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The Power of the Liver Transplant Waiting List: A Case Presentation

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Abstract

Background—End stage liver disease (ESLD) is the final stage of chronic liver disease. Liver transplant is the therapy for ESLD. Many patients develop serious ESLD related complications and are admitted to the intensive care unit for treatment. Consequently, such patients are temporarily unsuitable to undergo transplant surgery, and are placed into a temporarily inactive category, or *status 7*, on the transplant waiting list. Currently, status 7 patients account for approximately 15% of all patients on the list. Approximately 15% of patients die while waiting for a liver transplant.

Objective—To describe the experience of a patient being status 7 on the liver transplant waiting list from the perspectives of family members.

Methods—A case study design was used and included 38 hours bedside participant observation, 9 semi-structured interviews with 6 family members, and 9 semi-structured interviews with 8 health care professionals from nursing, medicine and other healthcare disciplines. Data were analyzed using content analysis.

Results—Family members' perspectives can be described in three phases: dealing with crisis, confusion and frustration, and back on the road to transplant. These phases correspond with the progression of the patient's clinical condition. All three phases were underscored by a single goal to get the patient's status re-activated on the liver transplant waiting list.

Conclusions—This case provides a window into the struggles patients with ESLD and their families may go through during the status 7 period and could serve as a starting point for further exploring this period.

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Keywords

Critical Care; Liver Transplantation

BACKGROUND

The Scope of the Problem

In the United States approximately 5.5 million Americans suffer from chronic liver disease.[1] End stage liver disease (ESLD) is the final stage of chronic liver disease progression. Liver transplant is the only definitive therapy for ESLD. Over the last two decades, advances in liver transplant technology, immunosuppression, and medical care have broadened its indications and improved its survival rate.[2] As a result, the demand for liver transplantation is increasing. However, the availability of donor organs has remained static, resulting in the number of potential transplant recipients exceeding supply.[3] To ensure fairness in the allocation of organs for transplant, in 1984 the National Organ Transplant Act established the Organ Procurement and Transplant Network (OPTN), an organ sharing system. The nonprofit United Network for Organ Sharing (UNOS) has operated OPTN under a contract with the Division of Transplantation in the Department of Health and Human Services. UNOS maintains a national list of patients waiting for transplants. There are more than 16,500 patients with ESLD awaiting liver transplantation in the United States.[4] Annually, approximately 6,000 patients receive a transplant, and approximately 15 percent die waiting for one.[5]

Liver Transplant Waiting List

Patients meeting criteria are placed on the national liver transplant waiting list. Given the shortage of donor organs, UNOS adopted the MELD in 2002 as the basis for organ allocation. MELD is based on statistical formulas that predict pre-transplant mortality risk from liver disease.[6,7] Its score ranges from 6 (less ill) to 40 (gravely ill). The higher the patient's MELD, the higher priority for the patient to get a transplant. The time that people wait for a liver transplant varies widely based on their MELD score, blood type, body size, and availability of donor organs.[8]

Status Seven

Like Mrs. Johnson, many patients deteriorate or develop serious ESLD related complications while waiting for a liver transplant. Complications such as spontaneous bacterial peritonitis and variceal bleeding while treatable, compromise patients’ general health and negatively affect transplant procedure survival and post-transplant outcomes. Consequently, such patients are temporarily unsuitable to undergo transplant surgery, and are placed into a temporarily inactive category, or *status 7*, on the transplant waiting list. Status 7 patients receive treatments for complications with the goal of being re-activated on the waiting list.

The number and proportion of patients with inactive status on the transplant waiting list has increased over the last several years. Currently, status 7 patients account for approximately 15% of all patients on the list.[3] However, a thorough search in Medline, CINAHL, and

Psych Info yield no research focused on this special population and their families' experiences during the inactive period. To better care for and support these patients and their families, the purpose of this case presentation is to describe the experience of a patient being "status 7" on the liver transplant waiting list from the perspectives of family members.

METHODS

The case reported here is an exemplar from a larger study. The parent study's design, setting, data collection and analysis methods have been described in details elsewhere.[9] Briefly, in the parent study, we used a prospective, multiple case study design to describe life-sustaining treatment decision-making for patients' with ESLD during their stay in ICU.

The case study design makes it possible to generate a rich, comprehensive data set that reflects multiple perspectives of the experience.[10] Data were analyzed using content analysis.[11-13] The Institutional Review Board at study sites approved the study. Study participants, patients' Authorized Research Representatives, or Legally Authorized Representatives gave written informed consent prior to being observed or interviewed.

The case presented here was selected to capture the status 7 period in the ICU. The case data set includes: 38 hours of bedside participant observation; 9 semi-structured interviews with 6 family member; 9 semi-structured interviews with 8 health care professionals from nursing, medicine and other healthcare disciplines; and a follow-up interview with the patient and her husband conducted one month post discharge from the hospital. To ensure the confidentiality of the participants, we have used pseudonyms and changed information that might directly identify participants.

RESULTS

Mrs. Johnson remained in the ICU for 5 days under the care of a team of health care professionals. She received massive blood transfusions, intubation, mechanical ventilation, endoscopic variceal banding, Minnesota tube, transjugular intrahepatic portosystemic shunt (TIPS) procedure, vasopressors, and tube feeding. She returned to active status on the liver transplant waiting list right before she transferred out of the unit, and was successfully transplanted one month later.

The Johnson family's rollercoaster-like journey through the inactive period in the ICU can be described in three phases: dealing with crisis, confusion and frustration, and back on the road to transplant. These phases correspond with the progression of Mrs. Johnson's clinical condition and were underscored by a single goal—to get Mrs. Johnson re-activated on the transplant waiting list.

Dealing with Crisis

The first phase started day one in the ICU when Mrs. Johnson was admitted and ended when her active variceal bleed was controlled following an emergent TIPS. We identified three themes from the phase one data: drastic shift in circumstance, emotional turmoil, and keeping the hope alive.

Drastic shift in circumstance—The Johnsons' experience was marked by a drastic shift from a treatable bacterial peritonitis to preparing for the possibility of her death. Prior to this admission, Mrs. Johnson was number one on the liver transplant waiting list. She was perceived by health care professionals as an excellent candidate and was predicted to "do very well post-transplant for the particular underlying disease she had" (physician). Mr. Johnson remembered that he chose to focus on these positives while waiting for a transplant: "...I refused to let myself think anything but positive..."

When Mrs. Johnson's condition started to deteriorate and the family became aware that she was not a transplant candidate, they faced the possibility of her imminent death. Mr. Johnson noted that the gastroenterologist confronted him with a "life-and-death" situation:

> At that point we were in the position of knowing that there was very little hope that she would live if they couldn't do anything...[the doctor] offered us TIPS...He says the only other choice is to do nothing and she will die.

This drastic change came as a surprise to the Johnsons. As one of the Johnson children explained:

> For me it was a huge shock...her liver doctor was here, and unloaded everything...it was, I was in shock. I knew she was sick, but...nobody [had said], there is a really good chance that she is going to die.

Emotional turmoil—The Johnsons responded to the crisis with a wide range of emotions. Mr. Johnson described this phase as a period of helplessness and uncertainty. He second guessed decisions he and his wife had made earlier that might have prevented her current medical crisis:

> The despair that you feel just helplessness that you've done everything you can possibly do and you go back and you second guess all the decisions you've made in the past...that shoulda coulda woulda happened had you not done something different. You've got all those things running through your mind...and then you try to be strong so you don't show the kids how serious you think it is....

Another Johnson family member expressed a range of emotions: "I was obviously scared. Very worried, stressed, nervous. It took a while to soak in. I didn't know what was going on."

Keeping the hope alive—Out of desperation, the Johnsons aggressively pursued every treatment. They hoped that the TIPS procedure would keep her alive, buy more time, and lead to a transplant. "We don't have a choice." Mr. Johnson explained: "...She's on the liver [transplant waiting] list. And this is just going to buy us enough time, hopefully, to wait long enough for a liver to get here..."

Confusion and Frustration

The TIPS procedure was successful but Mrs. Johnson's recovery was slow; her family was confused and frustrated during this phase that stretched from day 2 to day 5. Two themes emerged during this phase: mismatched communication and different perceptions.

Mismatched communication about status 7—In this second phase there were four categories of mismatched communication between health care professionals and the Johnson family related to Mrs. Johnson's inactive status. First, professionals would use the lay term “off the list” to replace the professional term “status 7” or “inactive status.” The meaning of status 7 was never explained to the family. Consequently, the Johnsons believed that Mrs. Johnson was officially off the waiting list. Because they equated being on the list as a chance for life, they were eager to do “whatever it takes to get her back.” One family member explained: “I wanted her back on the list, as I have this huge fear that the liver is going to come and she will not be on the list. I want her back on the list and bam! You know, like the doctor said [raining] livers.”

Second, the Johnsons were given different messages related to what it would take to get Mrs. Johnson reactivated on the waiting list. The bigger picture of her condition was rarely discussed. For example, we observed a gastroenterologist tell Mr. and Mrs. Johnson: “our biggest concern was whether your liver could handle the shunt...Our plan is to get you back in the running for 1st in line for liver...I just want you to slowly recover...get off blood pressure [medication].” The next day, a hepatologist stated to the family: “We'll see, giving bleeding...need to look at heart function...other things...it is a group discussion [getting you listed] based on overall health, not just [getting off of] antibiotics.” On day 4, another physician said that a “tap [paracentesis will be done] tomorrow. So that will tell us a lot.” If fluid from the peritoneal cavity showed no signs of infection, Mrs. Johnson would be reactivated on the transplant waiting list. Failing to fit the pieces of information together, the Johnsons focused on “specific items” as relayed to them by professionals and became increasingly frustrated: “You have to jump though all these hoops to do these things, which is crappy, because [Mrs. Johnson] is not up to jumping speed.” The Johnsons had thought that the use of a vasopressor was the only thing keeping Mrs. Johnson off the list. A nurse caring for Mrs. Johnson was aware of the family's frustration: “I think the family was thinking she had to get off the Dopamine for the liver transplant.... They were really fixated on the Dopamine.... It seemed to me they were a little bit frustrated with that whole experience.” As a family member said: “...what is actually keeping her off the transplant list. We thought it was only one thing, and then it turned out to be two or three things.”

Third, the family often received indirect or vague answers from health care professionals. The following exchange between Mr. Johnson and a physician illustrates this type of mismatched communication.

Mr. Johnson: “Does that mean that [Mrs. Johnson] is back on the list?”

Physician: “Tomorrow night is the last dose [of antibiotics].”

Mismatch in questions and answers deepened the Johnson family's feeling of confusion and frustration. As one of the children explained: “Frank discussions from the doctors are the most valuable thing we can have; noncommittal doctors is the worst thing for somebody in this situation. That is aggravating, stressful, it is worse than being in the ICU in the first place...”

Fourth, there was a contradiction between the Johnsons' stated information needs and their self-described selective acceptance of information. The following quotations from two different Johnson children demonstrated this:

> Child 1: "Anytime there is information to be had, we want it."
>
> Child 2: "When you are in such a high emotional state, as we are as families, sometimes we tend to only hear things that we want to hear, and sometimes we hear things different, because we don't like the way they are being said. So, we don't really hear them differently, we just remember them different because that is what we want."

This category of mismatched communication caused the Johnsons to feel that the health care professionals did not listen to them even though our observation indicated the contrary. This was especially the case when the communication related to the treatment with a vasopressor was perceived by the Johnsons as the obstacle to get Mrs. Johnson reactivated for transplant. For example, on day 4 we recorded the following observation: [Mr. Johnson] is telling RN that he is worried that they are trying too hard to keep patient's BP up and the RN reassured him: "We realize what you are saying, but patient's kidney weren't happy." Mr. Johnson did not seem to understand this message because later he expressed his frustration: "They were using the standard formula...and not looking at her as an individual...That bothered me...because they weren't listening to us that her normal BP is very low. Come on guys, how many times do I have to tell you?" The connection between level of blood pressure and kidney perfusion did not seem to have been explained to the Johnsons. This may be related to a perception by health care professionals that they had communicated the information.

Different perceptions—The health care professionals and the Johnson family had different perceptions about communication. Professionals thought their communication with the Johnsons was clear, as stated by a physician: "Everyone was on the same page." They also thought the Johnsons had "a fairly good understanding of what happened." A nurse summed professionals' perception:

> I felt like I was communicating pretty well with him [Mr. Johnson], what we were doing and why we were doing certain things, and explained ... I felt like overall he understood what was going on. I would say things and the doctors would come in and pretty much say the same thing, so I felt we were all communicating clearly with him...."

However, the Johnsons were quite confused about treatments. One of the children described the family's confusion about the vasopressor: "...that was confusing to me. Because from our understanding that was a huge part of [Mrs. Johnson] not getting put back on the list. Then we were told that it wasn't..."

Back on the road to transplant

In the third phase professionals confirmed to the family that Mrs. Johnson would be reactivated on the liver transplant waiting list. This was on day 5 before Mrs. Johnson was transferred to a medical floor. To the Johnsons, the list represented hope, "the light at the end of the tunnel." Therefore, Mrs. Johnson's re-activated status made the family feel

"Everything has been worth it." The family's relief and excitement was captured in an interview with one of the children:

> Whew. Thank goodness. That is all I can say right now. Very relieved. Whew .... I think I might be able to sleep now....Now we just have to wait for a liver, you know. We are back to where we were a couple of weeks ago...We have passed this huge hurdle. We have some more, but they are not near as big now that we have crossed this one.

DISCUSSION

A major finding in this case was the powerful influence of the transplant waiting list on the family. For the family, the ICU experience was focused on Mrs. Johnson's inactive status and trying to get her re-activated. To them, the list was the one "thing" they could grab on to. Even though being reactivated on the list was not a guarantee for a new life, and recurrent crises and death of Mrs. Johnson were highly probable, the family assumed that a liver transplant would offer long-term survival and good health. The transplant waiting list became equal to life itself. This assumption worked for Mrs. Johnson, she was successfully transplanted. In 2012, 1,558 patients listed on the liver transplant waiting list died while waiting, and 1,501 were too sick to be transplanted.[4]

That a liver transplantation offers long-term survival and good health is not certain. Some liver transplant recipients experience excess morbidity.[14] In the U.S., one year expected survival rate after liver transplantation is 88.2%.[3] From 1991 to 2004 the national five year survival rate increased from 56.6% to 67.1%.[15] Not surprisingly, liver transplant recipients in general experience significant improvements in their quality of life.[14,16-19]

For the Johnson family, the probability of Mrs. Johnson getting back on the transplant list kept their hope alive. Based on this probability, technological advances, and life-sustaining treatment availability in the ICU, patients and their families may have unrealistic expectations about patients' ability to survive liver transplant surgery. Their hope may make it difficult for health care professionals to communicate with them when re-activation on the liver transplant waiting is no longer realistic. This communication may be equally difficult for professionals to have when patients who are in the process of being worked-up for a liver transplantation are in the ICU for treatment of serious ESLD related complications. To qualify for a liver transplant, patients undergo extensive pre-transplant evaluation tests that they may not be able to complete due to their deteriorating health and serious disease complications. As a result patients, families, and health care professionals may favor aggressive life-sustaining treatments and their focus will be on cure rather than comfort, potentially postponing transition to palliative care.

The emotional turmoil, emotions, and stress experienced by the Johnson family, initially at Mrs. Johnson's admission to the ICU and during her stay have been reported in the literature.[20] When patients are at a high risk of dying family members most commonly experience stress, anxiety, depression, and symptoms of acute stress disorder.[20-22] The stress experienced by family members may be higher at the time of the patient's admission and decrease by the time he/she is transferred out of the ICU.[23,24] The stress experienced has also been found to be significantly higher if the patients’ ICU admission was unexpected [25] as in the case of Mrs. Johnson.

The confusion and frustration the Johnson family experienced related to communication is common in the ICU. Poor communication has not previously been documented in the context of a patient being status 7. However, “mismatches” between families of patients in the ICU and health care professionals[9,26-29] and the need for communication and information by families have been documented extensively in the literature.[30-34]

Nursing implication

The professionals involved in caring for Mrs. Johnson thought the family understood her health status. The family focused on individual medical factors and was unable to see the importance of how those factors interrelated and contributed to overall health. If the Johnson family who had experienced multiple hospitalizations with Mrs. Johnson had difficulty understanding her health status and inactive status, then families with less experience may experience even greater challenges. How do we support and prepare family members who are in emotional turmoil and who may or may not have realistic expectations about the probability of the patient being reactivated on the liver transplant waiting list or worked up for transplant and listed? Nurses in particular, who spend many hours at the bedside, may be able to reduce families’ emotional turmoil by taking the time to connect with them and to inquire about how the family sees the situation, acknowledge their feelings, provide opportunities for them to express those feelings, and offer information tailored to their needs. Nurses are members of interdisciplinary teams who care for patients and families. The care provided is interdisciplinary and so should connecting and communicating with families be.[35] Each member of the interdisciplinary team plays an important role in providing care and in communicating with families to potentially reduce their emotional turmoil and improve their experiences in the ICU.[35]

CONCLUSION

This case presentation provides a window into the struggles patients with ESLD and their families may go through during the status 7 period. The presentation could serve as a starting point for further exploring patients with ESLD and family experiences as they struggle during the inactive period. Further research with an interdisciplinary focus has the potential to afford greater insight into the challenges patients and their families face, and their needs for information and support. This may then help us to meet those needs sensitively and appropriately.

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