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Life-Sustaining Treatment Decisions in the ICU for Patients with ESLD: A Prospective Investigation

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Abstract

We conducted a prospective study in the ICU of life-sustaining treatment and comfort care decisions over time in patients with end-stage liver disease from the perspectives of patients, family members, and health care professionals. Six patients with end-stage liver disease, 19 family members, and 122 professionals participated. The overarching theme describing the decision-making process was “on the train.” Four sub-themes positioned patients and family members as passengers with limited control, unable to fully understand the decision-making process. Findings suggest that including patients and family members in non-immediate lifesaving decisions and verifying early on their understanding may help to improve the decision-making process.

Keywords

intensive care; qualitative research; decision making; liver diseases; life support care

It is frequently necessary to make decisions about life-sustaining treatments (LST) for critically ill patients in the intensive care unit (ICU; Kirchhoff, Song, & Kehl, 2004; Prendergast, 2000). As these patients are often too ill or sedated to participate in decision-making, family members and health care professionals commonly make the decisions (Prendergast, 2000; White, Curtis, Lo, & Luce, 2006). LST decision making is complex (Asch, Faber-Langendoen, Shea, & Christakis, 1999), and intervention studies to improve end of life care in the ICU have demonstrated that the withdrawal of LST is an area of care that can be improved (Curtis, 2005; Schneiderman et al., 2003). Research on LST decision making has focused on perspectives of patients (Fried, Bradley, Towle, & Allore, 2002), family members (Heyland et al., 2003; Meeker & Jezewski, 2008; Tilden, Tolle, Nelson, & Fields, 2001), and health care professionals (Rocker et al., 2005) and on factors influencing the decisions (Hansen, Archbold, Stewart, Westfall, & Ganzini, 2005; Frost, Cook, Heyland, & Fowler, 2011). Decisions have been examined as a single decision either to withhold or withdraw treatment (Jacob, 1998; Tilden, Tolle, Garland, & Nelson, 1995; Tilden et al., 2001), the duration and sequence of withdrawing treatments from patients for whom a decision has been made to stop LST (Gerstel, Engelberg, Koepsell, & Curtis, 2008), or as a

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process of decision-making about withholding or withdrawing treatment for critically ill, dying patients (Swigart, Lidz, Butterworth, & Arnold, 1996; Wiegand, 2008). Few researchers have prospectively focused on LST decision-making as a process or a cascade of decisions over time as patients' conditions change during their stay in the ICU (Cook, Giacomini, Johnson, & Willms, 1999; Kaufman, 1998; Slomka, 1992).

Patients with end-stage liver disease (ESLD), either those on the liver transplant waiting list or those being evaluated as candidates for liver transplantation, are frequently admitted to ICUs for LST due to complications from the disease. The complications leading to ICU admissions make patients, at least temporarily, ineligible for a transplant. To qualify to get back on the transplant waiting list, patients' disease complications must be treated and resolved.

Liver transplantations are limited by a shortage of available organs (Wiesner, 2005) and by patients' deteriorating health and limited survival time, yet many patients and their families have unrealistic expectations about outcomes (Roth, Lynn, Zhong, Borum, & Dawson, 2000). The hope, no matter how remote, that patients may receive a liver transplant and get well—makes it difficult for health care professionals to tell patients and families when transplantation is no longer realistic. As a result, professionals may postpone telling patients and family members that the focus of care should transition to comfort and not cure. The use of LST may be prolonged, which may increase patients' emotional and physical suffering and cause family members and professionals distress and conflict. Thus, knowing the ways in which patients, families, and providers decide to forgo LST and turn to comfort care is essential to effectively care for these patients. The purpose of this research was to prospectively describe the process of making LST and comfort care decisions for patients with ESLD during their stay in the ICU from the perspectives of patients, family members, and health care professionals.

Methods

Overview and Setting

We used a prospective, multiple case design (Muecke, 1994; Stake, 2005). A case was defined as beginning when an eligible patient was admitted to an ICU. Case studies began within 24–48 hours of ICU admission and ended when LSTs were withheld or withdrawn, or when a patient died or was transferred out of the ICU. Participants included the patient, family members who visited, and health care professionals who cared for the patient.

The study was conducted in two sites: a 26-bed cardiac-medical ICU in a university medical center and a 26-bed general medical-surgical ICU in a Veterans Affairs Medical Center. Institutional Review Board (IRB) approval was obtained from both medical centers. Study participants, patients' authorized research representatives, or legally authorized representatives gave written informed consent prior to being observed or interviewed. Data were not collected from individuals who declined to participate. Bedside observations did not take place, and the research team stopped taking field notes when individuals who had not provided or had declined to provide written informed consent were present during data collection. Prior to beginning data collection in the ICUs, we introduced the study to, and obtained written informed consent from, 109 ICU nurses. The preliminary provision of informed consent facilitated the consent process. The multi-disciplinary research team included a PhD-prepared principal investigator (PI) and co-investigators with varied backgrounds—nursing, medicine, and medical anthropology and three research assistants: a medical anthropologist, a registered nurse, and a nursing student. The data were collected from January 2008 to March 2009.

Participants

Patients with ESLD ≥ 21 years of age, regardless of decisional capacity, who were on the liver transplant waiting list or were being evaluated as candidates for liver transplants and admitted to an ICU were eligible. ESLD was identified by: (a) medical record documentation of cirrhosis and at least two of the following: a serum albumin level of 3.0 mg/dL or less, an International Normalized Ratio (INR; Schnell, Van Leeuwen, & Kranpitz, 2003) of 1.7 or above, uncontrolled ascites, hepatic encephalopathy, cachexia, or a massive upper gastrointestinal bleed defined as requiring two or more blood transfusions within a 24-hour period, either hematemesis or gross blood on endoscopic visualization or nasogastric tube aspiration (Roth et al., 2000), and (b) a Model for ESLD (MELD) score of > 6 . Patients were excluded if they had received a previous liver transplant. A purposive sampling strategy was used to obtain maximum variation in the patient sample based on professionals' uncertainty about a patient's outcome. Family members were eligible if they were ≥ 18 years of age and able to read and speak English. Health care professionals were eligible if they were ≥ 21 years of age and directly cared for the enrolled patient with ESLD and his or her family members.

Life-sustaining and comfort care decisions—These decisions were identified based on the literature (Prendergast, 2000) and expert clinician perspectives. LST were defined as therapies with the primary goal of extending life: antibiotics, artificially administered fluids and nutrition, blood products, cardiopulmonary resuscitation (CPR), therapeutic endoscopies, intubation, mechanical ventilation, hemodialysis, surgery and surgical procedures, and vasopressor agents. Comfort care was defined initially as individual or combined physical, psychological, social, and spiritual aspects of supportive patient care that could be offered simultaneously with LST. Later, we operationalized comfort care to include hospice referrals and palliative care consultations.

Data Collection

Qualitative ethnographic methods—including bedside observation, semi-structured interviews, and medical record reviews—were used to allow observation of real-time behaviors and communications. Ethnographic research aims to gather an in-depth, holistic understanding of human behavior and the reasons that inform such behavior. The method utilizes purposively selected samples smaller than what would be used in quantitative survey research but providing larger amounts of rich data from various perspectives on the event under investigation (Bernard, 2005). Observation at the bedside was conducted by individual research team members and took place for 4–10 hours each day, 3–6 morning hours and 1–4 hours from mid to late afternoon, capturing the period when most physicians and family members were present and most decisions were made. Number of days spent collecting observational data at the bedside for each patient ranged from 1 to 19. Number of observation hours for each patient was as follows: case 1 was 38 hours over 4 days, case 2 was 32 hours over 4 days, case 3 was 111.5 hours over 11 days, case 4 was 13.25 hours in 1 day, case 5 was 87.5 hours for 19 days, and case 6 was 32.75 hours over 6 days. Total number of observation hours for all patients combined was 315. In addition, the PI and research assistants observed three family care conferences. All observations were recorded in written field notes and transcribed.

To gain the broadest set of perspectives on each case, bedside observation was augmented by in-person, semi-structured interviews by the PI. Interviews with patients and family members were conducted daily; interviews with health care professionals were conducted after a decision had been made about LST and/or comfort care options. One to 3 months after the end of each ICU stay, patients and/or their family members were re-interviewed. All interviews were audio-taped and transcribed. Medical record reviews were conducted

daily by the PI to document LST and comfort care decisions and health care outcomes. Medical record data were recorded in written field notes and/or audio-taped and transcribed. As data collection progressed, medical record review took on a supportive role to observation and interview data, helping us identify when decisions had been made based on their documentation.

Data Analyses and Verification

Qualitative content analysis was used to analyze the data as it is the analysis strategy of choice in qualitative descriptive studies when straightforward and data-near interpretations are desired (Altheide, 1987; Hsieh & Shanon, 2005; Sandelowski, 2000, 2010). The purpose of the analysis was to identify and describe themes that emerged from the perspectives and experiences of the participants related to LST and comfort care decisions.

Data from bed-side and family conference observations and in-person interviews were transcribed, verified for accuracy, and entered into NVivo 7 data management software program (QSR International) for analysis. Data were coded line by line and recoded with comparisons of new and old data; codes were grouped and categorized. Comparisons were made among interviews within and across cases (Ayres, Kavanaugh, & Knafl, 2003). Within each case, data from observations and medical records were compared with interviews for validation and to capture the complexities of the decision-making process. Member-checking with patients, family members, and professionals was used to verify, confirm, or change the analysis to be more consistent with participant data (Creswell, 1998).

A combined deductive-inductive approach to the data was used. Some codes (e.g., factors that influence LST decision making) were developed from the literature; other codes were inductively derived from the data. All data were analyzed by four members of the research team. The analysts independently read all of the data to identify emerging themes and met regularly to discuss patterns and developed a codebook. Two dyadic coding pairs were created, and data were divided among the pairs for coding analysis. Members of a pair coded individually and then met with their coding partners weekly to discuss coding and come to consensus on discrepancies. Both coding pairs met weekly as a group to review, audit, and assess the emerging findings. When there was disagreement, the team discussed the codes until they came to consensus. This process ensured comparability of data collection and coding. Credibility of data was established by triangulation of respondents (i.e., patients, family members, professionals), data collection methods, and through peer debriefing techniques (sharing analyses and conceptual abstractions of the data) among the research team members and qualitative researchers (Patton, 1999).

Results

The final sample included six cases based on six patients, 19 family members, and 122 health care professionals. Patients included two females and four males, ranging in age from mid-30s to 60s. Five of the six patients were identified in the medical records as White non-Hispanic. Participant characteristics are detailed in Tables 1 and 2. Duration of patient stay in the ICU ranged from 5 to 20 days ($M=8$). Three patients died, two patients received a liver transplant within 1 month of ICU admission, and one patient's liver disease improved so that transplant was no longer needed. The number of health care professionals involved with patients ranged from 11 to 38. In all, 58 physicians, 54 nurses, 6 respiratory therapists, 2 social workers, 1 gastroenterology technician, and 1 chaplain were interviewed. All patients and family members approached agreed to participate in the study. Four professionals declined, citing time constraints and perceived minimal involvement with the patient. No enrolled participants withdrew.

Interviews provided detailed information on participants' perspectives about individual LST and comfort care decisions (Table 3). Although interviews about decision-making were conducted primarily with family members, nurses, and physicians, we also interviewed two patients, two respiratory therapists, and one social worker. During the six patients' stays in the ICU a total of 86 LST decisions (Table 4) were made, representing nine treatment categories and three explicit comfort care decisions (Table 4). Although these are listed as individual decisions, they must be understood within the course of the patients' ICU stays and the quest for liver transplant. What mattered most to all participants was getting a liver transplant. The focus was on treatments and not on comfort care until all treatment options had been implemented or considered (Table 4). None of the patients had a palliative care consultation. Family care conferences were conducted for only two of the six patients. One patient had two family care conferences; the other had one family care conference. Two members of the research team attended and observed all three family care conferences.

The analysis revealed one overarching theme elucidating the decision trajectory and the reasoning behind the LST and comfort care decisions. This theme is encapsulated by the metaphor "on the train" and four sub-themes that became evident during patients' stay in the ICU: (a) For families, life was the obvious answer; (b) Excluding families from "minor" LST decisions added to their limited preparedness for major ones that followed; (c) Multiple professionals, each with a narrow focus; and (d) Mismatches – different perceptions of patients' illness course.

On the Train

As the analysis proceeded, we identified the metaphor "on the train" as a descriptor of the decision-making process as experienced by patients, family members, and health care professionals. This metaphor was used by study participants. Physicians, in particular, employed the train metaphor when describing the decision-making process during interviews. For example, a physician said:

I guess, [I] just imagined the whole process as moving somewhere. The surgeons and the hepatologists, we're all on a train, so to speak, going to somewhere, and the family can either fight it and not go with us, or just kind of latch onto the process and accept it.

As this passage illustrates, the use of the train metaphor in this context enabled participants to conceptualize and articulate their experience of the decision-making process. It shows physicians as authoritative figures in charge of the process and families as having little choice but to latch on and accept the decisions as presented to them during the time the patients were in the ICU.

At the beginning of the decision-making process—immediately after admission to the ICU—patients, family members, and professionals shared the same goal: to stabilize the patient so that the liver transplant evaluation and waiting list activation process could continue. The anticipated outcome or destination of the train throughout the patients' stay in the ICU was a liver transplant. Physicians controlled the metaphorical train, acting as "engineers." For example, physicians often simply told patients and family members about non-immediate LST that they believed were needed. One physician acknowledged this approach by saying:

We didn't ask [the patient] about... the blood products last night. But, a lot of things [the patient] just needs, and so we just tell them that this is what you are going to get, and they are on the train.

As part of the health care team, nurses, and other professionals (e.g., respiratory therapists, and social workers) primarily acted in support of the physicians' engineer role, carrying out treatment decisions. Chaplains did not have an active role but rather offered spiritual support

through prayer or merely being present with patients and family members as they were making decisions. Nurses took on a “conductor” role as they communicated with physicians, implemented orders, and worked to ensure patient safety and comfort on the train.

Nurses identified physicians generally as in charge of when or if the train would stop during a patient’s stay in the ICU. For example, a nurse stated: “I think we have a good plan for now, I do. [The physician in charge] happens to be someone who will not throw in the towel until the very last.” We observed nurses reinforcing the physicians’ engineer role in communications with patients and family members, as was the case for this nurse as she informed a family member about a hemodialysis decision: “The kidney doctors are talking about another type of dialysis that is slower and more gentle. But they’ll decide and talk to you about that.” At times critical of physicians’ decisions or lack of decisions, nurses occasionally stepped forward to challenge physicians or call for the metaphoric train to stop.

Some family members identified and responded to physicians with seeming acceptance of their role as the engineer controlling the train, deferring to them on most or all decisions. For example, a physician noted how one family’s members placed their trust in the transplant team and identified them as having the final say on decisions: “[The family] always asked us when we were making decisions if it was okay with the transplant team.” This sense of patients and families being on the train was pervasive, even among those patients and family members who had considerable healthcare experience. However, family members with less experience and understanding -- based on length of time since the patient’s ESLD diagnosis, number and severity of complications, and prior ICU admissions for the patient or for other relatives -- participated less in decisions than family members with more experience and understanding and tended to place more trust in professionals’ expertise, expecting professionals to make the decisions.

Extending the metaphor of being on the train, one can see each LST was a “train station” along the ride, a place where patients and family members could theoretically choose to disembark. Yet even those with considerable experience with ESLD and ICU hospitalization did not seem to fully understand this aspect of the LST decision-making process. They did not attempt to stop the train by questioning the implementation of LST, nor is it clear that they saw these LST as implying potential places to “get off the train.” Four sub-themes together demonstrate how patients and family members became passengers on a train with limited control and comprehension of the decision-making process.

For families, life was the obvious answer—During most of the patients’ stays in the ICU, the purpose of LST decisions was to keep the patient alive and headed toward the goal of liver transplant.

Some life and death decisions presented by health care professionals were interpreted by family members as non-decisions because the obvious answer for them was life. Family members sometimes felt that “black and white” decisions were easier to make because they were seen as clear-cut, straight-forward, and without uncertainty. Family members, as well as physicians, ascribed weighted attributes such as “major” versus “minor” to decisions. LST decisions described as major involved life-threatening occurrences surrounded by a sense of urgency. For example, CPR, hemodialysis, mechanical ventilation, and transjugular intrahepatic portosystemic shunt carried more weight than minor decisions. These major LST decisions were straight-forward for family members because the choice was between life and death. One family member said:

To me that was a life and death decision. We made that choice, we had two choices. We had a chance, and [the physician] was very blunt, very open with us and told us you know, there’s only a 30% chance that [the patient] is gonna [sic]

live over 30 days even if we do this. So it's not a very good procedure, and it's even worse because if we don't do anything [the patient] will die, now. So [the physician] really gave it to us in black and white. I appreciate that because that gave it extra heavy weight. That was a super heavy weighted decision. *Not that I had a choice in that decision* [emphasis added], but that was a very heavy decision. And of course [the patient] would do it. I would grab at the chance of 30% versus 0 [%].

LST decisions, such as whether to start vasopressors or antibiotics, were perceived as minor when a sense of urgency was lacking or if the treatment did not involve an overt or visible use of technology. Family members viewed minor decisions as insignificant, and such decisions were difficult for them to comprehend. For example, hypotension and reduced tissue perfusion were not seen as immediately life-threatening to the patient by the family members, as illustrated by this spouse: "The dopamine is more of a, I don't think it's life and death whether [physicians] take [the patient] off of it or not. It's just a comfort thing, and it's just a can we get out of this ICU?"

Excluding families from "minor" LST decisions added to their limited preparedness for major ones that followed—Health care professionals often referred to certain decisions (e.g., starting vasopressors or giving blood transfusions) as minor LST decisions, as opposed to major LST decisions. Minor LST decisions were frequently made by individual physicians or decided by the medical team during rounds. Bed-side observations revealed such decisions or their significance in patients' current life-threatening illness were often not communicated and explained to patient or family members. Rather, minor decisions were looked upon by health care professionals as insignificant, and thus communication about them seemed to be an unnecessary burden for families. For example, when asked about the family's role in decision making, a physician stated:

In most sick, critical illness, there are a lot of details of care. A lot of technicalities of care that I think, um, most families, and maybe I am being patronizing here, but most families see as what happens in the ICU, big strokes of care, big ideas of what the direction is... and those are clearly areas that the family needs to be a full participant in decision making and fully informed. But, whether to pick CVVHD or hemodialysis or whether to give blood products or not in a situation where we don't know if it's a good idea or not. I think that, personally, that that kind of thing we can tell them about, but I don't think that they should be burdened with decision making at that level.

Several points are interesting in this passage. First, the physician appeared to have a clear mental map that s/he used to categorize LST decisions as major (big strokes of care, big ideas of what the direction is) or minor (give blood products). Second, it appears that some—or perhaps many—of these minor decisions may occur under conditions of uncertainty. This lack of certainty regarding the right action may be a key factor when deciding if and when to share these decisions with patients or families.

When minor LST decisions were communicated to patients and family, they were often presented as being merely part of routine clinical care. In turn, patients and family members may have seen the decision as insignificant or not as decisions at all. In one case, for example, a family member was informed that hemodialysis had been initiated to support the kidneys. No one explained to the family member that if dialysis was not provided, the patient would die. So when dialysis failed after several days and its withdrawal was presented to the family member, it came as a shock:

So, this group of doctors, and some students I suppose, came up and... I mean I had kind of suspected that maybe they were going to let [her/him] go, and then the morning that they were going to announce this a couple of the doctors came up and said, well, I think we have decided that there is nothing more we can do, and... I, I could hardly think straight after that. So finally they explained to me why they couldn't do anything more and that [the patient] had a stroke in the past and that [her/his] kidneys had failed.

Of the total number of LST decisions made for the six patients during their stay in the ICU, <30% were major and >70% were minor. The number of LST decisions for the patients ranged from 6 to 23. The total number of LST decisions did not seem to alert family members about the severity of patients' illness or serve as a foundation for major LST decisions that were to be made later in the patients' illness course. For example, the family members of the patient who experienced the largest number of LST decisions in this study, and who had been in the ICU 1 week, were unprepared to receive news from health care professionals during a family care conference that no more LST could be offered and that a liver transplant was no longer an option. A social worker described the spouse's response:

The attending doctor ... went ahead and began the meeting by discussing what we had found on the scan that was performed and what that meant to [the patient's] overall care, and that [the patient] wouldn't be able to have a liver transplant and all of that. The patient's [spouse] was very upset, visibly upset and very frustrated and not understanding and was crying and that kind of thing.

The social worker went on to describe other family members' reactions during the family conference:

They were sad but during the time of the meeting [the spouse] was so angry. [The spouse] had a point in which [s/he] was just so angry and frustrated, and at that point [the physician] just verbalized that [they] couldn't do anything, [the spouse] was feeling paralyzed and just like, disbelief...

Just the day prior to the family care conference, the patient's spouse had said s/he believed that the patient would eventually get back on the liver transplant-list:

And, um, still from the same day that we got here, I mean things have gotten a little worse [the patient's] situation and it's just that waiting game. You know, it is really not a game, it's [the patient's] life, and it's just all about waiting. But, like I said, they are the professionals and they are not going to throw [the patient] on the table to risk [the patient's] life. So, I am totally proud of that. And I believe in [the patient] and I believe in my faith, and they will keep [the patient] going until [s/he] is ready to be on that table. And that's where I'm at...

Multiple professionals, each with a narrow focus—Another aspect of care that made it difficult for patients and families to understand and take part in LST decision making was that patients with ESLD were cared for by a multitude of health care professionals from nursing, social work, and medicine. Medical specialties involved included hepatology, hematology, nephrology, cardiology, infectious diseases, liver transplant surgery, pulmonology, and critical care medicine. Individual physicians focused almost exclusively on the physiological function of the organ that was their specialty, and their communications to family members were often limited to how *that* organ was functioning. For example a nephrologist we observed speaking with a family member:

Nephrologist: "We'll wait until Monday to see if [the patient] needs dialysis. [The patient's] numbers look good."

Family member: “Will [the patient] be re-listed?”

Nephrologist: “Sorry. I can’t answer that. I’m renal, not liver. I’m sure liver will be by soon.”

It was infrequently explained to family members how the function of one organ interrelated with the function of other organs or what the functioning of an organ meant in the context of the overall picture of the patient’s illness and possible outcomes.

Professionals provided details of individual procedures or treatments (e.g. hemodialysis), but such information was rarely linked to other aspects of the patient’s care and health status or linked together between specialties. Family members were not able to pull together the information provided to them over time by multiple professionals, as illustrated by this quotation from a family member who suggested there be one person to pull it all together:

I thought the words “caseworker” to me meant somebody that would help to synthesize all of the different pieces and parts of the decision-making process, somebody that I could call if I needed to rather than just trying to guess who had the information that I might need. If the case—if I did have one person that I could go to that was the primary resource for me; that would have been much better. Throughout the entire process from the beginning, like the first entry into the hospital and the goodbye there ought to be somebody that really truly is *the* caseworker and that person is bright enough to know what all of these different practitioners are talking about and then can explain it in layman’s terms to everyone.

This narrow focus by each specialty and what seemed to be a lack of communication between them was experienced as a source of frustration, for example in this statement by one patient:

And, also there was just... there were so many doctors that would come in and out and I would have to explain over and over how I am doing, what’s been going on, what I did with *this* doctor, what I did with *that* doctor, what we did with dialysis and so on and so forth, I had to explain myself over, and over and over and over, and I just wished that there would be a few, a few doctors specifically that were assigned to my case that would come in, you know, rather than all these residents and all these other people, because that got just a bit much, yeah.

Mismatches – different perceptions of patients’ illness course—At the time of patients’ admission to the ICU, patients, family members, and health care professionals all boarded the train together, with a shared understanding of the patient’s diagnosis and a goal of treating disease complications and getting the patient onto—or back onto—the liver transplant waiting list. However, within a few hours of admission to an ICU, the shared view often fractured into different perceptions of the patient’s illness course among specialties, between professions, and between professions and patients/families. The differing perceptions, or mismatches, that developed early became clearer over time. The term mismatch is used here to describe the misalignment of these perceptions.

When members of different professions and/or specialties had differing views, these were not always expressed directly. For example, in two cases, nurses were concerned about low blood pressure readings and wished the decision to use vasopressors had been made earlier in the patients’ stay, but the concern was not shared by physicians. This is evident in the following quotation from a nurse: “No, we did not start any vasopressors on [the patient]. And, again, we approached the physicians about it, and they just did not seem concerned that much. That’s why I kept asking.” Nurses and physicians were often aware of patients’

deteriorating condition, but some physicians conveyed a message to family members that nurses did not agree with. During a shift report, one nurse relayed the following observation to the oncoming nurse:

Transplant team here. They were going on about transplant this and that: “We’ll get a new liver for you, etc...” Patient’s eyes were gleaming. Got [spouse] and patient all excited. We can’t even get [the patient’s] kidney up to goal!

In particular, we found mismatches between family members’ and health care professionals’ perception of the complexity of the patient’s illness. This is evident in this interview statement by a physician:

I think often times we see that, as care is becoming more complex and escalating in ICUs, often times families don’t sense that, you know, that the patient is now gravely ill and that we are really struggling to keep [the patient] alive. You know, it is just another day in the ICU to them, or the doctors will figure this out, or the transplant will make everything right.

Even though professionals, such as this one, may have been aware that families might not share their understanding, we found professionals did not always convey the complexity and severity of the patient’s illness to families. This led family members to focus on what was familiar to them and on what they could see happening to patients, such as a patient having a normal blood pressure, although, in fact, this was because a vasopressor had been started. In general, most family members focused exclusively on visible, tangible signs of worsening or improving illness that they could relate to—such as patients’ ability to eat or the color and amount of urine patients produced—without ever really grasping the overall complexity and severity of the patient’s illness.

At times, health care professionals would freely discuss among themselves how unlikely it was that the patient would receive a transplant, yet this would not be communicated to the family. Conversely, family members sometimes were aware of the patient’s grim prognosis but did not convey their awareness to professionals. In an interview, a patient’s spouse said:

I mean it was just like boohooohooohoooom... but yet [the physician] was still talking about the possibility of a transplant, you know, and it was like this is just amazing that, you know, the [patient] is like close to death, “but transplant is still possible in the future,” you know, “we could pull [the patient] out of it.”

In another case, a patient’s spouse proactively requested pain medication for comfort care when it became apparent to the nurse, physicians, and family that the patient was going to die within the hour, and plans were made to stop LST. The patient’s spouse reflected on the request for pain medication during an interview: “That is one thing that I insisted upon was take out the ventilator, give [the patient] some medication so [s/he] will go to sleep and take away all [her/his] pain, and just let [the patient] go.”

Families developed proactive strategies to understand what was really going on with the patient. In one family, the members planned that each family member would ask the same questions of various professionals, and they would compare the answers to get a better understanding about the patient’s condition. Another family asked one specific question of health care providers each day: “Is [the patient] getting on the waiting list?” Family members with prior LST decision experience were able to use medical language to communicate with health care professionals. Less experienced families searched the Internet for the meaning of terms they heard, such as bacteremia and sepsis, instead of asking professionals. Even when those family members became more comfortable with asking questions during the patient’s stay in the ICU, they never developed a strategy to get better information from health care professionals.

The different perceptions of the patient's illness course and professionals' practice of communicating only about organs and excluding families from minor LST decisions contributed to family members' inability to comprehend the course of the changing complexity and severity of patients' illness. For family members of the three patients who died, being excluded from minor LST decisions added to their limited preparedness for the major LST decisions when no other medical treatments were available. Because health care professionals did not perceive and engage minor LST as a cascade of decisions potentially leading up to major ones, minor LST appeared as routine aspects of on-going clinical care rather than events marking sometimes complex choice points. These incremental decisions, which might represent a potential stop or slowing down of the train to discuss the severity of patients' illness and families' comprehension of the illness, passed unperceived.

Discussion

To our knowledge, this is the first prospective study to describe LST and comfort care decisions for patient with ESLD during their stay in the ICU from the perspectives of patients, family members, and health care professionals. We identified one overarching theme—on the train—and four sub-themes describing why patients and family members may not fully understand or comprehend the LST decision-making process.

Being on the train was a common conceptualization of the decision-making process among study participants. A similar theme, “staying on the train,” was described by McCarthy and Dowling (2009) in their study of the experiences of patients living with a diagnosis of non-small-cell lung cancer. In their study, patients believed that stopping chemotherapy was not an option and that they did not have a choice. They knew that their cancer was incurable, and without chemotherapy there was no chance for prolonging survival. In one key aspect, the situation of patients with ESLD is different: unlike patients with non-small-cell lung cancer, those with ESLD have the possibility of a life saving intervention—receiving an organ transplant. Despite the severity of complications experienced by the patients with ESLD in the ICU, liver transplantation was a driving force for decisions to continue implementing LST. However, the contrast between these two conditions is not as stark as it might appear; three (50%) of the patients in our study died before or shortly after leaving an ICU, and only two received transplants.

The driving force of liver transplantation might have influenced the assessment by health care professionals regarding the appropriate time to inform patients and their family members that the patients would not be eligible for a transplant or to introduce the option to focus on comfort care. In this study, as in previous research (Baggs et al., 2007), a focus on comfort care was introduced when no other medical interventions were available. Based on the increasing focus on the use of palliative and comfort care earlier on in the course of illness in critically ill patients (Gott, Ingleton, Bennett, & Gardiner, 2011) and the potential for critical care and palliative care to coexist in the ICU (White & Luce, 2004), we defined comfort care as: individual and combined physical, psychological, social, and spiritual aspects of supportive patient care that could be offered simultaneously with LST. This definition was not developed from participant perspectives but instead was derived from experts and the literature (WHO, 2005). However it describes care that was not seen in this study. Therefore, we operationalized comfort care to include hospice referrals and palliative care consultations. The implementation of LST versus palliative and comfort care was a dichotomy. Other prospective observational and qualitative studies have been conducted on transition and end-of-life care in the ICU (Crighton, Bridget, Tate, Swigart, & Happ, 2008; Kaufman, 1998). Crighton and colleagues (2008) examined in a single case study the transition from LST to end-of-life care in the ICU from multiple perspectives. In their case study as in this study, perspectives were provided from patient, family, and professionals.

The case study exemplified how effective communication by health care professionals facilitated the transition to end-of-life care and the importance of providing time for family members to adjust to the transition.

One of the three “comfort care” type of interventions was requested by a spouse for pain medication to be given to her/his family member during the removal of mechanical ventilation. The small numbers of either comfort care interventions or family care conferences and the lack of palliative care consultations are of concern because research has shown both to improve patient- and family-centered outcomes (El-Jawahri, Greer, & Temel, 2011; Kaufer, Murphy, Barker, & Mosenthal, 2008; Lautrette et al., 2007; Scheunemann, McDevitt, Carson, & Hanson, 2011).

Routine family care conferences and printed family information improve decision making and decrease patients’ length of stay in ICU, non-beneficial treatments, and family member symptoms of anxiety and depression (Lautrette, Ciroidi, Ksibi, & Azoulay, 2006; Lautrette et al., 2007; Lilly et al., 2000; Scheunemann et al., 2011). Palliative care consultations improve communication, patient quality of life, patient and/or family member satisfaction with care, and decrease patients’ length of stay in ICU (El-Jawahri et al., 2011; Kaufer et al., 2008; Mosenthal et al., 2008; Norton et al., 2007).

We found that health care professionals generally did not share with family members the minor LST decisions or how they played into the overall picture of the patient’s illness. Minor decisions often served as the foundation for later major LST decisions and made up >70% of LST decisions in our study. By not communicating minor LST decisions, health care professionals potentially excluded large amounts of information that ultimately contributed to family members’ limited preparedness to participate in these later decisions. Although some professionals considered sharing minor LST decisions with families to be a burden for family members, we found some families wanted more information and help navigating the complexities of the patient’s illness. Professionals could help families understand the LST decision-making process by providing information about minor LST decisions and assessing families’ understanding of treatments and the interrelatedness of decisions throughout patients’ stay in the ICU.

Researchers are moving in this direction. Peigne and colleagues (2011) developed a list of questions important to family members of patients in the ICU. The questions were designed to help family members overcome situational stress and to improve their comprehension, and the quality of decision-making. The effectiveness of the list has yet to be demonstrated. It may provide important informational needs to family members, but how increased knowledge by family members may translate to and match with their preferred level of participation in LST decision making is uncertain.

Johnson and colleagues (2011) examined the degree of decisional authority preferred by surrogate decision makers in two clinical vignettes: decision makers preferred more control over a value-sensitive life support decision than over a technical decision about choice of antibiotics. We did not examine actual LST decisions as either value-sensitive or technical. Each LST decision may have a different degree of value sensitivity for participants. Research is needed to explore this, and to understand individuals’ level of value-sensitivity preference in LST decisions and the type and amount of information needed to support the preference.

Although each family member and patient brought a different level of health care experience and understanding of LST, we found that family members’ past experiences did not necessarily translate into a full understanding of the decisions being made. All family members placed a certain amount of trust in health care professionals. This trust may

inadvertently have reinforced physicians' role as the engineer of the train. Despite varying amounts of families' medical experiences, physicians, as a group, approached and worked with families and patients about decisions in the same general way. In this study, as in others, assessment of patients' and family members' understanding of LST decisions was lacking (White, Braddock, Berecknyei, & Curtis, 2007). White and colleagues (2007) measured 10 criteria for shared decision making in 51 end-of-life treatment decisions during physician-family conferences. They found the least frequently assessed criterion to be the family's understanding of the decision.

"Mismatches" among specialties, between professions, and between professions and patients/families in perspectives on events related to patients at the end of life have been documented. These mismatches have been observed in the context of transitioning from cure to comfort-oriented care (Badger, 2005), withdrawal of LST (Breen, Abernethy, Abbott, & Tulsky, 2001; Norton, Tilden, Tolle, Nelson, & Eggman, 2003), end-of-life situations (Cassell, Buchman, Streat, & Stewart, 2003) and decisions (Oberle & Hughes, 2000; Westphal & McKee, 2009), when physicians are offering treatment options that are not likely to change patients' prognosis (Badger, 2005), and when families feel pressured to hasten their relative's death (Abbott, Sago, Breen, Abernethy, & Tulsky, 2001). However, in our study we found mismatches that occurred as patients' conditions changed throughout their ICU stay. The different understandings included perceptions of level of aggressiveness with LST, of illness complexity and severity, and of the probability that patients would qualify for a transplant or get on the transplant waiting list. Although some professionals may be aware of such mismatches between themselves and family members, professionals may not take it upon themselves to clarify differences in understanding with families or patients.

This study had several limitations. The patient sample size was small (Bernard, 2005). However, 122 health care professionals participated in the care and LST decisions for the six patients studied. This large number and the inclusion of different disciplines caring for the patients provided us with an initial picture of how complex and multifaceted the LST decision-making process is during a patient's stay in an ICU. A second limitation was that only two patients were assessed to have decisional capacity to enroll in the study and participate in interviews, although this is not dissimilar to other studies of ICU patients. Third, the small patient sample size makes it impossible to determine the extent to which ethnic and cultural influences might affect LST decision making in the setting this study was conducted. Fourth, we were unable to observe decision-making events that may have occurred away from the patient's room (e.g., in physician workrooms).

Conclusions

The sub-themes presented in this paper are not exhaustive in explaining why family members may not fully understand LST decision making over time and be passengers on a train. However, they provide an initial picture of the process and may apply to other populations in ICUs as well. Including patients and family members in minor decisions and verifying early on their understanding of decisions might help to improve the decision-making process. Further research is needed to develop interventions that target concurrently patients, family members, and health care professionals, that are multi-faceted, and that could occur throughout the decision-making process.

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Table 1

Admission Diagnosis and Liver Transplant Waiting List Status for all Patients

Characteristic	Patients (<i>n</i> = 6)	
	<i>n</i>	(%)
Admission diagnosis		
Liver cirrhosis due to Hepatitis C	3	(50)
Liver cirrhosis due to auto immune hepatitis	1	(17)
Liver cirrhosis due to primary sclerosing cholangitis	1	(17)
Liver cirrhosis due to unknown cause	1	(17)
Status on the liver transplant waiting list		
Being evaluated as potential liver transplant candidate	4	(67)
On the list prior to Intensive Care Unit admission	2	(33)

Note. Percentages may not add up to 100% due to rounding.

Table 2

Demographic Characteristics of Family Members and Health Care Professionals

Characteristic	Family Members ^a		Health Care Professionals ^b	
	<i>n</i>	(%)	<i>n</i>	(%)
Sex				
Female	12	(63)	76	(62)
Age	<i>M</i> =43	<i>SD</i> =15	<i>M</i> =38	<i>SD</i> =9.2
Ethnicity				
Not Hispanic or Latino	9	(47)	104	(85)
Hispanic or Latino	4	(21)	4	(3)
Unknown/Declined to respond	6	(32)	14	(12)
Race				
White	11	(58)	102	(84)
American Indian or Alaska Native	1	(5)	0	(0)
Asian	0	(0)	12	(10)
Black or African American	0	(0)	1	(0)
More than one race	4	(21)	7	(6)
Unknown/Declined to respond	3	(16)	0	(0)
Level of education				
Some high school (including diploma or general education development)	12	(63)		
Some college	4	(21)		
Graduate or professional school	1	(5)		
4-yr college degree	1	(5)		
8 th grade or less	1	(5)		

Note. Percentages may not add up to 100% due to rounding. M=mean, SD=standard deviation.

^a
n = 19

^b
n = 122

Table 3

Number of Interviews Conducted for All Cases

Participant group	Case 1	Case 2	Case 3	Case 4	Case 5	Case 6	Total
Patients	0	0	0	0	5	1	6
Patient & Family members	1	1	0	0	1	0	3
Family members	9	6	10	5	2	4	36
Physicians	2	3	15	5	7	5	37
Nurses	5	4	12	6	20	6	53
Respiratory Therapists	1	1	0	0	0	0	2
Social Workers	0	0	1	0	0	0	1
Total	18	15	38	16	35	16	138

Table 4
Number of Life Sustaining Treatment Decisions and Comfort Care Decisions for all Patient Cases

Decision	Case 1	Case 2	Case 3	Case 4	Case 5	Case 6	Total
Life sustaining treatment							
Antibiotics	1	1	2	0	1	0	5
Blood products	4	4	6	4	10	2	30
CPR ^a	0	0	0	2	0	0	2
Feeding tube	1	0	1	0	1	1	4
Fluids	2	3	2	1	2	1	11
Hemodialysis	0	0	4	2	1	1	8
Procedures ^b	3	1	0	0	1	0	5
Vasopressors	2	3	6	1	0	0	12
Ventilation	2	1	2	1	2	1	9
Subtotal	15	13	23	11	18	6	86
Comfort care							
Pain medication	0	0	1	1	0	0	2
Hospice referrals	0	0	1	0	0	0	1
Subtotal	0	0	2	1	0	0	3

^aCardiopulmonary Resuscitation.

^bIncludes: endoscopy, transjugular intrahepatic portosystemic shunt, and Minnesota tube.