



The Organ Transplant Imperative

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Abstract

More than 120,000 US patients were listed for solid organ transplants in 2016. Although data are scarce, we suspect that many of these patients will die while awaiting transplant and without engaging in goals-of-care discussions with their physicians. The challenges of addressing goals of care in patients with malignancy, end-stage renal disease, and heart failure have been studied. However, there is sparse literature on addressing goals of care throughout the dynamic process of transplant assessment and listing. We propose the concept of an organ transplant imperative, which is the perceived obligation by patients and health care providers to proceed with organ transplant and to avoid advance care planning and triggered goals-of-care discussions, even in situations in which patients' clinical trajectories have worsened, resulting in poor quality of life and low likelihood of meaningful survival. We situate this concept within the paradigms of clinical inertia and the treatment and technological imperatives. We illustrate this concept by describing a patient with end-stage liver disease (ESLD) who was hoping for a liver transplant, who was caught between the conflicting perspectives of specialist and primary care physicians, and who died of complications of ESLD without experiencing the benefits of advance care planning. Greater awareness of the transplant imperative should generate a shared understanding among specialists, generalists, and patients and will provide opportunities for more formalized involvement of palliative medicine experts in the care of transplant patients.

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In 2015, a record high 30,974 solid organ transplants were performed in the United States. The year ended with more than 122,000 patients still on waiting lists.^{1,2} The number of transplants performed has continued to increase, with the demand for organs far exceeding the supply.³⁻⁶ These life-saving procedures are accomplished at a considerable price, as per-patient costs of organ transplants range from \$300,000 (pancreas, kidney) to \$1.5 million (intestine).⁷ Nonetheless, these costs result in tangible benefit in terms of patient life-years, with data suggesting that the mean survival benefit from organ transplants spans from 2.4 years in pancreas recipients to 4.9 years in heart recipients.⁸

The substantial planning, resources, and effort needed for successful organ transplant result in a commitment to the transplant process that is often burdensome for patients with severe organ failure and associated comorbidities, who would benefit from triggered goals-of-care discussions and early palliative medicine involvement, especially when the patient's clinical status worsens. Unfortunately, the expectation

for transplant may interfere with these discussions, which would otherwise occur in patients with serious illness and poor prognosis.

ETHICAL PARADIGMS

Several ethical paradigms underlie the phenomenon of pursuing interventions despite potential threats to patient well-being (Table 1). Chief among these is the treatment imperative, defined as the perceived need by physicians and patients to provide interventions.⁹ The treatment imperative is driven by physicians' desires to offer treatment and patients feeling bound to not refuse treatment, especially in settings of acute or worsening illness.¹⁰

Similarly, the technological imperative, described by Fuchs in 1968,¹¹ describes the tradition of offering the newest care that is technologically feasible and is driven by the rapid societal normalization of cutting-edge procedures, devices, and medications.¹² With the modern emphasis on cost-effectiveness, decisions made from a technological imperative may oppose the goal of providing indicated, high-value care.¹³ Furthermore,

TABLE 1. Medical Ethics Paradigms That May Lead to Ineffective Patient Care

Paradigm	Definitions	Comments
Therapeutic inertia	Adherence to a preconceived course of treatment even in the face of new medical problems or risk.	Therapeutic inertia can interfere with establishing goals of care or discussing the marginal utility of interventions.
Treatment imperative	The perceived need by physicians and patients to provide interventions.	This imperative is driven by physicians' desires to offer treatment and patients feeling bound to not refuse treatment, especially in settings of acute or worsening illness.
Technological imperative	Offering the newest care that is technologically feasible.	This imperative is driven by rapid normalization of cutting-edge procedures, devices, and medications. Technologically advanced interventions may be offered without realizing how they affect patients over time.
Organ transplant imperative	The perceived obligation to proceed with transplant and to avoid end-of-life planning even in situations where the patient is experiencing poor quality of life and low likelihood of meaningful survival.	Triggers for goals-of-care discussions and palliative interventions in patients with, for example, end-stage liver disease may include multiple hospitalizations, worsening performance status, hepatic encephalopathy, hepatorenal syndrome, bacterial peritonitis, and gastrointestinal bleeding.

technologically advanced interventions may be offered without realizing how they affect patients over time.¹⁰ Therefore, the technological imperative can weaken medical decision making by displacing assessments of risk and cost.¹¹

Patient care is also influenced by therapeutic inertia, which is adherence to a preconceived course of treatment even in the face of new medical problems or risk.¹⁴ One aspect of therapeutic inertia is respect for the referring or outpatient physician's existing plan; this can be addressed by communicating with the patient's primary physician during the course of care, especially when triggers for goals-of-care discussions occur. The relationship between therapeutic inertia and the treatment and technological imperatives is marked by the incremental nature of medical decisions and the promise of undiscovered interventions. Consequently, therapeutic inertia and the treatment and technological imperatives can interfere with establishing discrete goals of care and with recognizing the marginal utility of interventions.¹⁵

The treatment and technological imperatives drive the pursuit of organ transplant by patients with end-stage organ disease. Once the process of transplant is initiated, the expense of time, resources, emotion, and planning can result in a therapeutic inertia that precludes consideration of non-transplant-directed care, even as a patient's clinical trajectory worsens.

This unresolved strain between anticipating transplant and discussing goal-centered care can harm patients.

Trotter¹⁶ defines medical futility as pursuing an action with virtual uncertainty of the action achieving a predefined objective. Patients, loved ones, and the health care team bring their own perspectives on an intervention's ability to achieve the intended goal. Tension develops when these individuals have opposing perspectives. Among organ transplant patients, the perceived conflict between disease-directed therapy consistent with transplant and comfort-directed and supportive treatment can hinder a compassionate approach that would align with reasonable, prognosis-based expectations and goals of care.

EXAMPLES OF DISEASES WITH POOR SURVIVAL AND TECHNOLOGICALLY ADVANCED TREATMENT OPTIONS

When considering advance care planning for patients who are awaiting organ transplant, it is useful to review other conditions with poor survival and technologically advanced treatment options, such as malignancy, renal disease, and heart failure. Although these diseases have unique symptoms and end-of-life considerations,¹⁷ patients with these diseases have benefited from advance care planning, triggered goals-of-care discussions, and early involvement of palliative medicine physicians.

Patients with terminal malignancies have the highest rates of palliative care and hospice enrollment.¹⁸ However, patients with terminal malignancies frequently receive chemotherapy near the end of life, despite lack of evidence for increased longevity or quality of life.¹⁹ Predictors of suboptimal palliative interventions among patients with cancer include limited awareness of survival statistics, alternative treatment options, and treatment consequences.²⁰ Without such information, patients often accept treatments that involve higher risk and lower benefit than physicians would choose for themselves.²⁰ Nonetheless, studies have shown that early integration of palliative care is associated with decreased anxiety and depression²¹ and improved quality of life²² for patients and their family caregivers.²³

Patients with end-stage renal disease have quality-of-life and symptom burdens that are similar to those of patients with cancer.²⁴ The mere act of choosing between ongoing dialysis and transitioning to hospice has a profound effect on these patients' well-being and sometimes interferes with a palliative transition.²⁵ Reassuringly, studies of advance care planning in patients with end-stage renal disease have demonstrated improved congruence between patient wishes and care received.²⁶

Parallels can also be found in patients with heart failure, who experience substantial symptom burden, unpredictable clinical courses, and uncertain triggers for advance care planning.²⁷ Unfortunately, patients with heart failure enter hospice programs for a median of less than 1 month.²⁸ Fortunately, trials of triggered palliative care integration for patients with heart failure have shown increased patient satisfaction with physician communication regarding goals of care.^{29,30}

The topic of initiating goals-of-care discussions with patients with end-stage liver disease (ESLD) was first raised by Larson and Curtis in 2006.³¹ It has been observed that a focus on liver transplant status may interfere with providing palliative care.³² Furthermore, physicians may hesitate to recommend palliative care referral to liver transplant patients owing to perceived equivalence of palliative and end-of-life care, sensed patient resistance,³³ and the view that they are giving up. A study of elucidating goals of care from caregivers of post-liver transplant patients at intensive

care unit admission and at multidisciplinary care conferences in the first 72 hours revealed increased attention to goals of care, earlier and more frequent initiation of do-not-resuscitate code status, and more rewarding family experiences.³⁴ However, there seems to be no research involving goals-of-care discussions with patients with ESLD who are pretransplant and medically stable.

Finally, post-lung transplant patients are rarely cared for by palliative medicine providers, who, when present, usually intervene within the last 30 days of life.³⁵ Barriers to early evaluation of care preferences in lung transplant patients include the perception that these discussions would disqualify patients from disease-directed therapies, difficulty in leading goals-of-care discussions, and uncertainties about prognosis in this patient population.^{33,35}

THE ORGAN TRANSPLANT IMPERATIVE

Despite tens of thousands of patients awaiting organ transplants^{1,2} and the low overall survival benefit of transplant ranging from 2 to 5 years,⁸ there is limited literature regarding addressing goals of care throughout the process of transplant assessment and listing.^{31,33,36,37} We propose the concept of an organ transplant imperative, which is the perceived obligation by patients and health care providers to proceed with organ transplant and to avoid advance care planning, triggered goals-of-care discussions, and timely palliative consultations, even in situations in which patients' clinical trajectories have worsened, resulting in poor quality of life and low likelihood of meaningful survival.

CASE ILLUSTRATION

To illustrate the organ transplant imperative, we present the case of a 45-year-old man with alcoholic cirrhosis complicated by recurrent episodes of spontaneous bacterial peritonitis, hepatic encephalopathy, compensated diffuse intravascular coagulation, and multiple upper gastrointestinal bleeding episodes. He presented to the hepatology clinic with altered mental status, fatigue, and hypotension requiring hospitalization. Before admission, the patient and his hepatologist had discussed the possibility of being listed for liver transplant. Unfortunately, it was thought that the

TABLE 2. The Organ Failure and Transplant Conversation Approach

Conversation Flow	Description	Conversation Scripts
Prepare the conversation	Introduce the idea and benefits Ask permission	"Would it be okay to discuss where things are with your organ failure and the risks and benefits of organ transplant?"
Assess understanding		"What is your perception of where you are with your organ failure? What is your understanding about the risks and benefits of organ transplant?"
Assess information preferences		"How much information about what is likely to happen with your organ transplant would you like from me?"
Share prognosis	Tailor information to preference Allow silence Explore emotion	"I'm concerned that your time may be short" or "I'm concerned that this may be as strong as you will feel."
Explore key topics	Goals Fears and worries Function Trade-offs Family	"If your health declines, what are your main goals?" "What are your greatest fears and worries about the future of your health?" "What abilities are so important that you can't imagine living without them?" "If you become sicker, how much are you willing to endure for the possibility of gaining more time?" "How much does your family understand about your priorities and desires?"
Close the conversation	Summarize what you have heard Make a recommendation	"It sounds like [blank] is important to you." "Given your goals and priorities and what we understand about your organ failure at this stage, I recommend [blank]."
	Affirm your commitment	"We're in this together."

Data from *BMJ Open*⁴⁴ and *Serious Illness Conversation Guide*.⁴⁵

patient's continued relapses of alcohol abuse, suboptimal support system, and previous resistance to alcohol dependency treatment excluded him from being listed at the time of this acute decompensation. Further complicating his care, the patient had developed pneumonia and hepatorenal syndrome type 2, which has an estimated median survival of 3 to 6 months.³⁸

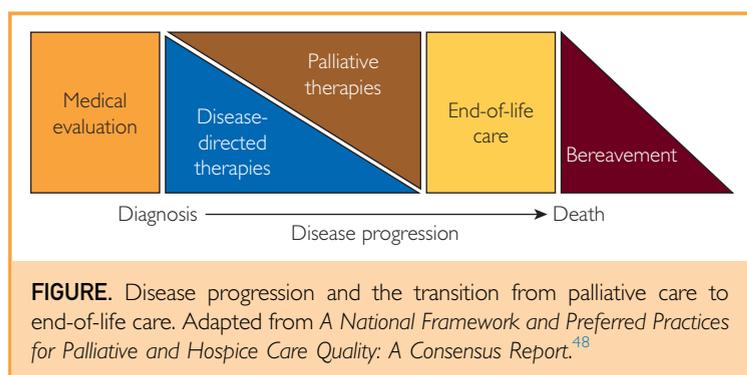
On admission to the internal medicine service, the patient's Model for End-stage Liver Disease (MELD) score was 41, yielding an estimated 71.3% likelihood of 3-month mortality.^{39,40} After admission, his hepatic encephalopathy was reversed with lactulose therapy. After being apprised of his situation, the patient elected to continue standard management, including paracentesis, laboratory monitoring, and treatment with midodrine, octreotide, albumin, and intravenous antibiotics.

During hospitalization, the patient had difficulty articulating his preferences for ongoing management. He understood the seriousness of his acute decompensation, but throughout the hospitalization he vacillated between desiring aggressive disease-directed therapy and transitioning to hospice care.

When asked what was most important to him given the severity of his illness, he identified spending time at home with his family and new fiancée and minimizing or eliminating admissions to the hospital. The patient's family struggled with supporting his decisions based on previous discussions of and not wanting to interfere with the possibility of transplant, and they expressed the need for guidance in deciding care goals.

The patient's inpatient medicine team, who knew him well from previous admissions, attempted to engage the patient and his family in conversations to elucidate preferences, concerns, and goals for his continued care. Because of the patient's complex disease, the inpatient hepatology consulting service became a critical part of these conversations. The hepatology service, not having a longitudinal relationship with the patient, wished to respect the outpatient hepatologist's intention to consider possible liver transplant in the future; therefore, they did not endorse end-of-life discussions, which could represent a drastic change from the previously discussed goal of liver transplant.

After much discussion with the patient and his family, he was presented to the institutional liver transplant board. Due to



preexisting concerns regarding his substance use and support system, he received “deferred status,” with definitive listing to be determined at a later date. The patient, his family, and members of the health care team expressed frustration with this situation because it presented the hope of listing him for transplant but no commitment to do so. Furthermore, the patient was understandably torn between the possibility of receiving a transplant and information from the medicine team that his prognosis was poor and that exploring symptom management and end-of-life care would be a realistic and compassionate approach.

The patient was eventually stabilized and then was dismissed from the hospital to the care of his family and friends. In outpatient follow-up, his MELD score continued to worsen, and his performance status rapidly deteriorated. He began attending Alcoholics Anonymous meetings in hopes of attaining the 6-month sobriety period required for transplant listing. Increasingly frequent paracenteses were required. Within 6 weeks, he developed spontaneous bacterial peritonitis and refractory hepatic encephalopathy and was again admitted to the hospital. Aggressive disease-directed measures were continued, with no improvement in clinical status. Ultimately, he died within 24 hours of transitioning to hospice care.

DISCUSSION

This case illustrates how a combination of patient, provider, and systems-based factors resulted in failure to deliver advance care planning, reassess goals of care at the pivotal point of patient decompensation, and provide early

involvement of the palliative medicine team. A critical juncture occurred when the patient, despite his terminal prognosis, received deferred status and was not clearly denied for receiving a liver transplant. If the patient had been denied a transplant, then he could have released his false hope for an extended life and begun grieving, thus providing emotional space for the needed end-of-life discussion. Conversely, the patient felt compelled to pursue medical interventions and transplant, and despite his high risk of mortality, to not consider comfort measures. Furthermore, the patient and his physicians disagreed on what constituted therapeutic effectiveness and goal-dyssynchronous care. Specifically, the hepatology team was determined to recommend strategies to maximize the chance of being listed for a transplant, the medicine team was obliged to label the patient’s high mortality risk and offer hospice, and the patient was caught between these perspectives. We believe that this combination of factors, specifically when considered through the lens of organ transplant, illustrate the organ transplant imperative.

STRATEGIES FOR DISCUSSING AND RESOLVING THE ORGAN TRANSPLANT IMPERATIVE

Strategies for discussing and resolving the transplant imperative are critical to providing compassionate, meaningful care to patients with severe organ failure, regardless of their candidacy for receiving a donor organ. Advance care planning has been studied extensively as an intervention in serious illness.⁴¹ For some diseases—such as cancer, end-stage renal disease, chronic obstructive pulmonary disease, and heart failure—robust triggers have been recommended for reassessment of goals of care.⁴² Although there are no formal recommendations regarding triggers for ESKD, the present patient had multiple hospitalizations, worsening performance status, hepatic encephalopathy, hepatorenal syndrome, bacterial peritonitis, and gastrointestinal bleeding, all of which have been identified as potential triggers for intervention by experts.³⁶ Using the MELD score to determine the timing of palliative care referral has also been preliminarily explored.³² Triggered goals-of-care conversations in other diseases have resulted in improved quality of life,

patient-physician communication, and congruence between care delivered and patient preferences.^{21,23,26,28-30} We are unaware of investigations regarding the outcomes of triggered goals-of-care discussions in organ transplant candidates or recipients.

Triggered goals-of-care conversations should occur in patients with serious illness, including those being considered for organ transplant. We believe that reluctance to have goals of care conversations results from unawareness of benefit, and from discomfort in leading these complex and highly emotional discussions. Additionally, a survey of transplant centers revealed that unwillingness to engage in goals-of-care discussions stems from concerns that patients would feel abandoned, or that medical care would be inadequate, after the initiation of palliative care.⁴³ Following a “conversation blueprint,” such as that elucidated by Bernacki et al,^{44,45} may be the solution (Table 2).

The present patient would have benefitted from a palliative care consultation. Potosek et al³⁷ and Larson⁴⁶ described a framework for the integration of palliative medicine into the care of patients with ESLD. Specifically, these patients should have robust advance care planning, advance directives, and appointment of surrogate decision makers with the resources necessary for proper substituted judgment. The most common symptoms of patients with ESLD include pain, nausea, decreased appetite, dyspnea, anxiety, and depression, all of which can be well-controlled with focused pharmacologic and nonpharmacologic interventions.⁴⁷ This patient and his family may also have benefited from the psychosocial and spiritual supports afforded by a longitudinal palliative care relationship. Furthermore, early and ongoing palliative care would make a future transition to hospice care seem less abrupt (Figure).⁴⁸

CONCLUSION

In 2016, more than 120,000 US patients were listed for solid organ transplants; most of these patients will die while awaiting transplant, and we suspect that many of them have not been engaged in goals-of-care conversations. Nonetheless, the need for goals-of-care discussions among patients who are unlikely to benefit from transplants should not overshadow the

immense, lifesaving benefit that numerous patients experience from receiving transplants. It is evident that advance care planning and triggered goals-of-care discussions would normally be initiated by internists and palliative medicine physicians, would occur long before the transplant occurs, and would not interfere with surgical decision making. Moreover, research on the outcomes of lung transplant patients has shown that palliative care can be provided without compromising eligibility for transplant.⁴⁹

The treatment and technological imperatives, along with the challenges of providing supportive care in patients with advanced malignancy, end-stage renal and liver disease, and terminal heart failure, have been defined and addressed. However, the organ transplant imperative is a new concept. We are hopeful that an awareness of the transplant imperative will lead to improved understanding among specialists, generalists, and patients and will provide opportunities for more formalized involvement of palliative medicine specialists in the care of transplant patients.

Abbreviations and Acronyms: ESLD = end-stage liver disease; MELD = Model for End-stage Liver Disease

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