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An Ethical Framework for the Care of Patients with Prolonged Hospitalization Following Lung Transplantation

Andrew M. Courtwright[1,2] · Emily Rubin[3] · Ellen M. Robinson[2,4] · Souheil El-Chemaly[5] · Daniela Lamas[5] · Joshua M. Diamond[1] · Hilary J. Goldberg[5]

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Abstract

The lung allocation score system in the United States and several European countries gives more weight to risk of death without transplantation than to survival following transplantation. As a result, centers transplant sicker patients, leading to increased length of initial hospitalization. The care of patients who have accumulated functional deficits or additional organ dysfunction during their prolonged stay can be ethically complex. Disagreement occurs between the transplant team, patients and families, and non-transplant health care professionals over the burdens of ongoing intensive intervention. These cases highlight important ethical issues in organ transplantation, including the nature and requirements of transplant informed consent, the limits of physician prognostication, patient autonomy and decision-making capacity following transplant, obligations to organ donors and to other potential recipients, and the impact of program metrics on individualized recipient care. We outline general ethical principles for the care of lung transplant recipients with prolonged hospitalization and give regulatory, research, and patient-centered recommendations for these cases.

Keywords Critical illness · Informed consent · Organ allocation · Survival · Transplantation

✉ Andrew M. Courtwright
Andrew.Courtwright@uphs.upenn.edu

[1] Pulmonary and Critical Care Medicine, Hospital of the University of Pennsylvania, 3400 Spruce Street, Philadelphia, PA 19104, USA

[2] Institute for Patient Care, Massachusetts General Hospital, Boston, MA, USA

[3] Pulmonary and Critical Care Medicine, Massachusetts General Hospital, Boston, MA, USA

[4] Yvonne L. Munn Center for Nursing Research, Massachusetts General Hospital, Boston, MA, USA

[5] Pulmonary and Critical Care Medicine, Brigham and Women's Hospital, Boston, MA, USA

Background

In 1999, the United States (US) Department of Health and Human Services (DHHS) issued the Final Rule on organ allocation, mandating the use of a system based on medical need rather than waitlist time to determine priority. This led to the development of the Lung Allocation Score (LAS) within the US lung transplant community, which was implemented on May 5th 2005 and subsequently adopted by several other European countries (Gottlieb 2017). The ethical underpinnings of the LAS were to balance net transplant benefit with medical need. Net benefit was defined solely in terms of one-year survival with and without transplant. There were no health related quality of life (HRQL) considerations included in the LAS (Egan et al. 2006; Egan and Kotloff 2005). The final LAS was calculated as [LAS = post-transplant survival − 2 × waitlist urgency]. The waitlist survival term was weighed twice as heavily to emphasize a duty of rescue rather than simply maximizing length of life saved. In order to improve interpretability, the LAS was normalized to a 0–100 scale. A candidate's LAS, therefore, reflects how likely he is to die in the next year without a transplant and, to a lesser extent, how likely he is to survive a year after transplant.

Although the LAS era has seen a reduction in candidate time on the waiting list and an increase in the total number of transplants, the emphasis on duties of rescue rather than long-term post-transplant survival or quality of life benefit has led to increased disability, poorer health-related quality of life, and higher long-term mortality among transplant recipients (Egan and Edwards 2016; Maxwell et al. 2015). Recipients in the United States are now sicker at the time of transplant and length of post-transplantation hospitalization and initial hospitalization mortality rates have slowly risen (Banga et al. 2017; Russo et al. 2010; Courtwright et al. 2018). In some cases, transplant recipients become—to use a term from elsewhere in the critical care literature—chronically critically ill (Nelson et al. 2010). The care for chronically critically ill transplant recipients can be ethically complex, with patients, families, transplant team members, bedside care providers, and health professionals both within and outside of the intensive care unit (ICU) raising concerns about whether the expected outcomes of a prolonged hospitalization could justify the discomfort and suffering necessitated by ongoing or escalating intensive interventions.

Complicating these discussions, which are not uncommon for any ICU patient with a prolonged stay and progressive debility, transplant programs are subject to regulatory review regarding their one-year outcomes. Both United Network for Organ Sharing (UNOS) and the Centers for Medicare and Medicaid Services (CMS) track data on program-specific one-year adjusted mortality rates. Programs that fail to meet certain benchmarks are at risk for auditing, probation, losing contractual agreements with private insurance companies to provide coverage, or even being effectively prohibited from performing lung transplantation. In our experience, there is often concern among patients, families, and non-transplant health care providers that the transplant team recommendations are colored by a focus that is not exclusively patient-centered. Patients and others may worry that transplant providers allow the current state of the program's one-year mortality rate to inform their recommendations about continuing aggressive treatment.

The goal of this paper is to provide an ethical framework for the care of lung transplant recipients with a prolonged hospitalization. Using a case based approach, our focus is primarily on the first year following transplantation where program benchmarks are most relevant and our discussion is intended to apply to other solid organ transplant recipients. We consider the nature and requirements of pre-transplant informed consent, the limits of health care provider prognostication, patient autonomy and decision-making capacity following transplant, obligations to organ donors and to other potential recipients, and the impact of program quality metrics on individualized recipient care. We make specific recommendations regarding research and regulatory priorities and conflict-resolution processes for lung transplant recipients with prolonged hospitalization.

Case

Mr. Samuel Jones first met the lung transplant team in the outpatient clinic.[1] He had been diagnosed with idiopathic pulmonary fibrosis (IPF) six months earlier after developing shortness of breath. At 66 years old, he had recently retired and was looking forward to spending time with his wife and grandchildren, not his pulmonologist. Despite a novel medication for IPF, he had worsening symptoms and was started on oxygen. Mr. Jones wanted aggressive treatment of his lung disease, including transplantation.

As part of his evaluation, Mr. Jones underwent extensive testing to look for other organ diseases that would make him too high risk for transplantation. He also met with the transplant team, including a surgeon, pulmonologist, social worker, nutritionist, nurse, pharmacist, nurse practitioner, financial coordinator, speech pathologist, and physical therapist, each of whom evaluated him for transplant candidacy from his or her individual perspective. He was given information about what life after transplant would be like, including ranges of post-transplant hospitalization duration, need for medication compliance and monitoring, the importance of a support team, and statistics on survival after transplant. He also attended a group meeting with other transplant candidates and recipients, had two educational sessions along with his wife about life as a transplant recipient, and completed a nine-page informed consent form.

Mr. Jones was listed for lung transplantation three months after he met the transplant team, with a LAS in the high 30s. At the time of listing, he told the transplant coordinator that he was an optimist and that he would deal with any post-transplant complications when the time came. Five weeks later, Mr. Jones became much sicker with an acceleration of his IPF. He was admitted to the hospital and needed to be placed on a ventilator. The transplant team updated his LAS, reflecting his higher likelihood of dying without transplant. After almost a

[1] This case is an amalgam of several transplant recipients for whom we have provided care as transplant physicians, critical care physicians, and/or ethics consultants. The case does not, however, represent the protected health information of any one specific patient.

week, an appropriately matched donor was identified. Mr. Jones' initially did well after surgery. On the third day, however, his blood pressure fell suddenly and he developed an irregular heart rhythm. Cultures showed fungus in his bloodstream. Over the next two months he had multiple complications related to this infection. The low blood pressure damaged the location where his old and new lungs were attached, leading to significant narrowing. Because his immunosuppression had to be lowered to fight the fungus, he developed low-level rejection. He eventually required a tracheostomy to allow a slow wean from the ventilator. The irregular heart rhythm led to a stroke that caused left arm weakness. He also developed an extremely painful bed sore.

During the third month, in order to optimize his respiratory care, he was transferred from the surgical ICU to the medical ICU. Over the next six months it seemed that every time Mr. Jones made a little progress he had a setback. He had frequent pneumonias, his bed sore did not heal, his muscles atrophied, and he was intermittently delirious. At first, Mrs. Jones was a constant presence at her husband's bedside. By the sixth month, however, she was running out of the savings they had set aside for post-transplant care and she started staying at home during the week. When she came in, particularly when her husband was delirious, she would wonder out loud, "How much can a body take?" The transplant pulmonologist reassured her that he had seen many patients go through this or worse and leave the hospital, doing well five years later.

By the eighth month, Mr. Jones was profoundly debilitated. Although off the ventilator during the day, he still required nocturnal support. His left arm never really recovered, he had nausea with the artificial nutrition, and he still had a painful bed sore. The medical ICU staff felt that Mr. Jones was suffering without a realistic chance for meaningful quality of life outside the hospital. At night, when he was most restless, Mr. Jones would tell the nurses that he just wanted to die. In response to these requests, the transplant team argued that he was depressed and recommended a psychiatry consult to adjust his medications. Interactions between the transplant clinicians, medical ICU team, and the Jones became increasingly tense. Multiple times Mrs. Jones told the medical ICU staff that her husband, "hadn't signed up for this," and that she, "just wanted to take him home to die." The medical ICU team was certain that Mr. Jones was done fighting and wanted to die with dignity. During breaks the nurses and junior doctors talked together about the transplant team, "They only care about their numbers, not what happens to their patients. I guess we'll see what happens on day 366." Finally, the nurse manager of the medical ICU requested an ethics committee consult.

Ethical Framework

In reflecting on this case, our aim is to provide a framework for ethics consultants, physicians, and other health care professionals to understand and address the issues that arise in the care of lung transplant recipients with a prolonged hospitalization.

Informed Consent

Principle One: Informed Consent is a Process not an Event

Informed consent requires a voluntary agreement to proceed with an intervention in which the interventionalist has provided all information that a prudent or reasonable person would require. Informed consent for most medical procedures or interventions is treated as a discrete event in which the physician or a representative discusses the diagnosis, prognosis, risks, benefits, and alternatives to the proposed treatment plan and the patient or his representative, after an opportunity for discussion, agrees or refuses to proceed. For complex, high-risk high-reward interventions such as lung transplantation, informed consent should be conceptualized as a process rather than a specific event (Lidz et al. 1988). The lung transplant evaluation process itself serves as an opportunity for multiple points of reflection on the surgical procedure and post-operative care. Meeting the multidisciplinary transplant team provides an opportunity for discussion of the transplant life. These interactions also allow the transplant team members to reflect on the patients' and families' capacity to manage post-transplant care. As with any complex medical decision, however, there is an experiential aspect to life as a transplant recipient that cannot be captured through advance conversations, no matter how comprehensive. Such conversations remain hypothetical until the patient is living through the experience (Scheiner and Liaschenko 2018).

Transplant consent, therefore, is a paradigm of "surgical buy-in" or the "surgical covenant," whereby consent is treated as not just for the procedure itself but for the steps necessary to ensure a good post-operative outcome (Schwarze et al. 2010). The transplant surgical consent starts with the premise that, as long as the relevant information is disclosed and the patient agrees pre-transplant, permission has been given for the ongoing use and escalation of post-operative interventions. Given the potential disconnect between discussing hypothetical complications such as stroke or dialysis dependence and the actual experience of those complications, surgical buy-in can lead to a misalignment of patients' and transplant teams' goals in the post-operative period. This, in turn, can lead to the perception among transplant physicians that the patient has failed to fulfill his commitment to the transplant process and, among patients and families, that they did not actually agree to life under *these* conditions.

We do not believe that merely providing additional pre-transplant information will alleviate the potential for post-transplant conflict. It may be helpful, however, to identify patients who have particularly unrealistic expectations or who are at high risk for intolerance of a complicated post-transplant course. For example, understanding which states of debility a particular transplant candidate would consider worse than death may allow targeted discussions of expectations for post-transplant life. Patients with serious illness have a wide range of intolerance for certain states—bowel and bladder incontinence, relying on a feeding tube, prolonged time on a ventilator—and simple surveys can help stratify individuals who are particularly likely to think of these outcomes as worse than death (Rubin et al. 2016). While not grounds on which to deny candidacy, incorporating such an assessment in the evaluation process would allow appropriate patient and family education. This

might prompt re-examination for some patients of whether lung transplantation is an intervention truly in line with his or her goals and values. Incorporation of prior transplant recipients and their caregivers within the program to assist with education of new transplant candidates can be invaluable, as no matter how aggressive the team's efforts, their representation of post-transplant life will never be as accurate as those who have fully lived it.

More importantly, however, conceptualizing transplant informed consent as a process means that consent should be re-visited with changes in the candidate's clinical status. It is not uncommon for patients to become sicker during their wait time, particularly given the structure of the allocation system, and some escalations in illness change the risks for a prolonged hospitalization and post-operative complications. As Mr. Jones' case illustrates, there are often opportunities for further discussion between when an underlying disease worsens and the actual transplant. It is incumbent on transplant teams to re-consent or review transplant consent at this time given the increased risks from worsening illness and debility. The transplant committee can also decide that the patient is too sick to be a transplant candidate and to inactive him, either permanently or temporarily, until clinical stabilization.

If the transplant team decides not to inactivate someone who is marginal at the time of transplant, the team must be prepared that this may be a patient who lacks the ability to tolerate a complicated post-transplant hospitalization. The decision to proceed to transplant for a patient in these circumstances should be treated as a two-way agreement: the patient/surrogate goes forward with transplant knowing that the post-transplant period will be longer with increased risk of debility and poor quality of life and the transplant team goes forward knowing that it is possible that this burden may prove too great. For a marginal candidate who goes on to have a prolonged and complicated course, the burdens of continuing post-transplant treatment should not be placed on the patient, family or surrogates, and the non-transplant providers alone. The transplant team must be prepared that transplantation under these circumstances may mean that some patients will find the post-transplant course to be a fate worse than death.

Prognostication

Principle Two: Prognostication is an Epistemic Enterprise with Moral Dimensions

Part of the challenge in weighing the burdens and benefits of ongoing or escalating intervention is the difficulty in assessing recipient prognosis. The likelihood of inpatient mortality, subsequent survival, and whether the patient might come to find his long-term quality of life acceptable (even with significant debility) can be difficult to predict (Courtwright et al. 2018). Recipients who have accumulated post-transplant complications such as stroke, renal failure requiring dialysis, or ventilator dependent respiratory failure are less likely to survive to discharge, but the inpatient mortality rarely exceeds 50% in these populations. This is true even for those recipients who have been in the hospital for three or more months following transplant. Unfortunately, even large national databases lack sufficient data to identify specific

individual or combinations of factors that uniformly portend extremely poor survival to discharge. Nor are there sufficient data on what fraction of recipients with a prolonged hospitalization are ever able to return home (versus long-term nursing facilities) or on their long-term quality of life.

In the absence of such information, there is a tendency among transplant and non-transplant health professionals to rely on anecdotes or their most recent experience when providing prognostic assessments (Sapsosnik et al. 2016). Most transplant physicians have one or two patients who have survived a prolonged hospitalization and who are now living independently or semi-independently in the community. Some have gone on to have kidney or other organ transplants to address diseases that developed during their hospitalization and some have even had a second lung transplant when their original graft failed. Reflection on these cases and what is possible even for very sick recipients in the hospital may lead to overestimation of what is probable for most patients. Similarly, the ICU team's experience with lung transplant recipients with a prolonged hospitalization may be based not on the long-term survivors (who, by definition, do not follow-up with the ICU) but on the patients who die despite the aggressive treatment.

In the absence of conditions that are clearly incompatible with short or long-term survival—untreatable infection, refractory multi-organ failure, persistent airway dehiscence—or a meaningful chance of acceptable recovery—massive stroke, high spinal cord infarct—transplant physicians typically err on the side of continuing life-sustaining treatment. The lack of definitive prognostic information, however, does not make it appropriate for the transplant team to hide behind the hope for a good outcome. The recommendation to continue life-sustaining treatment must come with a disclosure of the significant possibility that survival will not translate to a return home or to an acceptable quality of life. It is appropriate to be epistemically humble when deciding what can be predicted for an individual patient. It is not morally appropriate, however, to pretend that the lack of definitive information means that we have no ability to prognosticate whatsoever. In this context, instruments from palliative care such as the Best Case/Worst Case tool can help shape goals of care in the setting of epistemic uncertainty (Kruser et al. 2015).

Patient Autonomy and Decision-Making Capacity

Principle Three: Autonomy is a Property of Decisions and of Persons

In our experience, it is extremely common for lung transplant recipients with a prolonged hospitalization to express frustration with their clinical course or for their families to express frustration on their behalf. Sometimes these are transient, made in the face of a new challenge—starting dialysis, needing additional ventilator support, another infection—and other times they are consistent requests to be allowed to die. In many cases, a focused conversation about what factors are contributing to the patient feeling like life is no longer worth living can identify addressable conditions. Changes in pain medication, daily schedule, nausea or anxiety management, or additional support or encouragement from chaplaincy, social work, or volunteer

services can re-engage frustrated or despondent patients. In these cases, a patient feeling like he just wants to die is not the same thing as wanting life-sustaining treatment withdrawn.

In other situations, the continued expression of suffering and the request to limit life-sustaining treatment takes on a different moral cast. Preferences that persist over time, appear deeply held, and are consistent with other patient values or judgments (i.e., that life restricted to an ICU is not an acceptable quality of life) are more likely to be expressions of what the patient "actually wants." Or, in the language of bioethics, more likely to be autonomous decisions. Continuing to pursue invasive treatments with attendant pain and suffering in a patient who seems to be genuinely refusing those interventions can provoke significant moral distress (Elpren et al. 2005). At the same time, dismissing these preferences as just manifestations of depression or another clinical illness can be doubly discrediting insofar as this does not allow moral space to ask whether these decisions might genuinely be worthy of respect.

As with any request to withdraw life-sustaining treatment, it is important to assess the patient's decision-making capacity. According to standard frameworks, this involves evaluating the beliefs and desires that are leading to the decision to stop life-sustaining treatment. With regard to beliefs, does he have a basic understanding of his medical condition? Can he explain the risks of refusing or agreeing to a particular intervention? Is there delusion, psychosis, or delirium (from infection, medication, withdrawal, etc.) that may impact the ability to form true beliefs? With regard to desires, what does the patient expect or want from his medical care? Where does the decision fit within the scope of other things he cares about? What does he hope to achieve by accepting or rejecting medical intervention? Is the desire broadly consistent with other preferences the patient has or is it a transient frustration expressed in the setting of illness, a mood disorder, or his current circumstances? And, is the decision stable over time?

For any transplant patient who is persistently requesting to stop life-sustaining treatment or to not escalate interventions, health care professionals are obligated to assess formally his decision-making capacity. It is insufficient for the transplant team (or ICU team or family) to simply assert that the decision is related to a transient frustration or a psychiatric diagnosis without a complete assessment. Where there is legitimate concern that a mood disorder or delirium is impairing autonomous decision-making, additional psychiatric evaluation and management should be requested, as the mere presence of these conditions does not automatically undermine a patient's decision.

Importantly, capacity assessments are only about a specific decision—for example, declining life-sustaining treatment. A person can still be an autonomous agent—in the sense of having the ability to make independent decisions—even if he or she is not currently capable of making one specific decision. This means taking into account the expressed preferences of a patient with diminished capacity and using the least coercive and least invasive measures possible to protect the patient with diminished capacity from harming himself or others. Assessments should be subject to revision when there are changes in the patient's clinical trajectory or new information is uncovered about the burdens and benefits of the patient's refusal. At the

time of future re-evaluations, the presumption should be that the patient is an agent capable of engaging in an ongoing conversation about the recommended treatment plan rather than the presumption that the patient continues to lack decision-making capacity.

In addition, treating individuals as autonomous agents also means that we may still have obligations to allow the patient the opportunity to change his mind. We are required to continue to help him continue to weigh the risks and benefits, the expected outcomes, and the long-term support available to assist with his goals and plans. Efforts to convince patients with decision-making capacity that they are making a bad decision can shade into forms of soft coercion and an ongoing discussion may border on a disrespectful moralism (Korsgaard 1986). But, for life and death decisions, it is essential that the patient or surrogate be given the opportunity to choose differently. Conversely, it is equally important to recognize those patients and families who look to the transplant physician for direction with such respect and devotion that it blinds them to the increasing odds of dying in the hospital. This can be particularly tragic when the transplant team imparts hope for survival in the face of near-certain demise, especially for families exhausting their social and financial capital.

Balancing Program Metrics and Individualized Recipient Care

Principle Four: There is an Ethical Difference Between Reasons and Motives When Recommending Continued Life-Sustaining Treatment

As noted in the introduction, the lung allocation system in the US prioritizes minimizing the risk of waitlist mortality while transplant program quality metrics emphasize post-transplant survival to one year. Although theoretically "adjusted" for differences in candidates' illness severity at the time of transplant, the relatively small numbers of transplants performed at many individual centers means that unanticipated deaths can place a program in danger of probation. This, in turn, may make transplant committees more averse to accepting perceived higher-risk candidates and more focused on ensuring that recipients make it through their vulnerable first year. Although data are limited, there is some suggestion that program benchmarks may impact willingness to withdraw life-sustaining treatment until just after the one year transplant anniversary (Maxwell et al. 2014). For example, Maxwell and colleagues found an 8% increase in mortality in the month following day 365 among United States lung transplant recipients that could not be explained by available epidemiological factors (Maxwell et al. 2014). Plans to introduce a new "5-tier" system in which the United Network of Organ Sharing (UNOS) converts one year survival into a publically available rating (from 1 to 5) for individual centers may also incentivize pursuit of life-sustaining treatment for the sake of program metrics (Scientific Registry of Transplant Recipients 2017).

In our experience, it is not unusual for concerns to be raised about the impact of program metrics on whether continuing life-sustaining treatment is recommended. While this worry most often comes from non-transplant health care professionals,

members of the transplant team as well as other consulting services, such as palliative care, may also share these concerns. As in the case vignette, the feeling that the transplant recommendations are based on priorities other than individualized recipient care may come from different sources. There may be a disagreement about prognosis, including whether certain complications are survivable outside of the ICU or disagreement about the expected quality of life following a prolonged hospitalization. There may be different experiences of patient suffering, whereby bedside nurses or residents may see struggles that transplant professionals do not. Patients may also be more willing to express frustrations about the burdens of care to non-transplant providers, which may give the impression that the transplant team is ignoring or downplaying patient preferences. Finally, transplant professionals may directly mention the importance of one year benchmarks to program well-being, creating the impression that this is the motivation for continuing life-sustaining treatment.

Spoken or unspoken, the perception that program metrics drive provider recommendations can significantly impact trust and relationships. Pretending that program quality metrics do not matter to the transplant team is disingenuous—they strongly motivate the team to conduct morbidity and mortality reviews, to undertake quality improvement projects, and to focus on preventable complications in the first year following transplant and beyond. But, the mere fact that a consideration such as a program metric provides a *reason* for making a recommendation to continue life-sustaining treatment is not the same as it *motivating* the recommendation. There is an ethical difference between being motivated to continue life-sustaining treatment because a provider believes that the patient's prognosis is unclear or because there is still a reasonable possibility of a good quality of life versus being motivated to continue life-sustaining treatment because the program will suffer if the patient dies before the end of his first year.

In order to disentangle the motive for a recommendation from all the reasons for making that recommendation, it is important that transplant (and non-transplant) providers reflect on what is driving their decision-making. In cases in which there is not a realistic hope of a meaningful outcome or quality of life, sufficient reflection may reveal that the real motivation to continue is to avoid a "strike" against the transplant program. Or, for non-transplant providers, reflection may reveal that the motivation for wanting to withdraw life-sustaining treatment is that they themselves would not want to live in conditions like the patient is experiencing. Because it can be difficult to determine whether a particular reason, such as a program metric, is motivationally inert, it is important to engage in a transparent and open discussion about why a treatment course is being recommended.

In cases in which the only reason and motivation for pursuing life-sustaining treatment is because the program is placed at risk by the recipient's death, it is necessary to disclose this information to the patient and family. Patients who are nearing the one year time point may assent to continuing life-sustaining treatment if it means that the program can continue to offer transplantation to high or higher risk patients. But, it must be clear that the final decision is up to the patient or surrogate and that life-sustaining treatment is not being continued to benefit the patient.

Obligations to Organ Donors and to Other Potential Candidates and Recipients

Principle Five: Ethical Considerations Related to the Donor and Other Potential Recipients are Relevant but not Overriding

There are a number of additional ethical concerns that may be introduced in conversations about recipients with a prolonged hospitalization. These include perceived obligations that the recipient and the transplant program have to the organ donor and the donor's family. While somewhat nebulous, there may be an implicit or explicit sense that the recipient should continue life-sustaining treatment or agree to escalate interventions because he was given a gift or out of respect for the donor's family. As such, the transplant program should honor this gift by taking steps necessary to ensure a good post-transplant outcome. Relatedly, there may be considerations raised about the other potential recipients who could have used these lungs. Here, the suggestion is that continuing life-sustaining treatment is important because the opportunity was taken from another person who did not have the same chance for a post-transplant life. Or, in other terms, taking a gift away from another potential recipient creates responsibilities for appropriate stewardship of that gift. Finally, transplant physicians may focus on the opportunities that other potential candidates will lose if the program nears or goes on probation as a result of the recipient's decision to withdraw life-sustaining treatment. Because the recipient benefited from the program being able to perform transplants he has responsibilities to the program and to others so that they can benefit.

An extended discussion of these considerations—which involve the ethics of gift giving and receiving, the moral evaluation of counterfactual states of affairs, and individual responsibilities to benefit others at significant personal cost—is beyond the scope of this paper. We note, however, that even if there are other defensible ethical claims in this context, and they are not simply supererogatory, they would not override the responsibilities that health care professionals have to respect the choices of a patient with decision-making capacity. This again emphasizes the importance of early efforts to ensure appropriate informed consent and later appropriate evaluation of patient decision-making capacity.

Recommendations

In our experience, concerns about continuing or withdrawing life-sustaining treatment for recipients with a prolonged hospitalization are usually resolved with a combination of careful discussion of prognosis, identification of benchmarks that represent clinical progress, and development of a daily plan of care with input from the patient, family, nurses, and other health care professionals. In cases like Mr. Jones, however, conflict can become intractable and can undermine trust between the patient, family, and transplant and non-transplant teams. As each party begins to distrust the motives of the other, the care of future transplant recipients and potential candidates can be impacted.

In cases in which disagreement threatens to become intractable, we recommend a conflict-resolution process, facilitated by a standing or ad hoc ethics consultation service. Preventative or advanced consultation has the benefit of exposing ethics consultants and other non-transplant providers to a range of cases, including patients who have better long-term outcomes. As with other procedural approaches, the primary objective is to establish a forum for communication in which various parties can discuss their perspectives (American Medical Association 2016; Boslett et al. 2015). Ideally, the ethics consultants would include community members or others not directly affiliated with the hospital. Consultants would meet privately and separately with the transplant team, the ICU team, and the patients/surrogates to discuss their perspectives on the case. As part of this process, the ethics consultants should establish, utilizing appropriate resources, whether the patient lacks decision-making capacity. If so, they should also determine whether the surrogate decision maker is appropriately identified, documented, and able to provide sufficient substituted judgment as well as relevant best interest considerations.

Consultants should then arrange a team–family–patient meeting in order to reach consensus regarding continuing or withdrawing life-sustaining treatment. In this context, all parties should be clear on why they are making their specific recommendations, which includes both direct motivations and any other relevant reasons. In the absence of clear consensus but with willingness to allow more time to pass before a final decision, the group should identify additional, specific benchmarks (such as time off the ventilator, absence of new infection, ability to tolerate artificial nutrition without nausea) that would constitute a success or failure of a time-limited trial of treatment. If there is persistent disagreement but there is no concern about the ability of the surrogate decision maker to provide substituted judgment or to act in the patient's best interest, then the ethics consultants should work with the transplant and non-transplant teams to withdraw life-sustaining treatment without significant delay.

While the utilization of a conflict-resolution process may help in specific cases, there are several regulatory and research priorities that could provide a broader perspective on transplant recipients with prolonged hospitalizations. From a regulatory standpoint, UNOS mandates the reporting of a number of post-transplant outcomes, both medical—kidney failure, cancer, graft impairment, etc.—and social, including post-transplant employment. There are, however, limited HRQL or functional data. Mandating periodic reporting of a simple HRQL measures such as the short form survey would significantly improve discussions regarding expected health-state outcomes for recipients with a prolonged hospitalization (Singer and Singer 2013). At the same time, continued reflection on the most appropriate organ allocation framework to fulfill the Final Rule is essential. This would include further understanding of how metrics like one year survival impact program decision-making and delivery of patient-centered care.

From a research standpoint, gathering additional information on post-transplant outcomes for patients with prolonged hospitalization is essential for a fully informed discussion of what has happened to other patients with an extended course, including relevant complications. This would include information on the fraction of patients who eventually return to home and independence, partial independence, and

complete dependence in their activities of daily living. Such research would also utilize health-related quality of life data to better anticipate an individual patient's quality of life based on others with similar deficits. Finally, understanding long-term survival, including 1 and 5 year median and quartile survival, would be extremely relevant to a population already at risk for limited survival, even under ideal post-transplant circumstances.

Where possible, other research priorities would include identifying patients who are likely to request limitation of life-sustaining treatment during a prolonged hospitalization. This includes understanding pre-transplant demographic and clinical characteristics (including social support, burden of psychiatric co-morbidities, frailty, and pre-transplant debility), the tolerance of pre-transplant patients for various states of dependence and debility, and their understanding of the likelihood of certain adverse outcomes. It also involves capturing the post-transplant hospital features (including functional deficits, length of ICU time, frequent transfers) that help identify an at-risk population for limited tolerance of a prolonged post-transplant course. This could allow earlier interventions including framing of expectations and possible re-examination of the wisdom of transplant in patients who are at high risk, mobilization of resources for developing coping skills, and targeted frailty improvement programs that could potentially prevent subsequent conflict if a prolonged hospitalization occurs. Finally, knowing the long-term course of patients who consider limiting life-sustaining treatment but who decide to continue would provide additional information for families, surrogates, and health care professionals engaged in decision-making with these patients.

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Compliance with Ethical Standards

Conflict of interest The authors have no potential conflicts of interest.

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