Review

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Post-liver transplantation patient experience

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Summary

Given improvements in post-transplant patient and graft survival, there is a growing need to focus on patient experience and health-related quality of life (HRQOL). Though liver transplantation can be life-saving, it can also be associated with significant morbidity and complications. Patient HRQOL improves after transplantation, but it may not improve to that of age-matched cohorts. Understanding patient experience and the factors that contribute to it, including physical and psychological health, immunosuppression and medication adherence, return to employment or school, financial burden, and expectations, helps when thinking creatively about potential interventions to improve HRQOL.

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Introduction

Graft function and patient survival are the outcomes most traditionally used to assess the benefits of liver transplant(ation) (LT). Patient and graft survival rates now exceed 90% at 1 year, and 60% at 10 years.[1] Given improved patient and graft survival, patient-reported outcomes (PROs) are now recognised as equally important and are an emerging focus in LT research. In fact, many international organisations focused on the study of liver diseases, such as ELITA (the European Liver and Intestine Transplant Association), ILTS (the International Liver Transplantation Society) and AASLD (the American Association for the Study of Liver Diseases), have specific committees focused on the study and improvement of PROs. Studying PROs, such as symptoms, health-related quality of life (HRQOL), and daily functioning, helps us to understand if we are improving patient quality of life through LT.

Though LT is life-saving in most cases (given lack of bridging therapies like dialysis), it is a surgery that can be quite complicated and can be associated with both short- and long-term complications. While these complications, including rejection, infections, recurrence of disease, or biliary issues, are not usually life-threatening, they contribute significantly to morbidity. Additionally, as with other organ transplants, patients are required to take daily immunosuppression indefinitely. Complications and medication adherence can pose challenges for many patients and it is therefore important to understand how patients cope with life after transplant. In this review, we discuss patient HRQOL, physical and psychological symptoms, immunosuppression and medication adherence, return to employment, financial burden, managing expectations, and interventions after LT. We also discuss special populations, including paediatric/adolescent recipients and living donor liver transplant (LDLT) recipients.

HRQOL

First, it is important to understand what is meant by HRQOL more generally. The World Health Organization defines quality of life as an "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.[2]" HRQOL takes into account physical (ability to participate in usual activities and self-care), psychological (anxiety, depression, distress and cognitive functioning), and social (return to work, loneliness, and social interactions) dimensions of health.[3] Data on HRQOL is usually collected by questionnaire or self-report measures, such as the 36-item short form health survey (SF-36). Very few studies in LT have utilised liver-specific measures. It is therefore important to note that studies performed on HRQOL in LT recipients may fail to capture transplant-specific aspects of quality of life. Additionally, when analysing HRQOL, several different methodologies may be utilised which may make it difficult to compare studies. Lastly, studies on HRQOL may fail to capture a wide-range of individual variation.[4]

That said, most LT recipients experience a significant improvement in HRQOL soon after transplant.[5] Even after 20 years, patient quality of life after LT has been shown to be superior to pre-transplant.[6] However, despite this, patient quality of life after LT is lower than that in the healthy general population.[7] One 12-year follow-up study found that general health perception declined over time.[8] Much of this worsening was thought to be attributable to medical comorbidity,

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Keypoints

- There is a growing need to focus on post-liver transplant patient experience and health-related quality of life (HRQOL).
- Though liver transplantation is life-saving, it can be associated with significant morbidity, including persistent physical and psychological symptoms.
- There are several factors that may influence patient HRQOL after liver transplantation, including immunosuppressive regimens and adherence to immunosuppression, financial burden, return to work/school, and expectations; these factors may differ depending on the age of the recipient (paediatric/adolescent patients *vs.* adult patients) or the type of transplant (living donor *vs.* deceased donor).
- There are several interventions to consider to improve HRQOL, including physical and psychological interventions, technology-based interventions, and team-based interventions.

complications from transplant, recurrent liver disease, effects of immunosuppression, and challenges with reintegration into social and professional networks.[9,10]

The aetiology of liver disease can also play a major role in HRQOL after LT. For one, varying aetiologies of disease are associated with different chances of post-LT recurrence. For example, for alcohol-associated liver disease, the chance of recurrence post-LT is very low if the patient remains abstinent. On the other hand, for autoimmune hepatitis, primary biliary cholangitis, or primary sclerosing cholangitis, recurrence rates can be up to 25%.[11] Both recurrence of disease and fear of recurrence of disease can impair HRQOL. Table 1 demonstrates differences in HRQOL based on aetiology of liver disease, though notably, findings differ across studies.

In addition to aetiology of disease, sociodemographic variables can impact post-transplant HRQOL. In one study, married recipients, those with more than 12 years of education, those who returned to work after transplant, and those with private insurance had better HRQOL.[12] Other studied protective factors include younger age at LT, allograft longevity, and strong social support.[13] Pre-transplant MELD (model for end-stage liver disease) score has also been correlated to HRQOL, with higher pre-transplant MELD scores correlated to better HRQOL after LT.[14]

Physical symptoms after LT

Though patients with liver disease awaiting transplantation are often quite ill, many still experience physical symptoms after transplantation. Notably, physical symptoms can vary significantly when considering the early post-LT period compared to the late post-LT period. Immediately post-operatively, patients are often limited in their physical activity by pain, muscular weakness, fatigue, and sleep disturbances.[15] In fact, fatigue is one of the most frequently reported symptoms in the first month after transplant.[16] Many of these symptoms improve as patients leave the hospital and resume some of their activities of daily living. In one study, at 1-year post-LT, patients reported fewer disease-related symptoms and lower levels of distress.[17]

However, as time from transplant increases, many studies have shown that patients continue to report improved quality of life, but reduced physical functioning compared to the general population[18–20] In a study that measured patients' physical symptoms at 2, 6, 12, and 24 months after LT, patients were found to have improved health-related fitness compared to pre-transplant, but age-standardised overall health-related and cardiovascular fitness remained lower than recommended. By 5 years post-transplant, patient age over 60 and episodes of acute and chronic cellular rejection have been associated with decreases in physical functioning.[12]

One possible explanation for lower physical functioning compared to the general population could be related to skeletal muscle mass. Prior to transplant, the prevalence of sarcopenia, a pathological reduction in muscle mass and strength, is thought to be as high as 40-70%.[21] Post-transplant, especially in the immediate post-operative period, patients could experience a further reduction in lean body mass.[22] Thereafter, many patients gain weight, but in many, it is a gain of fat rather than muscle or lean body mass.[23] In one study, at 1-year post-LT, close to 30% of patients showed low skeletal muscle mass without any significant change in comparison to their pre-operative status. Post-operative intensive care unit stay, biliary complications, and pre-LT low skeletal muscle mass were predictors of low skeletal muscle mass at 1-year after LT.[24]

Another physical symptom that can be challenging for patients after LT is sexual dysfunction. In fact, up to 25% of patients report persistent sexual dysfunction after LT and about 33% report new sexual dysfunction.[25] Additionally, those with sexual dysfunction prior to transplantation have been found to be more likely to experience sexual dysfunction after LT.[26] The percentage of patients reporting problems with their sex life increased over long-term follow-up.[8] Though LT may result in improvements in hormone disturbances in both men and women, side effects of immunosuppression can lead to continued sexual impairment.[27] Additionally, psychological, social, or other health issues can contribute to poorer sexual health. Pharmacologic therapy for erectile dysfunction is not contraindicated after LT and is likely something that should be discussed and offered to patients with sexual dysfunction.[28]

The ability to conceive and become pregnant after LT is of upmost concern to many young women in need of LT. In fact, about 1 in 12 women undergoing LT are of reproductive age.[29] It is recommended that patients use birth control and wait to conceive for 6-12 months after LT, with some centres recommending waiting up to 2 years.[30] Despite immunosuppression, many women have had successful pregnancies after LT. Other than changing mycophenolate mofetil to azathioprine, it is typically recommended not to change immunosuppression during pregnancy. However, it is important to monitor drug

Table 1. HRQOL after LT based on aetiology of liver disease.

Aetiology of liver disease	HRQOL assessed in various studies
Alcohol-associated liver disease	• Decreased HRQOL in domains of physical distress, psychological distress, social/role function, personal function, and general health perception with greatest decreases in physical distress and person function post-LT.[8] • Compared to non-alcohol-associated liver disease, those with alcohol-associated liver disease are less likely to be involved in structured social activities and routine volunteer work post-LT.[105] • Comparable post-LT HRQOL to cholestatic liver disease.[42] • A cross-sectional HRQOL study found significantly impaired HRQOL scores for patients transplanted for alcohol-associated liver disease compared to patients transplanted for other conditions.[106]
NAFLD	• There is not much data on HRQOL in this population, but one publication by the British Transplantation Society Guidelines commented on stigma associated with LT for NAFLD and that persistent cardiovascular morbidity associated with NAFLD after LT should be discussed with patients and guidance provided.[107]
ALF	• One study found no statistical differences between HRQOL in patients with ALF or chronic liver disease. In this study, there was also no difference between HRQOL for acetaminophen overdose compared to other aetiologies of ALF.[108]
Cholestatic liver disease (*i.e.* primary sclerosing cholangitis and primary biliary cholangitis)	• HRQOL post-LT, especially with regard to physical functioning, has been demonstrated to be better in those with cholestatic liver disease than those with other aetiologies of liver disease.[14] • Those with cholestatic liver disease have comparable post-LT HRQOL to alcohol-associated liver disease.[42] • Several studies have noted improvement in well-being for cholestasis aetiologies of liver disease.[109,110]
Neoplasm	• HRQOL post-LT, especially with regard to physical functioning, has been demonstrated to be better in those transplanted for hepatocellular carcinoma than those with other aetiologies of liver disease.[14] • Patients transplanted for non-resectable colorectal liver-only metastases receiving liver transplant also have good long-term HRQOL.[111] • Compared to partial hepatectomy and resection of hepatocellular carcinoma, in one study, those who underwent LT, had higher HRQOL.[112]
Autoimmune liver disease	• HRQOL post-LT, especially with regard to physical functioning, has been demonstrated to be better in those with autoimmune liver disease than those with other aetiologies of liver disease.[14] • In another study, patients with autoimmune liver disease had decreased HRQOL with regard to physical distress, social/role function, personal function, and general health perception.[8]
Hepatitis B viral infection	• In one study conducted in China with a patient population of mostly patients with hepatitis B, LT improved HRQOL compared to pre-LT, but HRQOL still did not reach that of the general population.[113]
Hepatitis C viral infection	• Though recurrence is now rare with effective anti-viral therapy, recurrence of hepatitis C has been associated with impaired long-term HRQOL.[10,114]

ALF, acute liver failure; HRQOL, health-related quality of life; LT, liver transplant; NAFLD, non-alcohol-associated fatty liver disease.

levels carefully. LT has been associated with foetal loss, prematurity, and low birth weight as well as maternal hypertension, pre-eclampsia, gestational diabetes, and graft dysfunction. For these reasons, it is important that patients who become pregnant are monitored by a multidisciplinary team.[27]

Psychological symptoms after LT

Though most patients experience a physical improvement following LT, psychologically, transplant can be challenging. In one study of various different kinds of transplant recipients, >30% demonstrated features of clinically significant mental distress after transplant.[31] Immediately post-operatively, many patients report a decline in depression and anxiety scores, but these symptoms can worsen over time.[32] In fact, up to one-quarter of patients have persistent symptoms of anxiety and depression that are associated with lower HRQOL and medication non-adherence.[33]

Many patients report feelings of social isolation and helplessness secondary to being confined to the house to prevent infection and having to depend on others for care.[34] Depression has actually been associated with increased odds of mortality, graft loss, and graft rejection.[35] In one study of patients with alcohol-associated liver disease, even after controlling for medical factors associated with poorer survival, LT recipients with increasing or persistent depression had an all-cause mortality rate that was twice that of those with low rates of depression.[36]

Lastly, neuropsychologic impairment can be seen after LT. This impairment can be multifactorial and can be the result of immunosuppression, peri-operative complications, or consequences of long-standing hepatic encephalopathy.[37] The practice of transplanting older individuals with end-stage liver disease is growing and older individuals have an increased risk of long-term neurologic sequelae. One study looked at neuropsychologic tests and MR imaging before LT, during the first year after LT, and several years after LT to assess the different contribution of each period to neurologic outcome.[38] The authors found that neuropsychologic function improved after LT and remained stable up to 9 years after intervention, but there was progressive increase in both the volume of the ventricles and the number of white matter lesions in the brain that could theoretically lead to long-term cognitive disturbances. Another study found that 70% of LT recipients had a new cognitive impairment in domains including delayed memory, visuospatial ability, immediate memory, language and attention.[39] These neurologic and cognitive impairments could have an additive effect on other psychologic symptoms patients may be experiencing.

Immunosuppression and medication adherence

Immunosuppression for LT usually involves a combination of multiple drugs, all of which can be associated with unique side effects that can impact HRQOL. Steroids, which are used in

especially high doses immediately following transplant, can be associated with significant anxiety[40] and long-term, can lead to bone loss, as well as increased rates of diabetes and other complications. Calcineurin inhibitors can lead to nephrotoxicity, neurotoxicity, metabolic derangements, and hypertension. For this reason, they have a very narrow therapeutic window and require close monitoring.[41] There is conflicting literature regarding the differential effects of the two most commonly used calcineurin inhibitors – cyclosporine and tacrolimus – on quality of life. Some studies have shown improved quality of life with cyclosporine compared to tacrolimus,[42] but others have shown the opposite.[43]

In all chronic illnesses, medication adherence can be a challenge for patients. A study of patients 6-24 months post-LT found that 35% of patients had missed a dose of medication and an additional 14% had taken a different dose than prescribed. Additionally, 30% reported one or more 24-hour immunosuppression holidays in the past 6 months.[44] Other studies have reported even higher percentages of non-adherence of up to 73% in the first 6 months and 22-62% within 3 years.[45,46] Poor adherence to immunosuppression, specifically, is associated with greater risk of graft rejection and complications. Non-adherence to medication has been associated with both hospital readmission and increased healthcare costs.[47] Non-adherence to clinic visits has also been reported to be as high as 45%, though rates vary across studies.[48] It is important to note that, in general, adherence can be difficult to define and definitions may vary across studies.

There are many potential reasons for non-adherence to medication. In one study, predictors of missing doses were male sex, longer time since transplant, pre-LT mood disorder, and pre-LT social support instability, while predictors of taking a different dose than prescribed were pre-LT mood disorder and pre-LT social support instability.[44] Other factors that may impact adherence include treatment-related factors such as the cost and number of medications, the frequency with which medications are taken, and side effects associated with medications.[48,49] Some pre-transplant factors to consider that may predict non-adherence include self-reported non-adherence before transplant, lower social support, higher education levels, and lower conscientiousness.[50]

Return to employment

One of the goals of many patients after LT is to be able to return to work. It is important to consider, however, that only about 30% of LT recipients over age 50 return to work after transplant.[51] In fact, one study found that 1 in 10 patients did not return to work until ≥3 after LT.[52] Reasons for unemployment could be related to health complications, but unemployment itself can lead to loss of insurance, financial difficulties and lower adherence to medication, thereby exacerbating these health complications.[53,54] Unemployment has also been associated with stress, depression, and lower self-rated health.[55]

One qualitative study found that patients were motivated to return to work to be able to provide financially for their family and to escape feelings of "uselessness" or social isolation. However, these same patients reported concerns over physical limitations in their ability to work or concerns about being immunosuppressed.[34] Other factors that may contribute to unemployment include individual socioeconomic status, local labour market conditions, onset of diabetes, and acute rejection.[52]

Employment is, in fact, associated with better HRQOL.[56,57] However, it is hard to know whether it is the employment itself that is associated with better HRQOL or the factors associated with employment, such as few or minor complications, short hospital stay, or better support. Regardless, providing patients with resources and tools to help support their return to work is likely to improve their HRQOL.

Financial burden

Prior to being evaluated and listed for liver transplant, patients' insurance must be both in place and adequate. However, despite this, many recipients face significant expenses both at the time of transplant and thereafter that they may not have anticipated. Examples of these types of expenses include deductibles, co-payments, cost of transportation to and from visits, childcare costs, temporary lodging, and meals. There is also the indirect cost of lost wages. A study by Rodrigue *et al.* found that 42.6% of LT recipients reported that health problems related to their transplant caused financial problems for themselves and their families.[58] In fact, in this study, recipients reported an average out of pocket monthly cost of over $500 and 51.2% of recipients reported less income after transplantation. Interestingly, 8% of patients reported that they would not have undergone transplantation had they known its financial impact. Predictors of greater financial impact included older age, being unmarried, being unemployed in the year preceding transplantation, being currently unemployed, and longer time on the waiting list.[58]

In addition to the costs that recipients might incur during the index hospitalisation when transplantation takes place, there are additional costs that arise with complications and readmissions to the hospital. Complications, including infection, acute rejection, and biliary issues are actually quite common. One study looked at medical and financial records of adult LT recipients and found that the payor (the recipient) bears the financial burden for post-LT complications.[59] Quality improvement projects that aim to prevent complications and reduce costs for recipients of LT are important to improve HRQOL.

Managing expectations

Patient expectations prior to transplant play a large role in their experience post-operatively. Unrealistic or unfulfilled expectations may result in increased stress and worsened HRQOL after LT.[60] In a qualitative study conducted on patients pre-transplant, participants articulated the importance of establishing a plan and setting shared expectations between providers and patients.[61] In a study conducted in Germany, the majority of patients who expected their lives to normalize post-LT did not feel that their expectations had been met.[60]

Patients may define post-LT success very differently depending on what is most important to them. Understanding what is most important to patients can help to prevent disappointment, regret, and unhappiness. One study looking at patient expectations found that a mean reduction in pain of 33%, in fatigue of 56%, in emotional distress of 44%, and in interference with daily activities of 54% would be needed for patients to consider LT successful.[62] Not meeting these goals could be associated with reduced HRQOL.

Special populations

Paediatrics and adolescence

Paediatric and adolescent patients are a unique population. Multiple studies have suggested that paediatric/adolescent LT recipients have lower HRQOL than age-matched controls.[63] A meta-analysis published by Parmar *et al.* reported lower HRQOL scores, especially in the domain of physical functioning.[64] Even 20 years after LT, in one study, paediatric recipients reported lower physical, general, and mental health as well as lower social functioning.[13] However, when compared to paediatric recipients of other solid organ transplants and paediatric patients with other chronic illnesses, HRQOL for LT recipients was similar.[64]

There are several factors that have been demonstrated to impact HRQOL in the paediatric and adolescent population. For example, recipients with lower medication adherence reported lower HRQOL scores.[65] In an effort to improve both medication adherence and HRQOL, Jerson *et al.* developed an intervention targeted at adherence in the adolescent population. Though adherence improved with the intervention, HRQOL did not.[66] Additionally, those with greater sleep disturbances reported lower HRQOL scores.[64] Older age at transplant has been associated with lower HRQOL. Adolescents, compared to paediatric patients, may be increasingly aware of the traumatic life event and of how transplant will interfere with their daily lives.[67] Other factors associated with HRQOL include secondary chronic illnesses, symptom distress, history of emotional difficulties, self-esteem, and family conflict.[68]

Unlike adults who often have difficulties in returning to work, the majority of paediatric recipients go on to complete secondary education and about half go on to higher education.[13] One study found that most children were in age-appropriate and standard school classes or were only about 1 year behind. In fact, many children had improved cognitive and gross motor abilities when compared to pre-transplant.[69]

LDLT

There has been a growing body of research dedicated to determining both medical and psychological outcomes in LDLT recipients. Patient survival after LDLT is actually predicted to be higher than survival after deceased donor liver transplant (DDLT) according to recent meta-analyses,[70] but little is known about HRQOL.

One study examined longitudinal SF-36 scores in LDLT recipients prior to surgery, and at 3-, 6-, 12-, and 18 months after transplant. As in DDLT, HRQOL was severely impaired preoperatively and improved significantly after LT, but still remained lower than in healthy controls.[71] Additionally, as in DDLT recipients, physical functioning has been shown to improve after transplant in LDLT recipients, but not to the levels of non-transplant controls. In one study, younger age and higher skeletal muscle mass were predictors of improvement in moderate-to-vigorous physical activity in LDLT recipients.[72] Though there have been few studies comparing HRQOL after LDLT *vs.* DDLT, one such study did find that DDLT recipients were able to achieve higher HRQOL scores, as measured by the SF-36, in the majority of domains after transplant compared with LDLT recipients. However, this study did not account for severity of illness at the time of transplant, which could explain some of the observed differences.[73]

Interventions

Understanding factors that contribute to HRQOL in patients after LT is important, but it is imperative to begin to focus on

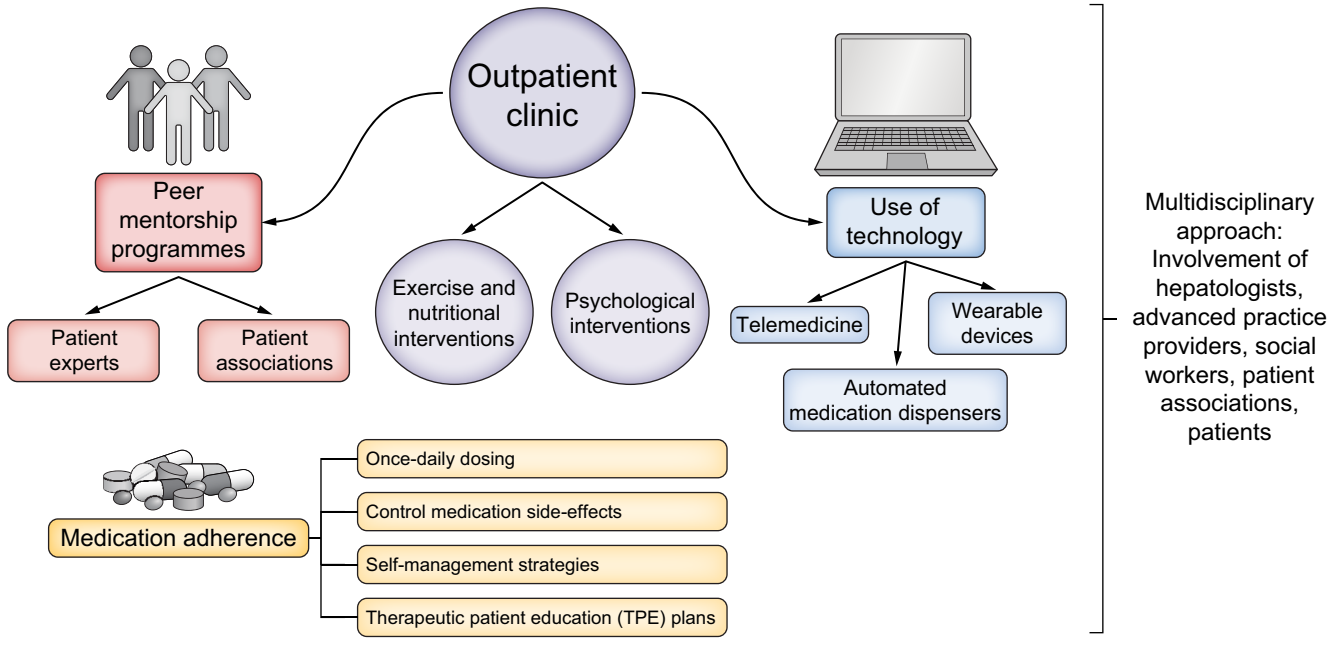


Fig. 1. Interventions to improve HRQOL in the outpatient setting. Overview of several interventions that can be implemented in the outpatient setting to improve HRQOL, including exercise and nutritional interventions, psychological interventions, peer mentorship programmes (with the help of patient experts and patient associations), use of technology (including telemedicine, wearable devices, and automated medication dispensers), and ways to improve medication adherence. HRQOL, health-related quality of life.

interventions to improve HRQOL in this unique population. Fig. 1 provides an overview of possible interventions that can be implemented in the outpatient setting. Each of these potential interventions are discussed in greater detail below.

Physical interventions

As already discussed, post-transplant physical activity and mobility are associated with improved HRQOL.[74] Therefore, interventions targeted at improving physical functioning in the post-LT population are important. In one randomised-controlled trial, an exercise and diet intervention led to greater exercise capacity and self-reported general health despite only 37% adherence.[75] In another smaller randomised trial, those randomised to a programme of 24 exercise treadmill sessions over 12 weeks *vs.* usual care, increased their 6-minute walk distance and resting energy expenditure.[76] A third randomised trial compared a 24-week exercise intervention involving two 75-minute sessions per week of moderate-to-high intensity resistance and aerobic exercise *vs*. usual care and found that VO_2 peak and global muscle strength increased in the intervention arm compared to the control arm.[77]

Psychological interventions

Though there have not been robust studies in patients after LT specifically, there have been studies conducted in other solid organ transplant recipients that have looked at psychological interventions to improve recovery. One study in renal transplant recipients examined a positive psychology intervention that involved verbal and non-verbal techniques, art therapy, and relaxation to facilitate coping and recovery, to elaborate on losses, to repair the injured body image, and to restore positive self-esteem; they found that this intervention led to better mental functioning and general well-being and that these improvements were actually associated with better kidney function.[78]

Interventions to improve medication adherence and manage expectations

Because medication non-adherence following LT is often secondary to medication side effects and confusing or frequent dosing intervals, attempts have been made to improve upon these factors and thereby increase adherence. One strategy has been to change the dosing interval of calcineurin inhibitors from twice daily to once daily with a longer-acting version of the medication. Once-daily dosing has been correlated with greater medication compliance.[79] In fact, this strategy of once-daily dosing has been associated with improved long-term graft survival with a minimal impact on costs.[80]

Self-management has also been shown to be a successful strategy to improve patient adherence to medication. LT recipients have identified that their ability to self-manage their disease and understand all of the information provided to them have improved their adherence to medical treatments.[81,82] In a qualitative study conducted in LT recipients, patients reported using a combination of strategies for medication adherence, including a medication card/list, travel bags with extra medications, phone alarms, and reminders from caregivers. Having a routine was also identified as important.[34]

Interventions to manage expectations pre-transplant can also have a positive impact on post-LT outcomes. Small group meetings have been suggested as a way to improve patient self-management and expectations and have been used across a variety of chronic diseases.[83] Peer-led discussions facilitate peer interaction and social support, as well as education. In LT specifically, discussions with prior LT recipients may be helpful for pre-LT patients to better understand the possible complications, immunosuppression requirements, and impact on daily living of LT. Expert patients, patients who are empowered with skills, confidence, and knowledge to play an active role in making informed decisions about their own health and chronic condition, can serve as key mentors to other patients.[84,85] Patient communities can also collaborate in medical research. Patient associations, such as the European

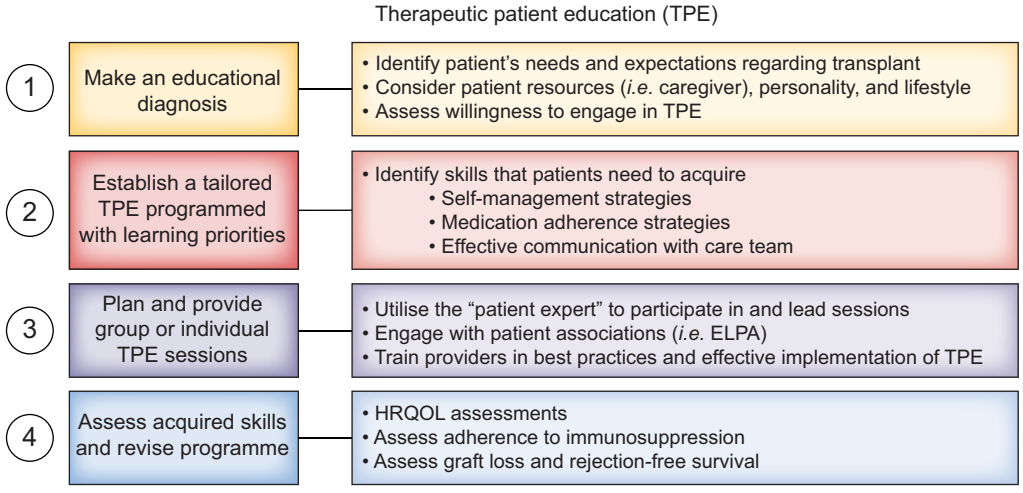


Fig. 2. Therapeutic patient education plan for patients after liver transplant. This sample TPE plan serves as a model that can be implemented by multidisciplinary teams caring for patients in the post-liver transplant setting. ELPA, European Liver Patient's Association; HRQOL, health-related quality of life; TPE, therapeutic patient education.

Liver Patient's Association (ELPA) have been involved in several research projects in Europe. In fact, in 2022, ELPA applied to 22 new medical research projects.[86]

ELPA has also been very successful in organising groups of patients to help with increasing awareness of liver disease, reducing stigma, providing mentorship, and sharing successful initiatives.[87,88] Lowering stigma in liver disease is especially important as the rates of non-alcohol and alcohol-related liver disease continue to rise. At a programme level, the University Health Network in Toronto, Canada, has successfully established a peer mentorship programme for heart, lung, and liver transplantation that has been popular among patients.[89] Lastly, these kind of mentorship programmes have also been successful in paediatric and adolescent recipients.[66,90]

Technology-based interventions

Telemedicine has grown tremendously since the start of the COVID-19 pandemic. As it does in other areas of medicine, telemedicine has the potential to improve the quality of care in patients after LT. One pilot-study randomised patients into standard of care *vs.* enrolment in a telemedicine-based home management programme. As part of this programme, patients received an electronic tablet and Bluetooth devices to support daily text messages, educational videos, and video FaceTime. Compared to the standard of care group, the intervention group had a lower 90-day readmission rate and showed improved quality of life with regard to physical functioning and general health.[91] Another study demonstrated that a telehealth-delivered diet and exercise programme was an acceptable alternative to face-to-face care for LT recipients.[92]

Studies conducted in renal and lung transplant recipients have demonstrated that the use of telemedicine has been shown to increase adherence to medications, self-monitoring and laboratory testing.[93–95] However, there are limitations to telemedicine-based approaches. Telemedicine may not be cost-effective and has the potential to further disparities for those that do not have access to electronic devices or for those who are not comfortable with technology.[96,97]

Other technology-based interventions, such as mobile apps or wearable devices, have the potential to improve HRQOL in patients with liver disease. Personalised daily texting, for example, has been shown to significantly improve medication adherence.[98] Theoretically, the data collected through wearable technology or phone-based apps could be fed back to healthcare professionals so that adjustments to medication dosage or timing can be made in real time. Though often expensive, automated medication-dispensing technology can also improve adherence. This type of technology can help to safely organise pills and provide reminders to take medications, dispense medications, and notify caregivers of missed doses.[99]

Though studies have not been conducted in LT recipients, mobile health applications have been demonstrated to be helpful in kidney transplant recipients. A systematic review demonstrated that information technology-based interventions, such as mobile health applications, wearable devices, and computer systems, can improve self-management in recipients, thereby leading to improved clinical and care process outcomes.[100]

Team-based interventions

Multidisciplinary care, with involvement of physicians, social workers, allied health professionals, and nurses, has always been associated with advantages in the care of transplant recipients. In fact, the implementation of a nurse practitioner-based post-LT care programme has been associated with decreased 30-day and 90-day readmission. Much of the success of this programme was attributed to earlier first follow-up clinical visits and earlier phone encounters.[101] It has also been suggested that better or more robust support groups or mentorship programmes could help post-LT recipients to navigate physical and emotional setbacks.[34]

Therapeutic patient education (TPE), as defined by the World Health Organization, helps patients to develop the skills they need to manage their life with a chronic disease.[102] TPE is best implemented by a multidisciplinary team. Educational programmes such as these have been shown to improve health behaviours, disease outcomes, and quality of life.[103] TPEs typically involve several steps: i) make an educational diagnosis; ii) establish a tailored TPE programme with learning priorities; iii) plan and provide group or individual TPE sessions; iv) assess acquired skills and revise programme. An example of a successful TPE programme in LT may follow the algorithm outlined in Fig. 2.[104]

Conclusions

Given improvements in post-transplant patient and graft survival after LT, there is a growing need to focus on patient experience and quality of life. It is clear that most patients experience improved HRQOL after LT; however, in most studies, quality of life is still lower than that of the general population, especially with regard to physical functioning. Some of this can be attributed to medical complications after LT, severity of illness pre-LT, and side effects of life-long immunosuppression. Financial burden and medication non-adherence are additional factors that can contribute to patient experience. Lastly, unrealistic or overly optimistic expectations of LT could also lead to lower perceived HRQOL.

There is already work being done to try to improve HRQOL in patients after LT. Interventions aimed at improving physical and psychological functioning as well as medication adherence and reduction in hospitalisations have already been developed in both adult and paediatric/adolescent populations. More work is needed to develop transplant-specific quality of life measures and to intervene where deficits are found. In future work, it will also be important to focus on caregiver burden in the post-transplant period as it is typically closely linked to and impacted by the recipient's experience.

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Abbreviations

DDLT, deceased donor liver transplant; ELPA, European Liver Patient's Association; HRQOL, health-related quality of life; LDLT, living donor liver transplant; LT, liver transplant(ation); PROs, patient-reported outcomes; SF-36, 36-item short form health survey; TPE, therapeutic patient education.

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Conflict of interest

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Authors' contributions

Conception and design of the manuscript: AK, MK, RSB. Drafting the manuscript: AK. Editing the manuscript: AK, MK, RSB.

Data availability statement

The data presented in this review manuscript is all publicly available in the manuscripts cited.

Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.jhep.2023.01.008.

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