Withdrawal of life-sustaining therapy after sudden, unexpected life-threatening illness or injury: Interactions between patients’ families, healthcare providers, and the healthcare system

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**Background** Withdrawal of life-sustaining therapy in intensive care units is increasing. Patients’ families are intimately involved in this process because the patients are usually unable to participate. Little is known about family members’ interactions with healthcare providers and the healthcare system during this process.

**Objective** To describe the interactions between patients’ family members, healthcare providers, and the healthcare system during withdrawal of life-sustaining therapy after a sudden, unexpected illness or injury.

**Methods** The investigation was part of a larger interpretative phenomenological study. Nineteen families (56 family members) who participated in the process of withdrawal of life-sustaining therapy for a family member were interviewed and observed. An inductive approach to data analysis was used to discover units of meaning, clusters, and categories.

**Results** The families’ experiences involved a variety of dimensions, including issues with healthcare providers (bonds and consistency with nurses and physicians, physicians’ presence, information, coordination of care, family meetings, sensitivity to time, and preparation for the dying process) and issues with the healthcare system (parking, struggles with finding privacy, and transfers of patients).

**Conclusions** Patients’ families need information, guidance, and support as the families participate in the process of withdrawal of life-sustaining therapy. The results of this study have important implications for clinical practice and future research. (American Journal of Critical Care. 2006;15:178-187)
Discussions between patients’ families and healthcare providers about life-sustaining therapy typically take place when a turning point occurs in the condition of the patient or when the families are ready for the discussions. Healthcare providers usually initiate the discussion. Mayer and Kossoff reported that the majority of family members (75%) thought that the family and physician should make decisions together about withholding and withdrawing life-sustaining therapy, whereas 25% of family members thought only the family should decide.

Swigart et al found that decisions to withhold or withdraw life-sustaining therapy were made by physicians on the basis of physiological data and then patients’ families were approached, more for assent than consent. Family members of patients who died when chronic dialysis was discontinued reported that physicians and nurses were usually the initiators of the discussion that led to withdrawal of life-sustaining therapy, whereas patients and families made the final decision.

Evidence suggests that the process of making decisions about life-sustaining therapy may differ between family members of patients with acute illnesses or injuries and family members of patients with chronic illnesses. Previous experience with losses associated with a chronic illness aided some family members in making final decisions about life-sustaining therapy. Tilden et al found that families of patients with acute illnesses or injuries recognized futility more abruptly after a period of denial.

Healthcare providers can hinder or help patients’ families with the process of withdrawal of life-sustaining therapy. Behaviors of healthcare providers that increase the families’ burden include postponing discussions about withdrawal of treatment, delaying withdrawal once it has been scheduled, placing the full burden of decision making on a single person, withdrawing from the family, and defining death as a failure.

Families have reported that many of the behaviors of healthcare providers were helpful as the families participated in the process of withdrawal of life-sustaining therapy. Families working with clinicians in a harmonious way had the easiest time with decision making. As stated by Tilden et al, “A sense of collaboration and inclusion was the single most important difference between a positive and a negative experience for most families.” Families found nurses and physicians helpful when the healthcare providers encouraged advance planning, communicated in a timely manner, clarified the roles of family members, facilitated consensus among the family members, and accommodated the family members’ grief.

Families found it especially helpful when healthcare providers were direct, honest, and realistic as the providers guided and facilitated the families through the process of withdrawal of life-sustaining therapy. O’Callahan et al also reported that family members found that frequent and clear communication with healthcare providers was helpful during decision making related to withholding and/or withdrawing life-sustaining therapy.

Families are intimately involved in the process of withdrawal of life-sustaining therapy, because patients are usually unable to participate in decision making because of the severity of the illness or injury or because of medications used to minimize discomfort. Little is known about interactions between patients’ families, healthcare providers, and the healthcare system during this process. This investigation was part of a larger interpretative phenomenological study to understand the experience of patients’ family members who participated in the process of withdrawal of life-sustaining therapy from patients who had a sudden, unexpected illness or injury. In the analysis reported here, I describe interactions of patients’ families with healthcare providers and the healthcare system during the process of withdrawal of life-sustaining therapy.

Methods
The goal of the larger study was to answer the question, What do families experience during the process of withdrawal of life-sustaining therapy from a family member with an unexpected, life-threatening illness or injury? A hermeneutic phenomenological approach was used in that investigation. For the analysis reported here, a descriptive phenomenological approach was used. The goal of this analysis was to describe the interactions between patients’ family members, healthcare providers, and the healthcare system during the process of withdrawal of life-sustaining therapy. The main question from the interview guide for the larger study was “Tell me about your family’s experience since your family member became seriously ill or injured.” As families participated in the interviews, they shared many stories, comments, and perceptions about experiences they had with healthcare providers and the healthcare system.

Interviews and observations were conducted prospectively with families as they participated in the process of withdrawal of life-sustaining therapy.

Families were enrolled into the study until reduct-
dancy was achieved, that is, until no new themes or new data were obtained. Families were studied during a period of days to weeks as the process of withdrawing life-sustaining therapy unfolded.

Sample
A purposive sampling strategy was used to select the family sample from 3 ICUs. With this strategy, families were sought so that the final sample would include families of patients with a variety of illnesses or injuries, families that varied in size, and families that had a variety of family experiences with withdrawal of life-sustaining therapy. Family was self-identified as those individuals who claimed to be family members. The inclusion criteria for the study were as follows: the patient had had an unexpected, life-threatening illness or injury; the patient was unable to participate in decisions related to life-sustaining therapy; the patient for whom life-sustaining therapy was being withdrawn was 18 years or older (all study units were adult ICUs); the patient’s family members were 18 years or older (although one 17-year-old emancipated minor was included); the patient’s family members provided written consent for participation in the study; and the family members were able to speak and understand English.

An unexpected, life threatening illness or injury was defined as an acute condition (duration <1 month) that required hospitalization in an ICU. Life-sustaining therapy was defined as any measure necessary to maintain life (eg, mechanical ventilation, use of vasoactive agents, use of cardiac mechanical assist devices, dialysis, nutrition/hydration). Family was defined as the individuals (not necessarily biological relatives) who were participating in and experiencing the process of withdrawal of life-sustaining therapy.

Patients were excluded if they met the criteria for brain death, were able to participate in decisions related to life-sustaining therapy, were hospitalized because of attempted suicide, were hospitalized because of domestic abuse, or had a chronic illness with a sudden catastrophic event related to the chronic illness.

Recruitment Procedures
Nurses and physicians referred families for consideration in the study when the healthcare providers thought that a patient might not survive and that withdrawal of life-sustaining therapy might be considered. When a patient was referred, his or her chart was reviewed and his or her critical care nurse was consulted to determine if the patient met the inclusion criteria for the study. Consent was obtained from the attending physician before the patient’s family was approached for informed consent. Two families (10%) refused to participate in the study. Approval was obtained from the appropriate institutional review board before data collection began.

Sequence for the Investigation
Each family interview was conducted at a time convenient for the participating family. All initial interviews were held before discussions related to withdrawal of life-sustaining therapy occurred. The interviews lasted 30 to 60 minutes and were usually held in a conference room close to the ICU. The first interview started with a general question, “Tell me about your family’s experience since your family member became seriously ill or injured,” and progressed to more specific questions related to each family’s experience. Additional interviews (conversations) were held with available family members daily and lasted 5 to 30 minutes each. Audiotapes were made of all interviews, or field notes were taken.

In addition to interviews, interactions between (1) family members, (2) family members and the patient, and (3) family members and healthcare providers were observed. Meetings between family members and healthcare providers were also observed and were audiotaped or field notes were taken.

Data Analysis
An inductive approach was used for data analysis. The selective or highlighting approach of van Manen was used to identify statements that were particularly essential or revealing about interactions between patients’ family members and healthcare providers and the healthcare system. As similarities were noted between units of meaning, clusters and then categories were determined. Data were managed by maintaining a family focus. Clusters or themes and then categories that emerged for each family were compared with themes and categories that emerged for other families.

Methodological rigor was established. Truth-value was obtained as data were confirmed with families. This analysis was specific to experiences related to withdrawal of life-sustaining therapy from patients with acute, unexpected illness or injury; thus, applicability (generalizability) is limited to families in this context. Multiple methods of data collection, in addition to multiple interviews and observations with the same family member or members, aided in determining consistency or dependability of the data. Neutrality is important to minimize the influence of the biases, motivations, interests, or perspectives of the researcher. Another expert qualitative researcher reviewed the data (audit trail) and confirmed findings.
Results

A total of 19 families with 56 family members participated in the study (Table 1). Patients had diverse illnesses and injuries (Table 2). Of the 19 families, 17 (89%) agreed with healthcare providers’ recommendations about withdrawal of life-sustaining therapy, and 16 patients died after life-sustaining therapy was withdrawn (Table 3). Two families did not agree to recommendations for withdrawal of life-sustaining therapy (Table 3). Therapies withdrawn included mechanical ventilation, use of vasopressors, administration of intravenous fluids, enteral feedings, total parenteral nutrition, dialysis, use of ventriculostomy catheters, treatment with antibiotics, blood transfusions, and additional infusions (eg, furosemide and insulin).

Key clusters or themes that aid in explaining the phenomenology are described in the following sections. The categories that emerged that aid in understanding the families’ experiences were issues with healthcare providers and issues related to the hospital system. Pseudonyms are used, and identifying information has been changed to ensure anonymity.

Issues With Healthcare Providers

Issues with healthcare providers influenced the families’ experiences. The key themes between families and healthcare providers included bonds and consistency with nurses and physicians, physicians’ presence, information, coordination of care, family meetings, sensitivity to time, and preparation for the dying process.

Relationships with healthcare providers were important to families. Patients’ families developed bonds with the nurses and physicians who were caring for the patient. Families found it helpful to see a consistent familiar face that they trusted and with whom they had developed a relationship. For example, Nina’s mother knew some nurses better than others and trusted some nurses more than others. The mother said that if certain nurses were working, “I could go to sleep. I could just lie down and trust them and go to sleep.”

Families indicated that it was important that the nurses and the physicians know both the family member who was the patient and the other family members. For example, the Lyle family wanted Mrs Lyle’s primary nurse, Ally, to be there the day that life-sustaining therapy was withdrawn because they had a close connection with her. In another example, the physicians who acted as attending ICU physicians in the units usually changed monthly. Although Mrs Keefer’s attending ICU physician technically was no longer on service in the unit, he remained Mrs Keefer’s attending physician because he thought it was “the right thing to do” for Mrs Keefer’s family.

Several families experienced broken bonds and inconsistency with nurses and physicians. Some of the broken bonds and inconsistencies occurred within the same unit, and some occurred because the patient was transferred. Without consistency in healthcare providers, unique nuances for a patient might not be known. Some families described experiences that they had with inconsistency among the medical team. As Mr Ragazo’s daughter described, “Dr Jones was the chief resident then, and he was wonderful, but then after 3 or 4 weeks, he was gone, and we never saw him again, and then you get somebody else.” Consistency would have been appreciated, or as Mr Ragazo’s daughter suggested, Dr Jones should have at least had “the new guy with him and say, ‘Look I’m going off, 

Table 1 Family participants

<table>
<thead>
<tr>
<th>Participants</th>
<th>No. of family members</th>
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<tbody>
<tr>
<td>Spouse</td>
<td>3</td>
</tr>
<tr>
<td>Wife</td>
<td>5</td>
</tr>
<tr>
<td>Husband</td>
<td>2</td>
</tr>
<tr>
<td>Adult child</td>
<td></td>
</tr>
<tr>
<td>Daughter</td>
<td>22</td>
</tr>
<tr>
<td>Son</td>
<td>10</td>
</tr>
<tr>
<td>Parent</td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>3</td>
</tr>
<tr>
<td>Father</td>
<td>1</td>
</tr>
<tr>
<td>Sibling</td>
<td></td>
</tr>
<tr>
<td>Sister</td>
<td>5</td>
</tr>
<tr>
<td>Brother</td>
<td>0</td>
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<tr>
<td>In-law</td>
<td></td>
</tr>
<tr>
<td>Sister-in-law</td>
<td>1</td>
</tr>
<tr>
<td>Brother-in-law</td>
<td>1</td>
</tr>
<tr>
<td>Daughter-in-law</td>
<td>1</td>
</tr>
<tr>
<td>Son-in-law</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>Aunt</td>
<td>1</td>
</tr>
<tr>
<td>Female cousin</td>
<td>1</td>
</tr>
<tr>
<td>Boyfriend</td>
<td>1</td>
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Table 2 Patients’ illnesses or injuries

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>No. of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurological events</td>
<td>4</td>
</tr>
<tr>
<td>Trauma</td>
<td>3</td>
</tr>
<tr>
<td>Pancreatitis</td>
<td>2</td>
</tr>
<tr>
<td>Gastrointestinal bleeding</td>
<td>1</td>
</tr>
<tr>
<td>Surgical complication</td>
<td>3</td>
</tr>
<tr>
<td>New cancer diagnoses</td>
<td>6</td>
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</tbody>
</table>
but this is the new guy.’’ Both the Warwick family and the Sanchez family had to develop a new bond with a new physician at a very critical point in Mr Warwick’s and Mrs Sanchez’s illnesses.

Families described challenges they faced when the patient was transferred. As Mr Ragazo’s daughter remarked, “We got really close to the nurse [primary nurse] there [surgical ICU], and we bonded with them [nurses], and then all of a sudden, boom, we’re out of there.” As she further described, “But then all of a sudden, we were like, just like ejected to here, and it was like, right away we didn’t know anybody and nobody knew us and that was hard.”

The presence of physicians was important for families. Each patient’s attending physician was very involved in the majority of family discussions related to withdrawal of life-sustaining therapy. Explanations and recommendations provided by attending physicians were important and helpful for families. Five families felt that the physician abandoned them. For example, Mrs Falotico’s son, Alex, was disappointed that he never saw his mother’s surgeon except for immediately before and after her surgery. Alex thought that the attending physician should have helped him as he [Alex] was making life-and-death decisions.

The Morelli family was also angry and disappointed that they had had little contact with their mother’s attending physician. Mrs Morelli’s daughter, Kay, said, “I’ve seen him [the physician] on the floor, but he doesn’t come in. I guess he feels that my mother is no longer really his patient, as there is nothing that he can do for you. I find that kind of rude.” Kay angrily added, “He’s done with me, he’s done with us.”

Information helped families understand the condition of their seriously ill family member. Frequent updates helped families understand if the family member was improving or not. Communication between healthcare providers and a patient’s family was clearest when consistency among healthcare providers was maintained. For example, the intensivist met daily with the Keefer family. This daily meeting was extremely helpful because the family members were kept up to date on Mrs Keefer’s condition and had the opportunity to have their questions answered.

In another example, the Sanchez family received conflicting information. Mrs Sanchez’s daughter, Rita, told the critical care intensivist that it was difficult because the family was getting different stories from each of the physicians and “It’s hard for us to really know what to believe or what, you know, is what we should kind of hang our hat on.”

Information provided to families needed to be presented within the larger context. In another example, Rachael’s brother, Dan, commented as follows:

I think we were pounding on them [the physicians] a little bit more yesterday, sort of like we hear hips are this or pelvis is this, head is that, you know. We keep getting these fragmented reports, and again what we need is information that can help us make a decision about what my mother’s life is going to be. Not about how her head is today and you know what her intracranial pressure is, and you know, how much of this, and how little of that, and what the technical procedure will be. We’re talking about, you know, help me understand if she were to survive, what would her life be like? And would she, you know, really hate us?

Coordination of care was especially important. Family members were at the patients’ bedside for long hours every day and observed care provided. Consistent information and consistent care helped families know that healthcare providers communicated with each other and knew what was going on. Several families thought that their family member’s care was fragmented. Mr Ragazo’s family questioned the coordination of his care. His daughter, Lynn, said the following:

Maybe there were too many cooks. Because somebody would come in and say something; . . . that person really didn’t know. Like, somebody was doing something to him one day, and I said something about how he had dialysis. “Oh he had dialysis?” So they didn’t really know his course. Or the one doctor would say something, and the other doctor

<table>
<thead>
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<th>Table 3 Family members’ responses to healthcare providers’ recommendations to withdraw life-sustaining therapy</th>
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<tbody>
<tr>
<td><strong>Response</strong></td>
</tr>
<tr>
<td>Agreed (n = 17)</td>
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<tr>
<td>Disagreed (n = 2)</td>
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then would come in and say, “Well no, he’s just being consulted. We’re really not going to do that. We just asked his opinion. We’re not really going to do what he said, because we don’t really believe in that.” So, it was just like too many, like is everybody on the same page? I think the hard thing for us is sometimes different people would say things to us, and then we weren’t sure whether they were communicating to themselves.

In another example, Mrs Donovan’s daughter, Rachael, said, “I believe that my mother is where she is and there is nothing that can be done for my mother. They’ve done the best they can, but the fragmentation of care is scary as hell.” Rachael described the intensivist, the orthopedic physicians, the ophthalmologist, and the neurosurgeons as “colliding together without a person coordinating care.” She added, “It’s as if this process would be made better if there was a translator . . . who remains constant. Who doesn’t change all the time. Who’s not you know, ‘Oh, you really need to talk to Dr So and So . . .’ It’s like you need a steward.”

Family meetings to discuss end-of-life issues were common. Of the 19 families, 17 had at least one family meeting that was scheduled and held in a conference room. Most family meetings lasted 30 to 45 minutes. People attending the family meetings usually included key family members involved in decision making for the patient, a physician, and the patient’s primary nurse or associate nurse (one who assisted the primary nurse). Some family meetings also included the patient’s nurse practitioner, residents, and the nurse ethicist. Family meetings were usually led by a physician and at times by a nurse practitioner. Critical care nurses helped coordinate the meetings, arranged a space for the meetings, contributed to the discussion during the meetings, provided support to the family, and at times helped a family develop questions before the meetings. One family meeting was cofacilitated by the critical care intensivist and the patient’s associate nurse.

Family meetings were beneficial to families in this study. Families found it helpful to sit down and talk with physicians, nurses, and other members of the healthcare team. Families valued having the opportunity to sit down and talk about everyone’s understanding of the patient’s condition and expected course.

Families were sensitive to time. It was important that family meetings and scheduled events (eg, withdrawal of life-sustaining therapy) occur on time. Delays were difficult for families. Families experienced intensified anxiety if a scheduled meeting was delayed. As Mrs Lyle’s daughter said, “If he’s [surgeon] not going to be around for a while, I’m . . . I can’t take this any more [the waiting].” Mr Warwick’s family was also very anxious when their family meeting was delayed for 2½ hours as they waited for the physicians to finish clinical rounds. A family meeting with the Miller family was delayed when the medical resident had to leave urgently to go to the emergency department.

When the time came for life-sustaining therapy to be withdrawn, families expected the withdrawal to happen quickly. Delays in withdrawing life-sustaining therapy were extremely difficult for families. For example, for the Johnson family, a delay of 40 minutes was too long. Any delay such as time needed to obtain a morphine infusion from the pharmacy or time spent waiting for a member of the healthcare team to arrive was almost unbearable for families.

For instance, the decision was made to withdraw life-sustaining therapy from Mrs Braitt the next day at 11 AM. However, the next day, the withdrawal of life-sustaining therapy was delayed for several hours. The delay occurred because the medical team did not have the paperwork done, and trying to get someone to do the paperwork was difficult. Residents from 2 different services (gastroenterology and critical care) refused to do the paperwork. One of the residents said that the physician “above me doesn’t agree with what we’re doing; he thinks we’re withdrawing too soon, so I don’t want my name on the chart.” Thus, the decision to withdraw life-sustaining therapy had been made the day before, but no paperwork had been done. Eventually, the attending physician left another hospital to come to the unit to sign the necessary paperwork.

In another example, Abby’s family also decided that life-sustaining therapy would be withdrawn the next day at 10 AM. After the family arrived at the hospital the next day, they spent time at Abby’s bedside. The nurse called the resident, and he met with the family at the bedside, and then everyone sat down to talk further in the family waiting room. The family wanted life-sustaining therapy withdrawn right after the meeting; however, they had to wait for several hours. The resident was unclear if he was able to complete the necessary paperwork, a delay occurred in obtaining the morphine infusion from the pharmacy, and then another delay occurred as Gift of Life was called and time was allotted for the nurse to perform an assessment to determine if Abby was a potential non–heart-beating organ donor. Family anxiety was especially high as the family waited.

Some families were prepared for the dying process, and others were not. If families were prepared,
they knew what to expect. Some families either were not informed about what to expect during the dying process or were told that when life-sustaining therapy was withdrawn their family member would die quickly. For example, the Johnson family was told that Mrs Johnson would die within 4 hours. She died 2 days after life-sustaining therapy was withdrawn. In another instance, Alex was told that his mother would more than likely die within a day. Even though he was told this, he expected her to die much more quickly. As he said, “It isn’t what I expected. I expected this to happen quickly. When you think of removing life support you think it’s going to happen quickly.” Alex’s mother died 5 days after life-sustaining therapy was withdrawn.

Issues With the Healthcare System

Families also experienced issues related to the hospital system. Key themes included parking, struggles with finding privacy, and transfers of patients.

Many families were unhappy with the parking service at the hospital. Parking was especially burdensome for families of patients with long lengths of stay, because it was quite expensive. For example, Mr Ragazo was hospitalized for several weeks, and his family was displeased with the amount of money they spent on parking. They were especially unhappy when they learned that families in another unit received discounted parking passes.

Mrs Brown was frustrated by the parking situation as well. She spent $60/wk on parking. She used valet parking every day and usually stayed at the hospital for 3 hours. If she parked in the garage, the parking was a little less expensive, but she had to walk farther. Since she had trouble walking, it was easiest to use valet parking, but it was costly.

The Sanchez family usually used the valet service, yet at times they found it frustrating. Dominic described an unpleasant interaction he had with a hospital valet parking attendant:

The attendant gave me such a hard time the other day. I was going to smack him. I came around to the main entrance, and he asked me in a belligerent tone, “Where are you going?” I said, “The hospital.” He said, “For what?” Just like that. What do you mean for what? What do you go to the hospital for? I am visiting a patient. Then he asked me another question. I said, “Yo buddy. My mother is in intensive care dying and you are going to bust on me now?” I was polite. He said, “Well we have to ask.”

As Dominic said, “This [confrontation] is just one more thing, even if it’s small. It is irritating.”

Finding privacy was important for families. Most families had a hard time trying to find a private area to be alone at the hospital. All of the ICUs had at least a single waiting room, but the waiting rooms were small and at times overcrowded. Sometimes as an individual or as a family, family members needed time alone. One family member sat on a step one day at the end of a hallway just to get away from it all and be alone. For example, Mrs. Morelli’s daughter, Kay, said the following:

Rooms like this (waiting rooms) are nice, but then you end up hearing about someone recovering, and I just want to say, shut up. And I know that cell phones are a great idea, but you are in a quiet room, and in a quiet place for families, and everybody is on their cell phones. One day, I was using the pay phone by the elevators, and I’m standing there crying, and there is no quiet little room that I can go into and talk with a family member. I was talking to my uncle, and I was standing there crying and carrying on, and people are getting on and off the elevator. Maybe a little cubbyhole or a small room to make phone calls.

Of the 16 patients who had life-sustaining therapy withdrawn, a total of 11 patients had life-sustaining therapy withdrawn in the ICU and died in the ICU. Once the decision was made that treatment was no longer going to be aggressive, patients were sometimes transferred out of the ICU. This transfer was difficult for some families. A total of 2 patients had life-sustaining therapy withdrawn in the ICU and then were transferred to the step-down unit, and 3 patients were transferred to a step-down unit and had life-sustaining therapy withdrawn there. Some families did not mind the transfer, and some families did. The Ragazo family did not mind the transfer, because Mr Ragazo was transferred to the step-down unit, which was a more private room, and the nursing staff was the same as in the ICU.

Other families did mind that their family member was transferred to a new unit. The evening that the decision was made to withdraw life-sustaining therapy, Abby was transferred from the ICU to the step-down unit. Her family was not called about the transfer and was quite shocked the next day not to find her in the ICU.

In another example, Mrs Falotico’s son, Alex, found his mother’s transfer very upsetting. The nurse
in the ICU prepared him for the transfer, but he would have preferred that his mother stay in the ICU. He said, “I knew the nurses. I knew the doctors. I had a relationship with them.” He really liked his mother’s primary nurse. Alex described feeling that his mother “was just being pushed out of the ICU to die.” His mother was transferred to a private room at the end of a long hallway. Alex did not like the environment. He said, “There’s a lot going on here; there’s a lot of noise here. It’s kind of like leaving a horse in a stable to die.” He also said, “I don’t know the nurses. I don’t know anybody here. I don’t know how often they’re going to come in and check on her. There are no familiar faces.” He also said, “Even leaving tonight, I don’t have the sense of comfort because I don’t know the people. I don’t know the nurses taking care of my mom.”

Discussion

Interactions between patients’ families, healthcare providers, and the healthcare system can greatly influence the families’ experiences in participating in the process of withdrawal of life-sustaining therapy from a family member with an unexpected, life-threatening illness or injury. Understanding issues created by interactions can help improve the process for patients’ families.

The results of this study reinforce the findings of Tilden et al12 that behaviors of healthcare providers that add to the distress of patients’ families include postponing discussions about withdrawal of treatment, delaying withdrawal once it is scheduled, and withdrawing from the families. Patients’ families often found it a challenge to coordinate activities so that all family members were at the hospital at a specific time for a family meeting or, more importantly, for the actual withdrawal of life-sustaining therapy. Delays often increased the families’ anxiety and left them feeling like they were a low priority.

The presence of physicians was important throughout the process of withdrawal of life-sustaining therapy. Some families in this study felt abandoned by their family member’s attending physician. Families were angry and hurt that the physicians did not care enough about the family member or family to be involved in the end-of-life decision-making process. Tilden et al12 also found that some physicians distanced themselves from the process of withdrawal of life-sustaining therapy.

Families who participated in the process of withdrawal of life-sustaining therapy have described feeling as if they were riding on a roller coaster.9 Information given by healthcare providers often contributed to the roller coaster ride, because pieces of “good news” or stable conditions were at times given to a family along with pieces of “bad news” or unstable conditions. Sometimes the good news was not placed in the context of the overall prognosis for the patient.

Patients’ families participating in the process of withdrawal of life-sustaining therapy need consistency among healthcare providers and the delivery of consistent messages. The families in this study and in other investigations12,18,21 have clearly described the need for consistent information. Families need timely, honest, clear information.13,16,23,24 Nursing systems should promote continuity of care with as few nurses as possible so that consistency in nurses can be achieved. In addition, a consistent attending physician needs to interact daily with a patient’s family. This physician should be responsible for obtaining daily updates from each of the consulting services, coordinating reports on the patient’s care, and providing updates and recommendations to the patient’s family. All members of the interdisciplinary team need to communicate effectively with each other so that families receive consistent information.25

Keenan et al1 found that critical care nurses were not likely to be included in discussions between physicians and patients’ families about withdrawal of life-sustaining therapy. In my study, critical care nurses were included in the majority of family discussions.

The healthcare team should schedule meetings with each patient’s family members to discuss the patient’s condition, goals of care, possible treatment options, and possible outcomes. More than a single meeting is usually necessary. The meetings should include all key family members and should be facilitated by a lead physician (either the intensivist or the attending physician) and the patient’s primary nurse. Other key members of the healthcare team should also be included. It is essential that families are prepared for and understand the purpose of the meeting. The nurse should advise family members to write down their questions so they do not forget the questions during the meeting. This step will help the family be better prepared. The meeting should be held in a private room, and the nurse should arrange for another nurse to care for his or her patients during the time that the meeting is held. The physician should also have another physician cover for him or her during the meeting so the meeting is not interrupted. Those healthcare providers with pager responsibilities should temporarily have other nurses or physicians be responsible for the providers’ patients and pagers during the length of the meeting. Because delays increase families’ anxiety, the meeting should begin as close to the scheduled time as possible.
Family meetings are an effective strategy for improving communications between patients’ family members and healthcare providers.26-28 McDonagh et al29 found that families’ satisfaction with family meetings improved when family members had plenty of time to talk during the meetings.

After a decision is made to withdraw life-sustaining therapy, the patient’s family members usually let the healthcare team know when the family would like life-sustaining therapy to be withdrawn. As in the study by Mayer and Kossoff,4 families in my study usually wanted life-sustaining therapy withdrawn as quickly as possible. It is important that physicians, nurses, pharmacists, respiratory therapists, and clergy coordinate their responsibilities to ensure that the scheduled time is kept.

Transfers of dying patients should be limited and should be the exception, not the norm. The majority of patients in this study had life-sustaining therapy withdrawn in the ICU, and the patients died in the ICU. Transfers out of the ICU were difficult for families who were separated from a familiar unit and from familiar nurses and physicians whom they trusted. Ideally, patients should be allowed to die in the ICU with familiar care providers.

The results of this study support the need for preparation of patients’ families. Families do not know what to expect after withdrawal of life-sustaining therapy and should be prepared for what to expect during the dying process. Families need to be informed about what to expect and how long the dying process might last. They should be told that after life-sustaining therapy is withdrawn, their family member may die within a few minutes to hours; however, the dying process is unpredictable and may take several days. Kirchhoff et al30 suggest that families should be prepared for physical sensations and signs that the dying patient may experience.

Families of the dying need the utmost support. Families should be offered supportive services from clergy, palliative care, and hospital bereavement experts. Most families want to be close to their family member during his or her final moments. Families need time to say final goodbyes to their family member.21 Families usually do not want to go home. Special attention should be given to the family’s need for privacy and comfort. Families may need a place to rest, shower, and be alone together as a family. Assistance should be provided to help families meet the expenses of parking fees. All families of dying patients should be given information on referral services, such as individual and group bereavement support.

Future researchers should continue to seek to better understand what patients’ families experience as the families participate in the process of withdrawal of life-sustaining therapy. Research needs to be done to develop and test interventions that are most effective in aiding families going through these experiences. Investigators might test the best approach to use when discussing the possibility of withdrawal of life-sustaining therapy with a patient’s family, the most effective strategies healthcare providers can use to facilitate the family’s decision-making process, and effective strategies to facilitate the family’s grief process.

One limitation of this study is that only a single researcher collected all data. An expert qualitative researcher reviewed an audit trail, and a sample of families reviewed the final phenomenology to ensure that researcher bias did not exist. In addition, distance and illness prohibited some family members from being present at the hospital, so they were not included in the study. Last, the method used in this study, phenomenology, has traditionally been used to study the lived experience of individuals, not families.

Conclusion
Families need information, guidance, and support as they participate in the process of withdrawal of life-sustaining therapy. Family services need to be in place to support families. Healthcare providers play an important role in helping families through this process.

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