are together, the longer the breath. Please also note that the capitalized h’s in example 2 indicate that this sound is markedly louder than the surrounding talk.