In Their Own Time: The Family Experience during the Process of Withdrawal of Life-Sustaining Therapy

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Abstract

Withdrawal of life-sustaining therapy (LST) occurs commonly in critical care units, yet little is known about the family experience with this process. The purpose of this study was to understand the lived experience of families participating in the process of withdrawal of LST from a family member with an unexpected, life-threatening illness or injury. A hermeneutic phenomenological approach was used as nineteen families were interviewed and observed. Within and across family analyses were conducted. Methodological rigor was established and redundancy was achieved. The categories that evolved from the data included: this happens to other families, time to understand the severity of the illness or injury, time to see if health would be restored, riding a roller coaster, family readiness: willingness to consider withdrawal of LST as a possible option, one step at a time, family readiness: time to make a decision, the family will go on, and waiting for a miracle. The family experience participating in the process of withdrawal of LST happened for families "in their own time." The results of this study have important implications for clinical practice and future research.

Introduction

MOST OF THE PATIENTS who die in U.S. hospitals do so under circumstances where decisions need to be made about how long to pursue life-extending treatments.¹ The majority of end of life decisions are made by patients' family members as patients are often too critically ill to participate in decision making.²⁻⁵ Approximately 1 in 5 patients die in critical care units² with over 90% of deaths in critical care preceded by decisions to withhold or withdraw life-sustaining therapies.^{7,8} Health care providers collaborate with patients' families as decisions are made to limit treatment and care for both patients and their families during the dying process. This study addresses an important problem that even though withdrawal of life-sustaining therapy (LST) occurs commonly in critical care units, little is known about the family experience during this process. Better understanding of the experience of families will guide interventions for these vulnerable patients and their families.

Significant contributions have been made to understanding families as they participate in end-of-life decision making. Important information has been found related to the patient's illness context, family context, and family and health care provider interactions. The nature of the patient's illness may influence the family decision-making process related to LST. For example, prior experiences of

patient losses associated with chronic illness aided some families with the final LST decision.^{1,5} Tilden and researchers¹ observed that family members of patients with acute illnesses or injuries recognized futility of treatment abruptly after a period of denial and cognitive dissonance. Thus, family experiences may be different if the patient has a sudden, unexpected illness versus an exacerbation of a chronic illness.

Researchers have demonstrated that the withdrawal of LST process occurs within a family context. Usually multiple family members are involved in making LST decisions.^{1,5,10,11} Although one family member may facilitate the family decision-making process,⁹ most families pull together and decide as a group.⁵ Family decision making about LST is a complex process.^{1,5,10,11} Tilden and researchers¹ found that families making withdrawal of LST decisions moved through four phases that included recognition of futility, coming to terms, shouldering the surrogate role, and facing the question. Several factors have been found to influence family members' decisions related to withdrawal of LST and include: a poor expected quality of life,^{1,5,12,13} a poor prognosis,^{5,12,13} the patient's current level of suffering,^{1,5,12-14} and previously discussed advance directives.^{1,9-13} Participating in end-of-life decisions related to withholding and withdrawing LST is quite a burden for families.^{1,5,15} Family members have described participating in the process of with-

drawal of LST as difficult, intense, painful, overwhelming, devastating, and traumatic.¹

Interactions between families and health care providers are important when making end of life decisions. Trust between families and health care providers is crucial. Mutual trust between families and health care providers is especially important in the context of making LST decisions.¹⁶ Swigart and colleagues⁹ reported that families were unwilling to forgo LST when there was not trust between the family and the patient's physician. Norton and researchers¹⁷ found that trust eroded when family members received misinformed or mixed messages about their critically ill family member.

Families have reported being helped with end-of-life decisions by nursing and physician behaviors such as: frequent and clear communication, clarification of family roles, collaborative (shared) decision making, facilitating family consensus, accommodating family grief and consultation with clergy.^{1,5,10,12,13,17,18} Families were also helped when health care providers were direct, honest, and realistic as they guided and facilitated the family through the withdrawal of LST process.^{1,17}

The purpose of this study was to understand the lived experience of families participating in the process of withdrawal of LST from a family member with an unexpected, life-threatening illness or injury. This study differs from previous investigations in that families were studied prospectively as they participated in the process of withdrawal of LST, the study focused on families with an acutely ill or injured family member, and the study was conducted from a family perspective, thus including multiple family members.

Method

A hermeneutic phenomenological approach was used to study families as they participated in the process of withdrawal of LST. This study sought to answer the question: What do families experience during the process of withdrawal of LST from a family member with an unexpected, life-threatening illness or injury? Van Manen's^{19,20} methodology for conducting phenomenological research was used to guide the investigation. Families were interviewed and observed over a period of time (days to weeks) as they interacted with the patient, with each other, sat in family waiting rooms, stood in hallways, and interacted in family meetings. Study procedures and an additional analysis were reported previously.¹⁸

Sample and setting

The family sample was recruited from three intensive care units (ICUs) of a single university medical center. Purposive sampling was used to obtain a diverse sample of families. Family members were considered for participation in the study if the patient was unable to participate in decision making, had an unexpected (previously healthy), life-threatening illness, or injury that was defined as an acute condition (less than 1-month duration), necessitating hospitalization in a critical care unit, and the health care team thought that LST might need to be withdrawn. LST was defined as any therapy necessary to maintain life. Family was defined as the individuals who were participating in and experiencing the withdrawal of LST process. Most of the family members were, but did not need to be, related biologically.

Recruitment procedures

Families were referred to the researcher as she rounded in the ICUs. After obtaining a referral, the researcher reviewed the patient chart and spoke with the patient's nurse to determine if the patient met the study criteria. Consent was obtained from the patient's attending physician prior to approaching the family and informed consent was obtained from each family member participating in the study. Institutional Review Board approval was obtained prior to data collection.

Sequence for the investigation

The first family interviews commonly occurred in a conference room located close to the ICU and lasted 30–60 minutes. All family members willing to participate were included in the interview. The first family interview was formal in that an interview guide was used.

Informal interviews followed the initial family interview. Informal interviews resembled conversations.^{21,22} Informal follow-up interviews and discussions usually lasted 5–30 minutes and were held with an individual family member, a dyad of family members, or with the entire family.

Interviews were held over a variety of time frames; most family members were interviewed and observed on multiple occasions over the days to weeks that they were involved in the withdrawal of LST process. The time frame varied as the withdrawal of LST process differed from family to family. Interviews were audio taped or field notes were taken.

Family, family/patient, and family/health care provider interactions were observed. Family and health care provider meetings were also observed and audio taped with permission. Observations added another dimension of understanding to the family experience. Observations also provided data to reinforce interview data or to prompt the researcher to ask further questions for clarification.

Data analysis

Data analysis used an inductive approach and thematic analysis as described by van Manen.^{19,20} Atlas.ti computer software²³ was used to help organize and manage data. The data were managed maintaining a family focus. Within and across case analyses were conducted.²⁴ Within case analyses were conducted with the data from each family.

Across case analyses were conducted as data were obtained from subsequent families. The across family analysis of the data helped to identify aspects of the experience that were shared by all the families. Clusters or themes that emerged for each family were compared with themes that emerged from other families. The clusters were further analyzed and grouped into categories. Similarities that emerged between families provided information that identified what was common to the experience. Data collection and data analysis continued until consistent categories emerged from the family level data.

Methodological rigor was established. The researcher had repeated contact with the families and thus had ample opportunity to confirm interview data and clarify data with families. A sample of family members reviewed the final summary of the phenomenology of the family. A good phenomenological description is something that we can nod to, recognizing it as an experience that we have had.^{19,20}

Consistency was determined by the use of multiple methods for data collection. The family interview, multiple informal family interviews, observations of family interactions, family/patient interactions, family/health care provider interactions, and family meetings provided opportunities to confirm information, clarify confusing/conflicting information and seek further understanding. An audit trail was established and evaluated by an expert qualitative researcher.

Results

All physicians gave their consent for the researcher to recruit potential families into the study. One physician, when initially contacted, for consent to approach a specific family, thought it was too early. One week later he gave consent and the family agreed to participate in the study. Nineteen of the 21 families asked to participate in the study agreed to do so (response rate of 90%). Two families did not want to participate in the study. Decisions had already been made regarding withdrawal of LST and 1 family was waiting for extended family to arrive prior to withdrawal of LST.

Seventeen of the 19 families (90%) agreed with health care provider recommendations to withdraw LST and 16 patients died after LST was withdrawn (one patient died prior to withdrawal). Two families did not agree to recommendations to withdraw LST (one patient died in the ICU and the other patient was still hospitalized when the study ended with plans to transfer to a long-term care facility). The primary LST withdrawn included mechanical ventilation, vasopressor therapy, or both. Demographic data for the 19 families (56 family members) are summarized in Table 1.

The main categories that evolved from the data included: this happens to other families, time to understand the severity of the illness or injury, time to see if health would be restored, riding a roller coaster, family readiness: willingness to consider LST as a possible option, one step at a time, family readiness: time to make a decision, the family will go on, and waiting for a miracle. The categories aided in understanding that the lived experience for families participating in the process of withdrawal of LST occurred "in their own time." Pseudonyms are used and identifying information altered to assure anonymity.

This happens to other families

Families were shocked that they were involved in the experience. Life was going along and then it was abruptly interrupted. As Dot, one patient's mother, stated, "Life can change so drastically from one day to the next."

Families could not believe this was happening to them. A common sentiment was, "this happens to other families, not ours." Families were distressed and distraught as they were faced with making end-of-life decisions for a family member who had become suddenly ill or injured. Jay's family was in disbelief of the suddenness, severity, and swiftness of Jay's illness. How could Jay be so ill? He was so young. It almost didn't seem real. As Jay's wife Leslie said, "Who would have ever thought."

Time to understand the severity of the illness or injury

Family members were told the seriousness of their family members' illnesses or injuries, yet although family members

TABLE 1. DESCRIPTION OF PATIENT AND FAMILY MEMBER PARTICIPANT DEMOGRAPHICS

<i>Demographic characteristics</i>	<i>n (%)</i>
Patients	19
Age (years)	63 mean 68 median 20–82 range
Gender	
Female	15 (78.9%)
Male	4 (21.1%)
Race	
Black, non-Hispanic origin	3 (15.8%)
White, non-Hispanic origin	16 (84.2%)
Religion	
Protestant	6 (31.6%)
Catholic	8 (42.1%)
Muslim	1 (5.2%)
Unknown	4 (21.1%)
Primary Diagnosis	
New cancer diagnosis (i.e., new diagnosis of liver cancer progressing to MODS)	6 (31.6%)
Neurologic events (i.e., cerebral aneurysm rupture leading to subarachnoid hemorrhage)	4 (21.1%)
Trauma (i.e., severe injuries sustained in a motor vehicle accident)	3 (15.8%)
Surgical complication (i.e., development of MODS after gastric bypass surgery)	3 (15.8%)
Pancreatitis (i.e., development of sepsis after acute pancreatitis)	2 (10.5%)
Gastrointestinal bleeding (i.e., development of ARDS after acute gastrointestinal bleeding)	1 (5.2%)
Advance Directive	
No	9 (47.4%)
Yes	10 (52.6%)
Family Members	56
Gender	
Female	37 (66%)
Male	19 (34%)
Race	
Black, non-Hispanic origin	5 (8.9%)
White, non-Hispanic origin	50 (89.3%)
Hispanic	1 (1.8%)
Relationship to Patient	
Adult child	32 (57.1%)
Spouse	8 (14.3%)
Sibling	5 (9.0%)
Parent	4 (7.1%)
In-law	4 (7.1%)
Other	3 (5.4%)

MODS, multiple-organ dysfunction syndrome; ARDS, acute respiratory distress syndrome.

heard the news they did not necessarily believe it. It took time for family members to understand. It was shocking for a family, for example, to see a family member who had made Thanksgiving dinner less than 1 week before now critically ill, fighting for her life.

Family members needed time to understand the patient's prognosis, especially when health care providers determined that the patient would never return to his or her prehospitalized condition. Families not only needed to know the prognosis, they needed time to understand the prognosis. It took time for family members to understand that their loved one was never going to be the same person again.

Families and individual family members within a family came to this realization at different times. For example Abby's sister, Claire, realized that her sister was critically ill, however her other sister did not. As Claire stated, "She just doesn't understand."

Time to see if health would be restored

All patient situations involved uncertainty. Life-sustaining therapies were emergently initiated and then families and health care providers waited to determine how each patient would respond. It was common for patients to have hours or days of stability followed by hours or days of instability.

The Johnson family became very upset when a resident was not optimistic the day after Mrs. Johnson's surgery. According to Mr. Johnson, "the resident said, 'we got her through the operation but you do know the situation?' Yeah, we know that she only has a little chance and all." Mr. Johnson and his family were upset as they felt the resident was not giving Mrs. Johnson a chance to improve.

Families hoped that ill or injured family members would beat the odds and respond to treatment. They waited and hoped that their family member would open his or her eyes, squeeze a hand, or wiggle a toe.

Riding a roller coaster

Numerous families described their experience as like riding on a roller coaster. Family members went through the ups and downs of the experience together. Their family member might have a day or a period of time where it looked like things were going well, and then the next day things looked less hopeful. As Mr. Ragazo's daughter described, "It's just been up and down. He was supposed to get off the vent [ventilator], and then he'd run a fever and he'd get a setback." Another patient's son described his mother as having 4 bad days and then 1 good day: "everything goes up and down, up and down."

The roller coaster experience had an effect on the family decision-making process. As a patient's son said:

It's one thing to make a decision if she was down here [he motioned with his arms down]; not doing well and stay down here, but now she has come up here [he motioned with his arms a step up]; she has improved a little bit. So, we can't really make a decision [about LST] when we see improvement.

Family readiness: willingness to consider LST as a possible option

Health care providers commonly had a family meeting during which key members of the health care team sat down with the patient's family and discussed the possibility of withdrawal of LST. This meeting was very emotional and difficult for family members. The timing of family discus-

sions related to withdrawal of LST was very important. Most families were willing to discuss the possibility of limiting LST only after they understood and accepted their family member's poor prognosis for recovery. If they were approached too early, families felt that the health care team was prematurely giving up on their family member, questioned the health care provider's credibility, became angry and lost trust in the health care providers.

During a family meeting Mr. Krieg's daughter and son-in-law told the health care team that they were not willing to discuss withdrawal of LST as a possible outcome. Mr. Krieg's son-in-law stated, "We understand that he (Mr. Krieg) is not going to survive, but we need time."

Individual family member readiness preceded family readiness to discuss the possibility of withdrawal of LST. For example, Nina's mother, Dot, was willingly to discuss withdrawal of LST as a possible outcome; however Nina's father was initially not willing to discuss withdrawal of LST as a possible outcome.

One step at a time

Over time families knew the decision that was needed, but didn't want to make it. Mr. Ragazo's daughter said, "We didn't want to make that difficult decision." Mr. Ragazo's daughter explained,

At this point he was in pre-organ shut down, and we all decided together, that we weren't going to do any more dialysis or blood transfusions, but we didn't want to just completely turn off the vent and give him morphine. . . . So we chose to keep him on the ventilator and make sure he's comfortable. We did stop the medications, like most of them, he was on a Lasix drip, one drip, and they were still sticking his finger, and we said, well you know, let's let him be and not do that.

Two days later, the Ragazo family asked if the ventilator could be withdrawn, and the ventilator was withdrawn later that day.

Families found that taking one step at a time made the process more manageable. When considering life and death decisions, the majority of families made decisions to withhold LST and decisions to withdraw LST followed at a later point in time. Most families were able to reach a decision to withhold LST, whereas decisions to withdraw LST required more time and contemplation. Several families said that they hoped that their family member would die on his or her own, thus they would not need to make a withdrawal of LST decision.

At a family meeting the Lyle family decided that cardiopulmonary resuscitation (CPR) and aggressive resuscitative measures would not be initiated if Mrs. Lyle experienced a cardiac arrest. The Lyle family decided to withhold LST, but needed more time to talk as a family prior to making a decision related to withdrawal of LST. Two days after the family meeting, the Lyle family came to the hospital having decided that LST would be withdrawn that day.

Family readiness: Time to make a decision

The decision to withdraw LST was a tremendous decision. Family members described the decision to withdraw LST as

"the hardest decision," "a horrific decision," and a "cosmic decision." Families needed to decide in their own time. Eventually, all families were able to achieve consensus. Soon after a discussion with the health care team some family members were able to decide quickly, whereas other family members needed more time. If families were pressured to make a decision the family became more protective, defensive, and insistent that all aggressive treatments continue.

For families it was very important that all of the family members were ready. Mr. Braitt wanted to wait a few more days before making a decision related to withdrawal of LST for his wife. As he described, we waited "just to satisfy the youngest daughter . . . I think the rest of us (he and his family) see it in a more realistic way, but she has more hope than we do that something good is going to happen . . . Technically, I think it is my decision, but I sort of let everybody get in. . . . I want to keep everybody happy, because I know, on something like this, it's a lot of stress on everybody."

Individual family member readiness preceded family readiness. Family consensus was important. Mr. Johnson stated, "I know that I have really the say for it, but I want consensus." Mr. Johnson talked with Mrs. Johnson's sister, Mrs. Johnson's mother, and all of Mr. and Mrs. Johnson's adult children. All of the family agreed with the health care team's recommendation to withdraw LST. Laura, Mrs. Johnson's oldest daughter said, "it's been really hard. I had a sense last week what we needed to do, but we needed to wait for everybody to come along." The decision to withdraw LST was a family decision and families needed time to come to consensus as a family.

The family will go on

The entire family was affected by the experience. Family members began to anticipate what the decision meant to the family and most family members began anticipatory grieving. Depending on the relationship, family members lost a spouse, mother, father, brother, sister, or child. Even while the family member was critically ill, the remaining family members began to adjust to changing roles, responsibilities, and relationships with each other.

Each family was faced with a changing future. Family members anticipated the loss of a future for and with their ill or injured family members. Life was suddenly changed and future possibilities were altered. Despite the loss of the ill or injured family member the family needed to go on.

Waiting for a miracle

Immediately after each patient's illness or injury, family members were very hopeful for healing and recovery. All of the families were very hopeful that the outcome would be good. When the condition of each patient failed to improve or in some cases deteriorated, families often hoped for a miracle. Families hoped and many prayed that their family member would prove the health care team wrong and improve. Jason knew that his mother had three organs that had failed (her heart, lungs, and kidneys), yet despite this, he continued to hope for a miracle. He knew it might not happen, but he was going to continue hoping for a miracle anyway.

Hope for a miracle continued for some families up until the very end. On the day that the Johnson family came in

expecting that LST would be withdrawn, Mr. Johnson approached his wife's nurse in the ICU hallway and told him, "We are here today to withdraw, unless a miracle happened." Even after LST was withdrawn, Mr. Johnson said, "I'm waiting for her to open her eyes and start talking."

Discussion

The results of this study offer a unique understanding of what families experienced as they participated in the process of withdrawal of LST from a family member with an unexpected, life-threatening illness or injury. This study supports findings of other researchers who have studied experiences of family members involved with the process of withholding and withdrawing LST. The investigation confirmed the finding that decisions to withdraw LST commonly include multiple family members.^{1,5,10,11} Families in this study tended to make the withdrawal of LST decision as a family through a consensus process. Tilden and colleagues⁵ also found that most families pulled together and made decisions related to withdrawal of LST as a group.

Families have described the decision to withdraw LST as the hardest thing they ever had to do.^{1,10,11} Families in this study echoed this sentiment as words such as "horrific" and "cosmic" were used to describe the decision. All families realized the intensity and the enormity of the decision.

Tilden and colleagues^{1(p436)} noted that "eventually, a turning point either in the patient's condition or the family's readiness arrived and was followed shortly thereafter by either the family or clinicians pressing toward a decision" (to withdraw LST). This study expands on the concept of family readiness and defines family readiness from two perspectives, family readiness to have the discussion regarding withdrawal of LST as a possible option and family readiness to make a decision regarding withdrawal of LST. Families were willing to have a discussion regarding withdrawal of LST as a possible option when the patients' family members understood the seriousness of the patients' illnesses or injuries and that the patients' prognoses, although tenuous, were poor. It took time for all family members within a family to understand the patient's condition and be willing to discuss withdrawal of LST as a possible option.

Decisions related to withdrawal of LST needed to be made by families in their own time and the timing varied for each family. Families were able to make decisions regarding withdrawal of LST when family members understood that patients' prognoses were poor and when all family members were ready. It took time for all family members within a family to understand the patient's condition, be willing to discuss withdrawal of LST as an option, and most importantly to come together as a family and agree to health care provider recommendations to withdraw LST.

Mayer and Kossoff¹³ found that although the majority of family members (79%) stated that the timing of the first discussion to withdraw LST was just right, 17% thought it was premature. This study found that families, who were approached too early, before they were ready, became more resistant to having discussions related to the possibility of withdrawal of LST and more insistent that aggressive treatments continue.

The current study offers new understanding of the family experience related to the process of withdrawal of LST. Fam-

ilies needed time to understand their family member's condition. This was especially important as family members' illnesses or injuries were sudden, unexpected and involved uncertainty. Families facing the sudden, unexpected illness or injury of a family member needed time to realize that life-sustaining interventions were not effective in restoring health and although their family member was alive, his or her life was drastically altered.

Families in this study described feeling like they were on a roller coaster. This was especially true as the condition of the patient often vacillated from stable at one point in time to unstable the next. This roller coaster effect was created by the patient and experienced by the family with families moving up and down and reacting variably to the roller coaster. Being on a roller coaster affected the ability of families to make decisions about withdrawal of LST.

Decisions to withdraw LST often involved a two-step process with many families in this study making decisions to withhold LST prior to making decisions to withdraw LST. Thus, a decision was made to withhold LST such as aggressive resuscitation if it was needed and at a later date, a decision was made to withdraw LST. For example, a decision was made to withhold aggressive resuscitation and any new treatments (e.g., renal dialysis) should they be needed before decisions to withdraw LST. A stepwise decision making process for families in this study was helpful. Many families hoped that their family member would die naturally without them having to make an active decision to withdraw treatment.

The results of this study have important implications for clinical practice (Table 2). The results of this study also have important research implications. The concepts of individual and family readiness in relation to end-of-life decisions need further exploration. Assessment of family readiness may prove invaluable to facilitating the family decision-making process. Future research should continue to help health care providers to better understand what families experience as they participate in the process of withdrawal of LST.

Limitations

Since one researcher collected all data for the study researcher bias is a potential limitation. Safeguards were put in place in an attempt to prevent this, such as the use of member checks for families to give feedback about the data and the use of an audit trail so that an expert qualitative researcher could review all data. Also since one person obtained data, that one person could not be at the hospital 24 hours per day, 7 days per week. Thus, the researcher did not directly observe all experiences that families told her about. Another limitation was that all family members participating in the withdrawal of LST process were not able to participate in the study. Distance or ill health prohibited some members of a family from being physically present at the hospital; however they were involved in the process via telephone or daily updates. Since they were not present in the hospital they were not included in the interviews and observations.

TABLE 2. POSSIBLE INTERVENTIONS TO USE WITH FAMILIES PARTICIPATING IN THE PROCESS OF WITHDRAWAL OF LST FROM A FAMILY MEMBER WHO EXPERIENCED AN UNEXPECTED, LIFE-THREATENING ILLNESS OR INJURY

<i>Family experience</i>	<i>Possible interventions</i>
This happens to other families (shock and disbelief)	Acknowledge family feelings
Time to understand the severity of the illness or injury	Offer family support Keep family informed Give family time to understand the serious nature of the illness or injury
Time to see if health would be restored	Keep family informed
Riding a roller coaster	Acknowledge the uncertainty of the illness or injury Acknowledge the up and down (roller coaster) course Offer family support
Family readiness: willingness to consider LST as a possible option	Assess if families are ready to consider withdrawal of LST as an option Does the family understand and accept that the patient has a poor prognosis?
One step at a time	Assist families with decisions to withhold LSTs prior to decisions to withdraw LSTs Assist families with shared decision-making
Family readiness: time to make a decision	Assess if families are ready to make a decision related to withdrawal of LST Assist families as needed to achieve family consensus Assist families with shared decision-making
The family will go on	Support the family throughout the process Incorporate additional services for families (palliative care team, clergy, bereavement support, etc.)
Waiting for a miracle	Support families desire for hope and help the family by balancing this with inevitable outcome Offer family support

LST, life-sustaining therapy.

Conclusions

An acute, unexpected life-threatening illness or injury of a family member leaves a family vulnerable. Each family has a unique experience based on the context of the illness or injury, the family, and the experience. The family experience participating in the process of withdrawal of LST happened for families "in their own time."

For families in this study their family members' illnesses or injuries happened suddenly and unexpectedly. Families needed time to overcome the initial shock, comprehend the severity of their family member's illness or injury, resolve the period of uncertainty, come together as a family to consider the possibility of withdrawal of LST, to eventually decide as a family to withdraw LST and to go on as a family. As one patient's daughter described, "It was a terrible experience but it was a good experience." It is our responsibility as health care providers to support and help families through this process.

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