The Psychosocial Effects of Solid Organ Transplantation on Living Donors: A Literature Review

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THE PSYCHOSOCIAL EFFECTS OF SOLID ORGAN TRANSPLANTATION ON LIVING DONORS: A LITERATURE REVIEW

by

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A thesis submitted in partial fulfillment of the requirements for Honors in the Major Program in Nursing in the College of Nursing and in the Burnett Honors College at the University of Central Florida Orlando, FL

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Thesis Chair: Leslee D’Amato-Kubiet
Abstract

Historically the source for most organ donations were from the cadavers of deceased donors. Over time living organ donation has become an important way to address the shortage of organ availability. The purpose of this literature review is to explore the psychosocial effect the organ donation process has on the living donor. The body’s physiological response to organ donation had been well documented. However, the psychosocial effect of donation is now being more appreciated and studies are being done to try to elucidate the factors that can influence the living donor’s response to the transplant process. The ultimate goal of these queries is to provide areas where clinicians can develop interventions that will enhance the post-donation experience for the living donor. To conduct this literature review peer-reviewed, English language research articles that were published between 2008 to the present were critiqued. In the end most living donors had a positive experience and would not hesitate to donate their organ again; however, there were a small minority of patients that did not fare well by psychosocial measures. These patients many times were aware that the graft had failed in the recipient. This was the single biggest factor in determining if the experience was positive or negative for the living donor. Strategies, such as internet-based cognitive behavioral intervention, are being to be developed to address the negative psychosocial outcomes that some living donors experience. Further studies are necessary to determine additional factors that may alter the living donor’s experience and to develop a tool-kit of interventions that can be applied as necessary to address the living donors specific needs.
Dedication

For my family whose support has enabled me to be successful throughout all my endeavors.
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Introduction

In the United States (US), 34,770 solid organ transplants were performed in 2017 (U.S. Department of Health and Human Services, 2018). The number of solid organ transplants performed in the US increases each year causing an ever-growing number of people with end-stage organ failure to be placed on waiting lists until a matched donor organ is available. As of 2018, there were 114,000 people awaiting a solid organ transplant (U.S. Department of Health and Human Services, 2018). Renal transplants comprise approximately 56% of the solid organ transplants performed in the US in 2017 while liver transplants account for approximately 23% of the solid organ transplants during that year (U.S. Department of Health and Human Services, 2018). Regretfully, many individuals with end-stage organ failure placed on waiting lists for solid organ transplant will not receive a transplant in time. As many as 20 people die each day in the US waiting for a compatible organ for transplant (U.S. Department of Health and Human Services, 2018). Unlike other solid organ transplants, organs for kidney and liver transplant can come from healthy living donors as well as recently deceased donors. In the case of liver and kidney transplantation, organs volunteered from living donors can greatly expand the availability of viable organs for transplant. In some instances, complications and side effects related to organ donation can arise that adversely affect the donor. In the proceeding fifty years much of the focus has been placed on long-term complications the recipient of an organ endures. However, there is a paucity of research that explores the long-term consequences of organ donation experienced by the living transplant donor.

There are several unique burdens a person donating an organ can experience during the years following surgical excision of a healthy organ. Organ donors may potentially have to take leave from work due to unforeseen complications arising from donation, and the donor can then
have problems paying their monthly bills. In addition, donors may be denied health insurance and life insurance following donation, which causes long-term financial difficulties. Besides the financial burden that donors may incur due to time off work and future insurability issues, donors may experience emotional, substance abuse, or other negative psychosocial burdens. While most living organ donors do not experience any ill effects from donating their organs, up to 10% of living kidney donors experience negative psychosocial outcomes (Jacobs, Gross, Messersmith, Hong, Gillespie, Hill-Callahan, Taler, Jowsey, Beebe, Matas, Odim, & Ibrahim, 2015). Some indicators such as underlying psychological distress and substance abuse problems are known before undergoing donation and can increase the likelihood of the donor experiencing negative psychosocial outcomes. On the other hand, lack of support and graft failure are important indicators that can lead to negative psychosocial outcomes but are not apparent until after the procedure. Jacobs and colleagues reported that up to 38% of kidney donors feel that they do not receive support even from hospital staff following organ donation (Jacobs, et al., 2015). However, graft failure was the greatest predictor of negative psychosocial outcome in post-transplant donors (Jacobs, et al., 2015). Despite recognition that the negative psychosocial outcomes can be problematic for a subset of organ donors, little has been proposed in the way of interventions that may improve the donor’s long-term experience.
Problem

Living donor organ transplantation provides organs to individuals with organ failure that would otherwise remain on waiting lists due to the lack of availability of solid organs suitable for transplantation. However, since the inception of living organ donor transplantation, little attention has been paid to the long-term consequences the organ donor has to endure following the procedure. Evaluation of transplanted organs has mainly focused on the physiologic and psychologic long-term outcomes in organ recipients, although more recently, problems experienced by living organ donors is gaining attention.

The negative financial and psychosocial effects organ donation has on the living donor has become more apparent. The single biggest predictor of the donor experiencing a negative psychosocial outcome is related to whether the graft fails after being implanted into the recipient. Identifying interventions aimed at alleviating the negative psychosocial effects of transplantation for donors would be beneficial in improving outcomes. Given that donors whose recipients had a graft failure are at the highest risk of developing negative psychosocial consequences, identifying the subset of living organ donors with recipients that have grafts failure or rejection might be an effective way of improving their transplant experience.
Purpose

The purpose of this literature review is to analyze the negative psychosocial effects that organ donors experience after donation and to understand which donors are most at risk for suffering negative experiences related to organ donation. It has been suggested that living kidney donors experience mood disorders, fear of future organ failure, body image issues, and life dissatisfaction more frequently than healthy controls (Rodrigue, Schold, Morrissey, Whiting, Vella, Kayler, Katz, Jones, Kaplan, Fleishman, Pavlakis, & Mandelbrot, 2017). Exploring effective interventions aimed at identifying possible complications of organ donation pre- and post-transplant in the recipient and in the living donor could be useful in ensuring the best possible psychologic and physiologic outcomes are experienced by the living donor.

The United Network for Organ Sharing (UNOS) has identified areas that can be assessed as part of a psychosocial evaluation prior to donation. The areas identified by UNOS include motivation to donate, social support, health behaviors, psychosocial history, psychiatric history, donor knowledge and understanding of the risks, and family history as well as financial history and legal preparedness (Rudow, Swartz, Phillips, Hollenberger, Schmick, & Steel, 2015). Another pre-donation screening tool developed is the Ethical, Legal, and Psychosocial Aspects of Organ Transplantation (EPAT) (Massey, Timmerman, Ismail, Duerinckx, Lopes, Maple, Mega, Papachristou, & Dobbels, 2017). Screening tools can assist the transplant team in the identification of living donors at risk for poor psychosocial and physiologic outcomes after donation and can raise awareness of the implications organ donation has on donor health status.

Understanding the effects of organ donation on the living donor will aid in caring for donors post-transplant. Many individuals donating an organ will have positive experiences before and after donation; however, organ donation has both physiologic and psychosocial
effects that can vary between individual experiences. Interventions can be developed to prevent or lessen the impact of the physiologic and psychosocial effects on the donor. The information synthesized from this literature review is expected to address physiologic and psychosocial experiences of living organ donors and to explore interventions aimed at reducing the negative aspects of organ donation pre- and post-donation.
Method

A review of the literature will be conducted to examine the physiologic and psychosocial effects of organ transplantation on living donors from the following online databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medical Literature On-Line (MEDLINE), Educational Resource Information Center (ERIC), and Psychological Information database (PsycINFO) (Appendix A, Figure 1). Searches used a combination of the following terms: ‘organ transplant*’, ‘living donor*’, ‘physiologic*’, and ‘psychosocial*’. Articles included in the review will be published from 2008-2019, in the English language from peer-reviewed journals. Articles will be reviewed to ensure relevance to the topic. Inclusion criteria will consist of 1) focus on physiologic and psychosocial health status of living donor pre- and post-donation, 2) experience of donation from the donor’s perspective, and 3) interventions aimed at minimizing negative experiences from the donor’s point of view. Articles that focus on the recipient experience in living donor organ transplantation will be excluded.

No relevant articles were identified when all four search terms were used. When, physiologic* was excluded from the search, 258 articles were found (Appendix A, Figure 1). 57 articles were evaluated and individually critiqued. Only one article met the inclusion criteria by specifically addressing both the psychosocial and physiological effects of organ donation. Another 17 articles were identified that pertained to the psychosocial effects of organ donation on the living donor. Three articles were identified that were outside the date range of the search but were included to provide historical context for studies pertaining to living liver donation.
Background

Organ failure

Organ systems in the human body have specialized tasks to perform functions that maintain homeostasis. In certain disease conditions, pathological changes can occur in the body’s organs and impair their ability to properly function. Overtime pathological changes can cause the organ to become permanently damaged, losing the ability to function and perform its physiological role. When this happens, it is difficult for the body to compensate for the loss of the organ due to tissue specialization innate to each organ and the biologic inability to regrow a new organ. Ultimately the failure of an organ can lead to death. Solid organ transplantation is a procedure that is performed when one or more organs have failed in attempt to restore organ function. The procedure requires an intricate process that involves the screening patients and donors, procurement of an organ, transporting the organ between institutions, and the implantation into the patient with the failing organ. When the first kidney transplant was performed in 1954 between two living identical twins, death would have been a common sequelae from organ failure (Keller, 2015). Over the 6 decades since solid organ transplantation has been performed great advances have been made in the types of organs that can be transplanted and the survivability of the procedure. Kidney, liver, heart, and lung transplantation are some of the most common solid organ transplants performed today (Keller, 2015). Postsurgical management following transplantation has been an important advancement that has enabled transplanted organs to function for extended periods of time. Early on survival rates were low, but the introduction of immunosuppressant therapy opened the door to improved treatment for organ transplant patients.

Living Organ Donation
Historically, transplanted organs were obtained from a deceased donor. Due to the nature of procuring organs from deceased donors, the need for organs greatly outpaced the availability of the organs. Most patients who received organ transplants obtained their organs from deceased donors. Lack of donations and the fact that all organs from deceased donors are not useable in transplantation greatly reduces the number of patients who can receive a new organ. While a majority of the organs utilized in transplantation still come from deceased donors, approximately 4 out of 10 are obtained from live donors (U.S. Department of Health and Human Services, 2018). Being able to remove a whole or part of an organ from a living donor and then implanting it into a recipient has greatly expanded the number of organs, such as the kidney or liver, that are available for transplantation. However, the ability to remove an organ or a part of one from a living donor and transfer the organ to a recipient presents a unique set of ethical and medical issues for all involved.

**Medical Management**

Advancements in post-surgical management of transplant recipients has increased their survival rate. Immunosuppressant therapy has assisted in reducing the incidence of organ rejection in transplant recipients. Cyclosporine, which was first used in the early 1980’s, was a mammoth advance that helps prevent the recipient from rejecting the donor organ (Keller, 2015). Another important area in the management of individuals with transplanted organs has been in preventing infections due to immunosuppression. However, much less research has been done to characterize the long-term effects of organ transplantation on the living donor. While living donors do not have to worry about rejecting their remaining organ or infections like recipients, other complications often arise that can greatly affect the living donor’s quality of life. It is possible for the donor’s remaining organ to fail, which would then necessitate them receiving an
organ transplant. Recognizing that organ donation is not a benign process and can have ramifications on the living donor’s life is an important advance in the transplant process.

**Psychosocial Effect in Transplantation**

Historically much of the attention has focused on the effects that organ transplantation has on the recipient. Besides having to consider organ rejection in recipients post-transplant, recipients are also at risk for developing negative psychosocial outcomes following the procedure. Depression, anxiety, aggression, and hopelessness are a few of the reported negative psychosocial changes that have been reported in people with chronic illnesses (Schulz & Kroencke, 2015). Addressing psychosocial issues has long-term implications for the health of the transplant recipient. For example, depression in a transplant recipient can lead to lack of compliance with their immunosuppressant regimen and a decrease in their quality of life (Heinrich & Marcangelo, 2009). This is important because without adhering to the immunosuppressant regimen, the recipient could possibly suffer organ rejection. After undergoing surgical implant of a donor organ, the potential for adverse psychosocial effects is greatest the first year after transplant. There are also financial pressures on living organ donors, just as there are for people with chronic illnesses, due to missing work following the procedure and due to the recovery period. One psychosocial dimension that is different for living organ donors pertains to whether the transplantation was successful or not. Graft success or failure is an important predictor of psychosocial outcomes experienced by the living organ donor with graft failure leading to potentially negative outcomes.

In the current body of literature, the effects of organ transplantation in living organ donors is not as well delineated. In living tissue donation, kidneys are the most common organ that is harvested and transplanted. The transplantation of livers from living donors is less
common but still represents a significant number of procedures. Recently, the risks posed by donating organs has been a focus of concern. Beyond having a potential effect on the donor’s health, other factors precipitated by organ donation can affect the donor’s quality of life. The adverse effects that occur to organ donors can determine how they perceive the procedure. Most donors donate their organs willingly to benefit those in need. This altruistic act normally has a beneficial psychological effect on the donor. However, a minority of organ living organ donors have a negative outcome from the donation process and this can greatly affect the donor’s perception of the procedure. When the living donor experiences either a negative health or psychosocial outcome, the living donor is more likely to regret the decision to donate their organ in the first place. Understanding which living donors are at risk for developing adverse effects from donating may allow health care providers to intervene, which will ultimately make for a more positive experience for the living organ donor.

Organ donation can have multifactorial effects on the living donor’s health status, as well as on the individual’s mental health well-being. In the case of kidney transplantation, the living donor undergoes surgical resection and harvest of a healthy kidney to a recipient. The living donor can successfully maintain physiologic homeostasis with one functional kidney, which is why the procedure is feasible. To compensate the remaining kidney might hypertrophy. The increase in size is indicative of the increased functional role even though the total capacity has been reduced by removal of one of the organs. Once the living donor has donated their kidney, the donor is at risk if their remaining kidney were to fail. The living donor in this situation would require a kidney transplant. Even if the living donor’s remaining kidney does not completely fail, it is possible that their kidney function may still decline. Meyer and colleagues reported that 26.7 percent of the living kidney donors had a low estimated glomerular filtration rate (eGFR)
(Meyer, Hartmann, Mjøen, & Andersen, 2017). A living donor was defined as having a low eGFR if it was less than 60 mL/min/1.73 m². In addition, Meyer and colleagues reported that 33.2 percent of the living donors in the cohort reported having hypertension following organ donation (Meyer, et al., 2017). In the study hypertension was defined as having a blood pressure greater than 140/90. One of the kidney’s functions is in regulating blood pressure. The alterations caused by donating a kidney might explain why living donors experience an increase in blood pressure.

The psychosocial effects of transplantation on the living donor are less understood. Since only a minority of living donors experience a negative psychosocial outcome, it is imperative to understand which donors are more likely to experience the complications. Factors such as age, relationship status, social support, financial status, and coping style have been looked at in relation to the development of negative psychosocial outcomes in living donors. Age has been identified as a predictor of negative psychosocial wellbeing after organ donation in living donors. Younger kidney donors who were not married are more likely to exhibit negative psychosocial effects post-donation. The same trend has been observed in living liver donors. Being 40 to 50 years old was associated with a more positive effect on the donation experience (Dew, DiMartini, Ladner, Simpson, Pomfret, Gillespie, Merion, Zee, Smith, Holtzman, Sherker, Weinrieb, Fisher, Emond, Friese, Burton, & Butt, 2016). Also, the financial burden resulting from organ donation can be substantial. The living donor may miss work, which can lead to a decrease in wages. In addition, the recovery period can sometimes be longer than expected. The longer it takes to recover can strain finances. Another financial hardship can be placed on the donor due to the inability to get health and life insurance years after the donation. Financial and
social support can affect the level of stress the living organ donor experiences. The living donor’s ability to cope with these stresses will affect their perception of the donation process.

Further, living organ donors have many of the same psychosocial changes experienced in the organ donor recipients. Living organ donors can have depression and anxiety due to changes in their health status and fear regarding what happens if their remaining organ fails. Living organ donor may be frustrated due to the perception that once they have donated their organ they are an afterthought and do not receive as much follow-up by the healthcare team following the procedure. There are also financial pressures on living organ donors, just as there are for people with chronic illnesses, due to missing work following the procedure and due to the recovery period. One psychosocial dimension that is different for living organ donors pertains to whether the transplantation was successful or not. Graft success or failure is an important predictor of psychosocial outcomes experienced by the living organ donor with graft failure leading to potentially negative outcomes.

Graft failure in organ transplantation has serious implications for the recipient’s ability to survive short of receiving another organ donation. While this is imminently more stressful for the organ recipient due to the life and death issues presented by the situation, it is also understandable that the person who just donated an organ could also be affected by this adverse outcome. Graft failure has been shown to be one of the few causes for living donors to have regrets in undergoing the organ transplantation process (Meyer, Wahl, Bjørk, Wisløff, Harmann, & Andersen, 2016). There are many reasons why graft rejection could lead to regrets the donor experiences. The donor could resent the time and financial burden that they went through if the graft rejects. Graft failure could be particularly difficult for the living donor if the recipient was a close relative. The donor could experience a feeling of guilt due to the fact that the recipient did
not survive. Understanding the guilt that living organ donors experience and developing nursing interventions to alleviate this negative psychosocial effect will be invaluable for improving the donor’s experience following the transplantation procedure.

**Education**

Interventions used to lessen the impact of transplant complications affecting the living donor would be useful to alleviate negative psychosocial effects of the transplant process on the living donor. Psychosocial causes of distress that effect the living donor can be difficult to target. Some examples have been suggested in the literature for interventions to prevent poor psychosocial outcomes. One example is of an internet-based cognitive-behavioral intervention (ICBT). In this pilot study the health-related quality of life, anxiety, and depression were observed before and after the intervention to see if the ICBT was effective at alleviating problems associated with organ donation (Wirken, van Middendorp, Hooghof, Bremer, Hopman, van der Pant, Hoitsma, Hillbrands, & Evers, 2018). The ICBT had extensive donation-related treatment modules, assignments, and psychoeducation. In the pilot study, most participants reported benefits on health and psychological health-related quality of life measures, depression measures, and in reports of fatigue. Further studies are warranted because the scores are based off the responses of eight living donors. This provides a starting point to develop this and other methods to prevent living donors from developing negative psychosocial outcomes that negatively affect their transplant experience.
Results

Twenty-one studies were identified related to the psychosocial effect organ donation has on the living organ donor. The studies were included in the literature review. Included in the articles were two sentinel studies, one of which was a pilot study in the discipline, from 2001 and 2002. Twenty studies had been published since 2008. All the studies were cohort studies. All the studies used various questionnaires to measure the living donors’ quality of life. Five of the studies involved qualitative interviews of the living donors following the transplant procedure.

Psychosocial Outcomes in Living Donors Post-Donation

The literature review identified two major groups of living organ donors. The majority of living organ donation involves transplantation of the kidney; however, there are a significant number of liver transplants involving living organ donors. The studies synthesized in the literature search identified certain factors that can negatively affect the psychosocial outcomes kidney and liver donors experience.

Psychosocial Outcomes in Living Kidney Donors

Ten studies were identified that explored the psychosocial effect of organ donation in living kidney donors.

The health-related quality of life (HRQoL) questionnaire was examined in living kidney donors (LKD) for a small cohort study, which involved the donors responding to the Short Form-36 (SF-36), Giessen Subjective Complaint List (GBB-24), and the Zerssen’s Mood Scale (Bf-S) questionnaires (Maglakelidze, Pantsulaia, Managadze, & Chkhotua, 2011). In the eight domains of the SF-36, social function (p=0.0001), bodily pain (p=0.0357), and vitality (p=0.0478) were domains the living kidney donors scored higher and more positive ratings than the control patients or renal tumor patients who had undergone nephrectomies (Maglakelidze et al., 2011).
In addition, the living kidney donors (LKD) scored higher in the GBB-24, and the only domain in which the difference in scores was statistically significant was in the gastric complaints domain (p=0.008) (Maglakelidze et al., 2011). In the Bf-S questionnaire, the living donors scored higher than both the control and renal tumor patients (p=0.0007 versus controls and p < 0.0001 versus patients) (Maglakelidze et al., 2011). This study indicated that LKDs fared well following organ donation by the measures of HRQoL included in the study.

Another study explored the effect organ donation had on psychosocial outcomes in LKDs. In the study, various questionnaires were employed to measure the effect organ donation had on the LKDs psychosocial outcomes (Maple, Chilcot, Weinman, & Mamode, 2017). The Short Form-12 (SF-12) was utilized to measure the LKDs physical HRQoL (Maple et al., 2017). The LKDs were found to have a significantly lower SF-12 score 3 months following donation (p < 0.05); however, the SF-12 score at 12 months following donation was lower than the pre-donation score but not significantly lower (Maple et al., 2017). This study also found that by all measures LKDs had very little change in their HRQoL by 12 months after kidney donation.

In another cohort study, the investigators were interested in determining the long-term effects on mood in organ donors following kidney donation. The investigators utilized the Patient Health Questionnaire (PHQ-9) depression screening instrument, the Life Orientation Test-Revised, and the 36-Item Short Form Health Survey to screen LKDs following donation (Jowsey, Jacobs, Gross, Hong, Messersmith, Gillespie, Beebe, Kew, Matas, Yusen, Hill-Callahan, Odim, Taler, & the RELIVE Study Group, 2014). The study found the biggest predictors of the living organ donor suffering from symptoms of depression following kidney donation consisted of being a race other than white (p=0.020), being younger when they donated their kidney (p=0.002), having a longer recovery time following donation (p=0.0009), having a
large financial burden (p=0.013), and feeling obligated to donate the kidney (p=0.003) (Jowsey et al., 2014). The study identified factors that could indicate the living donor was more likely to develop depression following organ donation even though the overall prevalence of depression was similar between LKD and the controls.

Other psychosocial outcomes evaluated following organ donation included mood, body image, fear of kidney failure, and decisional stability. One study used the Profile of Mood States (POMS) to assess anxiety, depression, and mood, the 5-Item Fear of Kidney Failure questionnaire, 10-Item Body Image Scale (BIS), and 5-Item Satisfaction with Life Scale (SWLS) to measure the psychosocial outcomes in LKDs (Rodrigue et al., 2017). The outcomes measured in this study yielded similar results for LKDs and healthy controls (HC). When looking for predictors of psychosocial outcomes following donation, older age was associated with less chance of developing a mood disorder post-donation (p=0.001) and having a mood disorder pre-donation was more likely to be associated with a mood disorder following donation (p=0.01) (Rodrigue et al., 2017). The predictors of fear of kidney failure were marital status with being married associated with less change of developing the fear (p=0.004) and pre-donation fear of kidney failure increasing the chances of developing the fear post-donation (p < 0.001) (Rodrigue et al., 2017). Pre-donation body image issues and feeling pressured to donate were predictors of having body image issues following donation (p=0.002 and p=0.02, respectively) (Rodrigue et al., 2017). Being white was associated with a decreased chance of developing life dissatisfaction while pre-donation life dissatisfaction was associated with an increased chance of developing life dissatisfaction following donation (p=0.003 and p <0.001, respectively) (Rodrigue et al., 2017). While the LKDs and HCs had comparable psychosocial outcomes, several predictors of negative outcomes for LKDs were identified in this study.
The factors that have negative and positive effects on LKDs along with the HRQoL were explored in a randomized, cohort study (Hsieh, Chien, Liu, Wang, Lin, & Chiang, 2017) following organ donation. In this study women demonstrated a higher positive psychosocial effect than men (p < 0.05) (Hsieh et al., 2017) following the donation and transplant experience. Also, lack of having a chronic disease was associated with having a positive effect on psychosocial perceptions of the donation experience (Hsieh et al., 2017). The psychosocial ratings were more favorable following organ donation if the person perceived themselves as having greater physical health prior to the organ donation (p < 0.01) (Hsieh et al., 2017). When the psychosocial effects of organ donation were rated as higher by the donor, the LKDs generally had higher HRQoL scores (p < 0.05) (Hsieh et al., 2017). This study indicated that LKDs rating their donation experience as positive with fewer negative effects had higher HRQoL scores.

To predict mental health following donation in LKDs, several psychological factors were explored to determine their effect on mental health. In one prospective cohort study (Timmerman, Timman, Laging, Zuidema, Beck, Ijzermans, Busschbach, Weimar, & Massey, 2016), the authors reported that being young (p=0.002) and having a deficiency in social support indicated and increased risk for negative psychological symptoms (Timmerman et al., 2016). Also, increased amounts of stress led to a decrease in overall well-being (p < 0.001) (Timmerman et al., 2016). Providers that recognize potential predictors of negative psychosocial outcomes in LKD can improve the organ donation experience by optimizing interventions aimed at decreasing stress in the donor and by surrounding the donor with supportive individuals.

Previously, Timmerman, Laging, Westerhof, Timman, Zuidema, Beck, Ijzermans, Betjes, Busschbach, Weimar, & Massey (2015) suggested there was no difference between the mental health outcomes for LKDs and HCs. The authors reported no change in psychological complaints
(p=0.20) or in well-being (p=0.10) for LKDs following organ donation (Timmerman et al., 2015). There was also no difference detected between the LKDs and HCs in regards to changes in psychological complaints and in well-being (p= 0.48 and p=0.85, respectively) (Timmerman et al., 2015). Ultimately this study suggests there are no discernible differences between LKDs and HCs in mental health outcomes.

Another group looked at the prevalence of anxiety, depression, and regret of donation in LKDs following donation. In this cohort study, the rates of anxiety, depression, and regret of donation in LKDs was 5.5%, 4.2%, and 2.1%, respectively (Holscher, Leanza, Thomas, Waldram, Haugen, Jackson, Bae, Massie, & Segev, 2018). The chances of a positive screening for depression were higher if the LKD screened positive for anxiety (p < 0.001) (Holscher et al., 2018). There was also an increased chance of having a positive depression screen if the recipient of the kidney lost the graft (p < 0.001) (Holscher et al., 2018). The LKD was more likely to regret the decision to donate the kidney if the LKD had a positive anxiety screen (p < 0.0001) (Holscher et al., 2018). These factors were the only ones that were found in this study to be predictors associated with anxiety, depression, or regret of donation.

Meyer, Wahl, Bjørk, Wisløff, Hartmann, & Andersen (2016) reported on quality of life (QoL) measures eight to twelve years following the living donor’s kidney donation. Most of the donors had high QoL scores. The only significant findings were that women had higher fatigue score than men (Meyer et al., 2016). Women scored significantly higher than men in general fatigue (p=0.01), physical fatigue (p=0.01), reduced motivation (p=0.04), and mental fatigue (p=0.03) (Meyer et al., 2016). Gender may be a factor that clinicians may look at in LKDs to ensure that female donors are not adversely affected by fatigue following donation.
Like other studies, graft failure was identified as a factor in poor psychological outcomes of LKDs (Jacobs, Gross, Messersmith, Hong, Gillespie, Hill-Callahan, Taler, Jowsey, Beebe, Matas, Odim, Ibrahim, & the RELIVE Study Group, 2015). The study suggested one in ten LKDs experienced a negative psychosocial or financial consequence following donation (Jacobs et al., 2015). The only predictor of a negative psychosocial outcome statistically significant was if the recipient’s kidney was no longer functioning (p < 0.001) (Jacobs et al., 2015). This is consistent with the findings of similar cohorts of living organ donors. Graft failure has been reported to have negative consequences on the LKDs psychosocial outcomes (Holscher et al., 2018).

**Psychosocial Outcomes in Living Liver Donors**

Ten studies were identified that addressed the psychosocial outcomes in living liver donors (LLD). Three of the cohort studies did not meet the inclusion criteria because they were published before 2008, when there was a sharp increase and better outcomes in living organ donation due to advanced drug therapies and surgical techniques but were included to give context to the topic.

Walter, Bronner, Pascher, Steinmüller, Neuhaus, Klapp, & Danzer (2002) looked at the psychosocial outcomes of LLDs at six months following the transplant procedure. Overall the participants in the study had a higher global quality of life 6 months after the procedure (p=0.044) (Walter et al., 2002). However, 26% of the LLDs also had high values for tiredness (p < 0.0012) and fatigue (p < 0.0012). Ultimately most of the LLDs in the study had a good QoL following donation, and the procedure could be done without the ethical dilemma of doing harm to the donor.
Another early article described the QoL of LLD before and after liver donation. The LLDs were assessed using the WHOQoL questionnaire (Walter, Dammann, Papachristou, Neuhaus, Danzer, & Klapp, 2003). Before donating the LLDs scored higher on the WHOQoL questionnaire than the general population ($p < 0.05$) (Walter et al., 2003). At six months, the LLDs were re-assessed with the WHOQoL and the LLDs score significantly lower on physical health ($p < 0.05$) and living conditions ($p < 0.05$) than before they donated their livers (Walter et al., 2003). This study suggested the LLD’s, had a positive psychosocial outcome after partial organ donation following transplantation to the recipient.

In the final early cohort study, the authors looked at the QoL that LLDs experienced following transplant. The LLDs scored similar to HCs on the SF-36, which has been a validated questionnaire to assess QoL. The only domains that the LLDs differed from the HCs were physical function, social function, and mental health ($p < 0.05$) (Trotter, Talamantes, McClure, Wachs, Bak, Trouillot, Kugelmas, Everson, & Kam, 2001). Ultimately, the some LLDs reported body image issues, mild ongoing symptoms such as abdominal discomfort, significant out of pocket expenses; however, all the LLDs stated that they would donate a portion of their livers again if given the chance (Trotter et al., 2001). This was an early study that demonstrated the lack of harmful effect for people donating a section of their liver to another.

DuBay, Holtzman, Adcock, Abbey, Greenwood, Macleod, Kashfi, Jacob, Renner, Grant, Levy, & Therapondos (2009) looked at the QoL living donors experienced and looked at predictors to those outcomes. The physical composite score as measured by the responses of LLDs on the SF-36 demonstrated a higher physical composite score ($p < 0.001$) (DuBay et al., 2009). Physical functioning ($p < 0.001$), role interference ($p < 0.05$), bodily pain ($p < 0.001$), general health ($p < 0.001$), and vitality ($p < 0.05$) were all domains that the LLDs scored better
than the average Canadian on (DuBay et al., 2009). While LLDs reported mental health scores on the SF-36 similar to the average Canadian, there were several predictors, such as age (p=0.023), presence of a psychiatric diagnosis (p=0.007), degree attained (p=0.001), and pre-donation concerns about donation all (p=0.029) that were all predictors of mental health changes seen following liver donation (DuBay et al., 2009). This study identified some predictors that could cause changes in a LLDs mental health outcomes following organ donation.

In a multicenter cohort study, the authors identified several factors that affect the psychological outcomes in LLDs. Butt, Dew, Liu, Simpson, Smith, Zee, Gillespie, Abbey, Ladner, Weinrieb, Fisher, Hafliker, Terrault, Burton, Sherker, & DiMartini (2017) identified factors that affect the Simmons better person score were time since donation (p < 0.001), being a first degree relative versus unrelated (p=0.012), female gender (p=0.008), recipient death (p < 0.001), ambivalence (p=0.005), and motivation to donate (p < 0.001) (Butt et al., 2017). The predictor that was more likely to be associated with a negative donation experience was the death of the recipient. Up to 22% of the LLDs felt responsible when the recipient died following the transplant (Butt et al., 2017). This study reiterated the fact that the recipient’s outcome can have a great effect on the donor’s experience.

A cohort study conducted in Japan, compared the psychological outcomes of recipient and donors three to five years following living donor liver transplants. In this study, the social QoL (p= 0.026) and total QoL (p=0.005) were lower after the donation procedure (Noma, Hayashi, Uehara, Uemoto, & Murai, 2011). LLDs also reported fewer anxiety symptoms following transplantation (Noma, et al., 2011). The study identified social support as a predictor of QoL following donation. Those living donors with less familial support had a greater chance of worse psychosocial outcome following organ donation. Knowing predictors of these outcomes
could allowed clinicians to target this patient population to prevent a negative experience following donation.

In a long-term study, Ladner, Dew, Forney, Gillespie, Brown, Merion, Freise, Hayashi, Hong, Ashworth, Berg, Burton, Shaked, & Butt (2015) followed LLDs for up to 11 years following transplant. The best predictor of a negative score on the SF-36 was if the recipient had died within 2 years of receiving the kidney transplant (Ladner et al., 2015). One factor that was identified as a protective factor was education. LLDs that had a bachelor’s degree generally reported a higher PCS score on the SF-36 (Ladner et al., 2015). Even though most LLDs have a positive experience following organ donation, and higher education was identified as a significant to improved quality of life following organ donation. This can assist clinicians with determining which LLDs need further education and reinforcement of the psychosocial expectations following donation to lessen the chance of adversely affecting the LLD’s HRQoL.

A long-term cohort study was conducted to evaluate the prevalence of adverse psychosocial outcomes in LLDs (Dew, Butt, Liu, Simpson, Zee, Ladner, Holtzman, Smith, Pomfret, Merion, Gillespie, Sherker, Fisher, Olthoff, Burton, Terrault, Fox, & DiMartini, 2018). The authors in this study found that LLDs were more likely to have anxiety and alcohol abuse disorder (Dew et al., 2018). Other factors, such as length of hospital stay, female gender, higher body mass index (BMI), fear of health related effects, and out-of-pocket expenses were associated with a worse QoL (Dew et al., 2018). Anxiety and substance abuse disorders can have a negative impact on the QoL that a LLD has. Screening prior to organ donation for individuals at risk of developing substance abuse problems in a LLD population would be beneficial.

Previously, Dew, DiMartini, Ladner, Simpson, Pomfret, Gillespie, Merion, Zee, Smith, Holtzman, Sherker, Weinrieb, Fisher, Emond, Freise, Burton, and Butt (2016) found several
factors that led to lower HRQoL. These factors included male gender (p<0.001) and being non-Hispanic white (p<0.001) (Dew et al., 2016). The authors also identified a factor that had a positive effect on HRQoL, which was being between 40 to 50 years old (p=0.008) (Dew et al., 2016). Additionally, the MCS scores were poorer in those donors that had extended hospitalizations following donation (p=0.009) indicating a decrease in the HRQoL (Dew et al., 2016). While age can be a protective factor, other predictive factors such as financial costs, extended hospitalization, race, and gender might be used to identify donors that require follow-up care and long-term surveillance.

Kimura, Onishi, Sunada, Kishi, Suzuki, Tsuboi, Yamaguchi, Imai, Kamei, Fujisiro, Okada, Ishigami, Kiuchi, & Ozaki (2015) evaluated the impact psychiatric conditions had on LLDs. The authors identified 6 individuals who had not had a psychiatric issue before donation and subsequently developed a psychiatric disorder following organ donation. The 6 individuals represent 4.2% of the total number of LLDs (n=142) screened for participation in the study (Kimura et al., 2015). The LLDs with a mental health disorder and were treated for the disorders, were evaluated before and after the organ donation process. Half of the LLDs were able to stop drug therapy during the donation process while the other half required therapy over an extended time frame (Kimura et al., 2015). The low prevalence of mental health disorders in individuals that donate organs can make it difficult to draw conclusions from a small cohort of living organ donors.

The Relationship Between Physiological and Psychosocial Outcomes in LKD

There was one study that met the inclusion criteria and addressed both the physiological functioning of the kidney following donation and the psychosocial impact of donation.
The long-term effects of kidney donation on the living donor are not well elucidated particularly when trying to determine whether physiological functions affect psychosocial outcomes. Meyer, Hartmann, Mjøen, & Andersen (2017) attempted to correlate physiologic functioning with QoL in LKDs. There were no significant associations that could be drawn between clinical variables, such as blood pressure (BP), creatinine, estimated glomerular filtration rate (eGFR), hemoglobin, or cholesterol panels, and QoL scores on the SF-36 (Meyer et al., 2017). The only correlations that could be discerned were between gender and general fatigue (p < 0.05) and between BMI and physical fatigue (p < 0.01) (Meyer et al., 2017). This small-scale study failed to really find a correlation between physiological function 10 years following kidney donation and the LKDs QoL.
Discussion

The studies included in this literature review can provide insight into the psychosocial effects that organ donation has on the living donor; however, other factors concerning the donation process and outcomes in the transplant recipient that may be important in the living donor’s experience following donation have yet to be identified. The main factor identified in several of the studies was that graft failure and the resultant death of the recipient led to feelings of guilt and negatively affected the psychosocial outcomes experienced by the living donors. Various studies also identified predictors that indicated whether the living donors experienced psychosocial sequelae from donating their organs.

Psychosocial Outcomes Experienced by Living Donors

Most LKDs and LLDs experienced no adverse effects from donating their organs to another person. Some living donors even demonstrated higher measures of psychosocial functioning after they had donated their organ. There were a number of LKDs that experienced mood disturbances following donation of their kidney. Up to 16% of LKDs were found to have new-onset mood disturbances following kidney donation (Rodrigue et al., 2017). The studies by in large used questionnaire to measure the living donors’ QoL. Several of the studies also employed interviews to ascertain the donors’ feelings about the transplant experience.

Most of the studies found that living donors had no negative consequences following the transplant procedure (Ladner et al., 2015; Maglakelidze et al., 2011; Maple et al., 2017; Meyer et al., 2017; Timmermann et al., 2015). There were several groups of people who seemed to have more negative psychosocial outcomes in the studies. The first group that had negative psychosocial effects form the donation experience had knowledge that the graft they had donated was no longer functioning in the recipient (Butt et al., 2017; Meyer et al., 2016). The other group
that tended to have a more negative QoL following donation were those that had pre-existing deficits in psychosocial functioning (Hsieh et al., 2017; Rodrigue et al., 2017; Timmerman et al., 2016). Several studies tried to identify predictors to determine which living donors were most at risk of having negative psychosocial outcomes.

Predictors of Psychosocial Responses Following Donation

The psychosocial factors identified in the studies synthesized for this literature review were associated with either positive or negative effects on the organ donation outcomes experienced by the living donor. There were no uniform predictors of psychosocial response to organ donation that could be identified. In several studies gender was predictive of QoL measures of psychosocial outcome, such as fatigue (Dew et al., 2016; Hsieh et al., 2017; Meyer et al., 2016; Meyer et al., 2017). Another predictor that was identified in some studies was age. Being older at the time of organ donation was considered protective and older individuals responded more favorable on QoL measures of psychosocial outcomes (Jowsey et al., 2014; Rodrigue et al., 2017). The existence of pre-existing mood or mental disorder was found to be a negative indicator of psychosocial outcome in living donors (Holscher et al., 2018; Rodrigue et al., 2017). The death of the recipient was also a negative indicator to the living donor's transplant experience (Butt et al., 2017; Jacobs et al., 2015; Rodrigue et al., 2017).

Barriers to Care of Living Organ Donors

Most of the studies suggested living donors should be monitored to ensure the donors did not experience any negative psychosocial effects from the transplantation process. One barrier to this involved the way the clinician would measure any changes. While the SF-36 was used in many of the studies, there were a variety of questionnaires employed in the studies included in this review. Without uniformity in the process of data collection, it is difficult to draw over-
arching conclusions and assumptions to identify psychosocial complications experienced by living organ donors and those in need of interventions following donation of an organ.

One other variable to address is when the evaluations for psychosocial complications should take place following organ donation. There were a wide variety of time points that were used to evaluate the psychosocial well-being of the living donors. Some studies looked at long-term effects of living organ donation by looking at living donor responses to questionnaires a decade or more from the time the procedure occurred (Jacobs et al., 2015; Ladner et al., 2015; Meyer et al., 2016; Noma et al., 2011). Other studies followed living donors for a much shorter time following the transplantation procedure. These studies might have followed the living donors for two or less years (Butt et al., 2017; Dew et al., 2018). Given that a living donor’s experiences are not likely to be the same at different time periods following the transplantation procedure, it is hard to compare studies that encompass such disparate time frames and apply the authors’ findings to the living donor population in general.

Financial barriers can also present a problem for living donors. There can be large sums of out-of-pocket expenses. Living donors can also experience problems obtaining health insurance and life insurance following the procedure. Without gaining an understanding of the financial implications of living organ donation, it will be impossible to develop ways to contain the cost and prevent undue financial harm to the living donor.
Limitations

The studies included in this literature review had several limitations. Using general keyword searches, such as organ transplant, living donor, psychosocial, and physiologic, provided numerous articles. When filtering for publication dates and language, the number of articles germane to the topic greatly diminished. Only one article was identified that completely met the inclusion criteria while looking at physiological data and QoL measures. The search was expanded by varying the keywords and expanding the search terms to include different permutations of the keywords like organ transplant*. The articles included in this review were analyzed after appearing in the keyword search to determine whether they met the inclusion criteria. This process is subjective, so some articles may have been overlooked while some may have been erroneously included.

One of the limitations that became apparent from the studies included in this literature review was the sample sizes of the studies. Several of the studies had sample sizes smaller than 50 individuals (Hsieh et al., 2017; Noma et al., 2011; Trotter et al., 2001; Walter et al., 2003; Walter et al., 2002). The sample sizes of these studies make it unlikely that the living donor population is diverse enough to apply the findings on the population at large. The largest studies were multicenter studies that had 2,455 participants (Jacobs et al., 2015; Jowsey, 2014). Not all the studies were made up of diverse populations. Several were conducted at single centers in Asian or European countries (Hsieh et al., 2017; Kimura et al., 2015; Maglakelidze et al., 2011; Meyer et al., 2017; Meyer et al. 2016; Noma et al., 2011; Walter et al., 2003; Walter et al., 2002). All the studies were a cohort design but given the nature of the question being researched that would be expected.
Retention and attrition rates in longitudinal, cohort studies can influence causal correlations that occur in a population. Large attrition rates or low retention rates can skew the results obtained. Even in the larger trials the response rate is important to note. Only 2,455 living donors participated in the study out of 6,909 who had been contacted after they were found to be eligible (a 36% response rate) (Jowsey et al., 2014). The people who ended up participating may not be representative of the general population. Rodrigue et al. (2017) reported an 84% response rate. The longer the study is designed to continue collecting data, the more likely the attrition rate will grow. Rodrigue et al. (2017) lost one living donor to follow-up because the donor died.
Recommendations for Living Donor Psychosocial Health

Future Investigations

There was one article identified that discusses an ongoing cohort study that seeks to also answer whether the physical function of the LKD’s body is correlated to any psychosocial outcomes. The study aims to see if kidney function is associated with changes in QoL (Suwelack, Wörmann, Berger, Gerß, Wolters, Vitinius, Burgmer, & the German SoLKID consortium, 2018). The primary outcome will be the association of the eGFR with the QoL obtained through the SF-36 in LKDs (Suwelack et al., 2018). The results from this study will add to the body of literature that meets the inclusion criteria that was set out for this literature review.

Further studies using the similar time frames and similar questionnaires are necessary to determine whether the psychosocial alteration observed post-donation are applicable across the living donor population. It is hard to compare a study carried out 10 years post-donation to one that looks at the living donor’s psychosocial outcome one year following donation. Several of the studies used several different questionnaires (Holscher et al., 2018; Maglakelidze et al., 2011; Maple et al., 2017). While one questionnaire might not be able to measure every aspect of the domains of the psychosocial outcomes, it can be hard to directly compare the data obtained from two different questionnaires.

Interventions

The predictors identified from studies are an important step in being able to identify where interventions can be strategically employed to improve the living donor’s experience following organ donation. These predictors allow the clinician to target those more likely to need the intervention. Given the multifaceted dimensions related to psychosocial health, it is likely that a variety of interventions will have to be developed.
Since there are not many examples of interventions to address psychosocial functioning in living donors, ideas can be generated from other conditions. Dew, Zuckoff, DiMartini, Dabbs, McMulty, Fox, Switzer, Humar, & Tan (2012) published a report where they had developed an intervention and did some feasibility testing to try to prevent negative psychosocial outcomes in living donors. The framework the authors used was based upon interventions for motivational interviews (MI’s). The goal was to motivate the living donor to change behavior thus improving their psychosocial outcome (Dew et al., 2012). While there was no data obtained that directly indicated the intervention improved psychosocial outcomes, the authors found that the living donors liked being able to talk and have their comments listened to so that any concerns could be addressed (Dew et al., 2012). Interventions based upon those used in other conditions might be a place to begin since there are a dearth of validated examples.

Another intervention, internet-based cognitive-behavioral therapy (ICBT), was proposed and tested for its feasibility (Wirken, van Middendorp, Hooghof, Bremer, Hopman, van der Pant, Hoitsma, Hillbrands, & Eveers, 2018). The authors developed an ICBT intervention for LKDs and donor candidates (Wirken et al., 2018). Anxiety and depression were assessed before and after the intervention. Wirken et al. (2018) suggested that the intervention improved measures such as depression in the eight living and candidate donors in the pilot study. The study was not designed to assess effectiveness so whether the intervention works in practice remains to be seen.

**Nursing Practice**

The findings synthesized in this review can have various implications to the practice of nursing. Nurses need to stay abreast of the research to practice effectively. This review condenses what is known about the psychosocial effects of donation on living organ donors. To be able to make sound clinical judgements, nurses need to know where holes in the current body
of knowledge are so that decisions can be based on the evidence. Nurses are also an advocate for their patients. Ultimately, nurses want to prevent harm to their patient by advocating on their behalf.

Psychosocial domains are multifaceted so will require a team approach to identify and address. Nurses are at the best position to help coordinate care to maximize the person’s psychosocial outcome. Nurses are frequently the first to see that there is a problem due to the amount of time that they spend with their patients. Nurses may be involved in the implementation of interventions to resolve any psychosocial problems that living donors have.

Conclusions

While most living organ donors have no problems following donation and report no negative psychosocial outcomes, there is a subset of living donors that do not have a pleasant experience following donation. The nurse may be involved in identifying living donors at most risk of having negative psychosocial outcomes through screeners or participating in a team to implement interventions to address any problems. The literature indicates that one of the leading factors associated with an adverse psychosocial outcome is related to the death of the recipient (Butt et al., 2017; Jacobs et al., 2015; Rodrigue et al., 2017). When the recipient dies following graft failure, this should be an indicator to follow the living donor more closely and implement any necessary interventions to lessen any negative psychosocial impact. Developing interventions to address changes in psychosocial functioning is vitally important. The examples found so far are feasibility studies, which while they are a necessary first step. These studies not sufficient to address the problem. Effectively identifying which patients are at risk for developing negative psychosocial outcomes is the most important action we have at this time.
Appendix A: Figure
Key Search Terms = organ transplant* AND living donor* AND psychosoc*
Limiters = English language, peer-reviewed, published between 2008-2018

Figure 1: Method for Literature Review Selection
Appendix B: Table
Table 1. Table of Evidence

<table>
<thead>
<tr>
<th>Author(s) Year Location</th>
<th>Study Design and Purpose</th>
<th>Sample Size</th>
<th>Intervention Protocol</th>
<th>Screening Measures</th>
<th>Outcome Measures</th>
<th>Key Findings and Limitations</th>
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<tbody>
<tr>
<td>Butt et al. (2017) United States</td>
<td>Cohort study Observational</td>
<td>n=278</td>
<td>Major depression, anxiety, and alcohol abuse modules of the Primary Care Evaluation of Mental Disorders (PRIME-MD) were employed to screen the LLD. Also, the Posttraumatic Growth Inventory-Short Form (PTGI-SF) SF-36 were used to assess the LLD.</td>
<td>The average age at donation was 36.79 years old. 63.1% were either married or in a long-term relationship. Most participants were white with 80.4% identifying as non-Hispanic white. Donors who were not proficient in English were excluded from the study. The better person scale and the PTGI-SF were used to screen the psychological characteristics. The PRIME-MD was used</td>
<td>Most LLD scored at the midpoint on the better person scale and the PTGI-SF. The factors associated with affecting the better person score were time since donation (p &lt; 0.001), first-degree relative versus being unrelated (p=0.012), female gender (p=0.008), recipient death (p &lt; 0.001), and ambivalence (p=0.005) and motivation to donate (p&lt; 0.001).</td>
<td>The rate of mental disorders in LLD were: 0-3% for major depression, 2-5% for alcohol abuse, and 2-3% for anxiety disorders. One of the factors that was identified that is associated with a negative experience from living liver donation is whether the recipient dies. The death of the recipient has a negative impact on the donor. Up to one third of those donors felt guilt following the death of the recipient and up to 22% felt some responsibility for the death of the recipient. Limitations: The sample did not have a large representation of minorities. Also, only 245 out of the 278 people enrolled completed the initial survey and one post-donation survey. At the two-year post-donation only 183 donors were eligible.</td>
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<tr>
<td>Dew et al. (2018) United States</td>
<td>Cross-sectional</td>
<td>n=424</td>
<td>During the study, participants were interviewed over the phone for 30-45 minutes. Research staff would also retrieve clinical data from the donor’s medical records.</td>
<td>The SF-36 was used to determine the donor’s QoL. The socioeconomic, clinical factors from medical records, and donor’s perception are assessed. Donors were over 18 years old and spoke English to be included in this study.</td>
<td>Anxiety and alcohol abuse disorder (p &lt; 0.001) were more common in LLDs. Also, the length of the hospital stay post-donation, being female, higher BMI, fear of health related effects, and out-of-pocket expenses were associated with a decrease in QoL.</td>
<td>Identification of factors adversely effecting LLDs is an important step forward in ensuring that the donation process is safe for the donors. The researches found that anxiety and alcohol abuse disorder were seen with an increased frequency in LLDs. Limitations: Some of the centers included in this study so they have relatively small sample sizes coming form that site. This could make it hard to see differences in those centers.</td>
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| Dew et al. (2016) United States | Cross-sectional long-term follow-up study | n=517 | Eligible donors had to speak English and be over 18 years of age. All the donors included were | The study assessed 3 psychosocial variable and general HRQoL. The assessments | Several factors were identified in the study that led to a lower HRQoL which include male gender (OR 6.23, p < 0.001) | The study found that LLD report adverse physical and socioeconomic effects from donation. Those at greatest risk are non-Hispanic white males. Up to 31 % of donors reported
9 transplant centers in the US and Canada are members of the consortium.

| DuBay et al. (2009) Canada | Cross-sectional study | n=143 | The LLD in this study completed a questionnaire 3 months after donation. The questionnaire collected demographic data, HRQoL following donation, and feelings about the overall donation process. To measure the HRQoL the participants in this study came from one transplant center in Toronto, Canada. The participants had donated their livers between April 2000 and March 2007. The donors who were at least 3 months post-donation received the SF-36 version 2. The results from the SF-36 were higher than when compared to the average Canadian. The physical composite score for the LLD was 56.4 versus 50.5 (p < 0.001). However, the mental composite score was not statistically different than the average Canadian score. Physical functioning (p < 0.001), presence of a psychiatric diagnosis (p=0.007), degree attained (p=0.001), and pre-donation concerns about donation all (p=0.029) were all predictors of mental health changes seen following liver donation. |  

The checklist of Donation-Related Physical Symptoms, the Posttraumatic Growth Inventory, the better person scale, and the SF-36 version 2. and being non-Hispanic white (OR 6.35, p < 0.001). Age 40 to 50 years old (OR 0.26, p=0.008) were more likely to have favorable psychological benefit and lower physical and economic concerns following donation. Limitations: The study is cross-sectional, which prevents comparing pre- and post-donation status. The study was conducted in adults so whether the findings correlate to the pediatric population experience is impossible to infer. |
<table>
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<tr>
<th>Study</th>
<th>Design</th>
<th>Country</th>
<th>Cohort</th>
<th>Sample Size</th>
<th>Methods</th>
<th>Outcomes</th>
<th>Limitations</th>
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<tr>
<td>Holscher et al. (2018)</td>
<td>Cohort study</td>
<td>United States</td>
<td>Ongoing study of living kidney donors.</td>
<td>n=825</td>
<td>Living kidney donors (LKD) were sent quality of life surveys and a survey detailing medical, surgical, hospitalization, psychiatric, and social history. Participants has a nephrectomy between 1982 and 2015. Enrollment started in 2011. The GAD-2 anxiety screen, PHQ-2 depression screen, and the 5-point Likert scale were employed to measure the incidence of anxiety, depression, and regretting the decision to donate their liver occurred in 5.5%, 4.2%, and 2.1% of the respondents. These conditions were very inter-related and a positive screen for one was often correlated with a positive screen for another. Limitations: Unlike other studies, this study was conducted at one transplant center, which limits the</td>
<td>Overall the incidence of anxiety, depression, and regretting the decision to donate their liver occurred in 5.5%, 4.2%, and 2.1% of the respondents. These conditions were very inter-related and a positive screen for one was often correlated with a positive screen for another. Limitations: Unlike other studies, this study was conducted at one transplant center, which limits the</td>
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<td>Hsieh et al. (2017) Taiwan</td>
<td>Cross-sectional study</td>
<td>n=41</td>
<td>The physical health of the LKD was assessed along with demographic data. The Medical Outcomes Study 12-Item Short-Form Health Survey measured physical health-related quality of life (HRQoL) through the physical domain. Patients were measured for positive and negative affect and HRQoL. Factors associated with positive affect were gender, chronic disease, and perceived physical health. Factors associated with negative affect are relationship to recipient, chronic disease, and poor physical health. Employment led to higher mental HRQoL (p &lt; 0.05). When LKD had a lower negative affect score, their mental HRQoL was higher (p &lt; 0.01). Men, donors who are siblings of the recipient, donors having chronic disease, and having poor physical health were more likely to have a decreased HRQoL. Limitations: This study was small and consisted of a potential pool of participants. The study may not have enough participants to truly see differences between the outcomes and donor characteristics.</td>
<td>Psychosocial domains screened positive for anxiety (p &lt; 0.001). A positive depression screen was also more likely to occur when the recipient experienced graft loss (p &lt; 0.001). In addition, regret was more likely to be seen when the person had a positive anxiety screen (p &lt; 0.0001). When the LKD had a higher positive affect, their HRQoL scores were generally higher (p &lt; 0.05). Employment led to higher mental HRQoL (p &lt; 0.05). When LKD had a lower negative affect score, their mental HRQoL was higher (p &lt; 0.01). Men, donors who are siblings of the recipient, donors having chronic disease, and having poor physical health were more likely to have a decreased HRQoL. Limitations: This study was small and consisted of a potential pool of participants. The study may not have enough participants to truly see differences between the outcomes and donor characteristics.</td>
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<td>Jacobs et al. (2015) United States</td>
<td>Cohort study</td>
<td>n=2455</td>
<td>Questionnaire s were mailed to 6909 kidney donors from three transplant centers in the US. 2455 responded to the 11-page questionnaire.</td>
<td>In regard to psychosocial outcomes, the authors looked at overall donation experience; financial burden due to donation; whether the donor would donate again; emotional, psychological, or substance abuse; or regrets with donating their kidney. The only A total of 231 patients reported that they experienced a negative psychosocial outcome following donation. Almost 1 in 10 donors experienced a negative consequence related to their decision to donate their kidney. One in 5 donors ended up taking unpaid leave and up to 2% reported having concerns with life and health insurance, which contributes to the financial burden of donation.</td>
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since donation was 17 years (ranged from 5 to 48 years).
Respondents were highly educated (21% had a 4-year college degree) and were white (93%).

predictor that was associated with poor psychosocial outcome was that the recipient’s kidney was no longer functioning (OR 1.77, CI 1.33-2.34, p < 0.001).

Limitations: While this study had a larger sample size, the response rate was only 36%.

Jowsey et al. (2014) United States

Cross-sectional cohort study

The purpose of this study was to reveal the long-term effects of LKD on the donor. The study was designed to see differences in depression in kidney donors.

n=2455

Researchers gathered data from LKD records. This occurred prior to the study. The donors were then invited to join the study. The participants completed a short questionnaire initially and then were given more in-depth questionnaires on their medical and

Donors who were targeted in this study donated their kidneys between 1963 and 2005 at one of 3 transplant centers. Areas queried in the questionnaire were: loss of interest, depressed mood, sleep, appetite and energy changes, alterations in self-worth, concentrating problems, alterations in

The study utilized the Patient Health Questionnaire (PHQ-9) Depression Scale, the Life Orientation Test-Revised (LOT-R), and the 36-Item Short Form Health Survey (SF-36) for measuring QoL. The PHQ-9 indicated that fewer depressive symptoms were associated in LKD who reported better physical health (p < 0.001), older when underwent

For the most part LKD do not experience an increase in depressive symptoms. The minority that do experience depressive symptoms have a history of depression that predates kidney donation. Longer recovery (p=0.009), financial stressors (p=0.013), younger (p=0.002), obligation to donate (p=0.003), and recipient graft status (p=0.007) are associated with a LKD more likely to develop depression.

Limitations: While the study included patients from three transplant centers, there was less representation of ethnic minorities than represented in the US population.
Kimura et al. (2015) Japan

Cohort study

The purpose of this study was to demonstrate whether there was a correlation between physiological variables and the LLDs quality of life.

n=142

The potential donors were evaluated by a team of psychiatrists and psychologists to determine their intent and to determine whether they understood the risks associated with donating their liver. The potential donors were evaluated for mental illness using a structured interview for the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). The donors identified in this study were selected between April 2004 and July 2005. The subjects included in this study did not have a mental disorder prior to donating their liver. Screening was performed and measured by the donor’s performance on the SCID. The donors with mental health disorders were monitored on the Global Assessment of Functioning (GAF) scale. Six (4.2%) of the 142 LLDs included in this study developed a mental health disorder. The donors who developed mental health disorders had complications post-transplant including inferior vena cava thrombosis, wound infection, severe anemia, and bile leakage. All the donors who had mental health disorders showed an improvement on their GAF scale scores. With therapy 3

This study was very small in scale. Essentially only 6 LLDs were identified as having a mental health disorder out of the 142 screened. In half the LLDs that developed a mental disorder therapy was required over an extended period of time. The exact cause of the mental disorders is not entirely clear. It could be due many factors including relationship problems with the recipient, death of the recipient following transplant, and environmental and genetic factors.

Limitations: The sample size in this study is small. Only 6 people out of the 142 total LLD identified as having a mental health disorder and followed through the course of their mental illness. This study was also conducted at one

Assessment of Functioning Scale (GAF).

achieved remission while 3 continued treatment.

transplant center in Japan, so whether the results would hold up nation-wide or in other countries has not been addressed.

Ladner et al. (2015) United States

Cohort study

The goal for this study is to characterize the HRQoL for LLD up to 11 years following donation.

n=374

The study was conducted using data from 9 transplant centers. The LLD were evaluated before the procedure and at 3 months, one year, and then yearly up to 8 years post-donation.

Between 2004 and 2013, LLD were evaluated with the Short Form survey (SF-36) for LLD who had donated between 1998 and 2010. The researchers looked at the physical and mental component summaries (PCS and MCS, respectively).

The SF-36 consists of 36 questions that provides data to compute the PCS and MCS scores. The average age at donation was 38 and 93% of the donors were white. 43% of the donors had a bachelor’s degree or higher. The largest predictor of a poor PCS or MCS score was the death of the recipient within 2 years of transplantation (PCS p=0.046; MCS p=0.0004).

While most LLD maintain their HRQoL post donation, there are a subset of LLD that are not able to maintain these levels and develop a poor HRQoL. Educational level is a protective factor in those with a bachelor’s degree or higher generally reporting a higher PCS score (p=0.023).

Limitations: This study was generated from several transplant centers; however, 93% of the participants were white, which does not reflect the general US population.
<p>| Maglakelidze et al. (2011) Georgia | Prospective cohort study | n=57 | The participants in this study received three questionnaires, the SF-36, Giessen Subjective Complaints List (GBB-24), and Zerssen’s Mood Scale (Bf-S). | The mean age of the LKD included in the study was 49 years old. There had been 61 kidney transplants since 2005 and 57 of the donors responded to the questionnaires. This gives a 93% response rate. The study uses the commonly used SF-36 to measure the HRQoL for LKD. The authors compare LKD to patients who had nephrectomies due to renal tumors. This is a novel approach and allows them to | The SF-36 found three domains where the LKD were seen to function statistically superior to the control groups. Social functioning (p=0.0001), bodily pain (p=0.0357), and vitality (p=0.0478) were three domains that the LKD scored higher than the control group. In the GBB-24, the LKD group scored higher than the other groups but only the gastric complaints were significantly better (p=0.008) better than the control’s scores. The mood of the LKD were also significantly better than the controls (p=0.0007). | This study found that the HRQoL was generally better for LKD. There were not any dimensions that the authors mentioned where either the controls or renal tumor patients out-scored the LKD. Limitations: The sample size is small and relatively homogenous given the countries size. It would be hard to extrapolate these findings due to these limitations. |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Participants</th>
<th>Study Details</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Maple et al. (2017) United Kingdom</td>
<td>Prospective longitudinal study</td>
<td>n=77</td>
<td>LKD were recruited for this study in their last preoperative visit before donating their kidney. The questionnaire consisted of two parts. The first part consisted of 11 validated measures of psychosocial outcomes. The second part asked questions related to transplantation.</td>
<td>At 3 months, LKD scored lower on physical HRQoL (p &lt; 0.05) compared to their pre-operative scores. While there was a general increase in the scores for depression, depression scores were not significantly different than pre-operative scores. From this LKD population, 6.8% regretted their decision to donate at 3-months, and 10.7% regretted their decision at 12-months. Overall, there was very little change in the overall psychosocial health of LKD in this study. The second part of the study reflected the feelings LKD had regarding the process. Most LKD had positive feelings about donating their kidneys. The authors purported no benefit from kidney donation for the living donor, but there was not a negative effect either. Limitations: This study had a relatively small sample size. Given that questions were added that were not part of validated questionnaires, the changes seen over time might not have been great enough to detect.</td>
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Compare LKD to others who have one functional kidney.
<table>
<thead>
<tr>
<th>Study</th>
<th>Study Type</th>
<th>n</th>
<th>Methods</th>
<th>Results</th>
<th>Limitations</th>
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<tr>
<td>Meyer et al. (2017)</td>
<td>Prospective follow-up cohort</td>
<td>202</td>
<td>This study involved obtaining clinical values such as blood pressure, serum creatinine,</td>
<td>There was no statistically significant association between the clinical variables and either the PCS or MCS. The only statistically significant correlations were seen between gender and general fatigue (p &lt; 0.05) and between BMI and physical fatigue (p &lt; 0.01).</td>
<td>This was one of the initial studies that looked to see if there was a correlation with the donors physiological state with the psychosocial outcomes a decade after donation. Hypertension may be more prevalent in the LKD group, but it does not achieve statistical significance. Limitations: The study may not have been powered to detect differences due to the size of the effects measured and the population included in the study. The study also took place in Norway, which is not as diverse as other places such as the US, so the authors’ conclusions might not have generalizability.</td>
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<tr>
<td>Norway</td>
<td>cohort study</td>
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<td>Those included in this study underwent donation between 2001 and 2004. Clinical data</td>
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<td>obtained for this study included: blood pressure, BMI, creatinine, eGFR, hemoglobin, PTH,</td>
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<td>cholesterol, triglycerides, HDL and LDL. Scores from the PCS and MCS were obtained from the</td>
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<td>SF-36v2.</td>
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<td>The SF-36v2 was employed to assess changes to HRQoL 10 years after organ donation.</td>
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<td>Most LKD participants in the study rated the HRQoL favorably. The most important</td>
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<td>implication of this study was the gender differences seen in the responses to the MFI</td>
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<td>questionnaire. This study demonstrated that women rated their fatigue higher than men</td>
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<td>within the cohort. This result is</td>
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<tr>
<td>Meyer et al. (2016)</td>
<td>Cross-sectional cohort study</td>
<td>217</td>
<td>The authors of this study employed the SF-36v2, the Multidimensional Fatigue Inventory</td>
<td>Most of the HRQoL domains did not demonstrate a difference in score</td>
<td>Most LKD participants in the study rated the HRQoL favorably. The most</td>
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<td>Norway</td>
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<td>(MFI), and donor specific questions,</td>
<td>related to age of gender. The exceptions were that females score</td>
<td>important implication of this study was the gender differences seen in</td>
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<td>The members of this cohort donated their kidneys between 2001 and 2004. To measure</td>
<td>significantly lower</td>
<td>the responses to the MFI questionnaire. This study demonstrated that women</td>
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<td>HRQoL PCS, MCS, physical functioning,</td>
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<td>rated their fatigue higher than men within the cohort. This result is</td>
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<td>Most of the HRQoL domains did not demonstrate a difference in score related to age of</td>
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<td>gender. The exceptions were that females score significantly lower</td>
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In this study both recipients and donors were followed after liver transplant. The donors reported less anxiety symptoms using the STAI-S following transplant (p=0.027). The main predictors of the donor’s psychosocial state following liver transplant were family or support system availability and the recipients’ depressive states when the liver transplant is performed. The social QoL was affected in both donors and recipients 3 to 5 years following liver donation.

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Population</th>
<th>Measures</th>
<th>Results</th>
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<tbody>
<tr>
<td>Noma et al. (2011) Japan</td>
<td>Prospective cohort study</td>
<td>n=30</td>
<td>The State-Trait Anxiety Inventory (STAI) and Beck Depression Inventory (BDI) were used to assess the participants’ mental health</td>
<td>Long-term Anxiety, Depression, and perceived quality of life were measured through the questionnaires were measured several years after transplantation. In this study both recipients and donors were followed after liver transplant. The donors reported less anxiety symptoms using the STAI-S following transplant (p=0.027).</td>
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<tr>
<td>Study</td>
<td>Study Design</td>
<td>Participants</td>
<td>Methods</td>
<td>Results</td>
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<tr>
<td>Rodrigue et al. (2017)</td>
<td>Observational cohort study</td>
<td>United States</td>
<td>n=193</td>
<td>The authors utilized the Profile of Mood States (POMS) to assess anxiety, depression, and anger. To assess the fear of kidney rejection the authors used the 5-item Fear of Kidney Failure (FKF) questionnaire. To assess body image, the 10-item body image</td>
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<tr>
<td>Timmerman et al. (2016)</td>
<td>Netherlands</td>
<td>Prospective cohort study</td>
<td>n=151</td>
<td>The purpose of this study</td>
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<td>domains: mood, fear of kidney failure, body image, life satisfaction, and decisional stability.</td>
<td>scale (BIS) was employed. The 5-item Satisfaction with Life Scale (SWLS) was employed to measure life satisfaction. A series of questions were employed to assess decisional stability. The questionnaires were conducted at 1, 6, 12, and 24 months.</td>
<td>poorer body image. A higher score in life satisfaction indicated increased life satisfaction.</td>
<td>kidney failure (p &lt; 0.001) and associated with a lower score for married individuals (p=0.004). Body image concerns were associated with higher scores for pre-donation body image concerns (p=0.002) and perceived donation pressure (p=0.02). Being white was associated with a lower life dissatisfaction score (p=0.003) while pre-donation life dissatisfaction was associated with a higher score (p &lt; 0.001).</td>
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</table>
is to determine whether stress mediates the psychosocial effects following LKD. A questionnaire prior to donation and at 3 and 12 months. 2012. LKDs had to be at least 18 years old and speak Dutch. and Negative Affect Schedule (PANAS). Well-being was measured by the Dutch Mental Health Continuum-Short Form (MHC-SF). Stress was measured through the Depression Anxiety Stress Scale. Coping scored using the COPE-Easy. respectively). More stress led to a decrease in overall well-being (p <0.001). Limitations: Some of the scales used to quantify the questionnaires have not had their validity confirmed in the situation. The sample size is relatively small which can affect the ability to see changes in outcomes.

<table>
<thead>
<tr>
<th>Author et al. (Year)</th>
<th>Country</th>
<th>Study Design</th>
<th>Sample Size</th>
<th>Methods</th>
<th>Results</th>
<th>Limitations</th>
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<tbody>
<tr>
<td>Timmerman et al. (2015) Netherlands</td>
<td>Cohort study</td>
<td>n=135</td>
<td>The authors got demographic data and measured QoL with the BSI and MHC-SF. The primary analysis was conducted at pre-donation and at 6 months. LKDs were recruited between July 2011 and September 2012. Mental health was assessed utilizing the BSI and MHC-SF. There was no change in psychological disorders (p=0.2) or well-being (p=0.1).</td>
<td>The analysis of the study fails to provide evidence that the HRQoL is affected by any of the factors identified in this study. Limitations: The patients in the LKD group are more likely to be older, which may not reflect the normal age distribution.</td>
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<td>Trotter et al. (2001) United States</td>
<td>Cohort study</td>
<td>n=24</td>
<td>The authors used the Medical Outcomes. In August of 2000, the 24 LLD that signed LLD scored similarly to the HCs in all domains of the</td>
<td>Major and minor complications occurred in 16% of the donors. Most LLD made a complete recovery; however, it took</td>
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<tr>
<td>Walter et al. (2003)</td>
<td>Cohort study</td>
<td>n=28</td>
<td>Study 36-Item Short Form Survey (SF-36) to assess the psychosocial domains of the donors.</td>
<td>SF-36 except for physical function, social function, and mental health (p &lt; 0.05) where the LLDs scores were higher than the controls.</td>
<td>Study 36-Item Short Form Survey (SF-36) to assess the psychosocial domains of the donors.</td>
<td>informed consent were sent the SF-36 questionnaire. The LLDs mean age was 33.2 years old. Men also made up 58% of the cohort.</td>
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<td>Germany</td>
<td>The purpose of this study was to see if one could correlate the donor’s QoL with complications that occur.</td>
<td>In this study the authors subjected the LLD to interviews and performed psychological tests. The authors used the WHOQOL questionnaire to determine any differences in QoL.</td>
<td>The LLDs were recruited between August 2000 to January 2002. The average age of the LLD was 41 years old. The domains included in the WHOQOL questionnaire are: physical health, psychological state, social</td>
<td>Before donating their liver, members of the cohort scored significantly better than the controls in all domains measured with the WHOQOL questionnaire (p &lt; 0.05). Once the donors made it to the 6-month mark, they scored lower on physical health (p &lt; 0.05) and</td>
<td>Before donating their liver, members of the cohort scored significantly better than the controls in all domains measured with the WHOQOL questionnaire (p &lt; 0.05). Once the donors made it to the 6-month mark, they scored lower on physical health (p &lt; 0.05) and</td>
<td>approximately 3.4 months to achieve. Even though the procedure was not painless and there was a significant out-of-pocket expense associated with donating their liver, all donors answered that they would donate again.</td>
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<td>In general, most of the LLDs reported that their QoL as good. This study served as an early example on which others have expanded our understanding of the HRQoL. The majority of donors in this study were not affected by the procedure; however, to really determine whether there is an effect there needs to be a larger sample size.</td>
<td>Limitations: This study is small and was included to provide some historical context.</td>
<td>Limitations: This study has a small sample size and the racial make-up of the study does not reflect the racial make-up of the US population. 71% of the participants were white in this study.</td>
<td>In general, most of the LLDs reported that their QoL as good. This study served as an early example on which others have expanded our understanding of the HRQoL. The majority of donors in this study were not affected by the procedure; however, to really determine whether there is an effect there needs to be a larger sample size.</td>
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<tr>
<td>Study</td>
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<td>Assessments</td>
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<tr>
<td>Walter et al. (2002)</td>
<td>Pilot study</td>
<td>n=23</td>
<td>Psychosocial parameters were measured through the following assessments: the Anamnestic Comparative Self Assessment Scale (ACSA), the Berlin Mood Questionnaire; Giessen Complaint Questionnaire; and the Self-effectiveness, Optimism, and Pessimism Questionnaire.</td>
<td>A total of 26 LDLT we identified at Virchow-Klinikum during the period of December 1999-October 2000. The average age was 41 years old (ranged from 20-years old to 66 years old). Donors were assessed using a variety of quality of life (QoL) measures. Three donors were excluded due to lack of German proficiency. Change in QoL 6 months following transplant from pre-transplant levels. Global quality of life significantly higher 6 months following donation (p=0.044). However, following donation 26% had high values for tiredness (p &lt; 0.0012) and fatigue (p &lt; 0.0012). Other measures of physical complaints were not statistically different from the average population.</td>
<td>Generally, LDLT donors rated their global QoL higher following donation of their liver. While donors reported increases in tiredness (p &lt; 0.021) and fatigue (p &lt; 0.0012) 6 months following organ donation (p &lt; 0.021), donors reported less anxious depression following donation (p &lt; 0.002). Post-operative complications did not significantly affect the QoL domains. Limitations: The sample size for this study is extremely small. Also, the donors were usually spouses or children of the recipients, which could affect perception of the experience.</td>
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List of References


