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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,

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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 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.

Trotter[16] 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.