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A “return to normalcy” or establishing a “new normal”: The patient experience of liver transplantation

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ABSTRACT

Background: The experience of liver transplantation is incompletely understood from the patient perspective. The purpose of this investigation was to characterize patient experiences central to the process of liver transplantation from the time of diagnosis through the first year after liver transplantation.

Methods: Semi-structured interviews were conducted at a liver transplant center from January 2021–August 2021 with liver transplant recipients one year following liver transplantation.

Results: Twenty patients and eight caregivers participated in the study. Participants described diverse experiences recognizing and accepting their illness. Motivations for pursuing transplantation were varied as was severity of illness, the perioperative course itself, and the process of recovery after transplant. The establishment of a “new normal” was a consistent theme across participants. Interestingly, we found a tension between the motivations described by many patients and the reality of the outcome many of them faced after transplantation. While, the motivation for many patients was to return to a previous level of physical and mental function they had before their liver disease they often were faced with a new improved status as opposed to a return to their previous full function. This new normal describes tension between restoration of physical function, acceptance of new limitations and a progression toward a new sense of values created by the transplant experience itself.

Conclusions: Many recognize that liver transplantation restores physical wellbeing, but few recognize that transplant often fundamentally recreates personhood. Sensitivity, to these changes should be recognized to maximize the success of liver transplantation patients.

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Background

In the United States, liver disease accounts for > 44,000 deaths, 1,000,000 outpatient visits, 325,000 emergency department visits and 200,000 hospitalizations per year [1,2] Liver transplantation provides an opportunity for patients with end stage liver disease to live longer and with an enhanced quality of life [3,4] In the United States there are over 11,000 people awaiting liver transplantation [5] Liver transplant recipients are a unique group of patients who traverse one of the most highly structured and regulated processes in the health-care system [6,7] Historically, quality measurement in transplantation has focused on 1-year patient and graft survival [8] Recently, transplant metrics have been expanded to include center organ offer acceptance ratios and waitlist mortality rates, as well as 90-day and 1-year survival [9] While hyperfocus on transplantation survival rates

may be necessary at a regulatory level, the lived patient experience of transplantation is often obscured [10,11] Understanding the patient experience of transplantation is essential to providing compassionate care and formulating a more holistic definition of success in transplantation.

Much of the previous qualitative work in liver transplantation has focused on specific timepoints in the liver transplant journey. A pre-transplant investigation of patient perceptions of high-quality care while on the waiting list found that managing expectations, providing education, responding to patient needs, executing care plans efficiently and utilizing interdisciplinary communication were highly valued by transplant candidates [12] In the post-transplant setting, the relationship between thoughts of the donor and psychological health and the impact of alcohol use disorder on patients outlook has been described [13,14] Lieber and colleagues have constructed one of the most thorough conceptual models for survivorship after liver transplantation [15,16] This model highlights achievement (enduring

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something difficult), gaining a second chance, and recovery as a continual process.

The aim of this study was to characterize the lived experience of liver transplant recipients from diagnosis through the end of the first post-operative year. Much of the work on quality in transplantation focuses on binary survival outcomes at this one-year landmark. Careful qualitative analysis of the lived patient experience of liver transplantation reveals a wide spectrum of outcomes. New understanding of how the transplant process alters personhood can aid in preparing patients as they go through this process.

Methods

Ethical considerations

This study was approved by our Institutional Review Board. Patients were informed that their participation in this study would have no impact on continued treatment and that they could withdraw consent at any time.

Study design and theory

This was an inductive qualitative study using grounded theory to comprehensively characterize the lived experience of liver transplant recipients from diagnosis of end stage liver disease through the end of the first post-operative year.

Recruitment and participants

Liver transplant recipients 10-14 months post-op between Jan 2021 to August 2021 were screened for participation and approached via convenience sampling. All participants were ≥ 18 years old, fluent English speakers, and able to discuss their care in a meaningful way with the research interviewer. Participants were approached at the conclusion of routine clinic appointments and informed as to the purpose of the study and what the interview would cover. Participants provided written consent prior to the interview and were given a copy of the consent which included contact information for the study personnel and institutional HIPAA and security personnel. Willing caregivers, if present, were also invited to participate and provided written consent for inclusion in the study. Patient participants received a single \$50 gift pre-paid gift card.

Setting

This study was conducted at a high-volume liver transplant center in the Midwestern United States.

Interviews

In-depth semi-structured interviews were conducted from February 2021 until August 2021. Each interview lasted between 32-92 minutes. (mean interview time = 57 minutes) Interviews were centered around an inductive exploration of the experience of liver transplantation from the time of diagnosis through transplantation and one year of recovery using open-ended questions and prompts to fully understand that experience. Questions related to topics surrounding how patients first found out about their liver disease, how they first found out that they would require transplantation, the experience of getting on the transplant list and then waiting and the arc of recovery after the transplantation. These were followed by a set of deductive questions designed to elicit patient opinions on what constitutes a successful transplant outcome.

Interviews were conducted in an iterative process. The interview guide was adjusted throughout data collection in response to ongoing analysis. All interviews were conducted by an interviewer trained

in qualitative methods (first author). Although the interviewer is a medical professional (resident in general surgical training at the time of the study) she had no prior clinical relationship to the participants. During interviews the researcher strove to maintain a neutral stance to minimize the biases and opinions of a researcher with clinical experience and to ensure that the experiences of the participants were fully reflected. Interviews continued until theoretical saturation was reached.

Analysis

Interviews were transcribed verbatim from audio recordings. Transcripts were coded and analyzed utilizing principles of grounded theory. Two primary data analysts analyzed and coded ten patient interviews in a line-by-line fashion. Each line of text was coded (usually with gerunds) to create a catalog of codes. From these "line-by-line" codes, emergent themes were identified and allowed to evolve throughout the analytic process. Data collection and data analysis occurred simultaneously to iteratively analyze and test themes and theories emerging in the data. The themes evolved over time and with the assistance of continual memo writing throughout the analytic process. A total of 35 themes were identified as listed in [Table 1](#) which were then loosely organized into seven analytic categories. Themes were then mapped to a patient timeline and effort was made to understand both common stages of the liver transplantation process and motivations that propelled patients forward during various stages of the process. All twenty interviews were then re-coded using these analytic categories.

Results

Patient demographics

The average patient age was 55 years old. (range 29-69 years). There were 9 females and 11 males. The most common indication for liver transplant was alcohol use disorder (45%). The median Model for End Stage Liver Disease (MELD) score at transplant was 27 with a range from 13-43 [17] The most prevalent cause of end stage liver disease was alcohol cirrhosis (45%) followed by non-alcoholic fatty liver disease (35%). The median length of stay was 12 days. 4 patients required dialysis in the first year after transplantation. No patients had rejection episodes. Average total bilirubin at one year was 0.56.

Motivation

Motivations that propelled participants throughout this process were both active and passive. ([Fig. 1: Motivations for Pursuing Liver Transplantation](#)) Passive motivations were primarily driven by the desire to avoid death. Patients described having had "no choice" and recognized that declining evaluation for transplantation would have been to acknowledge and accept that cirrhosis would take their life. In this respect some respondents felt passively "pushed into" transplant by the lack of any suitable alternative.

Active motivations to pursue transplantation were twofold. Many patients described their primary motivation to pursue transplant as the relief from physical symptoms that had consumed their lives. These commonly included painful edema, debilitating encephalopathy, and overall fatigue and malaise that interfered with activities of daily living. One patient described the disheartening cycle of repeated paracentesis. A second active motivation for seeking transplantation was to restore strained or severed relations with family and friends. Most patients expressed both their own desire to have more time with family and friends and a desire to *be there* for loved ones. The opportunities to see children grow up, attend marriages and spend time with spouses were as important as the need to be

Table 1
Analytic categories.

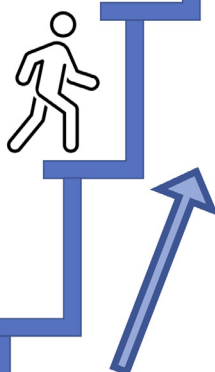
Category	Themes
1 Realization of New Disease	<ul style="list-style-type: none"> o Initial Reaction - Surprise o Thinking the transplant was a long way off o Family/friends first noticing signs and symptoms o Knowing something was wrong o Not recognizing the seriousness of the diagnosis at first o Growing in understanding about the process o Deciding to pursue transplant
1 Getting on the list	<ul style="list-style-type: none"> o Large time demands to get on the list o Frustration with delay of appointments or pre-transplant procedures o Committing to striving for transplant o Never considering not proceeding
1 Waiting on the List	<ul style="list-style-type: none"> o Worry about getting a liver 'in time' o Fear of complications and death o Preparing loved ones for their own death o Frustration with the system and coming in for organs that are not ultimately good o Patience with the process
1 Descent into Illness	<ul style="list-style-type: none"> o Physical changes o Mental confusion o Frequent requirement for medical care o Loss of independence
1 Getting the Transplant	<ul style="list-style-type: none"> o Feeling relief o Feeling grateful
1 Recovery	<ul style="list-style-type: none"> o Reality of recovery clashing with or exceeding expectations o Wanting independence o Limited movement o Changes regarding attitudes toward work. o New perspectives on life o Sustaining setbacks o Unanswered questions about longevity of the organ o Transplant impact on family relationships o Importance of family/social support o Coping with COVID impact on social support during recovery
Motivation	<ul style="list-style-type: none"> o Feeling there was "no choice"/avoiding death. o Seeking relief from physical/mental symptoms of end stage liver disease o Seeking time with family/loved ones.

Motivations



Moving Away:

- Death
 - *"I knew I didn't have a choice because I would die without one."*
 - *There was no other option. You can either A: get the transplant and have a possibility for a good outcome or B: you can no get the transplant and run the risk of dying. I'm gonna go with the one that is not dying."*
- Pain and discomfort as a result of liver disease
 - *"There was a lot of pain. Going through that [paracentesis], getting drained all the time, that was the worst. Because you build up until you hurt and going through the process hurt. To only know you are going to go back in five days and do it again."*



Moving Toward:

- Spending more time with family
- Being of service to family/loved ones
 - *"It was definitely just because I wanted to be there for my daughter. I didn't want her to go through life without a dad..Just being around for my daughter...If she decides she wants to get married. I wanted to be at her wedding. That is a big one. I feel like, with the transplant, I'll be there."*
 - *"I got two grandkids that are something else and I want to watch them grow up..I always through about my family, being with them and helping them out when I can. That is something that I ain't been able to do for a while. My dad he is almost 85 and he helps us out more than we help him out..he is something else. And I've always tried to help him out if he needed something to be picked up, I would go pick it up. I hate to see him doing stuff for me when I should be doing stuff for him. So that was motivation to get better for sure."*

Fig. 1. Motivations of pursuing liver transplantation.

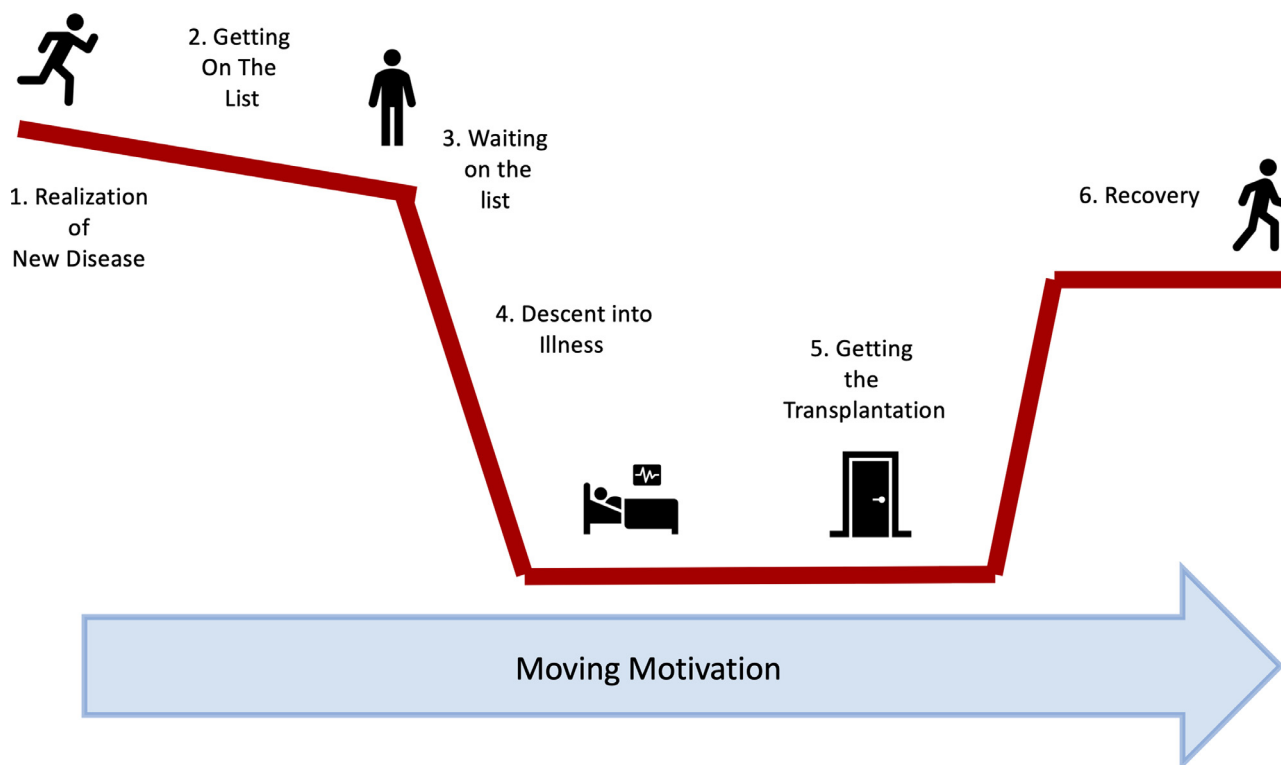


Fig. 2. The experience of liver transplantation recipients.

relied upon by family. The expressed desire to feel needed, useful or even essential to another human being was strongly articulated.

Conceptual framework

As participants recounted their lived experience of liver transplantation, they described distinct stages of their journey which allowed for conceptualization of a novel process. Because most patients described sequential achievement of specific milestones the process was characterized as linear. (Fig. 2: The Path of Liver Transplant Patients) (Table 2: Representative Supporting Quotes)

Milestones described by patients could have formed a cyclical process as well as a linear path and resolving this took some time to distinguish. Patients described some of their motivation for proceeding with transplantation as to achieve a “return” to normalcy. This “return” to a status of function that would implicate a transportation back to a previous state before illness. When characterized as a “return” that would seem to indicate a cycle that would repeat. However, liver transplant patients do not typically repeat the process of going through a liver transplantation, practically nor mentally. Patients instead arrived after the experience of transplantation with many new insights that irrevocably altered their life. For this reason, our conceptual framework depicts a linear pathway.

Realization of new disease

Recognition of illness occurred differently for each patient. For some, diagnosis occurred while asymptomatic and via routine screening. For others friends noticed changes in physical appearance or the patients themselves noted medical symptoms. Participants frequently suspected a benign diagnosis and were caught off-guard by a life-threatening diagnosis. Shock and difficulty accepting the diagnosis were common. Initially, questions regarding the timeframe of illness, eventual outcomes, and treatment options drove significant fear of the unknown. The transition from shock to acceptance

occurred as patients gathered information from online resources, physicians and fellow patients. Knowledge gathering lead to willingness to seek liver transplantation as a treatment.

For some, early-stage diagnosis created a false sense of security. One patient believed that she could avoid transplant by strict adherence to her physicians’ recommendations. Others were falsely reassured because their physicians did not express a sense of urgency for transplant. Still others were lulled into a false sense of security during times when low MELD scores were stable and follow-up became routine.

Getting on the transplant list

Almost universally, patients expressed frustration with the pre-transplant work-up feeling that it was slow, time consuming, and was in and of itself a new stressor in their lives. Most were extremely eager to get on the list as soon as possible. Despite frustration, many did acknowledge need for thorough evaluation prior to major surgery.

Waiting on the list

Being on the waitlist for solid organ transplant is unlike any other process in medicine due to the scarcity of the treatment. In other areas of medicine if a treatment exists for your condition, then it is typically provided to you. However, in the case of organ transplant, access to and receipt of treatment is not guaranteed.

Patients described constant worry about getting a liver and getting one “in time.” Once on the transplant list most had some appreciation of waitlist mortality and the shortage of donor organs. Preoccupations with “getting a liver in time” became psychologically intrusive for some:

Preparation for death was not uncommon. Many wrote letters to loved ones to be shared in the event of their death. One husband used retirement money to buy a generator so that after his death his wife

Table 2
The patient journey through liver transplantation.

Theme	Illustrative Quote
1 Realization of New Disease	<ul style="list-style-type: none"> • "20 years ago, I was applying for a job and they did my physical and they said my blood counts were off." • "Well my coworkers said my skin tone, skin color was off. . .we had to go get complete physicals and my doctor called me and said my levels were off." • "It was Thanksgiving 2018 and I just couldn't walk, like I'd walk maybe 500 feet and it took me 20 minutes. I had to sit and rest. So after Thanksgiving, I woke up and couldn't put my pants on. . .So, we went to an urgent care." • "It came out of nowhere, had no real hint there was anything wrong with my liver in particular." • "I don't know. That was when it was hard to wrap my head around. I didn't know where to go from there, how long it would take, if I needed one now, or down the line. Just a weird situation to be in." • "Well obviously there's a great deal of fear of the unknown it's kind of mixed in, overlaid with some misinformation." • "Neither one of us [patient or his spouse] understood it. I had managed to get on the web and if you've ever tried to do any research on a potentially deadly disease, there's all kinds of advice, opinions, some of which you can rely. . . And then some of the really credible references you definitely need to be a physician to really understand what they're talking about. So there kind of was a paucity of user friendly knowledge out there." • "I followed everything they say and I thought I'd be pretty good for a long time. If I just kind of maintained my salt intake. . .and I did really good with that. . .I honestly did not think my liver was that bad." • "Because I remember at one of the appointments Dr. H— said that I'll eventually need a transplant. But he didn't have a sense of urgency so I thought it was going to be 10 years down the line. I wasn't in a hurry. I didn't think I was that dire." • "Well, I had been seeing a gastroenterologist and doing blood work and ultrasounds and he kind of casually mentioned down the road you might need a liver transplant or you probably will. I never took him very serious at that time because everything was going on pretty good. I would do my blood work and it would be about the same."
1 Getting on the Transplant List	<ul style="list-style-type: none"> • "But then we have to go through the entire litany of testing that it takes to qualify or fortunately that was pretty straightforward although a very drawn-out process to go through that. . .the respiratory people and heart people, the conversation with the psychology." • "Just the demands on time and the number of appointments. That could really have a substantial impact on your work life, end up having to stop working just to be able to accommodate all the different steps that were involved."
1 Waiting on the List	<ul style="list-style-type: none"> • "[We] worried about getting a liver in time. We didn't think we would get one in time." • "People waiting on livers die before they get one. I don't know what the statistics are but I seen something, one that was 7/10 die before they get an organ" • "It was constant worrying and thinking about it, you know it seemed like everyday." • "I had prepared them for me not to be there. . .because I was afraid I wouldn't make it..We talked about it because I wanted them to be prepared in case I didn't come home." • "I got called in like three times and it didn't pan out. . .so I was getting a little discouraged and a little down mentally." • "Well, they had to go by the MELD score. I mean that was the main part of um..you just had to wait your turn."
1 Descent into Illness	<ul style="list-style-type: none"> • "I couldn't eat. I was sick all the time. If I did eat I threw it up..I lost so much weight. I was just skin and bones. Just skin over my bones. It got to where really either I had to have it [liver transplant] or I was going to die." • "I was feeling worse and worse. I went from getting drained once a month, then once every three weeks, then it ended up every five days and they were getting 6-8 L off of me every time. So I would get drained and by the next day I could feel it coming on again and I couldn't even tie my shoes I was so swelled up." • "I was finding myself doing the tip of the your tongue, just can't remember the word and then I started to do this [snapping fingers] every time I couldn't remember something. . .it was scarier than dying because you're still there, but you're not. Because at least when you die, you're gone and everyone can remember you that [in a capable] way."
1 Getting the Transplant	<ul style="list-style-type: none"> • "I was relieved. I mean since the time. . .I first had my blood work to find out why my count was like it was 20 years ago, that was all I thought about. It was always in my mind once they told me I was going to need a liver transplant. . .I don't have that worry anymore. I'm going to be alright. . .I'm relieved." • "I'm so thankful for this young liver that this person had to lose their life or lost their life and thankful that they donated their organs. Just so grateful to be given a second chance at life."
1 Recovery	<ul style="list-style-type: none"> • "I pushed myself more to get up and walk around because I wanted to be independent. So I forced myself to get up and do things I didn't want to. I went out and walked a lot. . .I was testing myself on walking to see how far I could get and there was one day where four or five days before I made it 100 yards and had to turn around because I was tired. Maybe it was a week after and I make it probably a little over a quarter mile and I looked back and I remember I was able to see my house and I was like, 'This is super far.'" • "But once I was normal feeling it was all I could do to hurry up because they told me how long in here [the hospital] is how much I get going. So when the physical therapy gentleman come I'd be like 'Okay what are we doing. Let's go. Whatever we got to do.'" And then finally he was like, 'you you're your ticket out of here is you doing those steps down there.'" And I says "alright."..I was determined to get out." • "My grandkids have always depended on me. And he [husband] did too, but now, I depend on him for everything. He has been my rock." • "Well before I felt like we would kind of fight a lot. . .well now we are so much closer because she's always checking in. Like even after transplant when I got home. . .we have been through so much together. . .I think it has brought us closer even." • "We were always close but, of course, naturally, it brought us a lot closer. Appreciation for each other, obviously, increased. Sure, there are times and you argue about 'why can't I have that?!' She was more like a mother he. I'm like "Come on" **eye roll**, the role reversal. . .she was very good about watching out for me and saying "Mom, you can't do that." . . .It was funny how she was just so good about taking care of me." • "I was really bad when I was younger, hot roddin', being a fool on motorcycles, not even thinking. Now I take life as it comes. Don't rush it. . .Used to be I would hear a bird chirp and not think anything of it. Now, I'll look for it, see what it is. . .I pay attention to life a lot more" • "Well before you take more things for granted. You don't look at things. When you are driving a car at 50 mph you see your surroundings. When you are driving a car at 90 mph you don't see your surroundings. . .When you actually see things you can enjoy it more than taking it for granted. Rather than seeing it go flying by." • "I don't like to wait on food when you are at a restaurant. Now stuff like that don't bother me. If you have the time to wait, wait." • "I enjoy my job a lot more. I find myself getting angry at people a lot less. Because it just like "Man, you can't bring me down. I'm not dead." I've always got the benefit of not being dead."

Table 3
Patient struggles with progression of illness.

Theme	Illustrative Quote
Physical Impairments	<ul style="list-style-type: none"> • "I went through a lot of swelling before I got the transplant, pretty consistent, it was hard to walk very far or anything and you had to keep your feet up." • "I couldn't eat. I was sick all the time. If I did eat I threw it up..I lost so much weight. I was just skin and bones. Just skin over my bones. It got to where really either I had to have it [liver transplant] or I was going to die."
Increasing Frequency of Medical Care	<ul style="list-style-type: none"> • "I was feeling worse and worse. I went from getting drained once a month, then once every three weeks, then it ended up every five days and they were getting 6-8 L off of me every time. So I would get drained and by the next day I could feel it coming on again and I couldn't even tie my shoes I was so swelled up." • "I was really weak all the time and I was going to the hospital like every 3-4 months, so I go to emergency room, then I get hospitalized, I spent like one week or sometimes two weeks [in the hospital]."
Struggles with Mental Confusion	<ul style="list-style-type: none"> • "Patient: I was a different person. Matter of fact, one time I hit her. . . And that [mental illness] come on fast. When it happened, it came on fast. . . .because I was basically unconscious. I was awake an hour maybe two hours max out of 24. That's how bad I got and it wasn't that I tried to fall asleep it was I would try to stay awake and couldn't. . . I was already experiencing death." • "I was finding myself doing the tip of the your tongue, just can't remember the word and then I started to do this [snapping fingers] every time I couldn't remember something. . .it was scarier than dying because you're still there, but you're not. Because at least when you die, you're gone and everyone can remember you that [in a capable] way."

would not have to deal with the frequent power outages in their area. One mother spoke about preparing her children to face her death.

A significant number of patients were called in for transplant only to be discharged if donor quality was insufficient or if deceased for cardiac death donors failed to progress. Patients felt unprepared for these "dry runs" and found the experience both mysterious and frustrating, negatively impacting their mental health. Despite the challenges of waiting, patients did acknowledge the scarcity of the resource and a sense of "necessary justice" in which waiting was inevitable.

Descent into illness

Most participants became quite ill before transplantation. The experience of illness varied but was primarily characterized by: physical changes, frequent requirement for medical care and problematic encephalopathy. (Table 3)

Physical manifestations included painful swelling that impaired mobility, reduced appetite, nausea, vomiting and weight loss. Concomitant with increased symptoms most participants experienced an increasing number of hospitalizations and invasive procedures.

Patients commonly struggled with encephalopathy which reduced their ability to manage ADLs and interact meaningfully with their families. Encephalopathy was consistently described as one of the most frightening symptoms because threatened personhood itself. One respondent noted that he was physically violent with his wife. He grieved when recounting these events and was humbled by her commitment and loyalty. When he spoke about himself prior to transplantation he referenced "Other B—" as if he was an entirely different person. Another interviewee had a conversation with his brother when he started to notice that he was having difficulty remembering things. He expressed fear that people would remember him not as the smart and capable person he identified as himself but as a lesser version of himself.

Getting the transplant

Two emotions overwhelmingly dominated receipt of an organ offer: relief and gratitude. Some respondents who had lived with their liver disease for a long time noted relief and reflected on the long path that brought them to transplant.

Recovery

When asked to reflect on recovery one year after liver transplantation, many respondents were unable to recall details of the first few days following transplantation. Elements that left a lasting

impression included remembrance of a drive to recover quickly, alterations in family dynamics, and the overall impression that transplant substantially changed their life. Patients often linked return of their physical capacities with recovery.

Upon arrival home, whether following discharge from the hospital or discharge from a rehabilitation facility, liver transplant recipients require significant support. Family members frequently provide this support and these circumstances often lead to significant changes in family dynamics. Role reversals are common as new individuals step into the role of "care provider" and were typical within both husband-wife and parent-child relationships. Parents expressed both pride and gratitude when their children rose to the challenge of being a caretaker despite some tensions that inevitably arose.

A final common theme expressed by participants captured their reflections of how the transplant experience changed their perspective on life. Recipients noted that they felt more grateful and felt as if they had more time.

Discussion

Our aim was to investigate the lived experience of liver transplantation from diagnosis through the first year following surgery as recounted by recipients. In so doing we hoped to better understand the process and experience of liver transplantation and identify areas for improvement in recipient care. Conceptualizing a common framework through which patients pass should enhance patient-provider communication, particularly as patients decide to pursue liver transplant and begin to formulate expectations for recovery. While most providers readily acknowledge the power of liver transplantation to restore health, we suspect few appreciate the frequency with which transplantation fundamentally alters personhood. We suggest the following three areas for provider reflection in attempts to better understand the lived patient experience.

Patients coming to understand their disease

The first theme that emerged was that of patients following disparate paths in discovery and recognition of their disease but ultimately acknowledging their diagnosis during descent into illness. Physician support is essential as patients confront new life-threatening medical illnesses. Charmaz and colleagues suggest that adjustment to serious chronic illness requires reconstruction of self [18,19] In comparison to Charmaz, who was working with oncologic diagnosis, liver failure distinguishes itself in that it is life threatening but curable. Likewise, our participants resisted a reconstruction of self in which liver disease was incorporated into their personhood but instead followed a journey in which they came to accept themselves as candidates for

cure. Having the defined goal of transplantation allowed transplant candidates to avoid the issue of assimilating their disease into their personhood.

Acceptance of disease often follows feelings of anger or denial as patients acknowledge their condition and begin to feel ready to cope with the associated challenges [20] Transplant patients are unique in that they often accept themselves as transplant candidates without the merger or self and disease state that is common in chronic or incurable illnesses. Transplant providers may benefit from understanding this gap between patient perception of disease and acceptance of candidacy early in the transplant process.

The highs and lows of the transplant wait list

The process of getting onto the transplant waiting list, and the experience of waiting, were significant milestones in the transplant journey. These were emotionally charged experiences that were recounted with surprisingly raw emotion and clarity. These findings are consistent with work by Shen and colleagues emphasizing the importance of managing expectations and providing ongoing education to patients seeking and awaiting liver transplantation [12] Patients must clearly understand that listing is not guaranteed at the outset of the evaluation process, that waiting times are highly variable, and that getting called in for an organ that is subsequently declined for quality occurs commonly [21,22] Although these are routine experiences for transplant providers, each creates a highly emotional situation for the transplant candidate. A need for ongoing education was particularly evident in higher-MELD candidates listed during an inpatient admission in which multiple factors lessened their ability to receive, absorb and process the information.

Conflicting emotions were universally described by patients on the waiting list. On one hand patients suffered from worry that they would not receive a liver “in time.” In the next breath patients described the necessity of “waiting their turn.” Fear of death while awaiting liver transplantation has been well described previously [12,23] We are not aware of previous data characterizing patients’ perception of organ allocation and the transplant system. Almost universally, our participants described awareness that other patients

were more ill than themselves. Some were emotionally burdened by the knowledge that someone must die for them to get well. None described “unfairness” and many articulated some concept of justice in which they did not want to “skip ahead” of someone else in greater need. Transplant providers must remain attuned to these countercurrents of emotion and should feel reassured to know that our patients perceive the overall process as fair.

“Return to normal” vs. a “new normal”

At the core of our findings is the concept that patients begin their transplant journey with a desire to “return to normal,” but end up with fundamental changes in their personhood leaving them with a “new normal.” Awareness of this transformation can help providers when establishing expectations and setting goals before transplant. Common motivations for transplant include the desire to be free of from illness, regain full physical functioning, and re-engage fully in their lives. These coalesce into a desire to “return to normal,” as previously described by Hickman et al. [24] We found, surprisingly, that even when all these goals were achieved patients found themselves fundamentally transformed by the journey itself. Personal insight grew and values shifted. We have termed this restoration of self and new mindset a “new normal.” (Fig. 3: Components of Establishing a New Normal After Liver Transplantation).

The term “new normal” has also emerged within the chronic disease literature. The Centers for Disease Control define a chronic disease as one that lasts for greater than one year and requires ongoing medical attention, limits activities of daily living, or both [25] Through narrative review of 36 studies involving patients with chronic illness, Ambrosio et al define four ways of “living” with chronic illness which include disavowal, false normality, new normal, and disruption [20] “New normal” is defined as a developed acceptance of circumstance that creates feelings of control and balance in day-to-day life. This allows patients to give meaning to their experience and this way of living is both sustainable and less vulnerable to disruption. Although transplantation is often curative, transplant recipients certainly live with a type of chronic illness by way of their need for lifelong monitoring and immunosuppression management.

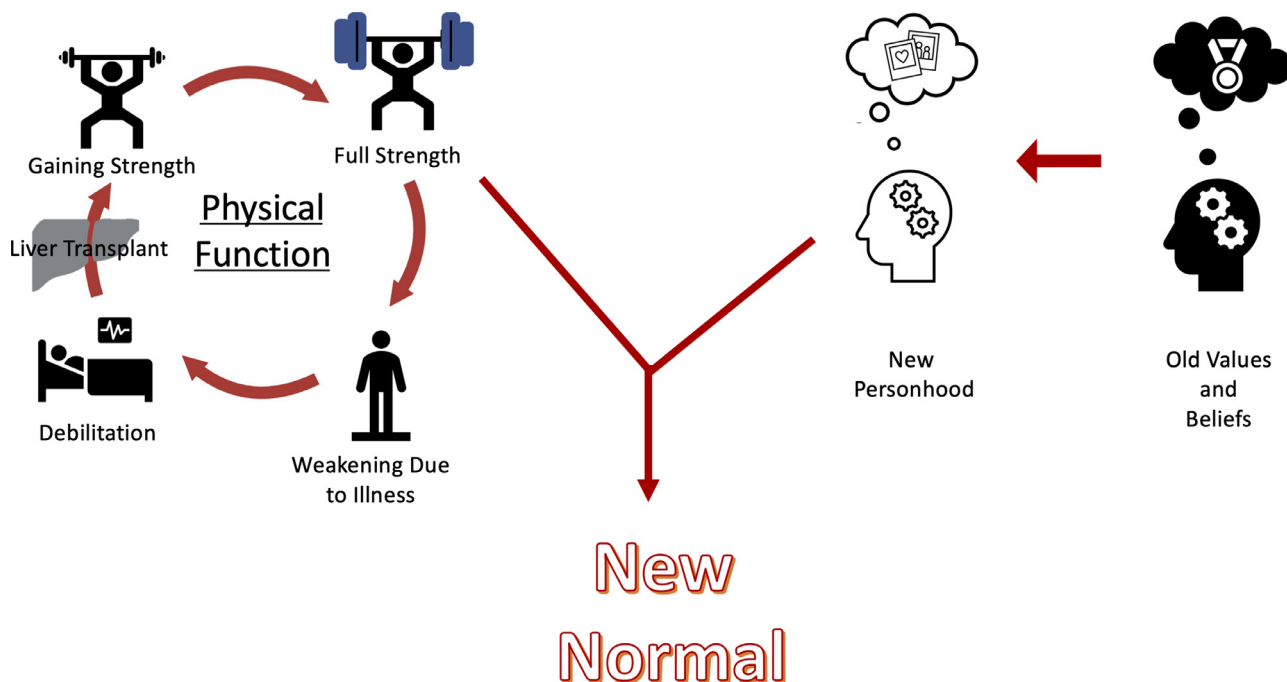


Fig. 3. The components of the “New Normal”.

Guiding patients to acceptance of a “new normal” should be viewed not as a compromise, but as an empowering step that will allow patients to embrace life under adjusted circumstances.

Limitations

Our study is limited by sample size and by the fact that this was a single-institution study. It is important to note that median MELD at transplant is lower at our center than in other regions of the country and the lived experience of transplantation may vary with severity of illness. We strove to maintain broad inclusion criteria and capture patients through the spectrum of age, severity of illness and causes of liver failure. We were unable to make any comparisons regarding MELD or indication for transplantation due to the relatively small numbers of participants. We also recognize that with a single interviewer our results could be subject to the bias of the interviewer as their perceptions or skills changed over time. Additionally, with only one interviewer we do not have any inter-observer comparisons which limits the strength of the conclusions reached.

Conclusion

The aim of this project was to understand the patient experience surrounding the process of a liver transplantation from diagnosis through the first year after transplantation. With this work we hope to ultimately improve the care that these patients receive and make meaningful strides to improving their pre-transplant experience and recovery.

Ethical Statement

Our study was approved by the Ohio State University Medical Center Institutional Review Board. (Approval No. 2020B0409)

Authorship

IW contributed to the study design, performance of the research, data analysis and manuscript preparation. DF contributed to the performance of the research, data analysis and manuscript preparation. SW contributed to study design and manuscript preparation. KW contributed to manuscript preparation. Finally, AS contributed to research design, data analysis and manuscript preparation.

Surgery – two sentence summary

Due to the incomplete understanding of liver transplant recipients' experiences, this study describes a qualitative, grounded theory investigation of their experiences at the critical one year milestone after liver transplantation. We found that there is an inherent tension between the motivation that many people cite to proceed with transplantation, that is to return to their previous level of functioning, and the health constraints they face after transplantation which limits their full achievement of this goal.

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None.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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