Waiting for a Liver Transplant: A Qualitative Study

Ayoka Badmus

University of Texas Health Science Center at Houston-Cizik School of Nursing

Follow this and additional works at: https://digitalcommons.library.tmc.edu/uthson_etd

Part of the Nursing Commons

Recommended Citation
https://digitalcommons.library.tmc.edu/uthson_etd/35

This is brought to you for free and open access by the School of Nursing at DigitalCommons@TMC. It has been accepted for inclusion in UT SON Dissertations (Open Access) by an authorized administrator of DigitalCommons@TMC. For more information, please contact digitalcommons@library.tmc.edu.
WAITING FOR A LIVER TRANSPLANT: A QUALITATIVE STUDY

A DISSERTATION

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS

FOR THE DEGREE OF DOCTOR OF PHILOSOPHY IN NURSING

THE UNIVERSITY OF TEXAS HEALTH SCIENCE CENTER AT HOUSTON

CIZIK SCHOOL OF NURSING

BY

AYOKA BADMUS, PhD(c), MSN, RN-BC, NE-BC

MAY, 2019
To the Dean for the School of Nursing:

I am submitting a dissertation written by Ayoka Badmus and entitled Waiting for a Liver Transplant: A Qualitative Study." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Nursing.

Geri Wood, Committee Chair

We have read this dissertation and recommend its acceptance:

[Signatures]

Accepted

Dean for the School of Nursing
Acknowledgements

First and Foremost, I thank the almighty God for being with me through this journey because except the Lord build the house, they labor in vain that build it. I would like to acknowledge my husband and children. My husband and soul mate, Dr. Lanre Badmus for his love, relentless efforts and encouragement. My children, Tolu, Temi and Tiwa for their love, prayers and making sure I didn’t overdo the coffee.

Receiving my PhD is a lifetime achievement that would never have been possible without the help and contribution of significant individuals. I am forever thankful to the people that made this achievement possible. My advisor and the chair of my committee, Dr. Geraldine Wood for believing in me when I had doubts, her extraordinary guidance and support helped me to achieve this dream. I am grateful to Dr. Joan Engebretson for her mentorship in guiding me through qualitative analysis, Dr. Rebecca Casarez for her supportive guidance and Dr. Angela Nash for helping me perfect the use of ATLAS.ti and listening to me. Furthermore, I would like to express my gratitude to Dr. Victor Ankoma-Sey, a physician that is truly a nurse champion, who is always ready to share his expertise and passion for knowledge. I am also grateful to the following people: To Ms. Susan Teer, my director at Houston Methodist Hospital for giving me the support and time off for school; Dr. Shannon Hamlin for her support and never being too busy to meet with me and to all the staff on D10E (transplant) that cheered me to the finish line. Finally to my colleague Dr. Nnenna Emelogu for keeping me on track.
Abstract

Waiting for a Liver transplant: A Qualitative Study

By Ayoka Badmus, PhD(c), MSN, RN-BC, NE-BC

May, 2019

Background: Advances in liver transplantation have significantly improved survival rates, making liver transplantation a viable option for those with End Stage Liver Failure (ESLF). However, patients diagnosed with ESLF may experience a significant period of waiting before a liver transplant surgery, due to a limited supply of donor livers. Empirical evidence is scarce on the experience of patients waiting for a liver transplantation.

Method: Using a generic qualitative approach, interviews were conducted with a purposive sample of twelve patients diagnosed with ESLF, actively wait listed for a liver transplant. Participants were admitted to the liver disease unit of a teaching hospital at the time of the study. Transcriptions of interviews and field notes were coded with Atlas ti. V8. Content analysis of the data identified themes and subthemes relevant to the objective of the study. May, 2019

Objective: The objective of this study was to explore the waiting experience of patients diagnosed with ESLF and to identify their perceived challenges and needs while waiting for a liver transplantation.

Results: Personal description of patients’ experience and challenges while waiting for a liver transplant. Qualitative analysis of the personal descriptions interview data revealed that patients have an overarching experience of waiting in limbo while waiting for a liver
transplant. Three themes (Uncertainty during the Waiting Period; Redefinition of Life; Challenges during the Waiting Period) and five subthemes (Fear and Anxiety; Physical Symptoms; Financial Worry; Existing versus Living; Support and Faith) emerged from the analysis of the data.

**Conclusion:** Healthcare treatment for patients waiting for a liver transplant needs to be tailored to accommodate patient reported experience and perceived challenges.

**Key Words:** liver transplant, Experience, qualitative
# Table of Contents

APPROVAL PAGE ........................................................................................................ ii  
ACKNOWLEDGMENTS .............................................................................................. iii  
ABSTRACT ................................................................................................................ iv  
SUMMARY OF STUDY ............................................................................................... 1  
PROPOSAL .................................................................................................................. 3  
Research Strategy and Approach ............................................................................. 6  
Human Subjects ........................................................................................................ 15  
References ............................................................................................................... 16  
MANUSCRIPT ............................................................................................................. 20  

Waiting for a Liver Transplant: A Qualitative Study.  

APPENDIXES  
A Approval Forms .................................................................................................... 54  
B Informed Consent .................................................................................................. 57  
C Study Protocol ..................................................................................................... 61  
D Study Flyer .......................................................................................................... 66  
E Interview Guide .................................................................................................... 68  
F Demographic Form .............................................................................................. 70  
G The experience of waiting for a Liver Transplant ............................................. 72  
H Demographic Table ............................................................................................ 74  
I Themes Table ....................................................................................................... 76  

CURRICULUM VITAE ................................................................................................. 78
Summary of Study

Advances in liver transplantation has significantly improved survival rates to over 90% and 80% at one and five years post liver transplant respectively, making liver transplantation a viable option for those with End Stage Liver Failure (ESLF). However, patients diagnosed with ESLF may experience a significant period of waiting before a liver transplant surgery, due to a limited supply of donor livers. Empirical evidence is scarce on the experience of patients waiting for a liver transplant. An understanding of the waiting experience is pivotal to designing appropriate patient centered care. There are currently 13,403 candidates listed for liver transplant in the United States alone (United Network for Organ Sharing, 2019). Without a liver transplant, the prognosis for these patients is grim with a life expectancy of approximately two to twelve years, depending on severity and comorbidities (Walling & Wenger, 2014; D’Amico & Pagliaro, 2006).

The waiting period before a liver transplant can be a difficult period for patients because of the symptoms of the disease, uncertainty of transplant surgery and surgical outcomes. ESLF patients have been shown to have a reduced quality of life that is mainly due to life-threatening complications of a failed liver (Benzing, 2016; Broschewitz et al., 2017). Liver transplant candidates are also faced with the stress of uncertainty associated with not knowing when or if they will be transplanted (Martin, Stone, Scott & Brashers, 2010). Therefore an understanding of patients’ experience during the waiting period is critical to designing and providing patient appropriate care. Hence, a generic qualitative descriptive approach (Crabtree & Miller, 1999) was used to describe the perspectives of ESLF patients waiting for a liver transplant. The goals of this dissertation were to 1) explore how patients diagnosed with ESLF listed for liver transplant surgery construct their experience
of waiting and uncertainty and 2) describe the perceived challenges and needs of ESLF patients waiting for a liver transplant surgery.

The dissertation is comprised of two sections, 1) the research proposal which follows the summary, outlines the specific aims of the study, the significance of the study and study methods and 2) manuscripts which includes findings, discussion and themes supported by participant quotations. Appendices A – I contains the supplemental information that includes study questionnaire and demographics. Approval for the study was obtained from the University of Texas Health Science center’s Committee for the Protection of Human Subjects (CPHS) and from the Houston Methodist Hospital Institutional Review Board. The PI also completed the Collaborative Institutional Training Initiative (CITI) modules for protection of human subjects. Interviews were conducted in February and January of 2019 with concurrent analysis of data from a purposive sample of patients admitted to a large academic hospital that have a diagnosis of ESLF and are listed for a liver transplant.
Proposal

Specific Aims

Chronic liver disease is on the rise and has become the 12th leading cause of death in the United States (Center for Disease and Control, 2017). Which is an indication that more patients will be diagnosed with End-Stage Liver Failure (ESLF) and listed for liver transplant. Thus, increasing wait times for liver transplantation. There are currently 13,902 candidates listed for liver transplant in the United States alone (United Network for Organ Sharing, 2018). Therefore, there is a significant need for transplant health care providers to be cognizant of the issues affecting the increasing population of ESLF patients waiting for a liver transplant.

Liver transplantation is the only life-sustaining treatment for ESLF patients (Walling & Wenger, 2014). Patients diagnosed with ESLF that meet transplant criteria are placed on the national liver transplant waiting list (Rahimi-Dehkordi et al. 2014). However, the waiting time for liver transplantation is prolonged due to the limited supply of donor organs (Bjørk & Nåden, 2008) and associated with significant stress (Aghahosseini, Nayeri, Shahsavari, & Tosi, 2017). Awaiting liver transplantation is accompanied with a fear of death and uncertainty, unfortunately for some listed patients, death precedes the availability of organs (Hansen, Yan & Rosenkranz, 2014). Provision of appropriate care to ESLF patients listed for liver transplant require an in-depth understanding of patients' experience during the waiting period.

The waiting period before a liver transplant can be a difficult period for patients because of the symptoms of the disease, the uncertainty of transplantation surgery and outcomes. ESLF patients have be shown to have a reduced quality of life that is mainly
due to the life-threatening complications of the failed liver (Benzing, 2016; Broschewitz et al., 2017). Understanding the experiences of patients when waiting for a liver transplant is pivotal to promoting improved quality of life. Liver transplant candidates are also faced with the stress of uncertainty associated with not knowing when or if they will be transplanted (Martin, Stone, Scott & Brashers, 2010). Therefore an understanding of patients’ experience during the waiting period is critical to designing and providing patient appropriate care.

However a current review of the literature found a dearth of studies that have explored the patients' perspectives and experiences when awaiting liver transplantation. The overall objective of this proposed study is to understand and describe the experiences, perceived challenges and needs of ESLF patients while waiting for a liver transplant. The rationale for this study is that the identification of issues that are most important to ESLF patients during the waiting period will advance care in liver transplantation. Transplant health care providers can apply the knowledge gained from this proposed study as a guide for the design of unique patient-centered care that will address issues that are most pertinent to ESLF patients awaiting liver transplant.

The overall objective of this proposed study will be achieved through the following specific aims:

**Specific Aims:**

- Explore how patients diagnosed with ESLF listed for liver transplant surgery construct their experience of waiting and uncertainty.
- Describe the perceived challenges and needs of ESLF patients waiting for a liver transplant surgery.
Research Questions:

- How do patients diagnosed with ESLF waiting for a liver transplant surgery perceive the waiting period before transplant?
- What are the perceived issues and challenges encountered by patients diagnosed with ESLF while waiting for liver transplant surgery?

The study will serve to illuminate the issues faced by ESLF patients and help clinicians to better understand patients' perceived needs, challenges and experience during the waiting period before a liver transplant surgery.
Research Strategy and Approach

Significance

Continual improvements in liver transplantation has led to a viable therapeutic option for patients with ESLF. The incidence of graft failure at one year has reduced to 9.8% and approximately 80,000 adults in the United States were living with a functioning transplanted liver in 2016 (Kim, et al 2016). Without a liver transplant, the prognosis for patients with ESLF is daunting, with life expectancy of approximately two to twelve years, depending on etiology, severity and comorbidities (D’amico & Pagliaro, 2006; Walling & Wenger, 2014) However, the demand for donor livers far exceeds the supply, therefore patients may encounter a significant wait time before liver transplantation (Brown, Sorrell, McClaren, & Creswell, 2006).

ESLF patients that meet the criteria for liver transplantation are ranked on a liver transplant waiting list based on risk of wait list death as defined by a national scoring system, known as the Model for End-Stage Liver Disease (MELD). A scoring system that was adopted by United Network for Organ Sharing (UNOS) in 2002, to help ensure a fair sharing of organs and is based on statistical formulas that are scored from 6 (less ill) to 40 (gravely ill) using the following patients medical and laboratory values: Bilirubin, Serum Creatinine, Serum Sodium, INR and if patient is on dialysis (Hansen, Yan & Rosenkranz, 2014). The amount of time the patient spends on the wait list is dependent on some factors such as blood type, body size, availability of donor organs and the MELD score, making it difficult for providers to accurately predict when a patient would be transplanted. The concept of wait list is not new to organ transplantation, it emerged when the number of transplant eligible patients began to exceed the supply of organs.
(Findlay et al. 2011), and this mismatch in demand and supply of organs continues today. There are currently 13,902 candidates on the liver transplant waiting list in the United States, compared to 10,636 in 2015 and 11,340 in 2016 (US Department of Health & Human Services, 2018), yet literature is limited on the waiting experience of this growing population.

There are several factors that may influence the patients’ experience of waiting for a liver transplant and an understanding of these factors is essential to care. The waiting period before liver transplant surgery has been associated with psychological and physiological stress that stems from both the disease process and the uncertainty of transplantation (Martin, Stone, Scott, & Brashers, 2010). Patients with ESLF have to deal with life-threatening complications and multiple hospital readmissions related to the disease process. ESLF is marked by physiological changes that triggers physical symptoms that impact physical and psychological wellbeing (Rakoski & Volk, 2015). Physical symptoms such as ascites, hepatic encephalopathy, muscle cramps, fatigue, bodily discomfort, gastrointestinal discomfort and psychological symptoms such as anxiety and depression (D’Amico et al, 2006).

The debilitating symptoms of liver failure has been shown to reduce quality of life by impacting patients’ physical and emotional health (Marchesini et al., 2001; Jara et al., 2014). In a qualitative study, Bjørk & Nåden (2008) found that patients waiting for liver transplants experience heightened emotions related to life and death and overwhelming lack of energy. Crone & Wise (1999) described a similar experience in patients waiting for a heart transplant and rightly characterized the waiting period as a “dance with death" because patients feel they have to prepare for the possibility of life and death.
simultaneously. The fear of death is not unfounded as some patients do not survive to transplantation (Baker & McWilliam, 2003). Waitlist mortality is a genuine challenge in liver transplantation and is correlated with severity of disease and wait list time (Fayek, Quintini, Chavin, & Marsh, 2016). Mortality is estimated at 17.6 per 100 waitlist years for MELD score under 35 and 339.8 per 100 waitlist years for patients with MELD score over 35 (Kim, 2018). Between patients deaths, de-listing due to severity and unavailability of livers, only about 50% of patients waiting for a liver received a liver transplantation in 2016 (Trieu, Bilal & Hmoud, 2017).

Despite all the challenges of the waiting period, little follow-up is available for patients with ESLF and patients seemed resigned to their fate of suffering while waiting for a liver transplant surgery (Bjørk & Nåden, 2008). In a qualitative study, Pierce (2014) identified the need for psychological support and enhanced communication between patients and health care providers as essential factors in the management of patients waiting for a liver transplant. The successful management of patients during the waiting period is important for improved well-being, quality of life and successful post-transplant outcomes in transplant patients (Brown, Sorrell, McClaren, & Creswell, 2006). Yet studies are lacking on the waiting period experience of ESLF patients. An understanding of patients’ needs and experience is useful for designing appropriate patient care and management.

The majority of literature in liver transplantation are biomedical with focus on quantifiable aspects of liver transplantation such as physical symptoms, MELD score and health related quality of life (Caccamo et al., 2001; Pierce, 2014). The aim of this study is to fill the existing gap in the knowledge of how patients waiting for a liver transplant
surgery describe their experience, challenges and needs while waiting. The objective of this study is best achieved by using a qualitative approach. Qualitative studies are useful when there is a need for patients’ perspectives and a more comprehensive understanding of an issue (Cresswell, Klassen, Plano clark, & Smith, 2011). An in-depth understanding of ESLF patients experience, how they integrate living with the uncertainty and the limitations of liver failure into their daily lives can help improve the care of patients waiting for a liver transplant.

Being listed on the transplant list is a major source of hope for patients but as time elapse, hope may gradually become uncertainty (Pierce, 2014). Therefore the theory of uncertainty in illness will guide this proposed study. Uncertainty, as described by the theory, is the lack of ability to determine the meaning of events that are related to illness, an inability to assign values or to accurately predict outcomes because of insufficient cues (Mishel, 1988). In the case of ESLF patients waiting for a liver transplant, the uncertainty experienced during the waiting period is associated with not being able to accurately predict when or if they will be transplanted. ESLF patients waiting for a liver transplant are faced with the uncertainty of receiving a transplant (Martin, Stone, Scott, & Brashers, 2010). Uncertainty is an identified source of stress during the waiting period before a liver transplantation that Pierce, (2014) clearly described as an “emotional rollercoaster”, with uncertainty being the one “constant in this state of flux”.

Thus, the overall objective of this study is to better understand the experience, challenges and needs of patients while waiting for a liver transplant, so to establish a foundation for developing appropriate and targeted support for ESLF patients awaiting liver transplantation.
**Innovation**

Advancement in technology and pharmaceuticals has generated changes in liver transplantation, influencing the age and severity of disease of listed patients. The number of listed candidates over 65 years of age has almost doubled from 2004 to 2014, similarly there has been an increase in patients listed with high MELD scores (Fayek, Quintini, Chavin, & Marsh, 2016). This study will consider these changes in practice, utilize the current scope of practice in study. The study will not have a MELD exclusion and will include adult patients, over 18 years, with no upper age limitation. Also the study will be guided by the theory of uncertainty. Although uncertainty has been studied in chronic illness but literature is lacking in the concept of uncertainty and the waiting experience of ESLF patients waiting for a liver transplant.
Research Design and Setting

A generic qualitative descriptive approach (Crabtree & Miller, 1999) will be used to describe the perspectives of ESLF patients waiting for a liver transplantation – how they perceive the waiting experience, including their perceived challenges and needs encountered during the waiting period. The method involves simultaneous data collection and analysis that is flexible and capable of adjusting to new information that may lead to the refining of research questions (Kahlke, 2014). Qualitative research methods are useful when there is a need for more comprehensive understanding of an issue (Cresswell, Klassen, Plano Clark, & Smith, 2011). Data collection and analysis will be conducted over a period of 12 weeks.

Population, Sample. Sampling Procedures

Purposive sampling will be employed to select participants that meet the inclusion criteria. The participants will be recruited from ESLF patients admitted to an in-patient liver failure unit at a Texas hospital (Houston Methodist Hospital) with a robust liver transplant program. Sampling will attempt to be representative of gender and race.

Inclusion criteria: patients diagnosed with end stage liver failure who are already listed and waiting for a liver transplantation, adult (18 years and older) with the ability to read, write and speak English. Exclusion criteria: patients currently admitted for Hepatic Encephalopathy, cognitive disturbances, history of a previous transplant and inability to read, write or speak English. Approval will be obtained from the University of Texas Health Science center’s Committee for the Protection of Human Subjects (CPHS) and from the Houston Methodist Institutional Review Board.
Following approval, a printed flyer (Appendix D) with details and objectives of the study will be posted at the nursing station and in the patient lounge on the liver failure unit. The flyer will include the Private Investigator’s (PI) contact information so that eligible participants can contact the PI. The nurses at the in-patient liver failure unit will serve as key informants to notify patients about the study but will not consent or actively recruit patients. The eligible participants will be provided with printed information about the study and the PI’s contact information. The PI will also attend a preexisting monthly liver transplant support meeting that is held at the teaching hospital and hand out flyers about the study to augment recruitment efforts. The planned sample size for this study is 12 – 20, based on similar studies found in literature and qualitative study sample, but recruitment will continue until no new concept is emerging from the data (Crabtree & Miller, 1999; Bjørk & Näden, 2008; Marshall et al., 2013; Moser & Korstjens, 2018).

Data collection Procedures

Following recruitment of eligible participants that meet the inclusion criteria, the PI will meet participants on the in-patient unit at which time, a written consent with full disclosure will be provided to those that agree to participate and an interview time will be set up. The informed consent to be used for this study is the Houston Methodist informed consent form for non-interventional research. The consent form include objectives of the study, participants’ rights to withdraw from study at any time without penalty and potential risks (Appendix B). Potential locations are the in-patient rooms on the liver failure unit, for patient privacy and comfort. Data to be collected include demographic data (Age, gender and race), MELD score, amount of time spent on waiting list and etiology of liver disease (Appendix F).
The PI will collect data using a semi-structured interview format. The participants will be interviewed individually, face-to-face. Participants may be interviewed more than once to reach saturation of an emerged concept (Marshall et al., 2013). Interviews will range from 30 minutes to an hour depending on participants comfort. The interview questions will include both broad and focused questions that will describe the needs, challenges and waiting experience of ESLF patients (Appendix E). The interview questions will be discussed with an expert faculty member for adequacy before data collection. The PI will use a reflexive journal to promote bracketing to prevent preconceived biases and assumptions regarding the phenomena under study (Crabtree & Miller, 1999). Data collection will continue until saturation. The interview will be audio-recorded with a digital voice recorder and the recording quality will be tested prior to the beginning the interviews. The recording is to reduce distractions during the interviews and also for play back of recorded interviews during transcription and data analysis. Transcription of the recordings will be the data. The transcription will be done verbatim by the PI and reviewed by the PI for completion and accuracy.

**Data Analysis**

Data collection and analysis will be conducted concurrently, whereby analysis begins with data collection, helping to direct the flow of the subsequent questions (Crabtree & Miller, 1999; Thorne, 2008). The PI will listen to the recorded interviews, verify the transcribed data and code the data. The PI will be immersed in the data, with the research aim in mind to identify overarching themes and meaningful thinking units for organization (Crabtree & Miller, 1999). A code book will be created for coding the data. Thematic content analysis that involves an iterative process of data reduction and
organizations into categories will be used to construct themes that describe participants’
experience of waiting for a liver transplantation. Insightful quotes from the interviews
will be used to support themes (Thorne, 2008). The PI and a faculty member will review
the data and discuss emerging concepts until consensus. A computer-assisted qualitative
data analysis software (ATLAS.ti 8) will be used to organize and manage the data in a
systematic format.

The study findings will be disseminated by publication in a peer-reviewed journal
at the conclusion of the study. The publication will include direct quotes from
participants and study methods will be substantially described to give readers a sense of
study rigor. Trustworthiness and rigor will be ensured using Lincoln and Guba’s criteria
of credibility, transferability, dependability and confirmability (Cobb & Forbes, 2002).
Peer debriefing will be done with a faculty member that has expertise in qualitative study
to ensure credibility. Transferability will be met by providing adequate description of the
study and context. Finally an audit trail will be provided for dependability and
confirmability. The use of a data analysis software (ATLAS.ti 8) will help to maintain an
audit trail. A journal will also be maintained documenting the decisional processes made
during the study (Crabtree & Miller, 1999).

Study Limitations

Potential loss of confidentiality may hinder recruitments. Patients may not want to
participate because of the fear that the information they provide may jeopardize their
listing status. This will be addressed by emphasizing confidentiality during recruitment
and there will be a statement in the consent to address this issue.
Human Subjects

Approval will be obtained from the University of Texas Health Science center’s Committee for the Protection of Human Subjects (CPHS) and from the Houston Methodist Institutional Review Board. The PI completed the Collaborative Institutional Training Initiative (CITI) modules for protection of human subjects. Participants will be informed that participation is entirely voluntary; they may exit the study at any time without providing a reason. Participants will also be informed that their confidentiality will be maintained by de-identification of transcripts and demographic questionnaires. Pseudonyms will be used in reporting of data. Subject codes will be assigned during the interview and used during transcription for confidentiality of participants. All transcripts will be stored in a password-protected computer and digital recordings will be stored in a locked cabinet in the PI’s locked office. All original tape recordings and full transcripts will be destroyed at the completion of the study.
Reference


Cobb, A. K., & Forbes, S. (2002). Qualitative research: what does it have to offer to the gerontologist?. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 57(4), M197-M202.


*Clinical Gastroenterology and Hepatology, 12*(4), 699-700.
May 31, 2019

Ayoka Badmus, PhD, RN, RN-BC, NE-BC
University of Texas Health Science Center- Houston
Cizik School of Nursing
6901 Bertner Avenue
Houston, TX 77030

Rebecca P Winsett PhD, RN
Editor in Chief,
Progress in Transplantation
RPWinsett@natco1.org

Dear Dr. Winsett,

Please find enclosed a manuscript for consideration to the Journal Progress in Transplantation, titled Waiting for a Liver Transplant: A Qualitative Study. Studies in Liver transplantation have primarily focused on quantitatively measurable outcomes such as health related quality of life. Thus, there is a lack of research exploring patients’ experience and perspectives. Using a generic qualitative approach, we conducted 12 qualitative interviews with patients diagnosed with End Stage Liver Failure, listed and waiting for a liver transplant. Through our analysis of the interview data, we described the experience and perceived challenges of patients waiting for a liver transplant. This manuscript is appropriate for the audience of the journal as it provides insight into the experience of patients with liver failure that are waiting for a liver transplant surgery. The authors all contributed significantly to the intellectual content and design of this manuscript and have all agreed to be listed as contributors. There are no financial interest received or associated with this manuscript and no part of it has been previously submitted for publication.

Thank you kindly for your consideration.

Best Regards,

Ayoka Badmus, PhD, RN, RN-BC, NE-BC
University of Texas Health Science Center - Houston
Cizik School of Nursing
Ayoka.k.Badmus@uth.tmc.edu
Waiting for a liver transplant: a qualitative study

Ayoka Badmus, PhD, RN, RN-BC, NE-BC
University of Texas Health Science Center – Houston
Cizik School of Nursing
Houston, Texas

Geri L Wood, PhD, RN, FAAN
Bette P. Thomas Distinguished Professor in Innovative Health Care Delivery
Director, PhD Program
Professor
University of Texas Health Science Center – Houston
Cizik School of Nursing
Judy Fred Professor in Nursing
Houston, Texas

Joan Engebretson, DrPH, AHN–BC, RN, FAAN
Judy Fred Professor in Nursing
Professor
Department of Research
University of Texas Health Science Center – Houston
Cizik School of Nursing
Houston, Texas

Rebecca L Casarez, PhD, RN, PMHCNS-BC
Associate Professor
Department of Graduate Studies
University of Texas Health Science Center – Houston
Cizik School of Nursing
Houston, Texas

Victor Ankoma-Sey, MD
Gastroenterology/Hepatology Physician
Liver Associates of Texas
6410 Fannin Street Suite 225
Houston, Texas
Manuscript

Abstract

Background: Advances in liver transplantation have significantly improved survival rates, making liver transplantation a viable option for those with End Stage Liver Failure (ESLF). However, patients diagnosed with ESLF may experience a significant period of waiting before a liver transplant surgery, due to a limited supply of donor livers. Empirical evidence is scarce on the experience of patients waiting for a liver transplantation.

Objective: The objective of this study was to explore the waiting experience of patients diagnosed with ESLF and to identify their perceived challenges and needs while waiting for a liver transplantation.

Method: Using a generic qualitative approach, interviews were conducted with a purposive sample of twelve patients diagnosed with ESLF, actively wait listed for a liver transplant. Participants were admitted to the liver disease unit of a teaching hospital at the time of the study. Transcriptions of interviews and field notes were coded with Atlas ti. V8. Content analysis of the data identified themes and subthemes relevant to the objective of the study.

Results: Personal description of patients’ experience and challenges while waiting for a liver transplant. Qualitative analysis of the personal descriptions interview data revealed that patients have an overarching experience of waiting in limbo while waiting for a liver transplant. Three themes (Uncertainty during the Waiting Period; Redefinition of Life; Challenges during the Waiting Period) and five subthemes (Fear and Anxiety; Physical
Symptoms; Financial Worry; Existing versus Living; Support and Faith) emerged from the analysis of the data.

**Conclusion:** Healthcare treatment for patients waiting for a liver transplant needs to be tailored to accommodate patient reported experience and perceived challenges.

**Key Words:** liver transplant, Experience, qualitative
Liver transplantation is the only life-sustaining treatment for individuals diagnosed with End Stage Liver Failure (ESLF) (Walling & Wenger, 2014). The incidence of graft failure at one year has reduced to 9.8% and approximately 80,000 adults in the United States were living with a functioning transplanted liver in 2016 (Kim, et al., 2016). Thus, the improvement in liver transplantation provides a viable therapeutic option for patients with ESLF. However, the waiting time for liver transplantation is prolonged due to the limited supply of donor organs (Björk & Nåden, 2008). There are currently 13,403 candidates listed for liver transplant in the United States alone (United Network for Organ Sharing, 2019). Without a liver transplant, the prognosis for patients with ESLF is grim with a life expectancy of approximately two to twelve years, depending on severity and comorbidities (Walling & Wenger, 2014; D’Amico & Pagliaro, 2006).

The demand for donor livers far exceeds the supply, therefore patients may encounter a significant wait time before liver transplantation (Brown, Sorrell, McClaren, & Creswell, 2006). The waiting period before liver transplant surgery has been associated with psychological and physiological stress that stems from both the disease process and the uncertainty of transplantation (Martin, Stone, Scott, & Brashers, 2010). Therefore, there is a significant need for health care providers to be cognizant of the experience and challenges of ESLF patients waiting for a liver transplantation.

ESLF patients that meet the criteria for liver transplantation are ranked on a liver transplant waiting list based on risk of wait list death as defined by a national scoring system, known as the Model for End-Stage Liver Disease (MELD). The MELD scoring
system was adopted by United Network for Organ Sharing (UNOS) in 2002, to help ensure a fair sharing of organs and is based on statistical formulas that are scored from 6 (less ill) to 40 (gravely ill) using the following patients medical and laboratory values: Bilirubin, Serum Creatinine, Serum Sodium, International Normalized Ratio and if patient is on dialysis (Hansen, Yan & Rosenkranz, 2014). The amount of time the patient spends on the wait list is dependent on factors such as blood type, body size, availability of donor organs and the MELD score, making it difficult for providers to accurately predict when a patient would be transplanted.

The concept of a wait list is not new to organ transplantation, it emerged when the number of transplant eligible patients began to exceed the supply of organs (Findlay et al., 2011), and this mismatch in demand and supply of organs continues today. The successful management of patients during the waiting period is important for improved well-being, quality of life and successful post- transplant outcomes (Brown, Sorrell, McClaren, & Creswell, 2006). Yet studies are lacking on the experience and challenges of ESLF patients waiting for a liver transplant. An understanding of patients’ challenges and experience is useful for designing appropriate patient care and management.

Most of the literature in liver transplantation are biomedical with focus on quantifiable aspects of liver transplantation such as health related quality of life (Pierce, 2014). The aim of this study is to fill the existing gap in the knowledge of how patients waiting for a liver transplant surgery perceive and describe their experience, challenges and needs while waiting. The objective of this study is best achieved by using a qualitative approach. Qualitative research methods are useful when there is a need for patients’ perspectives and a broader knowledge of an issue (Creswell, Klassen, Plano
Clark, & Smith, 2011). An in-depth understanding of ESLF patients experience, how they integrate living with the uncertainty and the limitations of liver failure into their daily lives can help improve the care of patients waiting for a liver transplant.
Method

Design

Using a generic qualitative approach (Crabtree & Miller, 1999), interviews were conducted to understand the perspectives of patients diagnosed with ESLF, listed and waiting for a liver transplantation. An understanding of how they perceive the waiting experience, including their perceived challenges and needs were explored.

Setting and Sample

The participants were all adults, ages 41 to 72 diagnosed with ESLF and on the waiting list for a liver transplant. Inclusion criteria: patients diagnosed with ESLF who are already listed and waiting for a liver transplantation, adult (18 years and older) with the ability to read, write and speak English. Exclusion criteria: patients admitted for Hepatic Encephalopathy, cognitive disturbances, history of a previous organ transplant and inability to read, write or speak English.

This study was conducted within a 30-bed liver disease and gastroenterology unit, staffed with a medical team that consists of physicians, nurse practitioners and registered nurses. The unit is housed in a large academic hospital situated in the United States. The academic hospital has a robust multi organ transplant program with a substantial population of pre-liver transplant patients. A purposive sampling of patients listed for liver transplant was conducted to obtain a representation of patients waiting for a liver transplant (Green and Thorogood, 2013).
Data Collection

At the time of the interview, each participant was given a detailed description of the study and participants’ questions answered before they signed the consents. Interviews were conducted using a semi-structured interview guide (Appendix E), developed to explore the experiences, and challenges of ESLF patients waiting for a transplant. The Interviews took place on the unit where the participants were admitted as in-patient for various diagnosis related to ESLF. Interviews were conducted in the participants’ private rooms to foster privacy. The Primary Investigator (PI) with the help of the nurses, scheduled interviews at the times that was not disruptive to planned medical treatment and patient care.

The interviews began with open-ended questions asking participants to describe their experience of waiting for a liver transplant. Interview questions included both broad and focused questions. Additional questions were added throughout the interviewing period to investigate emerging themes. Interviews were conducted between January and February 2019 and each interview took approximately 30 to 40 minutes. All interviews were taped recorded and transcribed by the PI into a word document for coding. All data were de-identified following transcription to safe guard participants’ confidentiality. Participants were recruited and interviews continued until redundancy in thematic content and saturation was achieved.
Procedure

Following approval, a printed flyer (Appendix D) with details and objectives of the study was posted at the nursing station and in the patient lounge on unit. The flyer included the PI’s contact information for eligible participants to contact the PI. The nurses on the unit served as key informants, notifying patients about the study. The nurses also informed the PI when a potential participant was identified. The PI went to the unit and provided a verbal description of the study to identified participants. Majority of those informed about the study agreed to participate instantly, while two participants contacted the PI within a few days agreeing to participate. Interviews were set up with those that agreed to participate. The PI gave a copy of the consent to the participants to sign, following a detailed explanation of the consent and after all participants’ questions were answered.

The PI for the study is well suited to conduct the study, having worked directly with ESLF patients waiting for a liver transplant and currently working with those that have been transplanted. The PI has over eleven years of working in pre and post organ transplant. With eight of those years working with patients waiting for liver transplant. This professional experience places the PI in a unique position to appreciate the waiting experience and challenges of individuals anticipating the gift of life that would be bestowed by a liver transplant.
Data Analysis

Following the transcription of interviews and verification of accuracy by the PI, interview transcripts and field notes were uploaded and stored in a qualitative software program, ATLAS.ti software (ATLAS.ti 7.1 User manual, 2013). The PI spent time to be immersed in the data for full comprehension through repeated listening to the audio-recordings and reading of the transcripts. Data analysis begins with keeping accurate records and immersion in the data, to develop a sense of the whole (Thorne, 2008). Interview data was transcribed and analyzed following each interview. The concurrent data collection and analysis helped to direct the flow of subsequent interview questions (Crabtree & Miller, 1999; Thorne, 2008).

The transcripts were analyzed by applying codes to meaningful phrases. Codes are words or phrases that are assigned to capture the meaning or essence of data (Saldana, 2012). A code book that was started from the analysis of the first transcript was used for subsequent analysis. The number of codes increased with the progression of analysis, and as new concepts that were relevant to the aim of the research emerged. Using thematic analysis, codes were organized to generate themes relevant to the aim of the study and insightful quotes from the interviews were used to support the themes (Thorne, 2008). Data was organized, connected and verified in an iterative process to provide an accurate representation (Caelli, Ray & Mill, 2003; Kahlke, 2014) of the experience and challenges of study participants.
Trustworthiness and rigor were ensured using Lincoln and Guba’s criteria of credibility, transferability, dependability and confirmability (Cobb & Forbes, 2002). Adequate description of the study and context is provided to meet transferability. An audit trail was maintained in ATLAS.ti 8 and journaling was done to document the decisional processes made during the study (Crabtree & Miller, 1999). The analyzed data, including codes and themes were debriefed with the PI and three research advisors with qualitative experience, to confirm that findings were congruent and supported by the data. A debriefing was also done with an academic peer of the PI with beginning experience in qualitative research.

**Ethical consideration**

Approval was obtained from the University of Texas Health Science center’s Committee for the Protection of Human Subjects (CPHS) and from the Houston Methodist Institutional Review Board (Appendix A). The PI completed the Collaborative Institutional Training Initiative (CITI) modules for protection of human subjects. Participants were informed that participation is entirely voluntary, and they may exit the study at any time without providing a reason. Participants were also informed that their confidentiality will be maintained by de-identification of transcripts and demographic questionnaires. Subject codes were assigned during the interview and used during transcription for confidentiality of participants. All transcripts were stored in a password-protected computer and digital recordings stored in a locked cabinet in the PI’s locked office. All digital recordings and identifying data were destroyed at the conclusion of the study.
Findings

Participants

Twelve participants were interviewed representing the general diversity of patients diagnosed with ESLF waiting for a liver transplant. As shown in Table 1 (Appendix H), majority of the participants identified themselves as Caucasians (83.3%) and were mostly males (66.6%). Ages of the participants were between 41 to 72 years of age. The MELD score of the participants at the time of the interviews ranged between 15 and 32. The etiology of liver failure varied but approximately 50% of the participants had a failed liver due to Non-Alcoholic SteatoHepatitis cirrhosis (NASH). Majority of the participants had been on the liver transplant wait list for over a year, with wait time ranging from two months to six years.

Themes

The identified themes and sub themes from the analysis of the data provides insight into the experience and challenges of ESLF patients waiting for a liver transplant surgery. Participants’ identified the experience of waiting for a liver transplant as temporary but an overwhelming experience that influenced all spheres of life. A period fraught with several uncertainties that is akin to waiting in limbo. An overarching theme of Waiting in Limbo resonated throughout the three identified themes (Uncertainty during the Waiting Period; Redefinition of Life; Challenges during the Waiting Period) and five subthemes (Fear and Anxiety; Physical Symptoms; Financial Worry; Existing versus Living; Support and Faith) that emerged from the experience of participants waiting for a liver transplant as shown in Table 2 (Appendix I). All the participants in the
study expressed a feeling of uncertainty with regards to time of transplant and surgical outcomes. The participants described how they have been changed by the challenges and uncertainty of the waiting period. Figure 1 (Appendix G) is a graphic representation of the interconnectedness of themes. The uncertainty and challenges experienced during the waiting period were overlapping. Patients redefined their lives to accommodate the challenges and uncertainty experienced during the waiting period. The overarching theme of *waiting in limbo* resonated throughout all through the experience.

**Theme 1: Uncertainty during the Waiting Period.**

This theme exemplifies that patients waiting for a liver transplant are faced with several uncertainties. Not knowing when or if they would receive a liver transplant before death and consequentially, an inability to plan. Study Participants spoke about the stress of not being able to predict or plan for the transplant or surgical outcome.

*Waiting is not easy, very stressful, you worry about everything and it does not help because you still don’t know what to expect. I have to keep waiting, hoping to make it… And if the transplant works, then it would all be worth the wait.* (P10)

The study Participants described the experience of not knowing when they would be transplanted after being placed on the waiting list. Although some participants felt a sense of accomplishment after being placed on the waiting list, the unpredictability of transplant was of significance during the waiting period. One of the study’s participants described the waiting experience vividly as, getting to a mountain top and not knowing where to go next.
...the best way I know to explain it is kind of you know, you get to the mountain top, you finally make it there, where do you go from there. You know, you already at the top, I guess that is the easiest way to explain it to you. (P3)

Patients waiting for a liver transplant are uncertain about when they would receive a transplant, the wait could be for a few months or several years. Not knowing when an organ will be available meant that patients waiting for a liver transplant had to be prepared at all times for surgery recovery or possible death. The participants in the study expressed how not knowing when a liver would be available influenced their lives and prevented them from making plans or accomplishing previously made plans.

You never know when you have to go to the hospital for emergency or even for when they find a liver, you have to almost have a bag packed and ready, it’s like when you are due for a baby but you don’t know when the baby is coming, you just get ready. (P9)

The unpredictable hospitalizations related to disease exacerbation or worsening symptoms was also a concern. The frustrations over severe and unexpected exacerbation of symptoms requiring hospitalization was verbalized by one participant as a hindrance to normal life

It is not a normal life because you don’t know when you gonna get sick, like now, I still don’t know why my esophagus or what they call it is bleeding...I hate to be working around with my grandkids and this happens, what are they supposed to do, how do know when to call 911...The last thing I remember was going to the bathroom, seeing all these blood and then I woke up, am in the ICU. (P7)
Subtheme 1.1: Fear and Anxiety.

The uncertainty of liver transplantation sparked a sense of anxiety and fear. When asked to elaborate on their experience of uncertainty about liver transplant, participants spoke about their fears and anxiety – fear of death, fear of being too sick for transplant, fear of the outcome and anxiety about the MELD score.

Scary, oh, very scary, a lot of anxiety, you know, I knew I had a bad liver... (P3)

It is the scariest time, I want the transplant, but I also worry about, hmm death, worse off... like not coming out of surgery. (P11)

People need to be encouraged, people are scared, dying is not easy. If they have somebody with them or have someone with the same disease, it helps a little bit... The goal is survival. (P1)

One Participant told of how this fear is not relived by familiarity with surgical procedure, liver transplant was considered a “big” surgery

...it’s still scary to me, you know, I know what’s coming and I know the risk, you know and I have been through many operations, you know I was in a car accident, you know, I went through neck surgery, I went through arm surgery, went through leg surgery, you know, but this is big. (P3)

All the participants identified how their wait time was dependent on their MELD score, but several participants expressed additional apprehension about the MELD score. The MELD score changed with severity of symptoms and although a high MELD score placed patients higher on the waiting list, it also signified a deterioration in condition.
My MELD score is gone up, it’s now 28 so am near the top, but my kidney is going bad, so my MELD score is gone high, they are saying I may need a kidney too, we just need to find a liver first before it gets late...not ready to die just now. (P10)

Not scared, am anxious, I like to get it done as soon as possible, my MELD score keeps going up and down and now it’s gone down, and I have to wait a little longer so that is a bit bothers me. (P4)

I just don’t know if am going to get a liver if the MELD score keeps going down, it was high before, but I did that procedure that stops me from bleeding, now they tell me it is going down. But I can go up to the top of the list if it is high... (P11)

**Theme 2: Redefinition of Life.**

The loss of independence and the inability to assign meaning or predict transplant timing or outcomes meant having to redefine life. The study participants of the study expressed that waiting for a liver transplant is significantly life altering. The waiting period represented a period of helplessness fueled by uncertainty and physical limitations but quieted by believing in a higher power. One of the participant identified how she perceived life during the wait from two view-points – vanity and spirituality

*From a vanity point, from a just raw woman feeling point, maybe a 1 out of 10...From a spiritual point maybe a 5 or 6 out of 10. Where I have awareness that no matter how bad this is, he is still present with me (Do you mean God?) yes, and there is somebody else going through worse things than this...* (P2)
Subtheme 2.1: Existing versus Living.

Participants voiced how the waiting period impacted their life and spoke passionately of their emotional struggles and feelings. They related how extensively their life has changed so much from what it used to be.

I feel like I don’t have a life anymore, am not suicidal even though my mother thinks I need some pills but no I don’t. But hmmm I feel like I want to live and not just exist, but right now I feel like am just existing... It is hard when you have been sick and other people are making your decisions for you. It is hard because you have been working all your life and now to totally dependent on my parents... I just want to take better care, take time out for me, I really want my strength back and just my life. (P2)

I have no life because every time I make plans to go with my daughter or someone to go to the movies or something, I end up in the hospital or am too sick to get out of bed...

This is what I feel, is that once the transplant is done and I get through the recovering part, that my life will go back, I will go back to being me and going out and doing different things. (P9)

Not being able to do what I used to do, have to stay closer to home, my doctor recommended a cruise at the best and to get insurance that can fly me back if I got sick but then I have to worry about if an organ becomes available. (P5).

Last week when I just wanted to die, I told my kids, tell the grandkids about me but this week am much better...There was one day last week, I told my kids, guys I love you but I just can do this anymore, I said am just going to go ahead and ask God to take me, I was so miserable but its not my call. (P1)
The changes that patients experience during the wait led them perceive their lives as not normal, at least not as they knew it. This caused an emotional turmoil that is evident in the manner they expressed themselves, as they struggled to hold on to the hope of a successful transplant outcome.

Subtheme 2.2: Support and Faith.

For many of the participants in this study, faith and family support were imperative to navigating through the perceived vulnerability and challenges of the waiting period. The intense reliance on God and family support is echoed in the statements of the participants:

*it is hard, I have moments, in my meditation, at least 3 times a week, where I kind of just think about it and cry out and I say to myself, I can’t stay in it, I can stay stuck in it. So I tell myself it will get better, and God has a plan.* (P2)

*I have a sister, but she lives out in ..., if you don’t have nobody, then you are all alone but am not alone, once I have God, am claiming it, Jesus is the way out of things...* (P6)

Many of the participants indicated that having a support system was helpful during the wait

*I would hate to go through this by myself. I don’t see how people do. I got a really good support system, that helps tremendously... the lord is in control, there is a reason for everything, makes it easier to deal with it.* (P1)

*I have a good family, we are real close and they support me.* (P4)

*I have good family and they are very supportive.* (P5)
Theme 3: Challenges during the Waiting Period.

When asked about challenges and issues encountered during the waiting period, participants expressed that they struggled with the constraints and worries imposed by physical symptoms and financial burden.

Subtheme 3.1: Physical Symptoms.

Several participants spoke vividly about the constraints and discomfort imposed by the exacerbation of symptoms. One participant complained mainly about jaundice and diarrhea, while another spoke about excess body fluid.

...have so many bad symptoms and Jaundice and it was out of control. I still have it but not as bad as back then, my eyes looked like a gorilla and hmm, the diarrhea and everything, it was just a lot. (P2)

All this fluid in my legs and tummy makes it difficult to walk, I have to get a tap (paracentesis) every week, very tiring but I feel more comfortable when they do the tap (P9)

While the majority of the participants grappled with disruption in sleep. Almost all the participants expressed a significant lack of energy and physical weakness. The impact of sleep disruption and weakness echoed in participants’ statements.

I go get my nails done and fall asleep. I do sleep a lot, and I just get so tired, it just wears your body down and I can’t drive. I have to sleep and cat nap, you can’t have a full night sleep..., oh oh, I would love to just have a full night sleep. (P5)
Just my weakness, being able to do stuff that I was able to do before, can’t go out...just miss being able to get out of bed, walk to the bathroom, am super weak. (P4)

A lot of weakness am tired all the time. I used to carry furniture and I can barely lift a chair now, I am so tired, I fall asleep if I drive so I can’t drive, I need a driver. (P8)

Not able to spend time with my grandkids, walk around the mall, doing something besides lying in bed... My wife and I before I got sick, we travelled a lot and have not been able to do that in a year and a half. (P1)

**Subtheme 3.2: Financial Worry.**

Participants expressed concerns about their financial limitations that was caused by either the loss of employment or cost of healthcare services. These concerns were irrespective of whether or not they had insurance. Even though they had insurance, there was still a co-pay that became significant considering a loss of employment or multiple hospital readmissions. One participant expressed a lack of sleep related to financial worries and another spoke about the cost of healthcare related services.

_I don’t sleep, all the time am worried, I worry how am going to make stuff, how to get a better camper, my living arrangements, where is this money going to come from, I got ulcer because I worry too much... (P3)_

_... Everybody needs money, but things get out of control real quick, get stressful, I have to pay every-time I come here, I pay parking, I pay insurance, I pay a little for the medications, not a lot but I still have to pay. (P10)_
Other participants stated that their employment had been affected and described the challenge in trying to maintain employment.

*I can’t work, the last time I tried to do some work, I don’t know what happened at work, and they had to call the ambulance.* (P2)

*I haven’t work since over a year, it was hard not being able to work but I was so tired, I could fall at sleep just like that.* (P5)

The loss of employment and cost of healthcare services makes it tough for patients waiting for a liver transplant. The additional cost associated with healthcare, such as parking and other miscellaneous expenses adds up for quickly.
Discussion

This study aimed to investigate the experience and challenges of patients waiting for a liver transplant. Three interrelated themes (Uncertainty during the Waiting period; Redefinition of Life; and Challenges during the Waiting Period) with an overarching theme (Waiting in Limbo) were identified in the interviews with study participants. The study is important in understanding the experience of patients waiting for a liver transplant from the patient’s perspective; as it is best to evaluate disease management from the perspective of the patients. The findings from this study provide insight into how ESLF patients experience the waiting after being placed on the liver transplant waiting list. Some older studies have shown that patients waiting for organ transplant have unique experiences and struggle with multiple challenges (Brown et al., 2006, Bjork & Naden, 2008, Wainwright, 1995).

The findings of this study reflects that waiting for a liver transplant is similar to waiting in limbo. The Oxford dictionary define limbo as “an uncertain period of awaiting a decision or resolution; an intermediate state or condition” (Oxforddictionaries.com, 2019). In analysis of the interviews and field notes, an overarching theme of waiting in limbo was noted. The study participants are faced with a day to day uncertainty of not knowing what to expect – a hospital admission for a liver transplant or a hospital admission for an episodic exacerbation of liver failure. The participants in this study perceived the waiting experience as an overwhelming experience that dominated over all aspects of their lives, whereby daily decisions were impacted by the nebulosity of waiting and the disease.
All the participants in this study expressed a feeling of uncertainty, not knowing what to expect during the waiting period. Participants were uncertain of the time of transplant, the outcome of the transplant and if they would survive to transplant. In an older qualitative study of patients’ experience of waiting for a liver transplantation by Bjørk and Nåden (2008), patients expressed uncertainty related to life and death. Similarly, Pierce (2013) also found that patients struggled with not knowing the time of liver transplant and were focused on “waiting for the phone call” – a call to let them know that a liver is available. Uncertainty has been a finding in patients waiting for organ transplant, irrespective of the organ. In a recent qualitative study by Burns, Fernandez, and Stephens (2017), uncertainty was also a major finding in the experience of patients waiting for a kidney transplant.

Uncertainty has been documented as a notable feature of the illness experience (Mishel, 1988), thus not surprising that it was a significant finding in ESLF patients waiting for a transplant. Mishel (1988) defined uncertainty as “the inability to determine the meaning of illness-related events” and proposed the theory of uncertainty in illness. The theory explains how individuals evaluate meaning during experiences of acute illness; a theory that was later expanded to include chronic illness. According to this theory, uncertainty occurs when the decision maker is unable to assign definite value to events or is unable to predict outcomes accurately as depicted by the participants of this study. The unknown timing for a liver transplant and or the onset of a severe symptom exacerbation meant patients could not make long or even short plans without contemplating the possibility of ending up in the hospital. For the participants in this study, time and planning was relative to transplant, whereby participants spoke in-terms
of life before transplant and after transplant. Brown et al., (2006) also had a similar finding and designated it “the paradox of time” in a phenomenological study of patients waiting for a liver transplant.

When participants in this study were asked to elaborate on their experience with uncertainty, they expressed feelings of fear and anxiety. Fear and Anxiety are predominant emotions that have been expressed by patients’ waiting for a liver transplant (Brown et al., 2006, Bjork & Naden, 2008, Wainwright, 1995). The uncertainty about a potential threat is disruptive to a person’s ability to mitigate the threat, hence results in anxiety (Grupe & Nitschke, 2013). Although the participants in this study used fear and anxiety interchangeably. In a simultaneous concept analysis of fear and anxiety by Bay and Algase (1999) “fear is defined as the result of disruption from a perceived source that is identified as threatening, while anxiety arises in response to a vague, nonspecific threat”. Both of which are applicable to patients waiting for a liver transplant from the perspectives of the participants in this study. The presence of fear and anxiety in patients waiting for a transplant is not surprising considering the perceived threats that were expressed. Participants in this study expressed fears, concerns and anxiety regarding transplant surgery, being too sick for transplant, the outcome of the transplant and fluctuations in MELD score.

Fear and anxiety are not uncommon to patients listed for a liver transplant. Aghahosseini, Nayeri, Shahravari & Tosi (2017) found that fear and anxiety were the most unpleasant emotional experience among hepatitis patients waiting for a liver transplant. Bjork and Nåden (2008) found the fear of death or developing cancer before transplant were common among patients waiting for liver transplant. Transplant
clinicians may help improve the waiting experience of patients by using strategies that reduce uncertainty, which will reduce fear and anxiety. Communication that has been shown to be effective tool in the management of uncertainty (Brashers, 2001). Nurses and other transplant healthcare providers can help lessen patients’ uncertainty and anxiety by maintaining an open channel of communication during the wait.

While Aghahosseini et al (2017) and Bjørk and Nåden, (2008) did not find the MELD score to be a source of fear or concern for patients, three of the participants in this study worried about the fluctuations in their MELD score. As expected, all the participants knew their Meld score and the significance of the score. The MELD score is an objective system used to rank liver transplant candidates on the transplant waiting list according to their severity of liver disease and risk of mortality (Wiesner et al., 2003). Although, patients desired a high MELD score to move up the transplant list, but a high MELD score also correlates to increased risk of mortality.

As patients waited hopefully to receive a liver, they redefined their life to accommodate the challenging experience of the waiting period. Patients waiting for transplant had to accept and negotiate the loss of health, physical limitations, wavering emotions, uncertainty and the challenges of waiting (Pierce, 2014; Bjørk and Nåden 2008; Brown et al., 2006). For the participants in this study, the waiting period was a time of helplessness fueled by uncertainty and physical limitations that is only relieved only by spiritual beliefs and family support. The study by Bjørk and Nåden (2008), and Brown et al., (2006) also found that patients waiting for a liver transplant experienced significant life changes during the wait. Pierce (2014) and Bjørk and Nåden (2008) found patients went through a redefinition of self as they negotiated the disruptions experienced during
the waiting period. Participants in this study perceived a change in their normal life and spoke about their loss of independence and emotional turmoil. One of study participant stated she felt like she did not have a life anymore, feeling that she was merely existing and not living.

For patients waiting for a liver transplant having support and faith are sources of strength to help endure the wait. As identified in this study and liver transplant literature, patients waiting for a liver transplant face a series of overwhelming emotional challenges and must rely on their spiritual beliefs and family support during the wait (Pierce 2014; Bjørk and Nåden, 2008). Participants in this study described how their faith in God and family support helped them to face the various challenges and emotional turmoil of the waiting period. They perceived family as a source of strength and hung on to their spiritual beliefs; trusting God to guide them through the wait. They expressed the importance of having a good family support and although, they sometimes felt like a burden to family, there was a sincere appreciation for the support. One participant stated he didn’t think anyone could go through the waiting experience without a support, validating the significant value of support.

The physical symptoms of ESLF was a common problem among the participants in this study. Participants found the physical symptoms of ESLF challenging and overwhelming. At the time of the interviews, participants of this study spoke of the distress experienced due to the core symptoms of ESLF as described in liver disease literature, including physical weakness, fluid overload, jaundice and fatigue. This is congruent with findings from the study by Bjørk and Nåden (2008), patients expressed how they experienced a mental distress related to physical limitation and a lack of
energy. In both this study and that of Bjørk and Nåden (2008), patients described the feeling of lack of energy and exhaustion that influenced their life. The underlying cause of liver associated fatigue is not completely understood, it is a common problem that impacts the quality of life of patients living with all forms of liver disease (Swain, 2006).

Some of the participants in this study also spoke of disruption in their sleep pattern that may or may not be related to fatigue. Although almost all the participants described an intense physical weakness and fatigue, there was no distinct pattern among the participants in relation to sleep. Some of the participants expressed the inability to have a full night sleep and took cat naps, while others stated they slept a lot.

Financial worry is a common challenge in the waiting period. Participants expressed concerns about financial constraints due to either the loss of employment or cost of treatments. A study by Martin, Stone, Scott & Brashers (2010) to identify the sources of uncertainty across the transplant trajectory found that patients worried about unclear financial consequences before an organ transplant. Participants in this study voiced concerns about their financial situations as related to loss of employment and the cost of healthcare services. This was irrespective of whether they had insurance. They had concerns with the cost of co-pay, particularly because they were unemployed and required recurrent healthcare services. Many individuals in the United States experience difficulty paying medical bills, even when insured particularly with chronic illness (Pollitz, Cox, Lucia, & Keith, 2014).
Limitations

The limitations of this study include the exclusion of non-English speaking patients, limiting the diversity of the study and the enrollment of only patients admitted at one medical facility. Also missing was the perspectives of non-acutely ill ESLF patients waiting for liver transplant. Although qualitative study results are not generalizable to the population, but their findings are useful for developing testable interventions and tools for the advancement of healthcare (Leung, 2015).

Relevance to Practice and Future Research

This study contributes to liver transplant literature and adds valuable insights about the experience and challenges of patients waiting for a liver transplant. An understanding of patient experience is critical to the selection of appropriate treatment (Fan & Eiser, 2012). The study has significant implication for practice because the findings may be useful by clinicians to design appropriate patient care pathways that incorporates patient experience. Future research should include out-patients participant to confirm that weakness and fatigue was not an exaggerated effect related to admission diagnosis but a true challenge of the waiting experience. As many of the participants spoke about weakness and fatigue, there is merit in exploring tools and interventions that would help patients increase and maximize energy. Since quality of sleep also appeared to be a significant issue, patients waiting for transplant would benefit from strategies that improve the quality of sleep. For example, the use of music assisted relaxation has been shown to promote sleep and it does not require intensive investment or training, therefore can be used in patients to improve quality of sleep (De Niet, Tiemens, Lendemeijer, & Hutschemaekers, 2009).
Conclusion

Patients waiting for a liver transplant may experience a significant amount of time waiting for a suitable donor liver. In describing the experience and challenges of patients waiting for a liver transplant, this study confirmed what has been described in liver transplant literature with additional insights. The waiting period is notably characterized with uncertainty, fear, anxiety, economic and physical challenges. Transplant clinicians can use the findings of this study to provide appropriate support and care to ESLF patients waiting for transplant.
Reference


Morse, J.M. (2000). Determining sample size. *Qualitative Health Research, 10*, 3-5


Streubert-Speziale, H.J. and Carpenter, D.R. (2007) Qualitative research in nursing: Advancing the humanistic imperative. Lippincott Williams & Wilkins, Philadelphia


Appendix A
Approval Forms
NOTICE OF PERMISSION TO RELY ON THE METHODIST HOSPITAL IRB

HSC-GEN-18-1109 - WAITING FOR A LIVER TRANSPLANTATION: A QUALITATIVE STUDY

CHAIRPERSON: L. Maximilian Buja, MD

PROVISIONS: This permission relates to the research to be conducted under the above referenced title.

CPHS has reviewed the above submission and determined that it meets the criteria for being reviewed by the Methodist Hospital IRB. Please submit an application to the Methodist Hospital IRB via their electronic system and await written approval.

Research participants must sign authorization for release of medical records unless such authorization is waived by the Methodist Hospital IRB or UT Houston CPHS.

The research should not be initiated until all necessary institutional approvals and signatures have been obtained including but not limited to a fully executed clinical trial agreement.
HMRI IRB 3

NOTIFICATION OF INITIAL APPROVAL TO BEGIN RESEARCH (EXPEDITED)

To: Dr. Ayoka Badmus

Date: December 3, 2018

From: Mary K. Clancy, MSN, CCRC, CIP

   Director, ORP

Study ID: Pro00020649

Title: Waiting for a liver transplantation

The Institutional Review Board reviewed your Request for Expedited Review and the above named project is determined to qualify for Expedited status according to 45 CFR 46.110. The study is approved from 12/03/2018 through 12/02/2021.

PROVISIONS: Unless otherwise noted, this approval relates to the research to be conducted under the above referenced title and/or to any associated materials considered by expedited review, e.g. study documents, etc.

[Files]

Study Protocol.docx(0.01)

Pro00020649 Consent V1 120318.docx

Abadmus demographic from.docx

Abadmus interview guide.docx

Final approved flyer for waiting for a liver with HMH brand (002).docx
Appendix B
Informed Consent
Informed Consent for Observational/Non-Interventional Research

Participant's Name: 

Principal Investigator: Ayoka Badmus

Study Title: Waiting for a liver transplantation

Principal Investigator: Ayoka Badmus

Study Purpose/Summary:
To explore and describe the experience of waiting for a liver transplant and the perceived challenges and needs of patients diagnosed with End Stage Liver Failure that are waiting for a liver transplantation from the patients' perspective.

Study Purpose/Executive Summary:
If you decide to be in this study, it will not impact any part of your routine care. The research study requires you to participate in an interview. You will be asked to talk about your experience of waiting for a liver transplant and challenges and needs of waiting for the transplant. The other information that you will provide is your age and the length of time you have been waiting on the liver transplant list. The information that will be taken from your medical record is your MELD (Model for End Stage Liver Disease) score and cause for liver failure.

You will be interviewed individually in your room on the hospital unit for your privacy or in a reserved room at the outpatient clinic by the principal study investigator named above. The interview will be for an hour or less or may stop at your request. You may be asked for a second interview for further clarification of information following the first interview. The interviews will be audio recorded for the investigator to transcribe for analysis. Your participation in this study is voluntary. You can choose to participate at any time without any penalty or loss of benefits to which you are entitled.

What risk will I face by taking part in the study and how will Researchers protect me from these risks?

- The potential loss of confidentiality is the only known risk of being in this study.
- Your name will be de-identified and pseudonyms will be used in reporting of data. All digital files will be encrypted and password protected. All transcripts will be stored in a locked cabinet, in a locked office. All original audio recordings and full transcripts will be destroyed at the completion of the study.
As with any research study, there may be additional risks that are unknown or unexpected. If these become known, the study team will notify you in a timely manner of any changes that may change your willingness to participate. If new information is provided to you after you have joined the study, it is possible that you may be asked to sign a new consent form that includes the new information.

**How could I and others benefit if I take part in this study?**

This study is unlikely to help you. This study may help us learn things that may help people in the future.

**If I want to stop participating in the study, what should I do?**

If you wish to stop your participation in this research study for any reason you should let the principal investigator/study coordinator know as soon as possible. You may be asked why you are leaving the study and your reasons for leaving may be kept as part of the study record. If your information has been de-identified, it may not be possible to delete your information. If you decide to leave the study before it is finished, please tell one of the persons listed in “Contact Information”.

**What are my rights in this study?**

Taking part in this study is your choice. No matter what decision you make, and even if your decision changes, there will be no penalty to you. You will not lose medical care or any legal rights.

For questions about your rights as a research participant or if you have complaints, concerns, or questions about the research, please contact Susan M. Miller, M.D., M.P.H., Chair, Houston Methodist Institutional Review Board for the Protection of Human Subjects, at 713-441-2750 or Ethan Nadelson, MD, Chair, Houston Methodist Research Institute Institutional Review Board for the Protection of Human Subjects, at 713-441-5154. You may also contact the Director, HMRI Office of Research Protections at HMRI Office of Research Protections, 1130 John Freeman, MG76-016, Houston, Texas 77030. Ph: 713-441-7548

The research team will take proper precautions to ensure that any information regarding your identity obtained in connection with this research will remain confidential.

**Authorization to use and disclose protected health information**

If you decide to participate in this study, information about your health may be used or disclosed (shared outside of the Hospital) for the purposes of conducting this study. This information may include information from your medical record that is relevant to this study, such as your medical history, medications, test results, diagnoses, treatments, operative reports (reports from operations that you have undergone), and discharge summaries. It may also include information relating to: Human Immunodeficiency Virus (“HIV”) infection or Acquired Immunodeficiency Syndrome (“AIDS”); treatment for or history of drug or alcohol abuse; or mental or behavioral health or psychiatric care. Information collected by the study doctor and/or research staff specifically for this study, such as test results, blood samples, physical examinations, information about possible side effects, and surveys you might be asked to complete could also be used or disclosed.
Your identifiable recording of the interview will be used by a transcription service. The transcription service will have processes in place to assure the safety and confidentiality of your information. Your identifiable information will not be used for future research. However, authorized representatives of the investigator, IRB, or government agencies may review records containing personal information to make sure that the study information is correct. Because of the need to provide information to these parties, absolute confidentiality cannot be guaranteed.

Because this information is being disclosed for research use, there is no expiration date for the use of your information. This authorization is valid until you revoke it. You can revoke this authorization at any time by contacting the investigators and if possible any identifiable information will be destroyed. The revocation will not apply to information that already has been released or actions that have already been taken in response to this authorization. You have a right to request a copy of any of your health information that is released under this authorization.

Other researchers or institutions that receive your information may not be covered by Federal or Texas privacy laws. As such, your information may not be protected under these laws once it is disclosed and, therefore, may be subject to re-disclosure or use by such individuals or institutions.

Where can I get more information?

If you have any questions regarding your participation in this study, please ask us. If you have any additional questions later, please contact the researchers listed below to:

Principal Investigator: Ayoka Badmus  
Mailing Address: 6565 Fannin Street, Houston Texas 77030  
Telephone: 832 293 9067

Study Participant:

I have read this consent form or had it read to me. I have discussed it with the study team and my questions have been answered. I will be given a signed copy of this form. I agree to take part in this study.

Signature of Study Participant:

_________________________________________ Date: __________ Time: __________

Name (Print Legal Name): ______________________________

Person Obtaining Consent:

I have given this research subject (or his/her legally authorized representative) information about this study that I believe is accurate and complete. The subject has indicated that he or she understands the nature of the study and the risks and benefits of participating.

Name: ___________________________ Title: ___________________________

Signature: ___________________________ Date of Signature: ____________

*FOR IRB OFFICE USE ONLY*  
IRB No. ___________  
Consent Approval Date: ______/____/____  
Expiration Date: ______/____/____

Page 3 of 4

NMRI non-interventional ICF template v. 8/25/14
Appendix C

Study Protocol
Study Protocol

Overall objective:
To understand and describe the experiences, challenges and needs of ESLF patients while waiting for a liver transplant.

Specific Aims:
- Explore how patients diagnosed with ESLF listed for liver transplant surgery construct their experience of waiting and uncertainty.
- Describe the perceived challenges and needs of ESLF patients waiting for a liver transplant surgery.

Research Strategy

Research Design and Setting
- A generic qualitative descriptive approach (Crabtree & Miller, 1999) will be used to describe the perspectives of ESLF patients waiting for a liver transplantation.
- Simultaneous data collection and analysis that is flexible and capable of adjusting to new information that may lead to the refining of research questions to pursue fruitful lines of inquiry (Kahlke, 2014).
- Data collection and analysis will be conducted over a period of 12 weeks.

Population and Sample.
- Purposive sampling will be employed to select participants that meet the inclusion criteria.

Inclusion criteria:
- Adult (18 years and older).
- Patients diagnosed with end stage liver failure.
- Patients that are listed and waiting for a liver transplantation.
- Patients that have the ability to read, write and speak English.

Exclusion criteria:
- Patients currently admitted for Hepatic Encephalopathy.
- Patients with cognitive disturbances.
- Patients with history of a previous transplant.
- Patients that are unable to read, write or speak English.

Sampling Procedures and Recruitment
- Following approval from Houston Methodist Hospital Institutional review Board and, the University of Texas Health Science center’s Committee for the Protection of Human Subjects (CPHS), a printed flyer with details and objectives of the study will be posted at the nursing station and in the patient lounge on the liver
failure unit. The flyer will include the contact information for eligible and interested participants to contact the Primary Investigator (PI).

- The use of unit nurses will only inform patients of study but will not actively recruit or consent patients for the study.
- The planned sample size for this study is 20 – 25, based on similar studies found in literature and recruitment will continue until no new concept is emerging from the data (Moser & Korstjens, 2018; Marshall et al., 2013; Bjørk & Nåden, 2008).

**Data collection Procedures**

- A written consent with full disclosure will be provided to those that agree to participate and an interview time will be set up (consent form include objectives of the study, participants’ rights to withdraw from study at any time without penalty and potential risks).
- Interview location is the patient rooms on the liver failure unit, for patient privacy and comfort.
- The participants will be interviewed individually, face-to-face., using a semi-structured format

**Data to be collected (Appendix B):**

- Age
- Gender
- Race
- MELD score
- Amount of time spent on waiting list
- Etiology of liver disease

*The interview questions will include both broad and focused questions that will describe the needs, challenges and waiting experience of ESLF patients (Appendix A). The interview will be audio-recorded so as to reduce distractions during the interview and also for play back of recorded interviews during transcription and data analysis. The transcription will be done verbatim by the PI and reviewed by the PI for completion and accuracy.*

**Data Analysis**

- Data collection and analysis will be conducted concurrently, whereby analysis begins with data collection, helping to direct the flow of the subsequent questions.
- The PI will listen to the recorded interviews, verify the transcribed data and code the data.
- A code book will be created.
- Thematic content analysis will be used to construct themes that describe participants’ experience of waiting for a liver transplantation.

*Note: A computer-assisted qualitative data analysis software (ATLAS.ti 8) will be used so as to organize and manage the large data in a systematic format.*
**Human Subjects**
- Subject codes will be assigned during the interview and used during transcription for confidentiality of participants.
- The document with patient names will not be kept with transcript and audio recording.
- All transcripts will be stored in a password-protected computer and tape recordings will be stored in a locked cabinet in the PI’s office.
- All original tape recordings and full transcripts will be destroyed at the completion of the study.

**Study time frame**
- Recruitment and data collection will begin in December 2018, following IRB approval. Data will be analyzed concurrently with data collection to be concluded by February of 2019.
References


Appendix D

Study Flyer
Opportunity for patients waiting for a liver transplant

Participants needed for a research study

The research study will help healthcare providers understand more about the experience, challenges and needs of patients awaiting a liver transplant.

What is required from you?
Spend 30 minutes to an hour in an audio-recorded, confidential interview in which you share your experience of waiting for a liver transplant.

Who is eligible?
- Persons who have been diagnosed with end-stage liver disease or liver failure.
- Those who are on the liver transplant list.

When and where?
The interviews will take place in your room at Houston Methodist Hospital at a time of your choosing.
Appendix E

Interview Guide
Interview Guide

Begin with welcome and gratitude for participation.

Reiterate (study purpose, interview is recorded, no wrong or right answers and participants may stop at any time for any reason).

Ask if participants have any question before the beginning of the interview.

Interviews will begin with the open ended broad questions. The rest of the interview will proceeded with PI listening and using probe questions for clarification of concepts.

Questions

Broad Questions:

1. Tell me about your experience of waiting for a liver transplant.

2. How would you describe your life after you were listed for a transplant?

Probe Questions:

3. What is the impact of waiting for a liver transplant on your everyday life?

4. What is it like to wait for a liver transplant?

5. What are your specific challenges during this waiting period?

6. What are your specific needs during this waiting period?

7. Are your healthcare providers meeting your needs? And if not, explain how healthcare providers can better meet your needs.
Appendix F

Demographic Form
Demographic Information Form

Study ID (First 2-digit of interviewee’s cell phone number and interview date):

How old are you?

What race do you identify yourself as?

Gender:

☐ Male
☐ Female

How long have you been waiting on the liver transplant list (Months/Years):

What is your MELD score?

What is the reason for your liver failure?

☐ Viral Hepatitis
☐ Alcoholic Cirrhosis
☐ Non Alcoholic Fatty Liver disease
☐ Hepatocellular Carcinoma
☐ Autoimmune
☐ Other:
Appendix G

The experience of waiting for a Liver Transplant
The experience of waiting for a Liver Transplant

Figure 1. The experience of waiting for a Liver Transplant.
Appendix H
Demographic Table
Demographic Table

Table 1

Demographics of study participants

<table>
<thead>
<tr>
<th>Study Participant</th>
<th>Age</th>
<th>Race</th>
<th>Gender</th>
<th>Wait time</th>
<th>MELD score</th>
<th>Etiology of ESLF</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>65</td>
<td>Caucasian</td>
<td>Male</td>
<td>1.5 years</td>
<td>28</td>
<td>NASH cirrhosis</td>
</tr>
<tr>
<td>2</td>
<td>48</td>
<td>African American</td>
<td>Female</td>
<td>2 years</td>
<td>18</td>
<td>Autoimmune</td>
</tr>
<tr>
<td>3</td>
<td>41</td>
<td>Caucasian</td>
<td>Male</td>
<td>2 months</td>
<td>16</td>
<td>NASH cirrhosis</td>
</tr>
<tr>
<td>4</td>
<td>66</td>
<td>Caucasian</td>
<td>Female</td>
<td>4 months</td>
<td>27</td>
<td>NASH cirrhosis</td>
</tr>
<tr>
<td>5</td>
<td>62</td>
<td>Caucasian</td>
<td>Female</td>
<td>1.2 years</td>
<td>22</td>
<td>NASH cirrhosis</td>
</tr>
<tr>
<td>6</td>
<td>60</td>
<td>Caucasian</td>
<td>Male</td>
<td>2 years</td>
<td>18</td>
<td>Hepatitis C Virus</td>
</tr>
<tr>
<td>7</td>
<td>53</td>
<td>Hispanic</td>
<td>Male</td>
<td>1 year</td>
<td>14</td>
<td>Alcoholic Cirrhosis</td>
</tr>
<tr>
<td>8</td>
<td>63</td>
<td>Caucasian</td>
<td>Male</td>
<td>6 years</td>
<td>22</td>
<td>and Hepatocellular Cirrhosis</td>
</tr>
<tr>
<td>9</td>
<td>66</td>
<td>Caucasian</td>
<td>Female</td>
<td>2 years</td>
<td>31</td>
<td>Alcoholic Cirrhosis</td>
</tr>
<tr>
<td>10</td>
<td>55</td>
<td>Caucasian</td>
<td>Male</td>
<td>4.4 years</td>
<td>28</td>
<td>Alcoholic Cirrhosis</td>
</tr>
<tr>
<td>11</td>
<td>72</td>
<td>Caucasian</td>
<td>Male</td>
<td>1.5 years</td>
<td>32</td>
<td>NASH cirrhosis</td>
</tr>
<tr>
<td>12</td>
<td>62</td>
<td>Caucasian</td>
<td>Male</td>
<td>3.6 years</td>
<td>25</td>
<td>NASH cirrhosis</td>
</tr>
</tbody>
</table>
Appendix I

Themes Table
### Overarching Theme, Themes and Subthemes

Table 2

<table>
<thead>
<tr>
<th>Overarching Theme:</th>
<th>Waiting in Limbo</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Themes</strong></td>
<td><strong>Uncertainty during the Waiting Period</strong></td>
</tr>
<tr>
<td><strong>Subthemes</strong></td>
<td>Fear and Anxiety</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
CURRICULUM VITAE
Ayoka Badmus, PhD, RN, RN–BC, NE–BE

EDUCATION

DOCTOR OF PHILOSOPHY IN NURSING: COURSE WORK COMPLETED, Graduation Date: May 16 2019 | University of Texas Health Science Center • Houston, TX, USA

MASTER OF SCIENCE IN NURSING (2012) | Texas Woman’s University • Houston, TX, USA

BACHELOR OF SCIENCE IN NURSING (2005) | University of Alberta • Edmonton, AB, Canada

NURSING DIPLOMA (2000) | MacEwan Community • Edmonton, AB, Canada
LICENSE PRACTICAL NURSE (1997) | Centennial College • Toronto, ON, Canada
BACHELOR’S DEGREE IN BIOLOGICAL SCIENCE: (1990) | Nnamdi Azikwe University • Awka, Nigeria

PROFESSIONAL POSITIONS

HOUSTON METHODIST HOSPITAL • Houston, TX

Nurse Manager | Apr 2016–Present
- Expertly directs a team of approximately 60 nursing staff within a post-transplant unit.
- In charge of developing, teaching, guiding, and hiring staff, as well as administering disciplinary actions and budgeting.

Registered Nurse IV – CLINICAL EDUCATOR | Aug 2014–Apr 2016
- Served as clinical leader and scholar in managing direct care.
- Assumed accountability in handling interdisciplinary study, education, and research.
- Closely evaluated systems to efficiently improve patient safety and quality.

ALVIN COMMUNITY COLLEGE • Alvin, TX

Instructor and Course Coordinator | Aug 2012–May 2014
- Facilitated advance medical-surgical course, which involved teaching advance critical thinking concepts to nursing students.
- Offered mentorship to new staff members and coordinated with faculty members to create a curriculum for the nursing program which fostered learning through innovation.

THE METHODIST HOSPITAL • Houston, TX

Registered Nurse, Medical – Surgical Floor | Apr 2007–Aug 2014
- Played a significant role in mentoring new graduates and nursing students while serving as charge nurse.
- Maintained active participation in the unit shared Governance Council.
- Executed effective ideas to enhance and continue patient safety.
EARLIER CAREER

SSM REGISTRY (AVANTAS) • St. Louis, Missouri, USA
Staff Nurse

EDMONTON GENERAL CONTINUING CARE CENTRE • Edmonton, AB, Canada
Administrative Resident Care Manager

ROYAL ALEXANDRA HOSPITAL • Edmonton, AB, Canada
Registered Nurse, ICU

EDMONTON GENERAL CONTINUING CARE CENTER • Edmonton, AB, Canada
Licensed Practical Nurse

NATIONAL YOUTH SERVICE CORP (MINISTRY OF HEALTH) • Ibadan, Oyo State, Nigeria
Research Assistant

PROFESSIONAL DEVELOPMENT

License: REGISTERED NURSE
Certification: Certified, Medical – Surgical Nursing (RN-BC) and Nurse Executive (NE-BC)
Certified, Cardiopulmonary Resuscitation (CPR)
Training: Collaborative Institutional Training Initiative (CITI), Houston Methodist Hospital

PRESENTATIONS

Presenter, PeraHealth – Rothman Index (2012)

POSTER PRESENTATIONS


AWARDS AND HONORS

TOP 15 NURSES HOUSTON CHRONICLE AWARD WINNER: 2018 | SPIRITUALITY NURSE AWARD WINNER: 2017