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Authors

Lai, Jennifer C
Ufere, Nneka N
Bucuvalas, John C

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Liver Transplant Survivorship

Jennifer C. Lai, MD, MBA,

Department of Medicine, University of California-San Francisco, San Francisco, CA

Nneka N. Ufere, MD,

Department of Medicine, Massachusetts General Hospital, Boston, MA

John C. Bucuvalas, MD

Department of Pediatrics, Kravis Children's Hospital and Icahn School of Medicine at Mount Sinai, New York, NY

Abstract

For both children and adults with end-stage liver disease, liver transplantation represents a life-long treatment, not a cure. The physical and psychological process of undergoing transplantation begins well before the surgery itself. Concerns regarding suffering and death from end-stage liver disease are replaced by a life-long need for multiple medications, ongoing monitoring of graft function, and heightened vigilance for complications related not only to the transplant itself but to long-term immunosuppression. The psychological toll from the entire transplant experience on the patient and caregivers, as well as the strain that such a major treatment places on these human interactions can leave emotional scars that persist longer than the surgical healing process itself. The concept of “survivorship”, originally applied to patients with cancer, acknowledges the ongoing spectrum of care and support that patients and their caregivers require to optimize long-term outcomes after serious medical treatment. *Transplant* survivorship would expand the focus of care of a patient with end-stage liver disease beyond disease-specific issues and survival alone. This viewpoint explores the need for such a construct in the field of liver transplantation to promote a more holistic approach that encompasses the overall physical, psychological, social and spiritual well-being of the liver transplant patient.

Keywords

end-stage liver disease; solid organ transplantation; patient-centered outcomes; quality of life

Since the first successful liver transplant in 1968, ongoing advances in the field of liver transplantation have led to enormous success in extending the lives of patients with end-stage liver disease.¹ Five-year survival rates for liver transplantation now approach 76% for adults and 90% for children.² This is particularly remarkable given that these patients, prior

Corresponding Author: Jennifer C. Lai, 513 Parnassus Avenue, UCSF Box 0538, San Francisco, CA 94143. Jennifer.lai@ucsf.edu; tel: 415-476-2777; fax: 415-476-0659.

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to their transplant, had been diagnosed with an otherwise terminal condition whose prognosis could be measured *in mere months* in the absence of life-prolonging therapies. For this reason, liver transplantation is often considered a “cure” for end-stage liver disease by patients and their families.

However, liver transplantation is, in reality, a *therapy*, not a cure. Adult liver transplant recipients remain at risk for recurrent disease from the chronic condition that originally led to liver failure. For pediatric liver transplant recipients, recurrent disease is a relative rarity, but the risk of immunological graft damage and ultimately graft loss secondary to inadequate immunosuppression are insidious—and persistent—threats to the graft extending over one’s life-time. Regardless of how old the recipient is at the time of liver transplantation, care of the liver allograft itself requires intensive monitoring and surveillance that, while lessening over time, is a life-long commitment. The psychological toll from the entire transplant experience on the patient and caregivers, as well as the strain that such a major treatment places on these human interactions, can leave emotional scars that persist longer than the surgical healing process itself.

Despite these well-recognized physical and psychological challenges of the transplant experience, management of the liver transplant patient has largely focused on disease-specific issues and the function of the allograft itself.³ As a result, delivery of care to the liver transplant patient—both before and after transplant—has remained siloed within disciplines with little emphasis on the global well-being of the patient and their caregivers.

Survivorship, as a concept

Originating in the field of oncology, survivorship is a construct that focuses on the health and well-being of a person from the time of diagnosis through treatment and beyond.^{4,5} In addition to the medical effects of cancer and its treatment, the survivorship experience also includes psychosocial concerns such as coping with the diagnosis of cancer and addressing the burdens of the caregiver(s). By considering the experience of a patient holistically, rather than *solely* from the perspective of the chronic disease, the survivorship model encompasses a broad range of dimensions central to quality of life, including physical, psychological, social, and spiritual well-being.⁶

The experience of the liver transplant patient shares many parallels with that of a cancer patient. If we use cancer survivorship as our model, then transplant survivorship conceptually would begin at the time of diagnosis of end-stage liver disease and last through the patient’s entire lifespan, through transplant until death (Figure).⁷ Issues specific to transplant that emerge in each phase of the transplant patient’s experience—from diagnosis to life after transplant—are explored here.

Transplant-specific issues across the healthspan of the liver transplant survivor

Diagnosis of end-stage liver disease

Patients with advanced liver disease often initially present either with a new symptom or laboratory/radiographic abnormalities that lead to their diagnosis. Initially, these symptoms may be easily managed with medications (e.g., ascites, hepatic encephalopathy) or are asymptomatic altogether (e.g., nodular liver, thrombocytopenia, esophageal varices). In this stage of the patient's experience, he or she, together with caregivers, must cope with not only the new diagnosis of a serious chronic medical condition, but also with the uncertainty of the timing of progression to liver failure. If diagnosed early enough, patients may be afforded the hope that they can halt progression of their condition to avoid transplantation. For those whose etiology of end-stage liver disease is not reversible, this diagnosis is terminal in the absence of transplantation.

Progression to end-stage liver failure

This stage is predominantly characterized by the management of the debilitating symptoms of liver failure. Escalation of doses of diuretics, initiation of new medications, and performance of procedures to manage refractory symptoms, such as large volume paracenteses, a transjugular portosystemic shunt, or variceal banding, may be attempted to slow the symptoms and sequela of progressive portal hypertension. Although these strategies may be effective in managing the symptoms for months and even years, none resolve the primary liver failure itself nor completely eliminate the eventual need for liver transplantation.

In addition to the complications of liver failure, patients with end-stage liver disease also experience high symptom burden and emotional distress. Symptoms such as pain, physical disability, insomnia, anorexia, fatigue, sexual dysfunction, depression, and anxiety are both highly prevalent and undertreated.⁸ As liver failure progresses, patients become increasingly reliant on their caregivers for support, which can lead to family distress, financial strain and caregiver burden.⁹ Furthermore, the uncertainty of the timing of transplantation can exacerbate an already overwhelming fear of death, which is often greater than fear of the transplant surgery itself. The loss of control in the setting of uncertainty and fear can affect the coping skills and spiritual well-being of patients and their caregivers who may become desperate to achieve transplantation, as each day with the failing liver represents another day of risk of death or being identified as someone for whom transplant is futile.

Life after liver transplantation

In the immediate post-transplant period, there is an abrupt, dramatic shift in the physical and emotional experience for the patient and caregivers. While the physical symptoms related to end-stage liver disease may resolve quickly, they are replaced by post-operative pain, other symptoms related to technical complications of the transplant surgery, and the side effects of immunosuppressive therapy. Emotionally, concerns about death on the waitlist are replaced by anxiety over whether the allograft will function, anticipation of early surgical

complications, and confusion over the indications and ever-changing dosing of multiple new medications.

Once out of the hospital, patients and their caregivers begin the process of adjustment to their new life. Prior to transplant, patients and their caregivers were so singularly focused on surviving *to* liver transplant that they did not consider what life after transplant might look like. More often than not, the expectation—that their “new” life after transplant will be their “old” life before they became ill—is misaligned with reality. Years of severe, chronic end-stage liver disease, coupled with frequent hospitalizations and then a major surgery, can result in irreversible depletion of muscle mass reducing a patient’s ability to resume the physical activities they once previously enjoyed. Patients may experience survivorship-related distress such as post-traumatic stress disorder, survivor’s guilt from receiving a life-saving organ from a deceased donor, and fear of disease recurrence or relapse, which may be unanticipated. Patients and their caregivers also have to adapt to new treatments and medication adherence. Medications that patients were taking prior to transplant to manage symptoms of their end-stage liver failure are replaced by an equal—if not greater—number of medications to prevent rejection and alleviate the side effects from—or manage new conditions that developed as a direct result of—immunosuppression. The neurocognitive effects related to chronic hepatic encephalopathy and potentially, of long-standing immunosuppression may impair a patient’s ability to resume professional activities to the same degree as prior to their illness, which can exacerbate financial strain. For children, the neurocognitive effects of both pre-transplant liver failure and post-transplant immunosuppression can compromise their potential for physical, emotional, and intellectual development. Lastly, relationships and dependency that had been shaped around the patient’s serious, life-threatening illness must adapt to a new life with an equally chronic, but less-debilitating condition.

Conclusion and Future Directions

The concept of transplant survivorship acknowledges the ongoing spectrum of care and support that patients and their caregivers require to optimize long-term outcomes in liver transplantation. It expands the focus of care of a patient with end-stage liver disease beyond disease-specific issues and promotes a more holistic approach that encompasses the overall health and well-being of the patient. Importantly, it recognizes the critical role that the caregiver(s) plays in achieving optimal outcomes in liver transplantation.

Advancing clinical care and research related to liver transplant survivorship will require the following:

1. Performing routine, longitudinal screening of patient- and caregiver-centered outcomes across the domains of physical, psychological, social, and spiritual well-being using consistent and standardized measures;
2. Collaborating with services such as specialty palliative care, social work, mental health providers, spiritual care, and support groups that are important psychosocial resources for patients and their caregivers;

3. Developing interventions targeted to improve patient and caregiver quality of life across the continuum of care, from diagnosis through liver transplant and beyond.

Introducing the concept of survivorship into liver transplantation will pave the way for development of programs to deliver such holistic, multi-disciplinary care to transplant patients, similar to models of care delivery for cancer survivors that exist today.¹⁰ While liver transplantation may, perhaps, remain the most effective treatment for end-stage liver disease, embracing a more holistic approach to the care of liver transplant patients—from diagnosis of liver disease to well beyond the transplantation itself—will enable this ever-growing population of patients to not just survive to transplant but thrive after.

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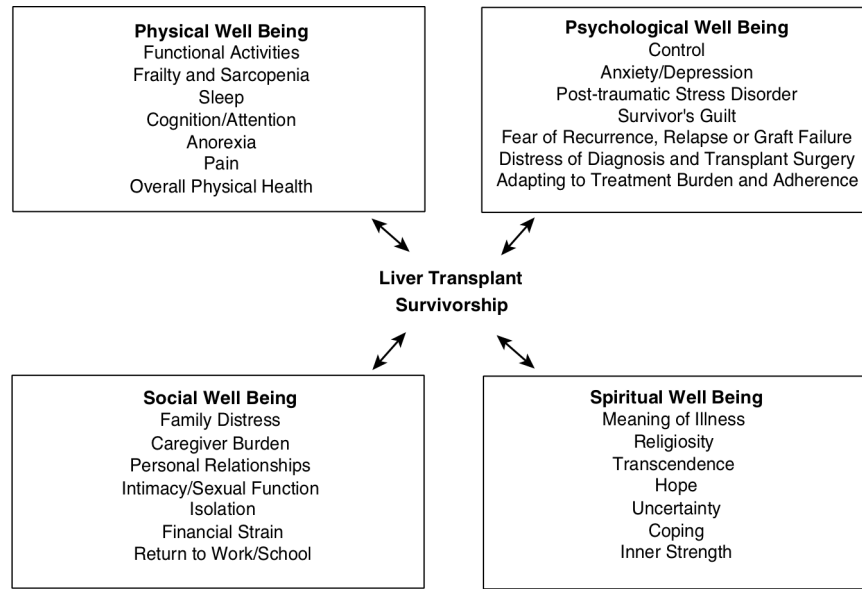


Figure. The conceptual model for liver transplant survivorship. Adapted with permission from Ferrell(7) (2004).