2022

Social Work Participation in Living Donor Education to Organ Transplant Candidates

Mary Rzeszut
Walden University

Walden University

College of Social and Behavioral Sciences

This is to certify that the doctoral study by

Mary Rzeszut

has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
the review committee have been made.

Review Committee
Dr. Carolyn Ewing, Committee Chairperson, Social Work Faculty
Dr. Tracey McElwee, Committee Member, Social Work Faculty
Dr. Nancy Campbell, University Reviewer, Social Work Faculty

Chief Academic Officer and Provost
Sue Subocz, Ph.D.

Walden University
2022

Abstract

Social Work Participation in Living Donor Education to Organ Transplant Candidates

by

Mary E. Rzeszut

MS, Fordham University, 2006

BS, Molloy College, 2005

Project Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Social Work

Walden University

August 2022

Abstract

Living donor transplantation (LDT), despite its documented benefits, does not occur as often as deceased donor transplants (DDT). Transplant social workers are an integral part of the transplant interdisciplinary team and are well trained in conducting psychoeducation. This action research study involved examining social work practice challenges that transplant social workers experience that prohibit them from conducting effective LDT education. The study was guided by family problem solving theory, social cognitive theory and the Afrocentricity perspective to determine how transplant candidates and families can best learn information to discuss and recruit potential living donors. The research questions were about roles transplant social workers engaged in related to living donor education for organ transplant candidates, challenges transplant social workers faced that impeded providing living donor education, and whether transplant social workers received any training on facilitating living donor education to organ transplant candidates. Fourteen transplant social workers from across the United States participated in this study, and data were collected via semi-structured interviews using Zoom. The study led to four themes: living donor education, social work roles, patient barriers, and ethical issues. Study findings concluded transplant social workers face practice challenges that interfere with providing effective education to organ transplant candidates involving (LDT). In addition, this study identified patient barriers that affect their access to transplant surgery options. Findings can be used by social workers for positive social change in working with transplant patients and families.

Social Work Participation in Living Donor Education to Organ Transplant Candidates

by

Mary E. Rzeszut

MS, Fordham University, 2006

BS, Molloy College, 2005

Project Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Social Work

Walden University

August 2022

Dedication

First and foremost, I would like to dedicate this project to my daughters, Stephanie and Victoria. I love you with all my heart and you both have made me very proud. May you always strive to your fullest potential, never be afraid to take chances and live life to its fullest. I wish you a lifetime full of blessings. I would like to extend thanks to my family and friends that provided support and encouragement during this journey. Lastly, I would like to dedicate this project to all those who live with end stage organ failure who have taught me to face adversity with courage and strength.

Acknowledgments

I would like to extend my sincerest thanks to my chairperson, Dr. Carolyn Ewing and my committee member Dr Tracey McElwee for your guidance during this study. Thank you to my academic advisor Catherine Heck for your never-ending encouragement throughout this process. Thank you to all the Walden staff and faculty who have been a part of my academic journey. Finally, thank you to my transplant social work colleagues who participated in this study. Without you, the project would not have been possible.

Table of Contents

Section 1: Foundation of the Study and Literature Review

Introduction

Benefits of living donor transplantation (LDT) have been widely established in literature. LDT decreases mortality for those on the national organ waiting list and leads to longer graft survival compared to deceased donor transplantation (DDT; Fisher, 2017). Organ transplant candidates experience various barriers that impede opportunities to obtain a living donor transplant. Lack of education involving LDT is one such barrier. Education provided to organ transplant candidates and their families regarding LDT and its benefits can increase opportunities for discussion and recruitment of potential donors. Education involving living donation for organ transplant recipients is pivotal for increasing the likelihood that patients will pursue this option (Waterman et al., 2016). However, many transplant centers are unsure how to effectively provide LDT education to organ transplant candidates.

Transplant social workers are considered an integral member of the organ transplant multidisciplinary team consisting of nursing, physicians, surgeons, social workers and nutritionists. According to the Centers for Medicare and Medicaid (CMS, 2008), transplant social work services include initial psychosocial assessments, psychoeducation, psychosocial interventions, care planning, and discharge planning. Historically, in healthcare, social workers were considered experts in terms of facilitating psychoeducation; however, today social workers may find their roles overlap with other disciplines (Dziegielewski & Holliman, 2020). This action research study was used to explore social work practice challenges to providing comprehensive LDT education to organ transplant candidates. Identifying obstacles in social work practice can create opportunities for transplant social workers to advocate for and improve LDT psychoeducation.

Section 1 includes an introduction, problem statement, purpose statement, research questions, nature of the project, significance, theoretical framework, values and ethics, review of professional and academic literature, and a summary. Section 2 includes an introduction and information about the research design, methodology, data analysis, ethical procedures, and a summary.

Problem Statement

In 2022, there are approximately 116,500 people in the United States (US) waiting for an organ transplant (Organ Procurement and Transplantation Network, 2022). According to the U.S. Department of Health Resources and Services Administration (n.d.), an organ transplant is defined as the surgical transfer of one person's organ to another when experiencing end stage organ failure. Those waiting for a kidney represent the largest group on the transplant waiting list (85%), followed by liver (10%), heart (3%), lung (1%), and other organs (1%; Organ Procurement and Transplantation Network, 2022). In 2019, due to the insufficient number of available organs, approximately 17 individuals died each day waiting for an organ transplant (United Network of Organ Sharing, 2022).

Organ transplantation is the life-saving treatment for someone in end stage organ failure. Since the first organ transplant in 1954, advances in medicine have improved graft and patient survival in the US (Wang et al., 2016). Rana and Godfrey (2019) said the median lifetime survival rate among organ transplant recipients is 12.4 years, compared with 5.4 years for organ transplant candidates on the waiting list.

Organs are transplanted from both deceased and living donors. Typically, a higher number of DDTs occur and lead to lower survival rates. In 2021, there were 41,350 organ transplants in the US; 34,800 (84%) were from deceased donors and 6,500 (16%) were from living donors (Organ Procurement and Transplantation Network, 2022). Between 2004 and 2009, the 5-year graft survival rate for deceased donor kidney transplants was 72.4%, while rates for living donors was 84.6% (Wang et al., 2016). Survival outcomes for LDTs are considerably higher compared to DDTs (Gruessner & Gruessner, 2018). In addition, LDTs result in a better quality of life (Waterman et al., 2015). Though medical outcomes have improved for both DDT and LDT in the US, these improvements have not caused an increase in the number of LDTs (Gruessner & Gruessner, 2018).

The scarcity of available organs for transplant is a serious issue in the state of New York (NY). So far in 2022, there are 8,600 organ transplant candidates on the transplant waiting list in NY (Organ Procurement and Transplantation Network, 2022a). Organ transplant candidates are those who have been evaluated, deemed medically and psychosocially cleared for surgery, and are actively waiting on the organ transplant list. In 2021, there were a total of 3167 organ transplants in NY; 2568 (81%) were DDTs, and 599 (19%) were LDTs (Organ Procurement and Transplantation Network, 2022a). So far from January through April 2022, there were 1,111 organ transplants in New York, 952 (86%) deceased donors, and 159 (14%) living donors (Organ Procurement and

Transplantation Network, 2022a). Therefore, despite the benefit of LDT, only 14% have recently occurred in NY.

The national organ shortage and long wait times for available organs can be resolved through an increase of LDT. During initial transplant evaluations, the transplant team provides patients with information regarding differences between DDT and LDT either during a group educational PowerPoint discussion or the individual medical evaluation. Transplant centers provide formal comprehensive educational presentations to organ transplant candidates during evaluations which involve whether the candidate is suitable for transplant and excludes important information regarding LDT (Weng et al., 2017). These discussions are typically brief in nature and do not include how to recruit potential living donors or provide strategies to manage potential barriers. Lapoint-Rudlow et al. (2015) said transplant programs typically spend 1 hour on educating organ transplant candidates on the overall transplant process, including LDT, which occurs during the initial transplant evaluation.

Psychoeducation is a typical social work practice skill in medical social work and is incorporated into a biopsychosocial evaluation. According to Sher and Maldonado (2019), transplant social workers are typically the first interdisciplinary team members to interact with potential transplant candidates. The initial social work psychosocial evaluation can potentially be used to identify patient strengths and possible risk factors that could interfere with managing the complex organ transplant process. In addition, providing psychoeducation during psychosocial evaluations can enhance organ transplant candidates’ understanding and knowledge of the transplant process, including LDT.

Despite benefits of transplant social work services, social workers face many challenges that impede effectiveness of their interventions. Ferguson et al. (2018) said work-related challenges experienced by transplant social workers include difficulties managing patient needs, dividing time between several transplant programs, and large patient caseloads. In addition, transplant social workers may not be viewed by the transplant team as the most appropriate team member to facilitate psychoeducation. This study involves examining social work practice challenges that transplant social workers experience that prohibit them from conducting effective LDT education. It is important to understand if LDT conducted by transplant social workers can assist organ transplant candidates in terms of working through psychosocial barriers to more effectively discuss LDT and possibly recruit potential donors.

Purpose Statement and Research Questions

Receiving a LDT requires that organ transplant candidates and their families have a thorough understanding of this transplant process. Organ transplant candidates face many obstacles when obtaining LDTs, including recruiting potential living donors. These obstacles include lack of sufficient education regarding LDT, difficulty beginning discussions, unexpected out of pocket costs to donors, and extensive donor evaluations (Fisher, 2017; Hunt et al., 2018). In addition, organ transplant candidates experience worries and concerns regarding harming the health of living donors or feeling obligated to donate. According to Waterman et al. (2016), education that addresses recipients’ fears about transplantation, explains living donors’ experiences, and teaches patients how to pursue living donation may increase their chances of receiving a LDT. Education for

LDT is most effective when information is extensive in nature, delivered via various formats, and provided more than once (Waterman et al., 2016).

Transplant social workers are essential in terms of determining the wide spectrum of social and emotional challenges that affect organ transplant surgery and survival (Sher & Maldonado, 2019). In addition, social workers are skilled in terms of assessing psychosocial vulnerability, health literacy, and interventions that guide and support patients and families. In following the National Association of Social Workers (NASW) ethical standard to promote the wellbeing of clients, transplant social workers have an ethical obligation to ensure transplant candidates have a full comprehension of the solid organ transplant process. Social workers should use clear and understandable language to inform clients of the purpose of services, risks related to services, and limits to services (NASW, 2021). This study can be instrumental in terms of addressing transplant social work practices involving LDT education that are sufficient for transplant candidates to build confidence and knowledge and successfully discuss LDT with families and friends.

The purpose of this qualitative action research study is to identify challenges that transplant social workers experience related to delivering LDT education to organ transplant candidates.

The following research questions were used in this research study to determine the gap in social work practice:

RQ1: What roles do transplant social workers engage in related to LDT education to organ transplant candidates?

RQ2: What challenges do transplant social workers see as organ transplant candidate barriers to receiving LDT?

RQ3: What specific training have transplant social workers received related to the educational process involving LDT to organ transplant candidates?

Key terms throughout this paper are as follows:

Deceased donor transplantation (DDT): Surgery that involves removing an organ at the time of the donor's death and transplanting it into a living person (United Network of Organ Sharing, 2022).

Living donor transplantation (LDT): Surgery that involves transplanting a healthy organ from one living person to another with end stage organ failure (United Network of Organ Sharing, 2022).

Organ transplantation: Transfer of organs from a living or deceased donor to a recipient which restores organ functioning in the body (World Health Organization [WHO], 2008).

Organ transplant candidate: Someone registered on the organ transplant waiting list (Organ Procurement and Transplantation Network, 2022b).

Psychoeducation: A psychotherapeutic intervention designed to educate patients and caregivers on physical diseases and mental disorders to build their ability to cope with illnesses (Bonsack, 2015).

Transplant evaluation: The process of undergoing medical and psychosocial evaluations to determine if a candidate is medically emotionally suitable for transplant surgery as well as long-term care involved (United Network of Organ Sharing, 2022).

Transplant waiting list: List of candidates who have been evaluated and are registered for organ transplant surgery (WHO, 2008).

Nature of the Doctoral Project

This study was a qualitative action research study. Qualitative research involves defining how one sees the world and their experiences in it (Merriam & Tisdell, 2016). Action research is defined as research with the purpose to facilitate social change or improve practice (Merriam & Tisdell, 2016). This action research study involved determining if transplant social workers provide LDT education to transplant candidates that improves their ability to promote discussions regarding LDT and recruit potential living donors. Results of this study can facilitate the development of formalized LDT education interventions or programs to improve ease of discussions involving LDT. In addition, social workers will be able to address other psychosocial barriers that may be prohibiting LDT discussions such as cultural and ethnic issues or health literacy. In 2021, of the 3058 organ transplants to African American recipients, only 8 percent were living donor transplants (Organ Procurement and Transplantation Network, 2022a). These low rates of LDT within the African American community can be attributed to cultural beliefs and lack of adequate information about LDT (Davis et al., 2017).

Data was collected by conducting individual interviews using the Zoom platform with14 abdominal transplant social workers from United States transplant centers. Qualitative interviews provide the opportunity to develop a deeper understanding of social issues. Interviews are used to explore perceptions, experiences, and opinions involving specific topics (Gill et al., 2008). More specifically, semi-structured interviews were used and designed to allow for specific discussions and elaboration of thoughts and responses. They are typically used in healthcare research where there is little known about a social issue (Gill et al., 2008). Participant responses were audio-recorded and transcribed verbatim.

Significance of the Study

Providing educational interventions increases opportunities for LDT among organ transplant candidates (Kumar et al., 2016; Strigo et al., 2015; Weng et al., 2017). Patient navigators have been found to be helpful in terms of assisting organ transplant candidates develop a complete understanding of LDT, which can increase engagement of transplant candidates and their donors (Nishio-Lucar et al., 2020). However, there is limited research on transplant social work-facilitated education programs involving LDT. A study conducted by Boulware et al. (2013) discussed the effectiveness of social work interventions in producing higher rates of kidney transplant discussions.

Social workers have made significant contributions to healthcare. However, as healthcare systems continue to face many challenges, it is crucial that the social work profession clearly define their roles and advocate for continued involvement and representation. While medical practitioners are capable to conduct informational and educational seminars, transplant social workers have the additional capability of determining on site if organ transplant candidates are facing psychosocial challenges that present as possible barriers to considering LDT. According to Strigo et al. (2015), social workers are skilled in terms of assisting patients with psychological challenges and barriers that impede their ability to pursue LDT.

Social work services in healthcare are focused on maximizing wellbeing and medical outcomes for patients (McCoyd & Kerson, 2016). This study involved addressing social work practice challenges involving organ transplantation that interfere with providing psychoeducation. Addressing these challenges can increase future social work participation involving living donor transplant education as well as opportunities to assess organ transplant candidates' abilities to discuss living donation, which can lead to a significant increase in the number of LDTs that are performed. In addition, this could demonstrate the importance of the social work role within the transplant interdisciplinary team.

Theoretical/Conceptual Framework

This study involved assessing LDT education conducted by social workers to increase transplant candidate's knowledge and motivation to recruit potential donors. The theoretical frameworks applied to this study were family problem solving theory and social cognitive theory. Comprehensive education about LDT requires communicating risks and benefits of transplant surgery to recipients and donors. This education should involve various people in the organ transplant candidate's support network. Family problem solving theory was developed by Oliveri and Reiss in 1981. The family unit system determines family members' interpretations of events and interactions within the environment (Oliveri & Reiss, 1981). Supportive and involved family members who are educated regarding LDT can assist organ transplant candidates in terms of recruiting potential donors. Information that is provided to transplant candidates' family members and friends may facilitate discussions regarding LDT and reduce patients' hesitancy to discuss the topic with others (Hunt et al., 2018).

Social cognitive theory (SCT) was developed by Albert Bandura in 1986 and posits learning occurs through social interaction and reinforcement of experiences, which determines if someone engages in behavior changes (Bandura, 1986). The framework of SCT assumes when detailed education is provided to organ transplant candidates on LDT in a group or individual format this will build self-efficacy in starting LDT discussions and potentially increase the opportunity for LDT. One's goals, motivation and behavior must be in concert with one's beliefs, which includes cultural and ethnic obligations and beliefs (Bandura, 1998). SCT aligns with this study's problem statement, research question, and purpose involving type of LDT educational interventions that are provided by social workers that could facilitate discussion and recruitment of LDT.

Transplant candidates' ethnic or cultural backgrounds are potential barriers to receiving LDT. According to Sieverdes et al. (2017), cultural barriers that impede the opportunity for LDT need to be addressed so all organ transplant candidates have an opportunity to receive benefits of LDT. When developing culturally competent educational interventions, it is critical to understand one's culture in order to ensure interventions are effective. To address these issues, the Afrocentricity perspective was appropriate for this study. Afrocentricity was developed by Molei Kete Asante in the 1970s and posits the importance of understanding the African American culture when communicating information (Asante, 2001). This theory provides the ability to view this culture with a new perspective. In healthcare, developing an understanding of a culture can improve health outcomes. According to Eissa et al. (2021), incorporating Afrocentric health promotion and counselling approaches have been successful in terms of improving both influenza and COVID vaccinations among Black populations in Canada. Educational interventions regarding LDT increase opportunities for organ transplant candidates to undergo LDT. The family problem solving theory, Afrocentricity, and social cognitive theory were used to support this study which involves education for organ transplant candidates and their families as well as recruitment and potential living donors.

Values and Ethics

The NASW Code of Ethics offers social workers ethical guidelines for practice. In addition, the Code of Ethics outlines the profession's core values which social workers are obligated to uphold. One social work core value that aligns with this study is the core principle of service. Social workers draw on their knowledge, values, and skills to help people in need and address social problems (NASW, 2021).

This study involved addressing the need for educational interventions on LDT for organ transplant candidates in order for them to obtain benefits of this surgery. According to Hunt et al. (2018), LDT education provided to organ transplant candidates is inadequate. In addition, transplant teams typically do not evaluate types of education t provided to ensure each organ transplant candidate comprehends or has retained the information. Transplant social workers can be guided by the profession's core value of service and use their knowledge and skills to develop and facilitate thorough LDT educational interventions to address possible psychosocial barriers that impede LDT.

Social workers respect the inherent dignity and worth of people, treating each person in a respectful manner while being mindful of cultural and ethnic diversity while they seek to enhance clients' capacity and opportunity to change and address their own needs (NASW, 2021). Transplant social workers can provide interventions, referrals, and resources to those organ transplant candidates who are challenged with cultural psychosocial or environmental issues that impede their ability to potentially receive LDT. Axelrod et al. (2017) said psychosocial barriers such as socioeconomic status or ethnicity can be underlying causes of inability to understand educational information delivered by the transplant team.

Review of the Professional and Academic Literature

The need for effective and comprehensive living donor transplant education in order to increase LDTs has been established in literature. While LDT can involve the kidney, liver, pancreas, lung and intestine, when searching the majority of research conducted on LDT has been related to kidney transplant surgery. In 2014, the American Society of Transplantation convened healthcare providers, administrators, government agencies, and transplant recipients together to discuss concerns and develop recommendations for increasing LDT. Several barriers to organ transplant candidates receiving appropriate education exist and are outlined in this literature review. Lapointe-Rudlow et al. (2015) suggested kidney transplant interdisciplinary team members attend a national training program to develop knowledge and competency to guide kidney transplant candidates in order to recruit potential living donors.

The ability to discuss LDT with family, friends, and community takes knowledge and confidence, which then creates the ability to comfortably provide information and answer questions. Social workers are practitioners in healthcare who typically provide patients with education involving medical conditions. This literature review was conducted to determine types of living donor education presently offered to organ transplant candidates and barriers transplant social workers face when conducting LDT education. I began searching literature during fall 2019 and have continually added and updated the literature review. Databases used for literature were: *Google Scholar*, *ProQuest Central*, *ProQuest Health and Medical Collection*, *PubMed*, *MEDLINE*, *SAGE Journals*, *Walden University Library and Adelphi University Library*. .Key terms used for the literature search were *living donor transplantation*, *social work and living donor transplant*, *living donor transplant education*, *barriers to living donor transplants*, *transplant social work*, *benefits to social work practice in health care*, *social work practice challenges in healthcare*, *barriers to living donor transplants*.

Benefits of LDT

LDT has been determined to have potential benefits in comparison to DDT (Abu-Gazala & Olthoff, 2018; Gruessner & Gruessner, 2018; Kim & Testa, 2016). Fisher (2017) discussed benefits and success of liver LDT in comparison to those who received a deceased donor organ. Living donation is a resolution to the organ shortage in addition to benefits of decreased waiting time and mortality. Continued advocacy was necessary to decrease social, financial, and emotional barriers that prevent transplant candidates from obtaining a living donor (Fisher, 2017). Olthoff et al. (2015) compared 10-year survival outcomes of liver LDT and DDT and determined liver LDT resulted in significant benefits in comparison to DDT, which included allowance of a lower MELD (model for end stage liver disease) score at transplantation. The MELD score is a blood test that determines how ill the liver is; a score of 30 or higher is necessary for DDT. LDT can occur when a MELD score is 15 or higher. A decrease in waiting list deaths and long-term graft survival were also noted as benefits to LDT as compared to DDT. Benefits of LDT are noted in patients who are diagnosed with end-stage renal disease (ESRD) and require dialysis. According to Garg (2018), kidney transplant surgery is the best treatment option compared to hemodialysis, one of the treatment options for ESRD. Of all the treatment options for ESRD, transplant surgery ensures the best chance for a longer life. It is estimated kidney transplantation offers a 96% chance of 3-year survival versus a 66% chance of a 3-year chance of survival after undergoing hemodialysis.

Barriers to LDT

Organ transplant candidates rely on the altruism of potential living donors in order to obtain benefits of LDT. However, some organ transplant candidates do not demonstrate the confidence, motivation, or initiative to actively recruit potential living donors and often lose out on opportunities. The likelihood organ transplant candidates will find a potential living donor can be increased by providing education to both organ transplant candidates and their support network throughout the transplant evaluation process (Hunt et al., 2018). In addition, electronic modes of providing information have been determined to be effective; however, it is unclear if they are as effective as in-person educational sessions. Getchell et al. (2017) surveyed Canadian kidney transplant candidates to understand causes and barriers to obtaining living donor kidney transplants. Barriers for kidney transplant candidates were lack of education for patients and families and lack of public awareness regarding living donor kidney transplantation. Development of an educational toolkit with information on LDT for organ donors and recipients as well as peer mentors to educate patients and families were possible solutions. Peer mentors can offer education regarding LDT in addition to emotional support and guidance based on their experience.

According to Sandal et al. (2019), typically research efforts have focused on the patient's barriers to receiving education on LDT. However, these authors discuss that are the health care providers barriers to providing LDT. Some barriers include discomfort felt by practitioners due to lack of training on LDT, lack of communication between healthcare members, and lack of formalized guidelines. Organ transplant candidates rely on guidance from their healthcare team for decisions regarding transplant surgery and living donation. It is recommended healthcare providers receive formalized training in order to provide lengthy and detailed discussions (Sandal et al., 2019).).

Ethical and Cultural Barriers

Organ transplant candidates face ethical and cultural barriers involving obtaining LDT. From 1989 to 2020, 32% of all living donor transplants in the US (178,390) were non-Whites (Organ Procurement and Transplantation Network, 2022). This disparity is an important public health issue as minority groups represent 64% of all kidney transplant candidates waiting for organs (Organ Procurement and Transplantation Network, 2022). Minority groups may be challenged due to lower socioeconomic status, limited income, education, and healthcare access, which results in differences in health outcomes (U.S. Government Information on Organ Donation and Transplantation, n.d.). Lentine and Mandelbrot (2018) said racial disparities have been recognized as causes for decreases in kidney LDT. This issue is a growing concern as not having access increases mortality. These barriers can affect aspects of medical care including access to specialists, acquiring a transplant, LDT education, referral to transplant institutes, and acquiring potential living donors. Siervedes et al. (2015) evaluated African Americans diagnosed with ESRD to determine potential barriers to living donor kidney transplantation. Several barriers were identified such as knowledge and learning, communication, financial burden, and effect on relationships as well as overall lack of knowledge about LDT and lack of behavioral skills regarding how to approach others. Findings recommended educational programs led by an African American living donor transplant recipient which included discussions and practices explaining how to approach others. Recommendations would increase the likelihood of African Americans receiving a LDT. There are fewer LDT among Hispanics compared to non-Hispanics. Alhalel et al. (2019) conducted a study within the Northwestern Medicine Hispanic Kidney Transplant Program (HKTP), a program designed to provide culturally sensitive care to Hispanic patients. This program has reduced the health care disparities in the Hispanic population and increased LDT's. The HKTP has been successful in terms of changing perspectives and increasing education regarding LDT in the Hispanic population.

Health disparities can also be related to health literacy. Health literacy is a barrier to healthcare access and receiving LDT. Grubbs et al. (2009) reported 78% of dialysis patients with inadequate health literacy were not referred for kidney transplant evaluations. According to Taylor et al. (2019), low levels of health literacy decrease organ transplant candidates' opportunities to be selected for the organ transplant waiting list, preemptive transplantation, and LDT. Limitations in health literacy can create beliefs that transplants are not an option and limit patients' abilities to engage with the healthcare team, which can be psychologically stressful. Miller-Materao et al. (2016) said patients are less likely to listed for transplant and removed from the transplant waiting list when they display low levels of reading and math ability.

Educational Interventions

Lack of extensive knowledge on LDT creates cognitive and behavioral challenges for organ transplant candidates which hinders skills needed to communicate information to potential recipients. Extensive education on the LDT that provides enough information for organ transplant candidates to confidently discuss the topic should be addressed, along with effective communication techniques and assistance involving providing sample phrases and discussion openers. There is a gap in the literature involving communication skills and effective LDT. However, Traino et al. (2017) discussed a pilot study to determine the effects of a behavioral communication intervention program called Communicating about Choices in Transplantation (COACH). This program was designed to improve organ transplant candidates' communication about transplantation. The study findings concluded an increase in knowledge about transplantation and decrease in difficulties in communicating information on transplantation. Waterman et al. (2016) reported the importance of evaluating an organ transplant candidate's motivation for health behavior change when presenting education on LDT and suggested education programs grounded in theory increase patients' clarity in terms of personal values and goals as well as their knowledge of behavior change which leads to an increased ability to overcome barriers to health behavior changes.

Media has been widely used in LDT education. The initial transplant evaluation conducted at hospital-based transplant clinics is typically between 3 and 5 hours where the patient meets with each member of the interdisciplinary team: surgeon, physician, transplant coordinator, RN and social worker. LDT education is typically discussed briefly during this evaluation. Weng et al. (2017) evaluated if an intensive educational intervention involving LDT during initial transplant evaluations increased organ transplant candidates' ability to pursue a living donor, and results demonstrated an increase in LDT knowledge after 1 week. Kayler et al. (2020) studied the effectiveness of an animated video education series on kidney living donation. A simple and autonomous educational approach through the use of videos for patients, families, and potential donors was effective in terms of increasing knowledge involving LDT, affirming the importance of providing educational information to target all literacy levels and encourage discussions and conversations about LDT.

Social media has also been used for LDT education and recruitment. Education delivered at home and at the convenience of the organ transplant candidate can be more effective in terms of learning. In addition, information can be viewed by families and other support networks on their own time. Patzer et al. (2016) tested the efficacy of the use of a mobile health application called the iChoose Kidney program developed to improve communication between health care providers and patients regarding transplantation. Providing patient-centered education involving healthcare choices improves patients' understanding and decision-making abilities, increases patient empowerment, and improves knowledge and understanding of treatment choices. Social media has also been a vehicle for organ transplant candidates to recruit potential living donors directly. Face-to-face discussions involving interest in donating can be anxiety inducing even with adequate education and support. Kumar et al. (2016) developed a media app that allowed organ transplant candidates to create a Facebook post sharing their story regarding the need for an organ transplant. Results were positive, demonstrating 13 of 54 participants obtained a potential living donor through this app. Henderson et al. (2017) said despite the benefits of social media for living donor recruitment, it can create challenges in maintaining confidentiality of personal and identifying information as well as the potential increase of cohesion in potential living donors coming forward.

Social Work and Transplant Education

It is suggested patients who receive educational interventions by medical providers other than physician improves health related behavior change (Bayliss et al., 2011). Patient navigators are used in some areas of medicine, such as oncology, to ease the burden of navigating through the health care system and are typically registered nurses or nurse practitioners. Basu et al. (2018) said using social workers as patient navigators for LDT education would improve the number of potential living donors for kidney organ transplant candidates. Patient navigator duties include LDT education, appointment scheduling and reminders, financial aid, transportation, referrals to community resources, and serving as a liaison between patients and transplant centers (Basu et al., 2018). Shanley (2008) stated social works are trained to assist patients with a number of psychosocial and psychological challenges and are well equipped to educate patients and families on LDT.

Social Work in Healthcare

The role of social work in health care has undergone changes as a result of a multitude of variables. Browne (2019) reported changes in the roles of health social workers have been dependent on federal, state, and local policy changes, trends in disease treatments, changing roles of other healthcare providers and health care systems' focus of reducing costs and decreasing hospital stays. The author mentions interdisciplinary collaboration is challenging as each health care professional has unique training, education, and perspectives towards their service to patients. Health care social workers are continually faced with the inequity of their voice in the health care team's care planning process, interdisciplinary professional roles may not be clear, and perspectives and ethics may clash. In addition, other disciplines have taken over tasks that historically have fallen under the rubric of social work. This book chapter mentions the importance of medical social workers remembering patients do not present to emergency rooms for social work services; they are seeking medical needs that have psychosocial components. It is the social worker's responsibility to be familiar with the biopsychosocial care model and should develop an understanding of medical issues and terminology so that they are knowledgeable when talking to patients and their families and can participate fully on interdisciplinary healthcare teams. Steketee et al. (2017) conducted a systematic review of the literature to demonstrate the health and cost savings benefits of social work interventions in health care. This was the first literature review of its kind. The authors report social work specific contributions to health and cost containment outcomes are unknown despite social work services of psycho-education, integrated health care, and assisting with the social determinants of health (housing, employment). The findings from this review of 16 studies indicated social work interventions displayed positive effects on health outcomes and were less costly than care that did not include social work services. The authors recommended the continuation of future research on this topic to better understand the potential benefits of social work services for improving health and health care delivery. Social workers who work specifically with organ transplant candidates aid patients in optimizing themselves for transplant candidacy. West and Winnike (2019) discussed the important role of transplant social workers in determining the psychosocial risks of an organ transplant candidate that can complicate transplant surgery. Assessments conducted by transplant social workers provides the multidisciplinary transplant team with information that identifies patient strengths as well as possible risk factors that can lead to negative health outcomes. Psychoeducation is discussed and the benefits of providing workshops, videos, and handouts to improve patients and families understanding of the complex transplant process. The authors recommend transplant social workers conduct further research in this specialty area of practice to demonstrate the effectiveness of social work practice interventions.

The changes in health care delivery and the lack of understanding of the value and roles of health care social workers has created challenges in social work practice to patients and families. Dziegielewski (2020) discussed how hospital administrators have drastically changed the structure of social work services over the past 20 years to include an overlap of roles such as; nurses facilitating therapeutic support and psychoeducational groups; social workers reassigned to service provision areas such as discharge planning and social work supervisors replaced by nursing or other health care administrative personnel. The author described this process as “splitting” and reports medical social workers feel they are losing their identity; the strength that comes with having a solid departmental structure and a voice to advocate when faced with large caseloads and reassignment of work. It is recommended that health care social workers develop a strong understanding of current health care delivery and utilize evidence-based practice interventions with an emphasis on cost containment and outcome measures to assist the individuals, groups, and families they serve. Stickney- Ferguson et al. (2018) conducted a survey of 159 transplant social workers in hematopoietic cell transplantation programs to understand social work structure, roles and staffing at transplant centers. The results highlighted several practice challenges; prioritizing patient needs; dividing work times across several transplant programs and large patient caseloads. In addition, one third of survey participants reported that their clinical social work expertise was not used to its fullest potential which effects patient psychosocial care and health outcomes.

The review of the literature establishes the lack of sufficient education provided to organ transplant candidates which decreases an opportunity to receive LDT. More importantly, however, the literature illustrates the gap in social work involvement in facilitating LDT education to organ transplant candidates. Historically, social work has been known for effective psychoeducation in group practice. Psychoeducational groups are empowering and provide members with new information and skills to improve coping, overall quality of life and have been known to be an integral component of social work practice (Gitterman & Knight, 2016). Health care social workers are facing practice challenges brought about by current health care delivery (Dziegielewski, 2020) This research study attempts to investigate the challenges faced by social workers that inhibit the opportunity to provide living donor transplantation education to organ transplant candidates.

Summary

LDT has been determined as the most optimal organ transplant surgery for long graft survival and medical outcomes (Olthoff et al., 2015). Organ transplant candidates can benefit by receiving LDT education to increase the possibility of receiving a LDT (Waterman et al., 2016). Transplant social workers are trained to provide psychoeducation and assess barriers that impede LDT (Boulware et al., 2011; Boulware et al., 2013). This qualitative action research study involved identifying challenges transplant social workers experience related to delivering LDT education to organ transplant candidates.

Section 2: Research Design and Data Collection

Introduction

In Section 1, benefits of LDT were discussed and lack of education that impedes organ transplant candidates' opportunities to obtain LDT. Social workers are skilled in psychoeducation and typically assist patients with barriers to care. This action research study involved exploring social work practice challenges to providing comprehensive LDT education to organ transplant candidates. Section 2 includes the research design and data collection methods used for this study, as well as the methodology, participants, instrumentation, data analysis, and ethical procedures that were used. Section 2 concludes with a summary.

Research Design

This study involved examining social work practice challenges that transplant social workers experience that prohibit them from conducting effective LDT education to organ transplant candidates. The study's research questions are:

RQ1: What roles do transplant social workers engage in related to LDT education to organ transplant candidates?

RQ2: What challenges do transplant social workers see as organ transplant candidate barriers to receiving LDT?

RQ3: What specific training have transplant social workers received related to the educational process involving LDT to organ transplant candidates?

Education on LDT to organ transplant candidates has been proven to increase opportunities for LDTs. Previous studies on LDT education to organ transplant candidates have typically been facilitated by transplant interdisciplinary team members as educators. There is a gap in literature involving transplant social workers providing living donor education to organ transplant candidates. Therefore, a qualitative action research study design was used to explore LDT education that is presently provided by transplant social workers to organ transplant candidates and practice challenges that might interfere with conducting this education. In addition, barriers experienced by organ transplant candidates involving receiving LDT education were also explored. This information can be useful in terms of creating changes involving the ways LDT is provided to organ transplant recipients and extend greater opportunities to receiving LDT.

Methodology

LDT surgery occurs among those diagnosed with kidney, pancreas, or liver end stage organ failure. Data for this study were obtained via semi-structured interviews using Zoom platform with 14 adult and pediatric abdominal transplant social workers from US transplant centers between May 18 and July 28, 2021. Semi-structured interview questions are the most predominately used type of data collection in social science research studies (Bradford & Cullen, 2012). They allow the researcher to explore a specific topic while allowing participants to respond based on their opinions and perspectives (Choak, 2012).

Open-ended questions were used (see Appendix A) to obtain information regarding transplant social workers' roles in LDT education. I explored transplant social work responsibilities, practice challenges, transplant candidates' barriers to receiving LDT education, and how LDT education is presently delivered to organ transplant candidates and by whom. Interviews were between 15 and 30 minutes and recorded for data analysis. I asked participants for clarification when needed or to inquire further about a response.

Participants

Participant recruitment began with contacting members of the Society for Transplant Social Workers who are abdominal transplant social workers responsible for evaluating adult or pediatric kidney, pancreas, or liver transplant recipient candidates. This is a specialty social work practice field. According to the Society for Transplant Social Workers (2022), transplant social workers provide comprehensive social work services to patients and families through all phases of organ transplantation, which includes referral for pretransplant evaluation, transplant surgery, and lifelong posttransplant follow-up. In order to have participants who were knowledge on this specific topic, homogeneous sampling, a type of purposive sampling, was the best approach in order to obtain rich, extensive data. Purposive sampling involves intentionally selecting participants who have been identified with characteristics that are needed in the sample that best matches objectives of the study (Campbell et al., 2020).

Email invitations with informed consent form were sent to 196 society members. Fourteen abdominal transplant social workers responded and consented to participate in the study. Follow-up emails were sent arranging for and confirming individual Zoom interviews.

The sample size in this study was sufficient to gather data needed for this study. Mason (2010) said when conducting in-depth interviews, a sample size between eight to

10 interviews is considered sufficient. Guest et al. (2006) said when gathering thematic data from a homogenous sample group, a sample size of 12 is sufficient.

Instrumentation

Interviews was the qualitative instrument utilized in this study. Interviews are designed to inspire the participant to discuss detailed information on the research topic (Warren & Karner, 2005). Eleven open-ended interview questions were developed in order to create robust discussions and obtain rich data from study participants. Open-ended questions allow study participants to offer detailed responses involving their views on the research topic (Bradburn et al., 2004). Four demographic questions were included involving state license designation, length of social work experience, transplant social work experience, and type of organ transplant program. Remaining questions were focused on LDT education that was provided to organ transplant recipients by transplant social workers or any other interdisciplinary team member. In addition, there were questions involving challenges transplant social work experience when conducting LDT education and participants' perspectives regarding barriers organ transplant candidates might experience that prohibit them from receiving LDT education.

Data Analysis

Semi-structured interviews in this study were recorded and transcribed. Inductive analysis was used to analyze data. According to Hsieh and Shannon (2005), inductive analysis involves deriving coded categories from data when there are no previous studies on the issue to generate possible themes. To make myself familiar with data, printed transcripts were reviewed, important data were highlighted, and emergent codes either involving single words or statements were determined and written on the printed transcripts. Braun and Clarke (2006) said data should be reviewed at least once before beginning the coding process to become familiar with data and format ideas and identify patterns within data.

Next, a computerized Word document with all transcripts was reviewed again. Important data were highlighted, and either the same or different codes were named. In a qualitative study, a code is a word or statement that captures the meaning of data (Saldonia, 2016). Next, a data collection template in the form of an Excel spreadsheet was created in order to organize and sort responses for both qualitative and demographic questions. Codes were reviewed again, and new codes were created when appropriate. Coding is designed to find repetitive patterns and requires more than one review of the data (Saldaña, 2016).

Codes were reviewed a third time and further synthesized to develop categories. From there, key categories were reviewed and final themes developed. A theme summarizes the data and captures the underlying meaning (Scharp & Sanders, 2019). This form of thematic analysis involves determining if data answers research questions in a meaningful way (Braun & Clarke, 2006).

Rigor is an important component of qualitative research. According to Stringer (2014), the purpose of rigor in action research is to ensure research is trustworthy and free from researcher bias, and outcomes are a result of data analysis, not perspectives of the researcher. The recorded transcripts and rich data that was obtained reflects the thorough discussion by the participation and demonstrates the credibility of this study. Prolonged engagement is a form of credibility in action research and allows the participant opportunities to discuss their full experience with the problem that is being investigated (Stringer, 2014).

The transparency of the research process can demonstrate trustworthiness of a research study. According to Stringer (2014), dependability ensures all processes of the research study have been followed. The order of this study was as follows; collecting the data through the semi-structured interviews; review of the data for understanding and clarity of data; coding the data at least three times, categorizing the data for similarities and finalizing the data analysis by identifying themes. All of this data analysis can be easily followed. In addition, all detailed transcripts of the recordings are accessible and are evidence the study occurred.

Ethical Procedures

The Walden University IRB approved this study (approval number (05-05-21-06071). In order to protect the participants from any risk or harm, an invitation with the informed consent was sent to the participants for full disclosure. Researchers are required to take necessary steps to ensure the participants do not experience any harm as a result of their participation in the research study (Stringer, 2014). After informed consent was reviewed if the participant was interested, they responded to the email with “I consent.” The confidentiality and anonymity of the participant was reinforced at the beginning of the zoom interview. Participants were not asked any identifying questions during the interview. In addition, participants were notified and consent was given for the recording of the zoom interview. According to Archibald et al. (2019) a key of feature of utilizing Zoom to collect research data is its ability to securely record and store sessions.

All participants were given a numerical identifier and all identifying information of participant name and email was kept on a password protected lap top computer. The written transcripts of the zoom interviews do not contain any identifying information of the participant and is stored in a locked cabinet to ensure privacy of information. The researcher is the only individual who has access to any data. Computer data files will be deleted and paper transcripts shredded after 5 years.

Summary

Semi-structured interviews via Zoom were the method of data collection for this study to explore social work practice challenges involving providing comprehensive LDT education to organ transplant candidates. The study was approved by the Walden University IRB. Purposive sampling was used to recruit participants who were organ transplant social workers. All ethical research guidelines were followed to protect confidentiality of study participants. Data analysis was conducted using content analysis. Rigor of the study was established by using credibility and dependability.

Section 3: Presentation of the Findings

Introduction

The ability to receive a LDT requires that organ transplant candidates and their families obtain a thorough understanding of this process. Organ transplant candidates face many obstacles involving obtaining LDTs which include lack of knowledge of surgery processes, financial issues, and recruiting potential living donors. The purpose of this study is to identify challenges that transplant social workers experience delivering LDT education to organ transplant candidates. Identifying obstacles in social work practice can create opportunities for transplant social workers to advocate for and improve LDT psychoeducation in addition to providing interventions that assist organ transplant candidates with psychosocial barriers that impede opportunities to obtain LDT. The following research questions were explored in this research study to determine the gap in social work practice.

RQ1: What roles do transplant social workers engage in related to LDT education to organ transplant candidates?

RQ2: What challenges do transplant social workers see as organ transplant candidate barriers to receiving LDT?

RQ3: What specific training have transplant social workers received related to the educational process involving LDT to organ transplant candidates?

Section 3 includes data analysis techniques and study findings arranged by theme as well as findings that were unexpected.

Data Analysis Techniques

Data were collected between May 18 and July 28, 2021 during individual Zoom semi-structured interviews. Interviews were between 15 and 30 minutes. Fourteen master's level social workers participated in this study, of whom 13 held the highest designation in their state, LCSW (Licensed Clinical Social Worker or equivalent), and one was a LMSW (Licensed Masters Social Worker). Six participants had between 1 and 10 years of experience, two had between 11 and 20 years of experience, and six had over 21 years of social work practice experience.

Recruitment began after the study was approved by the Walden University IRB. Social workers were recruited from the Society for Transplant Social Work. They received invitation emails to join the study along with informed consent forms. Interested participants responded to the invitation email with the words "I consent." Followup emails were sent to arrange for days and times of Zoom interviews.

Interviews were recorded and verbatim data from written transcripts were obtained. Content analysis was used for the study with the purpose of developing codes and categories and identifying repetition of similar themes throughout data. Content analysis is an approach to identify patterns or trends through use of codes and categories to explore large amounts of textual information (Gbrich, 2007). Once codes and categories were developed, several major themes were identified. Themes in a research study are significant concepts that link substantial portions of data together (DeSantis & Ugarriza, 2000).

Validation of data occurred during data collection and analysis. This is demonstrated through an audit trail, prolonged engagement, reflexivity, and transferability. I used an audit trail that included video and audio recorded data, printed transcripts, and an Excel data analysis template where codes were created and categories were developed and gathered in order to identify themes. According to Given (2012), an audit trail is a transparent description of the research process, data collection, and steps involved that demonstrate how concepts and themes emerge from data.

Interviews were 15 to 30 minutes in length and began with a detailed background of my interest in the topic, followed by the interview questions. I also included follow-up questions to clarify responses or encourage participants to discuss their responses further. Prolonged engagement is defined as allowing sufficient engagement with participants to obtain ample time to build trust and gather rich data as well as test for misinformation (Tracy, 2010).

Validation

Researcher bias is one reason for addressing validity of research studies. Mauthner and Doucet (2003) said it is important to be self-aware during the process of collecting and analyzing data as well as interpreting research data in order to avoid potential bias. Reflexivity was incorporated in this study in order to prevent biases that may occur when analyzing data. According to Gilgun (2008), reflexivity involves recognizing the effect the research topic has on the researcher as well as possible influences on the research topic.

As a social worker who works with organ transplant candidates, it was important that I was aware of any potential biases or judgements regarding participant responses. Reflexivity was helpful in terms of understanding participants' responses. One participant reported she was not able to pass the licensing exam but had worked as an organ transplant social worker for several years. I remained focused on her responses as they related to the research questions and purpose of the study and did not take her lack of license into consideration. Whether the participant was licensed or not was not relevant for the purpose of this study. In addition, how participants conducted social work practice was not relevant to this study. I transcribed verbatim responses and was consciously aware of not adding my opinions or judgements during interviews. Reflexivity involves researchers' conscious and deliberate efforts to be aware of their own reactions to responses from participants. It helps in terms of identifying personal biases that could affect findings of the study (Mason, 1996).

Findings of this study are not transferable to other contexts or situations. Purposeful sampling was used in this study to obtain data from participants with specific knowledge regarding the subject matter, and findings were unable to be generalized. Purposeful sampling involves identifying and selecting individuals who are especially knowledgeable about a specific phenomenon of interest (Creswell & Plano-Clark, 2011). Study findings are not applicable to all social work practice. However, findings involving health disparities may be applicable to social work practice in healthcare.

Limitations or Problems

The original sample for the study was organ transplant social workers in the state of NY. Recruitment sample size was not sufficient, and therefore it was decided to open up recruitment to all organ transplant social workers in the US. This change was approved by the Walden University IRB. A limitation of the study is the data reflects only a small number of organ transplant social workers who are working with abdominal organ transplant candidates in the US.

Findings

Fourteen abdominal organ transplant social workers working at transplant centers across the US participated in this study. Eight were from the East Coast; five of those were from New York, one was from the West Coast, two from the Mid-West; one from the South-Central Region and two from the Mountain States. Each of the social workers had experience in organ transplant social work ranging from 6 months to 25 years with the average amount of experience ranging between 2-10 years. Ten of the social workers work primarily with adults and four work with pediatrics.

Transplant centers are diverse in the number of surgeries they perform and how they structure their clinics. This will determine the population the organ transplant social worker is responsible for. In some clinics social workers will work with one organ or with two or more. In this study four of the participants work with adult liver candidates; two with adult kidney candidates; one works with both adult liver and kidney candidates; three with both adult kidney and pancreas candidates; two with both adult and pediatric kidney candidates and two with pediatric kidney and liver candidates.

The interviews obtained comprehensive data relevant to the research questions and after extensive analysis 4 themes and 28 subthemes emerged. The themes were living donor education, social work role, patient barriers and ethical issues.

Theme 1: Living Donor Education

Psychoeducation is an important social work practice role with working with organ transplant candidates. An important finding from this study was thirteen of the fourteen participants reported they provide some education on LDT. The education is typically informal in nature, providing general information regarding risks and benefits of surgery, insurance coverage, and confidentiality. Some social workers provide recruitment information such as how to begin a conversation and how to find a donor, while others refer the patient to their specific living donor program to learn more information. Most of the education given is verbal, however, some provide written information. One participant relies on other transplant team members to provide education while another who works with pediatric candidates reports she is not allowed to provide education on recruitment. Typically, with pediatric transplant candidates the child's parents consider being a donor. The transplant team believes there is a fine line with pushing living transplant surgery and being supportive. Finally, the findings revealed there was one social worker who does not provide any type of discussion or education on LDT.

Another finding from the study is other health care providers discuss LDT. The majority of the participants reported the transplant coordinator (nurse) provides education and some participants reported the physician and surgeon will discuss the benefits of living donor surgery and will inquire if the patient might have a potential donor. One program has a formal LDT workshop which is facilitated by the transplant coordinator while another reported that the living donor program conducts the education to the organ transplant candidate. One participant reported their program needed to improve their education process while two participants remarked that LDT is a huge focus for their program and feel confident with their LDT education. A few of the participants discussed how patients are not interested in having a discussion on LDT. They commented patients who are not interested in LDT and do not want their family member, especially adult children, donating prefer not to receive the information.

Theme 2: Social Work Role

The time frame of when the transplant social worker educates the transplant candidate might determine how much time is allocated for LDT education or how thorough the education is. The study's findings uncovered the majority of the social workers provide LDT education during the initial pre-transplant psychosocial evaluation. At an initial transplant evaluation, the patient meets with several providers on the transplant team which consists of social work, transplant coordinator (nursing), physician, surgeon, nutritionist and finance team, all who determine the eligibility of the patient. There were two participants who reported they might discuss LDT during a followup phone call or clinic visit. There was one participant in the study who reported she facilitates a formal educational workshop designed specifically on LDT education in addition to the education she provides during the initial psychosocial evaluation.

Uniquely, one transplant clinic has a social work navigator whose role is to provide in-depth LDT education and assists organ recipient candidates on recruiting potential donors. This role is separate from the social worker who conducts the initial evaluation.

In order to provide education on LDT organ transplant social workers should have sufficient knowledge on living donor transplantation. Six out of the fourteen participants stated they do not feel adequately trained to provide LDT education. Some learn from practice experience, attending workshops, listening to the medical providers or discussing with social work colleagues. The rest of the participants (eight) feel that they are adequality trained to provide LDT education, however this did not indicate they received formal training. Many still pursued the knowledge on their own, however felt they have enough information to provide adequate education.

Caseloads can vary for social workers in transplant centers and large caseloads are not uncommon. The study revealed eight out of the fourteen social work participants report their caseload impacts their ability to provide thorough LDT and report they do not have as much time as they would like to spend on LDT education. One social worker reported when time is an issue in completing the psychosocial evaluation, she will eliminate the LDT education. The remaining six participants reported their caseload does not impact their ability to provide LDT education.

The role of the social worker is viewed differently in many transplant clinics. One participant revealed that transplant social work is the most appreciated form of social work. While another reports that social work is in a unique role to educate patients and she advocates for herself and her colleagues to provide LDT education while another reported social workers are a vital member of the transplant team and are not fully recognized for the roles they play.

Theme 3: Patient Barriers

The lack of LDT education received by organ transplant candidates can be due to the challenges faced by the candidate. This study has revealed several potential barriers that prohibit transplant candidates from receiving or obtaining LDT education.

Immigration Issues

The results of this study report immigration issues are a huge barrier to receiving LDT education and, in addition, will affect their opportunity for organ transplant candidacy. The participants state undocumented citizenship status or temporary status in the US as common immigration issues. Undocumented patients lack the health insurance coverage needed to cover the costs of transplant surgery. According to Shen et al. (2018) Emergency Medicaid is awarded to those who need medical treatment for life threatening conditions like renal replacement therapy. Although some states provide funding for kidney transplantation for this population, presently there are no federal mandates to subsidize kidney transplantation. Most undocumented immigrants rely on either charitable donations or private insurance to cover the costs of transplant surgery making it unfeasible for the vast majority of these patients (Grubbs, 2014).

Lack of Understanding

Research suggests patients often misunderstand health information provided to them by their health care providers which leads to decisions that critically effect medical outcomes (Kreps, 2018). It is common to believe health literacy is determined by one’s intellect. However, according to Amann et al. (2015) health literacy is influenced by physical, cognitive, emotional and situational factors. The results of this study determined language, cognition, literacy and cultural issues are barriers to a patient receiving information on LDT. One participant specifically reported organ transplant candidates sometimes appear overwhelmed by the information received surrounding their medical condition and expressed concern if the information on LDT education is understood by them. Kreps (2018) reports many patients believe they are comprehending the health information provided to them when in actuality they are not fully understanding important information. Medical compliance was another factor discussed in this study which is a result of lack of understanding. The research suggests adherence to medical treatment is driven by many factors including a patient's lack of understanding of their disease and recommended treatment (DiMatteo et al., 2012).

Technology Barriers

Technology was determined to be another barrier to LDT education in this study. Social media is a platform for organ transplant candidates to recruit potential living donors. Media sources have been found to motivate potential living donors through emotionally powered narratives (Novogrdsky et al., 2019). The study participants reported some transplant candidates lack the ability to navigate technology or social media or they lack access to internet services.

Patient Lack of Interest or Comfort

Living donor transplantation requires the transplant recipient to allow someone to donate for them. Transplant candidates may feel ambivalent or conflicted regarding a living donor. The study findings reported some transplant candidates' discomfort with allowing someone to donate on their behalf especially if it is a family member. Some organ candidates believe it is inappropriate to ask someone to donate and refuse to hear the information at all. One participant remarked on how discussions of living donation to family and their social network is an uncomfortable conversation for the candidate; they are unsure how to begin and often experience feelings of guilt if they discuss it. Hanson et al. (2015) discussed a candidate's hesitation to recruit a donor which may include fear of putting the potential donor's health at risk, the donor feeling obligated or pressured and feelings of rejection if no one comes forward.

Program Issues

The results of this research study reported transplant programs might impose their own biases to providing LDT education to transplant candidates. One study participant discussed their transplant program's focus on the reputation of their program and therefor might not offer that surgery option to a candidate. Another participant who works with the pediatric population remarked cadaver organs may be a faster option for pediatric transplant candidates than living donors and therefore decide not to discuss LDT with the family.

Psychosocial Issues

This study determined socioeconomic factors can be a potential barrier to LDT education and surgery. In living donor transplantation, the recipient's insurance is responsible for payment of the donor's surgery and travel expenses. One participant reported transplant candidates might not have sufficient insurance or finances to cover all expenses. Another participant reported transplant candidates might not meet the criteria for financial assistance provided by community resources. In pediatric transplant recipients, a family member is typically the living donor. One participant remarked on how stress can be a barrier in the family of pediatric transplant recipients. If one family member is a donor and is recovering this puts additional burden both emotionally and financially on the other parent or caregiver.

Health Disparities

The literature suggests ethnic minorities have less access to transplant surgery, are less likely to be approved for transplantation, and experience a higher rate of graft failure (Malek et al., 2011). Purnell et al. (2018) said the number of living donor kidney transplant patients for Whites increased from 7.0% in 1995 to 11.4% in 2014, decreased from 3.4% to 2.9% among Black patients, decreased from 6.8% to 5.9% among Hispanic patients, and increased from 5.1% to 5.6% among Asian patients.

One transplant program is beginning a new health initiative to address health disparities in LDT. The program will target the African American population to increase education for both deceased and living donor transplants. At the time of data collection for this study this initiative was in its early stages of planning and therefore the information on the program was limited.

Theme 4: Ethical Issues

In organ transplantation ethical issues can arise for transplant social workers. The results of this study found some areas where ethical issues arose within the social worker’s scope of practice. One participant reported in her program there is a fine line between pushing the pediatric patient and family towards LDT and supporting them. It was reported that living donor transplant is discussed as an option and then if the family shows an interest further discussions and education will continue. According to the NASW (2021), social workers must respect and promote the right of clients to self-determination and assist clients in their efforts to identify and clarify their goals. Another participant reported the ethical issues she encounters in allowing transplant candidates who report a history of high-risk behaviors to recruit family members for LDT. Specifically, the participant discussed the common medical diagnosis for end stage organ failure of alcohol cirrhosis. She reports the ethical issue is when there is demonstrated family dysfunction and a family member is interested in donating. The participant reported it can be unclear at times if the candidate and family member understand the complexities surrounding living donor transplant surgery. The concern is if the transplant candidate is coercing the family member to donate or if there is alcohol misuse/abuse behavior in family members as well. Social workers have an ethical principle of integrity which is to act honestly and responsibly and promote ethical practices on the part of the organizations with which they are affiliated (NASW, 2021).

Unexpected Findings

The discussion by the study participant who reports she does not discuss LDT to high-risk transplant candidates and their dysfunctional family members was an unexpected finding of this study. In this transplant program these transplant candidates are more likely to be considered for deceased donor transplants due to the dysfunctional family dynamics which might make family members inappropriate candidates for LDT.

The participant remarked on how she has reflected on this belief and questions if it could be her own possible bias. She reports this is the first time she has openly discussed this issue. This specific transplant program relies on a separate living donor program to discuss LDT to transplant candidates, evaluates the donor and determines the final decision for LDT. The NASW Code of Ethics states social workers should be alert to and avoid conflicts of interest that interfere with the exercise of professional discretion and impartial judgment (NASW, 2021).

Summary

Themes that emerged from the findings were living donor education, social work role, patient barriers, and ethical issues. Data included type of LDT education that was provided by transplant social workers, roles of social workers, and training. In addition, data involved potential challenges candidates face and ethical issues that arise for transplant social workers when working with this population.

Transition

The purpose of this study is to identify challenges that transplant social workers experience delivering LDT education to organ transplant candidates. Section 4 includes a summary of study findings and ethical considerations as they relate to this study. This section also includes recommendations for social work practice as they relate to the population in this study as well as recommendations for social work practice on a broader scale. Limitations and recommendations for future research are discussed as well as implications for social change. Finally, Section 4 concludes with an overall summary of the study.

Section 4: Application to Professional Practice and Implications for Social Change

Introduction

A diagnosis of end stage organ failure is life-threatening. Organ transplant surgery can extend life, and LDT has been determined to be the best option for graft survival and mortality. The purpose of this study is to identify challenges that transplant social workers experience delivering LDT education to organ transplant candidates. Identifying obstacles in social work practice can create opportunities for transplant social workers to advocate for and improve LDT psychoeducation. This study includes literature that demonstrates the lack of thorough LDT education organ transplant candidates receive due to a combination of provider and patient barriers. According to Weng et al. (2013), improved education involving LDT surgery may increase organ candidates' knowledge of LDT and improve comfort levels when discussing LDT with others.

Findings and Knowledge in the Discipline

Transplant social work is a specialty social work practice that has its own membership society and certification, which makes the findings of this study not generalizable to social work practice. The study concluded transplant social workers provide some education on LDT to organ transplant candidates but typically as part of the overall initial transplant psychosocial evaluation. This type of education is basic in nature and covers surgery, recovery, and suggestions regarding how to begin the conversation and recruit a living donor. This is eliminated if the social worker finds there is not sufficient time to complete the psychosocial evaluation. All members of the transplant team typically inquire if patients have potential living donors and provide general education involving LDT. Transplant programs have separate living donor programs which involve medical teams for donors and evaluating and approving them for clearance. This is to ensure there is no coercion from the recipient and the living donor is exercising free will. Living donor programs provide more extensive education regarding LDT to potential living donors, and some of these programs provide education to recipient candidates as well. Transplant programs are guided by the direction and philosophy of medical and surgical directors. Social workers whose programs placed more focus on LDT offered specific workshops on LDT or supported a specific navigator role whose sole responsibility is to provide LDT education to transplant candidates.

As the literature suggests, lack of knowledge involving LDT by healthcare providers is a barrier to organ transplant candidates' understanding and receiving this surgery option. Garg (2018) said some medical providers may misunderstand or have a lack of knowledge of LDT. Six of the fourteen study participants reported they did not feel adequately trained regarding LDT. Education was gained by practice experience or due to the initiative of social workers who were proactive in terms of gaining education on their own. Caseload was a factor which also interfered with opportunities to provide LDT education according to eight of the fourteen study participants. Merighi et al. (2009) said transplant social workers work at a faster pace and have a higher volume of work compared to other medical professionals.

Organ transplant candidates face various barriers involving receiving LDT education or opportunities to receive LDT. Immigration issues are a barrier to medical care and specifically for receiving transplant surgery. Patients who are uninsured and undocumented immigrants who are unable to pay for transplant surgery are routinely excluded from transplant lists (Laurentine & Bramstedt, 2010). Health literacy, language, and cognitive issues are also barriers to transplant candidates receiving LDT education. Lack of understanding of medical information and poor management of chronic diseases is a result of inadequate health literacy (Edwards et al., 2012).

Many patients prefer not to discuss LDT since they feel to ask someone to donate is inappropriate or they feel uncomfortable bringing up the subject. Initiating effective communications regarding living donation has been cited as a major challenge by potential donors and recipients (Weng et al., 2017). In addition, lack of access to internet services or lack of understanding of how to manage social media platforms are barriers to LDT since many transplant candidates use social media to narrate their story. Technology is often used when developing educational material on LDT, and in addition, has become an important tool for transplant candidates and recruitment for living donors. Waterman et al. (2016) said web-based educational interventions have been successful in terms of increasing awareness of LDT.

Recognition of diversity as a barrier to LDT education was an important outcome of this study. Health disparities in medical care are well documented in literature and were found to occur among those who receive transplant surgery. Purnell et al. (2017) said racial and ethnic disparities are a result of insufficient knowledge of organ transplant surgery and how to pursue potential living donors.

Despite findings that study participants report time-consuming workloads or lack of training involving LDT, many participants said social work is the appropriate discipline to provide LDT education to transplant candidates. They said social workers are trained to understand patients’ perspectives, skilled in terms of engaging and approaching patients, assisting them with their challenges, and effectively informing them about LDT.

Application to Professional Ethics in Social Work Practice

Social work practice is guided by standards of professional ethics developed by the NASW. Three ethical principles or standards that relate to this social practice problem are commitment to clients, self -determination, and cultural competence and ethical standards of social justice.

Commitment to Client

When working with clients, social workers have an ethical responsibility to promote their wellbeing (NASW, 2021). In this study, participants stated they have an ethical responsibility to ensure all transplant candidates are educated regarding all surgery options. Participants also discussed systemic, practitioner, and patient challenges that deter them from meeting needs of patients regarding education on LDT. These barriers that prevent patients from receiving LDT education represents an ethical conflict and disservice to patients.

Self-Determination

It is in every person’s right to make decisions that are best suited for themselves, unless those decisions harm the life of that person. In social work practice, the right to self-determination is a fundamental principle of the NASW Code of Ethics. It ensures social work practitioners respect self-determination of patients and assist clients in terms of clarifying their values and goals (NASW, 2021). In healthcare, these ethical boundaries may not be clear when it comes to recommendations involving preferred medical treatment. Participants in this study demonstrated their ethical responsibility to patients when highlighting boundaries and difference in terms of supporting and influencing patients to choose LDT surgery. It is recommended transplant candidates select a point person in their support network who can advocate for them when recruiting a living donor.

The study participants also discussed working with organ candidates who find it inappropriate to ask someone to become a living donor. The participants reported they will respect the decision of the patient. However, patient choice is not always the first consideration for the medical providers on the transplant team. Many times, health care practitioners might influence the patient to choose a treatment option. When discussing medical care, Kelly (2020) recommends practitioners should assess the patient’s values and goals. The author argues the goal is not to change or manipulate these values but to include these values while providing the best medical care possible.

Cultural Competence

The ethical principal of cultural competence has several components to guide social workers; the understanding of culture and its effect on human functioning; developing knowledge that guides practice of various cultures; an awareness of one’s own bias; developing an understanding of social diversity and oppression and to be aware of the difference; to access electronic technology and to assist clients with those barriers (NASW, 2021).

Many study participants identified patient barriers of health literacy, language, culture and access to technology.as barriers to LDT education which has created inequity in transplant surgery

Social Justice

The final ethical principle that is relevant to this study is social justice. According to the NASW ethical principle social workers should challenge social injustice and pursue social change to ensure all people have access to information, services, resources and equal opportunity (NASW, 2021). The barriers to receiving LDT were discussed by all study participant, however, only one transplant program is addressing the health disparities.

The organ transplant area of medicine is a collaborative where all members of the transplant team provide input on a patient’s candidacy. Transplant social workers can advocate for transplant programs to improve transplant evaluations and surgery for minority and oppressed populations. Rosenblatt et al. (2021) reported the American Association for the Study of Liver Diseases recommends organ transplant associations, health systems and the transplant community must come together and build programs to address social determinants of health and health disparities in organ transplantation.

Recommendations for Social Work Practice

Action Steps

This was the first study conducted to evaluate how transplant social workers provide LDT education to organ transplant candidates and the barriers they face in providing this education. After evaluating the results of this study, an action step that could be considered by transplant social workers is to formulate a culturally competent workshop/presentation on LDT education to be delivered separately from the initial psychosocial evaluation. It was mentioned by the study participants. social workers are the appropriate interdisciplinary team member to conduct LDT education. According to Gehlert and Brown (2019) social workers in health care consider the patient’s and family’s literacy, language barriers and visual or hearing impairments when providing education on diseases. Some study participants believed including a nurse in an educational workshop would be beneficial to address any medical questions that may arise. A workshop can not only provide the LDT education but hopefully a space to invite patients/families to discuss challenges and barriers to living donor transplant surgery.

A second recommendation or action step for transplant social workers is to be reflective on how our own implicit bias can interfere in the recommendation for a patient’s transplant candidacy. FitzGerald and Hurst (2017) said the literature has supportive evidence of implicit biases among health care worker and its negative effects on patient care. Zestcott et al. (2016) said implicit bias in healthcare providers is one possible cause of health disparities in stigmatized groups. Social work practitioners may not have complete understanding of implicit bias and therefore is an opportunity for educational training on implicit bias for transplant social work colleagues and other team members.

As a transplant social worker working with liver transplant candidates, on a practice level I plan to discuss the study findings with my transplant team in hopes of developing and facilitating a more formal LDT education workshop that includes culturally competent interventions. Suggested culturally targeted interventions include addressing the fear of surgery, health and language literacy, financial concerns, communicating with and trusting health care providers and addressing the concerns regarding the living donor’s well-being (Purnell et al., 2018; Gordon et al., 2018). In addition, I plan on developing educational workshops on LDT for presentation to transplant social workers to enhance their knowledge on LDT. On a broader scale I have an interest in increasing awareness on implicit bias in the transplant medical team and to bring attention through conference presentations.

Gordon et al. (2018) said there have been very few culturally targeted interventions to address health disparities in other areas of medicine. In addition, the author states there are very few interventions that address health care provider behaviors towards health disparities. Though transplant social work is a unique field of practice, the findings from this study related to health disparities in health care are transferable to clinical social work practice in hospitals. Mitchell (2012) said important component of social work practice is addressing the needs of oppressed and disadvantaged populations. Medical social workers assess the psychosocial needs of patients and understand the challenges patients face in accessing medical care. They are the most appropriate interdisciplinary team member to develop and engage in culturally targeted interventions to decrease health disparities in medical care. Healthcare organizations and providers have a responsibility to reduce racial/ethnic disparities in health to improve equity, and by embedding interventions into their quality improvement initiatives (Chin et al., 2012).

Limitations and Recommendations

A limitation of this study could be the small sample size. Further research is recommended to include other transplant programs across the United States. Additional research recommendations are to evaluate transplant programs that have initiated cultural targeted interventions for living donor transplantation and to evaluate the health disparities in transplant programs across the US.

Dissemination of the Study

This study will be submitted to appropriate medical or social work journals for consideration for publication. In addition, this study will be submitted to the Society of Transplant Social Workers to be considered for a poster presentation or presentation at their annual national conference.

Implications for Social Change

The outcomes of this study are very timely to issues being addressed in health systems across the United States. Diversity, equity and health disparities are a main focus in health care today. The Office of Disease Prevention and Health Promotion's (ODPHP) Healthy People 2030 program has called for action to eliminate health disparities, achieve health equity, and to attain health literacy to improve the health and well-being of all people. The value of social work practice is not always acknowledged by medical provides or health systems. Medical social workers experience significant challenges as they provide superior care to patients in need while working within a healthcare system that is limited in their understanding of the critical services they provide (Mitchell, 2012). Social workers who choose to become involved in social justice have an opportunity to promote the field of social work while advocating for the needs of their patients. One suggestion could be involvement in quality improvement committees where hospital policies are reviewed and changed if needed. Active social work participation in health system initiatives to address health inequity increases the visibility and the value of clinal social work practice. Gould (2006) said in order not to be marginalized and insignificant in relation to their health care colleagues, social workers need to clearly demonstrate their contribution to integrated medical care.

The results from the study may also be helpful in advocating for the justification for transplant centers to increase education on LDT. The findings concur with the literature that the education provided on LDT to transplant candidates is limited. In addition, the results of this study can be presented to administrative and medical personnel of transplant institutes to demonstrate the need for improvements in social work services within transplant programs. Improvements in social work services and addressing the psychosocial needs of the patients can increase the medical outcomes of organ candidates, recipients and ultimately increase transplant program outcomes (Sher & Maldonado, 2019).

Summary

This purpose of this action research study purpose was to identify the practice challenges transplant social workers experience that prevents them from providing those diagnosed with end stage organ failure with education on the most effective, faster transplant surgery option; living donor transplantation. In addition to the social work practice challenges, this study also identified patient barriers that prohibit them from obtaining this surgery option and which also contributes to racial/ethnic health disparities. Transplant social workers have an ethical obligation to their patients but also to the social work profession to offer interventions that improve access to healthcare for all, to advocate for social justice and to improve the visibility of the social work profession in medicine.

References

Abu-Gazala, S., & Olthof, K. M. (2018). Status of adult living donor liver transplantation in the United States: Results from the adult-to-adult living donor liver transplantation cohort study. *Gastroenterology Clinics of North America, 47*(2), 297-311. https://doi.org/10.1016/j.gtc.2018.01.004

Alhalel, N., Francone, N. O., Salazar, A. M., Primeaux, S., Ruiz, R., Caicedo, J. C., & Gordon, E. J. (2019). Patients' perceptions of a culturally targeted Hispanic Kidney Transplant Program: A mixed methods study. *Clinical Transplantation*, *33*(6), e13577. https://doi.org/10.1111/ctr.13577

Amann, J., Rubinelli, S., & Kreps, G. L. (2015). Revisiting the concept of health literacy. The patient as information seeker and provider. *European Health Psychologist*, *17*(6), 286-290.

Archibald, M. M., Ambagtsheer, R. C., Casey, M. G., &.Lawless, M. (2019). Using Zoom videoconferencing for qualitative data collection: Perceptions and experiences of researchers and participants. *International Journal of Qualitative Methods, 18,* 1-8 https://doi.org/10.1177/1609406919874596

Asante, M.K. (2001). *Afrocentricity: The theory of social change*. Peoples Publishing Group.

Axelrod, D. A., Kynard-Amerson, C. S., Wojciechowski, D., Jacobs, M., Lentine, K. L., Schnitzler, M., Peipert, J. D., & Waterman, A. D. (2017). Cultural competency of a mobile, customized patient education tool for improving potential kidney transplant recipients’ knowledge and decision-making. *Clinical Transplantation*, 31, e12944. https://doi.org/10.1111/ctr.12944

Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Prentice-Hall.

Bandura, A. (1998). Health promotion from the perspective of social cognitive theory, *Psychology & Health, 13*(4), 623-649. https://doi.org/10.1080/08870449808407422

Basu, M., Petgrave-Nelson, L., Smith, K. D. Perryman, J. P. Clark, K., Stephen O. Pastan S. O., Pearson, T. C., Larsen, C. P., Paul, S., & Patzer, R. E. (2018). Transplant center patient navigator and access to transplantation among high-risk population: A randomized, controlled trial. *Clinical Journals of American Society of Nephrology*. *13*(4) 620-62. https://doi.org/10.2215/CJN.08600817

Bayliss, E. A., Bhardwaja, B., Ross, C., Beck, A., & Lanese, D. M. (2011). Multidisciplinary team care may slow the rate of decline in renal function. *Clinical Journal of the American Society of Nephrology*, *6*(4), 704-710. https://doi.org/10.2215/CJN.06610810

Bonsack, R. (2015). Psychoeducation: Definition, history, interest and limits. *Annales Médico Psychologiques, 173*(1), 79 84. https://doi.org/10.1016/j.amp.2014.12.001

Boulware, L. E., Hill-Briggs, F., Kraus, E. S., Melancon, J. K., McGuire, R., Bonhage, B., Senga, M., Ephraim, P., Evans, K. E., Falcone, B., Troll, M. U., Depasquale, N., & Powe, N. R. (2011). Protocol of a randomized controlled trial of culturally sensitive interventions to improve African Americans' and non-African

Americans' early, shared, and informed consideration of live kidney transplantation: The Talking About Live Kidney Donation (TALK) Study. *BMC Nephrology*, *12*(34), 1-10. https://doi.org/10.1186/1471-2369-12-34

Boulware, L. E., Hill-Briggs, F., Kraus, E. S., Melancon, J. K., Falcone, B., Ephraim, P. L., Jaar, B. G., Gimenez, L., Choi, M., Senga, M., Kolotos, M., Lewis-Boyer, L., Cook, C., Light, L., DePasquale, N., Noletto, T., & Powe, N. R. (2013). Effectiveness of educational and social worker interventions to activate patients' discussion and pursuit of preemptive living donor kidney transplantation: A randomized controlled trial. *American Journal of Kidney Diseases. 61*(3), 476–486. https://doi.org/10.1053/j.ajkd.2012.08.039

Bradburn, N. M., Sudman, S., & Wansink, B. (2004) *Asking questions: The definitive guide to questionnaire design— For market research, political polls, and social and health questionnaires*. John Wiley & Sons, Inc.

Bradford, S., & Cullen, F. (2012). *Research and research methods for youth practitioners*. Routledge.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*,77–101. https://doi.org/10.1191/%201478088706qp063oa

Browne, T. (2019). Social worker roles in health care settings. In S. Gehlert, & T. Browne (Eds.), *Handbook of health social work* (3rd ed.). John Wiley & Sons, Inc.

Campbell, S., Greenwood, M., Prior, S., Shearer, T., Walkem, K., Young, S., Bywaters, D., & Walker, K. (2020). Purposive sampling: complex or simple? Research case examples. *Journal of Research in Nursing*, *25*(8), 652–661. https://doi.org/10.1177/1744987120927206

Centers for Medicare and Medicaid Services (2008). *Organ transplant program interpretive guidelines*. https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/downloads/SCLetter08-25.pdf

Chin, M. H., Clarke, A. R., Nocon, R. S., Casey, A. A., Goddu, A. P., Keesecker, N. M., & Cook, S. C. (2012). A roadmap and best practices for organizations to reduce racial and ethnic disparities in health care. *Journal of General Internal Medicine*, *27*(8), 992-1000. https://doi.org/10.1007/s11606-012-2082-9

Choak, C. (2012). Asking questions: Interviews and evaluations. In S. Bradford, & F. Cullen, *Research and research methods for youth practitioners* (pp. 90–112). Routledge.

Creswell, J. W., & Plano-Clark, V. L. (2011). *Designing and conducting mixed method research*. (2nd ed.). Sage Publications, Inc.

Davis, L. A., Grogan, T. M., Cox, J., & Weng, F. L. (2017). Inter- and Intrapersonal barriers to living donor kidney transplant among Black recipients and donors. *Journal of Racial and Ethnic Health Disparities*, *4*(4), 671–679. https://doi.org/10.1007/s40615-016-0270-8

DiMatteo, M. R., Haskard-Zolnierek, K. B., & Martin, L. R. (2012) Improving patient adherence: A three-factor model to guide practice. *Health Psychology Review, 6*,74–91. https://doi.org/10.1080/17437199.2010.537592

DeSantis, L., & Ugarriza, D. (2000). The concept of theme as used in qualitative nursing research. *Western Journal of Nursing Research*, *22*, 351–372. https://doi.org/10.1177/019394590002200308

Dziegielewski, S. F., &. Holliman, D. C. (2020). *The changing face of health care social work: Opportunities and challenges for professional practice.* (4th ed.). Springer Publishing Company.

Eissa, A., Lofters, A., Akor, N., Prescod, C., & Nnorom, O. (2021). Increasing SARS-CoV-2 vaccination rates among Black people in Canada. *Canadian Medical Association Journal*, *193*(31), E1220–E1221. https://doi.org/10.1503/cmaj.210949

Edwards, M., Wood, F., Davies, M., & Edwards, A. (2012). The development of health literacy in patients with a long-term health condition: the health literacy pathway model. *BMC Public Health*, *12*(1), 130. https://doi.org/10.1186/1471-2458-12-130

Ferguson, S. S., Randall, J., Dabney, J., Kalbacker, M. E., Boyle, N.,Thao, V., Murphy, E. A., Ellen M. Denzen, E. M. (2018). Perceived workforce challenges among clinical social workers in hematopoietic cell transplantation programs. *Biology of Blood and Marrow Transplantation, (24)*5, 1063-1068. https://doi.org/10.1016/j.bbmt.2017.12.793.

Fisher, R. A. (2017). Living donor liver transplantation: eliminating the wait for death in end-stage liver disease? *Nature Reviews Gastroenterology & Hepatology*, *14*(6), 373-382. http://dx.doi.org.ezp.waldenulibrary.org/10.1038/nrgastro.2017.2

FitzGerald, C., & Hurst, S. (2017). Implicit bias in healthcare professionals: a systematic review. *BMC medical ethics*, *18*(1), 19. https://doi.org/10. 1186/s12910-017-0179-8.

Garg, A. X. (2018). Helping more patients receive a living donor kidney transplant. *Clinical Journal of the American Society of Nephrology*, *13*(12), 1918–1923. https://doi.org/10.2215/CJN.00760118

Gbrich, C. (2007). *Qualitative data analysis: An introduction*. Sage Publications.

Gehlert, S., & Browne, T. (2019) Handbook of Health Social Work, (3rd Edition). John Wiley & Sons, Inc.

Getchell, L. E., McKenzie, S. Q., Sontrop, J. M., Hayward, J. S., McCallum, M. K., & Garg, A. X. (2017). Increasing the rate of living donor kidney transplantation in Ontario: Donor- and recipient-identified barriers and solutions. *Canadian Journal of Kidney Health and Disease*, *4*, 2054358117698666. https://doi.org/10.1177/2054358117698666

Gilgun, J. F. (2008). Lived experience, reflexivity, and research on perpetrators of interpersonal violence. *Qualitative Social Work*, *7*(2), 181–197. https://doi.org/10.1177/1473325008089629

Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Methods of data collection in qualitative research: Interviews and focus groups. *British Dental Journal*, *204(6)***,** 291–295. https://doi.org/10.1038/bdj.2008.192

Gitterman, A., & Knight, C. (2016). Curriculum and psychoeducational groups: Opportunities and challenges. *Social Work, 61*(2), 103–110. https://doi.org/10.1093/sw/sww007

Given, L. M. (2012). The SAGE encyclopedia of qualitative research methods. Sage Publications.

Gordon, E. J., Lee, J., Kang, R. H., Caicedo, J. C., Holl, J. L., Ladner, D. P., & Shumate, M. D. (2018). A complex culturally targeted intervention to reduce Hispanic disparities in living kidney donor transplantation: an effectiveness-implementation hybrid study protocol. *BMC Health Services Research*, *18*(1), 1-15. https://doi.org/10.1111/ajt.16857

Gould, N. (2006). An inclusive approach to knowledge for mental health social work practice and policy. *British Journal of Social Work*, *36*(1), 109-125. https://doi.org/10.1093/bjsw/bch243

Grubbs, V. (2014). Undocumented immigrants and kidney transplant: costs and controversy. *Health Affairs, 33*(2), 332-335. https://doi/10.1377/hlthaff.2013.0462

Grubbs, V., Gregorich, S. E., Perez-Stable, E. J., & Hsu, C. Y. (2009). Health literacy and access to kidney transplantation. *Clinical Journal of American Society of Nephrology, (4)*1, 195–200. https://doi.org/10.2215/CJN.03290708

Gruessner, R. W. G., & Gruessner, A. C. (2018). Solid-organ transplants from living donors: Cumulative United States experience on living donor transplants over 28 years. *Transplant Proceedings*, *50*(10), 3025-3035. https://doi.org/10.1016/j.transproceed.2018.07.024

Guest, G., Bunce, A. E., & Johnson, L. (2006). How many interviews are enough? *Field Methods*, *18*, 59-82. https://doi.org/10.1016/j.jobe.2014.12.001

Hanson, C. S., Chadban, S. J., Chapman, J. R., Craig, J. C., Wong, G., Ralph, A. F., & Tong, A. (2015). The expectations and attitudes of patients with chronic kidney disease toward living kidney donor transplantation: a thematic synthesis of qualitative studies. *Transplantation*, *99*(3), 540-554. https://doi.org/10.1097/TP.0000000000000433

Henderson, M. L., Clayville, K. A., Fisher, J. S., Kuntz, K. K., Mysel, H., Purnell, T. S., Schaffer, R. L., Sherman, L. A., Willock, E. P., & Gordon, E. J. (2017). Social media and organ donation: Ethically navigating the next frontier. *American Journal of Transplantation*, *17*(11), 2803–2809. https://doi.org/10.1111/ajt.14444

Heyman, J. C. & Congress, E. P. (2018). *Health and social work: Practice, policy and research*. Springer Publishing Company. 10.1891/9780826141644

Hunt, H. F., Rodrigue, J. R., Dew, M. A., Schaffer, R. L., Henderson, M. L., Bloom, R., Kacani, P., Shim, P., Bolton, L., Sanchez, W., & Lentine, K. L. (2018). Strategies for increasing knowledge, communication, and access to living donor transplantation: An evidence review to inform patient education. *Current Transplantation Reports*, *5*(1), 27–44. https://doi.org/10.1007/s40472-018-0181-1

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, *15*(9), 1277–1288. https://doi.org/10.1177/1049732305276687

Kayler, L. K., Dolph, B., Seibert, R., Keller, M., Cadzow, R., & Feeley, T. H. (2020). Development of the living donation and kidney transplantation information made easy (KidneyTime) educational animations. *Clinical Transplantation*, e13830. https://doi.org/10.1111/ctr.13830

Kelly, M. P. (2020). Is it justifiable to make self-determination illusory to motivate a specific health outcome?. *AMA Journal of Ethics*, *22*(9), 767-772. https://doi.org/10.1001/amajethics.2020.767

Kim, P. T., & Testa, G. (2016). Living donor liver transplantation in the USA. *Hepatobiliary Surgery and Nutrition*, *5*(2), 133–140. https://doi.org/10.3978/j.issn.2304-3881.2015.06.01

Kreps, G. L. (2018). Promoting patient comprehension of relevant health information. *Israel Journal of Health Policy Research*, *7*,56. https://doi.org/10.1186/s13584-018-0250-z

Kumar, K., King, E. A., Muzaale, A. D., Konel, J. M., Bramstedt, K. A., Massie, A. B., Segev, D. L., & Cameron, A. M. (2016). A smartphone app for increasing live organ donation. *American Journal of Transplantation*, *16*(12), 3548–3553. https://doi.org/10.1111/ajt.13961

LaPointe-Rudow, D., Hays, R., Baliga, P., Cohen, D. J., Cooper, M., Danovitch, G. M., Dew, M. A., Gordon, E. J., Mandelbrot, D. A., McGuire, S., Milton, J., Moore,

D. R., Morgievich, M., Schold, J. D., Segev, D. L., Serur, D., Steiner, R. W., Tan, J. C., Waterman, A. D., Zavala, E. Y. and Rodrigue, J. R. (2015), Consensus conference on best practices in live kidney donation: Recommendations to optimize education, access, and care. *American Journal of Transplantation, 15*(4), 914-922. https://doi.org/10.1111/ajt.13173

Laurentine, K. A., & Bramstedt, K. A. (2010). Too poor for transplant: finance and insurance issues in transplant ethics. *Progress in Transplantation*, *20*(2), 178-185. https://doi.org/10.7182/prtr.20.2.xhu0678655331488

Lentine, K. L. & Mandelbrot, D. (2018). Addressing disparities in living donor kidney transplantation: A call to action. *Clinical Journal of the American Society of Nephrology*, *13* (12) 1909-1911. https://doi.org/10.2215/CJN.06250518

Malek, S. K., Keys, B. J., Kumar, S., Milford, E., & Tullius, S. G. (2011). Racial and ethnic disparities in kidney transplantation. *Transplant International*, *24*(5), 419-424. https://doi.org/10.1111/j.1432-2277.2010.01205.x

Marlow, N., Kazley, A., Chavin,K., Simpson, K., Balliet, W., & Baliga, P. (2016). A patient navigator and education program for increasing potential living donors: a comparative observational study. *Clinical Transplantation, 30*(5), 619-627. https://doi.org/10.1111/ctr.12728

Mason, J. (1996) *Qualitative researching*. Sage Publications.

Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews. *Forum: Qualitative Social Research*, *11*(3)8, 1-19. http://nbn- resolving.de/urn:nbn:de:0114- fqs100387

Mauthner, N. S., & Doucet, A. (2003) Reflexive accounts and accounts of reflexivity in qualitative data. *Sociology, 37*, 413–431. https://doi:10.1177/00380385030373002

McCoyd, J. L., & Kerson, T. S. (2016). *Social work in health settings: Practice in context*. Routledge.

Merighi, J. R., Browne, T., & Keenan, S. (2009). Emotional exhaustion and workload demands of kidney transplant social workers. *Journal of Nephrology Social Work, 32*, 32-36.

Merriam, S. B., & Tisdell, E. J. (2016). *Qualitative research: A guide to design and implementation*: (4th ed.). Jossey-Bass.

Miller-Matero, L. R., Bryce, K., Hyde-Nolan, M. E., Dykhuis, K.E., Eshelman, A., & Abouljoud, M. (2016). Health literacy status affects outcomes for patients referred for transplant, *Psychosomatics, 57*(5), 522-528. https://doi.org/10.1016/j.psym.2016.04.001

Mitchell J. A. (2012). Integrating education on addressing health disparities into the graduate social work curriculum. *Journal of Teaching in Social Work, 32*(5), 471–486. https://doi.org/10.1080/08841233.2012.725458

National Association of Social Workers (2021). *Code of ethics.* https://www.socialworkers.org/About/Ethics/Code-of-Ethics/Code-of-Ethics-English

Nishio-Lucar, A. G., Locke, J. E., & Kumar, V. (2020). Use of patient navigators to reduce barriers in living donation and living donor transplantation. *Current Transplantation Reports*, *7*, 72-80. https://doi.org/10.1007/s40472-020-00280-4

Novogrodsky, E., Yaghoubian, A., Connor, S. E., Hicks, E., Vargas, G. B., Nassiri, S., Maghen, A., Kwan, L., Waterman, A. D., Maliski, S. L., & Veale, J. L. (2019). The role of media in non-directed (altruistic) living kidney donation. *Health Communication*, *34*(2), 259–267. https://doi.org/10.1080/10410236.2017.1405480

Nyumba, O. T., Wilson, K, Derrick, C. J., & Mukherjee, N. (2018). The use of focus group discussion methodology: Insights from two decades of application in conservation. *Methods in Ecology and Evolution*, *9*(1), 20-32. https://doi.org/10.1111/2041-210X.12860

Office of Disease Prevention and Health Promotion (ODPHP) (2022). *Health People 2030*. https://www.healthypeople.gov/2020/About-Healthy-People/Development-Healthy-People-2030/Framework

Oliveri, M. E., & Riess, D. (1981). A theory-based empirical classification of family problem-solving behavior. *Family Process*, *20*(4), 409-418. https://doi.org/10.1111/j.1545-5300.1981.00409.x

Olthoff, K. M., Smith, A. R., Abecassis, M., Baker, T., Emond, J. C., Berg, C. L., Beil, C. A., Burton, J. R., Jr, Fisher, R. A., Freise, C. E., Gillespie, B. W., Grant, D. R., Humar, A., Kam, I., Merion, R. M., Pomfret, E. A., Samstein, B., & Shaked, A. (2015). Defining long-term outcomes with living donor liver transplantation in

North America. *Annals of Surgery*, *262*(3), 465–475. https://doi.org/10.1097/SLA.0000000000001383

Organ Procurement and Transplantation Network (2022). *National Data* https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/#

Organ Procurement and Transplantation Network (2022a). *Regional Data* https://optn.transplant.hrsa.gov/data/view-data-reports/regional-data/#

Organ Procurement and Transplantation Network (2022b). *Glossary.* https://optn.transplant.hrsa.gov/resources/glossary/#C

Patzer, R. E., Basu, M., Larsen, C. P., Pastan, S. O., Mohan, S., Patzer, M., Konomos, M., McClellan, W. M., Lea, J., Howard, D., Gander, J., & Arriola, K. J. (2016). iChoose Kidney: A clinical decision aid for kidney transplantation versus dialysis treatment. *Transplantation*, *100*(3), 630–639. https://doi.org/10.1097/TP.0000000000001019

Purnell, T. S., Luo, X., Cooper, L. A., Massie, A. B., Kucirka, L. M., Henderson, M. L., Gordon, E. J., Crews, D. C., Boulware, L. E., & Segev, D. L. (2018). Association of race and ethnicity with live donor kidney transplantation in the United States from 1995 to 2014. *JAMA*, *319*(1), 49–61. https://doi.org/10.1001/jama.2017.19152

Rana, A., & Godfrey, E. L. (2019). Outcomes in solid-organ transplantation: success and stagnation. *Texas Heart Institute Journal, 46(1), 75-76.* https://doi.org/10.14503/THIJ-18-6749

Rosenblatt, R., Lee, H., Liapakis, A., Lunsford, K. E., Scott, A., Sharma, P., & Wilder, J. (2021). Equitable access to liver transplant: bridging the gaps in the social determinants of health. *Hepatology*, *74*(5), 2808-2812. https://doi.org/10.1002/hep.31986

Saldaña, J. (2016). *The coding manual for qualitative researchers* (3rd ed.). Sage publications.

Sandal, S., Charlebois, K., Fiore, J. F., Jr, Wright, D. K., Fortin, M. C., Feldman, L. S., Alam, A., & Weber, C. (2019). Health professional-identified barriers to living donor kidney transplantation: A qualitative study. *Canadian Journal of Kidney Health and Disease*, *6*, 2054358119828389. https://doi.org/10.1177/2054358119828389

Scharp, K. M., & Sanders, M. L. (2019) What is a theme? Teaching thematic analysis in qualitative communication research methods. *Communication Teacher, 33*(2), 117-121. https://doi.org/10.1080/17404622.2018.1536794

Sieverdes, J. C., Price, M., Ruggiero, K. J., Baliga, P. K., Chavin, K. D., Brunner-Jackson, B., Patel, S., & Treiber, F. A. (2017). Design and approach of the Living Organ Video Educated Donors (LOVED) program to promote living kidney donation in African Americans. *Contemporary Clinical Trials, 61*, 55–62. https://doi.org/10.1016/j.cct.2017.07.007

Shanley, C. (2008). Supporting family carers through telephone-mediated group programs: opportunities for gerontological social workers. *Journal of*

Gerontological Social Work, *51*(3-4), 199-209. https://doi.org/10.1080/01634370802039460

Shen, J. I., Hercz, D., Barba, L. M., Wilhalme, H., Lum, E. L., Huang, E., Reddy, U., Salas, L., Vangala, S., & Norris, K. C. (2018). Association of citizenship status with kidney transplantation In Medicaid patients. *American Journal of Kidney Diseases*, *71*(2), 182–190. https://doi.org/10.1053/j.ajkd.2017.08.014

Sher, Y., & Maldonado, J. R. (2019.). *Psychosocial care of end-stage organ disease and transplant patients*. Springer International Publishing.

Society for Transplant Social Work (2022). *Transplant social worker job description*. https://stsw.wildapricot.org/Professional-Standards

Steketee, G., Ross, A. M., & Wachman, M. K. (2017). Health outcomes and costs of social work services: A systematic review. *American Journal of Public Health*, *107*(S3), S256–S266. https://doi.org/10.2105/AJPH.2017.304004

Stickney- Ferguson, S., Randall, J., Dabney, J., Kalbacker, M.E., Boyle, N., Thao, Murphy, E. A., Denzen, E. M. (2018). Perceived workforce challenges among clinical social workers in hematopoietic cell transplantation programs. *Biology of Blood and Marrow Transplantation*, *24*(5), 1063:1068. https://doi.org/10.1016/j.bbmt.2017.12.793.

Strigo, T. S., Ephraim, P. L., Pounds, I., Hill-Brigs, F., Darrell, L., Ellis, M., Sudan, D., Rabb, H., Segev, D., Nae-Yuh, W., Kaiser, M., Falkovic, M., Lebov, J., F., & Boulware, L. E. (2015). The TALKS study to improve communication, logistical, and financial barriers to live donor kidney transplantation in African Americans:

protocol of a randomized clinical trial. *BMC Nephrol*ogy, *16*(1)**,** 160. https://doi.org/10.1186/s12882-015-0153-y

Stringer, E. T. (2014). Action research: A handbook for practitioners (4th ed.). Sage Publications.

Taylor, D. M., Bradley, J. A., Bradley, C., Draper, H., Dudley, C., Fogarty, D., Fraser, S., Johnson, R., Leydon, G. M., Metcalfe, W., Oniscu, G. C., Robb, M., Tomson, C., Watson, C., Ravanan, R., Roderick, P., & ATTOM investigators (2019). Limited health literacy is associated with reduced access to kidney transplantation. *Kidney International*, *95*(5), 1244–1252. https://doi.org/10.1016/j.kint.2018.12.021

Tracy, S. J. (2010) Qualitative quality: Eight “big-tent” criteria for excellent. qualitative research. *Qualitative Inquiry*, *16(*10), 837-851. https://doi:10.1177/1077800410383121

Traino, H. M., West, S. M., Nonterah, C. W., Russell, J., & Yuen, E. (2017). Communicating About Choices in Transplantation (COACH): Results of a pilot test using matched controls. *Progress in Transplantation*, *27*(1), 31-38. https://doi.org/10.1177/1526924816679844

United Network Organ Sharing (2022). *Living donation. Information you need to know.* https://unos.org/wp- content/uploads/unos/Living_Donation-1.pdf

United Network Organ Sharing (2022a). *Talking about transplantation: What every patient needs to know.* https://unos.org/wp-content/uploads/unos/WEPNTK.pdf

United Network Organ Sharing (2022). https://unos.org

U.S. Department of Health Resources and Services Administration. (n.d.). *The organ donor process*. https://www.organdonor.gov/about/process/transplant-process.html

Wang, J. H., Skeans, M. A. & Israni, A. K. (2016), Current status of kidney transplant outcomes: Dying to survive. *Advanced Chronic Kidney Disease, 23*(5), 281-286. http://dx.doi.org/10.1053/j.ackd.2016.07.001

Warren, C., & Karner, T. (2005). Discovering qualitative methods: Field research, interviews and analysis. Roxbury

Waterman, A. D., Morgievich, M., Cohen, D. J., Butt, Z., Chakkera, H. A., Lindower, C., Hays, R. E., Hiller, J. M., Lentine, K. L., Matas, A. J., Poggio, E. D., Rees, M. A., Rodrigue, J. R., & Lapointe-Rudlow, D. (2015). Living donor kidney transplantation: Improving education outside of transplant centers about live donor transplantation recommendations from a consensus conference. *Clinical Journal of the American Society of Nephrology*, *10*(9), 1659–1669. doi:10.2215/CJN.00950115

Waterman, A. D., Robbins, M. L., & Peipert, J. D. (2016). Educating prospective kidney transplant recipients and living donors about living donation: Practical and theoretical recommendations for increasing living donation rates. *Current Transplantation Reports*, *3*(1), 1–9. https://doi.org/10.1007/s40472-016-0090-0

Watson, J. B. (1913). Psychology as the behaviorist views it. *Psychological Review, 20*(2), 158-177.

Weng, F. L., Brown, D. R., Peipert, J. D., Holland, B., & Waterman, A. D. (2013). Protocol of a cluster randomized trial of an educational intervention to increase knowledge of living donor kidney transplant among potential transplant candidates. *BMC Nephrology*, *14*(1), 1-10. https://doi: 10.1186/1471-2369-14-256.

Weng, F. L., Peipert, J. D., Holland, B. K., Brown, D. R., & Waterman, A. D. (2017). A clustered randomized trial of an educational intervention during transplant evaluation to increase knowledge of living donor kidney transplant. *Progress in Transplantation*, *27*(4), 377-385. https://doiorg.ezp.waldenulibrary.org/10.1177/1526924817732021

West, C. J. & Winnike, K. (2019) Social work interventions in end-stage organ disease and transplant patients. Y. Sher, & J. R. Maldonado (Eds.). *Psychosocial care of end-stage organ disease and transplant patients*. Springer International Publishing.

Wood, E. H., Waterman, A.D. & Pines, R. (2021) "Storytelling to inspire dialysis patients to learn about living donor kidney transplant. *Blood Purification*. *50*(4-5), 655-661. https://doi.org.10.1159/000512651.

World Health Organization (WHO) (2008). Global glossary of terms and definitions on donation and transplantation. https://apps.who.int/iris/bitstream/handle/10665/341813/WHO-HTP-EHT-CPR-2009.01-eng.pdf?sequence=1

Zestcott, C. A., Blair, I. V., & Stone, J. (2016). Examining the presence, consequences, and reduction of implicit bias in health care: A narrative review. *Group Processes & Intergroup Relations, 19*(4), 528–542. https://doi.org/10.1177/1368430216642029

Appendix A: Interview Questions

1. How long have you been a social worker?
2. Do you have a LMSW or LCSW designation?
3. How long have you practiced transplant social work?
4. To what organ transplant programs do you provide social work services?
5. What specific living donor transplantation education do you presently provide to transplant candidates?
6. In what capacity do you provide living donor transplantation education to organ transplant candidates?
7. Do you feel adequately trained to provide living donor transplantation education to transplant candidates? Why or why not?
8. Does your caseload or other job responsibilities impact your work with providing living donor education to organ transplant candidates?
9. Are there any other current challenges you as see the transplant candidate’s barriers to receiving living donor transplantation?
10. How is the organ transplant candidate presently educated on living donor transplantation? By whom?
11. Is there anything else you would like to add?