Original Article

Changing End-of-Life Care Practice for Liver Transplant Service Patients: Structured Palliative Care Intervention in the Surgical Intensive Care Unit

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Abstract

Context. Patients, families, and surgeons often have high expectations of life-saving surgery following liver transplantation (LT), despite the presence of a severe life-limiting underlying illness. Hence, transition from curative to palliative care is difficult and may create conflicts around goals of care.

Objectives. We hypothesized that early communication with physicians/families would improve end-of-life care practice in the LT service patients.

Methods. Prospective, observational, pre/poststudy of consecutive LT service, surgical intensive care unit (SICU) patients, before and after a palliative care intervention was integrated. This included Part I (at admission), family support, prognosis, and patient preferences delineation; and Part II (within 72 hours), interdisciplinary family meeting. Data on goals-of-care discussions, do-not-resuscitate (DNR) orders, withdrawal of life support, and family perceptions were collected.

Results. Seventy-nine LT patients with 21 deaths comprised the baseline group and 104 patients with 31 deaths the intervention group. Eighty-five percent of patients received Part I and 58% Part II of the intervention. Goals-of-care discussions on physician rounds increased from 2% to 38% of patient-days. During the intervention, although mortality rates were unchanged, DNR status increased (52–81%); withdrawal of life support increased (35–68%); DNR was instituted earlier; admission to DNR decreased (mean of 38–19 days); DNR to death time increased (two to four days); and SICU mean length of stay decreased (by three days). Family responses suggested more "time with family"/"time to say goodbye."

Conclusion. Interdisciplinary communication interventions with physicians and families resulted in earlier consensus around goals of care for dying LT patients. Early integration of palliative care alongside disease-directed curative care can

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be accomplished in the SICU without change in mortality and has the ability to improve end-of-life care practice in LT patients. J Pain Symptom Manage 2012;44:508–519.

Key Words

Liver transplantation, palliative care, surgical intensive care unit, end-of-life care, end-stage liver disease, interdisciplinary model

Introduction

Liver transplantation (LT) is the most effective treatment for many patients with acute or chronic liver failure resulting from a variety of causes. It was declared a valid nonexperimental therapy for the irreversible and fatal complications of end-stage liver disease (ESLD) in the 1980s.[1,2] The most commonly used technique is orthotopic transplantation, where the native diseased liver is replaced by a liver from a recently deceased donor. Because of the regenerative properties of liver tissue, living-donor LT is sometimes used when a portion of a healthy liver from a living donor (often a parent) is used to replace the diseased liver in a recipient (often a child).[3] Currently, increased experience, in combination with the advent of better immunosuppressive agents, has dramatically improved short- and long-term clinical outcomes after LT. One year patient survival rates now approach 90%, with seven- to 10-year survival rates of 60–80%, depending on the underlying disease process necessitating LT.[4,5] This is in stark contrast to the almost zero 10-year survival in advanced ESLD without transplantation.[2] It is, therefore, not surprising that despite having a severe life-limiting illness and a high age-adjusted mortality, patients, families, and transplant clinicians have high expectations of transplant surgery. Currently in the U.S., approximately 17,000 patients are on the liver waiting list and around 6000 liver transplants are performed annually, so demand far exceeds availability.[5] The median wait for a liver is variable and may depend on how sick the patient is or where they live (in 2007, the median time to transplant was 319 days).[5] Patients may be removed from the waiting list because of death or being too sick for a transplant, and this "dropout" rate averages around 150 per 1000 patient-years at risk.[5]

The overall curative disease-directed approach of transplantation may seem to be at odds with the concept of palliative care.[6] Similar to other surgical disciplines, transplant clinicians often perceive palliative care as a last resort measure when "nothing more can be done."[6–8] However, the LT service patient population with ESLD often suffers from a high social, economic, physical, and emotional burden related to their chronic illness.[9] They face multiple quality-of-life challenges like fatigue resulting from malnutrition, mobility impairment from ascites, and depression and cognitive loss as a result of encephalopathy.[9,10] Despite this underlying progressive illness, goals of care and end-of-life issues are seldom discussed before LT.[10–12] A sequential approach is often followed, with disease-focused aggressive care until patients are removed from the transplant list because of disease severity or poor survival chance and then the involvement of palliative care. This sequential approach often results in patient death shortly thereafter, without a chance for meaningful contribution and optimization of end-of-life care.[11] For the patients who undergo transplantation surgery, the practice of using mortality statistics to measure a program's performance or success may contribute to the value placed on prolonging the "quantity" of life.

The provision of appropriate end-of-life care to the critically ill LT service patients may be challenging, in the setting of an aggressive disease-directed focus. The surgical intensive care unit (SICU) is often the setting where a patient on the transplant service may die either because of a catastrophic event while awaiting LT (before any surgical intervention) or