Looking beyond Mortality in Transplantation Outcomes

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Consider three of our patients, nearly 1 year after lung transplantation. Mr. S., who is 67 years old, underwent transplantation for pulmonary fibrosis. He is alive, but weak, intermittently delirious, and unable to breathe without a ventilator.

Ms. L., who is also in her 60s and has emphysema, was discharged home weeks after receiving her transplant and hasn’t been hospitalized since. Approaching her 1-year transplantation anniversary, she is riding motorcycles with her son down the coast.

Ms. P., who is in her late 40s and has cystic fibrosis, made it home after her transplantation and was considering a return to work when an invasive fungal infection brought her back to the hospital, in shock and with her kidneys failing. When it was clear that she would never be able to return to the independent life she had valued, her surrogates and doctors decided together to focus her care on prioritizing her comfort, and she died.

Which of these outcomes are successes and which are failures? To the Centers for Medicare and Medicaid Services (CMS), whose benchmarks are the basis for whether a program is certified as a transplant center, success means being alive — no matter what that life looks like — at 1 year.1 By this measure, a patient such as Ms. P. might jeopardize a program’s status, whereas Mr. S. would not, regardless of the quality of his life.

But people have priorities other than simply being alive. And yet despite an increasing emphasis on patient-centered outcomes in medicine, transplant centers do not systematically report information on health-related quality of life, nor are such measures incorporated into algorithms for organ allocation or program assessment. As a result, clinicians are encouraged to reduce post-transplantation mortality without key information about what matters most to patients, whether those outcomes are physical, emotional, or cognitive. Though we come to this issue from different backgrounds and sometimes conflicting perspectives — as transplant, critical care, and palliative medicine specialists — we share the opinion that if we hope to offer the best possible care to the recipients of medicine’s most aggressive interventions, we must begin to track, make public, and ultimately consider prioritizing outcomes beyond mortality.

In the case of lung transplantation, the importance of the 1-year survival benchmark begins long before patients reach the operating room. A place on the waiting list for transplantation is based on a calculation that weighs the patient’s probability of dying while waiting against the patient’s probability of living for 1 year after transplantation.2 Although the goal is to prioritize urgency of need (rather than accrued time on the list), the prioritization of patients with the highest risk of death over the short term has meant that a disproportionate number of people undergoing lung transplantation are acutely ill. Such patients are also especially likely to have post-transplantation complications that can affect their quality of life.

Yet for a patient or family member who is faced with treatment decisions and wants to know what to expect moving forward, data on quality of life are far less readily accessible than mortality statistics. Although transplant programs are required to report information on a comprehensive set of factors, including clinical and demographic data, to the Scientific Registry of Transplant Recipients (SRTR), on its public website, the SRTR typically provides data only about the waiting list and about survival. The SRTR has even started to beta-test a Yelp-style five-tier system to rank programs on the basis of their 1-year mortality statistics.3 As a result, there are many questions that matter to our patients that we are not well-equipped to answer. Such was the case with Mr. S. Intermittently ventilator- and dialysis-dependent, he had been transferred again from the long-term acute care hospital to the intensive care unit. The transplant team believed that
Mr. S. was improving. His mind was clearing, and he had been spending more time off the ventilator, at least until his most recent infection. His goal had been to make it home, and his transplant doctors assured him, on the basis of their experience with other patients and their knowledge of his course, that his goal was still achievable.

In contrast, when the critical care team looked at Mr. S., they saw a chronically critically ill man and a beleaguered family — yet another example of a patient being pushed beyond what was reasonable by the medical system. The palliative care team saw distress everywhere and felt unable to address this suffering without a view of what was possible to expect in the future. The existing research on quality of life after lung transplantation suggests an overall benefit, but studies have been limited by small sample sizes and survivor bias, and follow-up rarely extends beyond 1 year. As a result, even if our patient could in fact survive, we didn’t understand what effect our interventions to keep him alive might have on the outcomes that mattered to him. Furthermore, like most patients in similar situations, Mr. S. gave ambiguous responses regarding his hopes, goals, and emotions. When asked what he wanted, he often articulated the desire to press on, but intermittently refused dialysis or panicked when he was taken off the ventilator. His wife was exhausted after months at her husband’s bedside.

We were also struck by the concern — expressed largely by the house staff — that Mr. S. was being “kept alive” against his wishes by the transplant team to make it to the 1-year survivorship mark. This concern created a painful tension between providers. In the one study to date addressing this issue, researchers found an unexplained rise in deaths in months 13 and 14 after transplantation. They hypothesized that this finding might be the result of a “deferment of deaths” until after the 1-year mark — an unintended consequence of the current regulatory metrics. In our experience, the medicine we practice feels no different on day 340 than on day 366, but we don’t know to what extent the incentives surrounding the 1-year benchmark shift the care our patients receive, even in subtle ways. This issue is an important target for future research and education, since we know that decisions based on survival or quality metrics can have downstream repercussions.

Concern regarding the unintended consequences of using such metrics recently led CMS to propose that transplant center reappraisal no longer be based on outcomes such as mortality. The proposal is currently open for public comment; if it moves forward, it would represent an important step in the right direction. The CMS proposal would not change the criteria for initial approval or ongoing approval from the United Network for Organ Sharing, however, nor would it address the lack of data on quality of life. Right now, we can only hope that’s true — but we also hope for a day when the data we analyze and share can help us better educate our patients and ourselves.

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1. Centers for Medicare and Medicaid Services, Department of Health and Human Services. Medicare program; hospital conditions of participation: requirements for ap-
Reimagining Development Assistance for Health
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Financing priorities in global health continue to lag behind the changing realities in lower- and lower-middle-income countries, where the burden of non-communicable diseases (NCDs) is growing. In 2017, global health funding allocations remained essentially the same as they had for years: 5% and 7% of total development assistance for health (DAH) was targeted to tuberculosis and malaria, respectively, while child health received 21%, maternal health 11%, and NCDs 2%. While enormous strides have been made in reducing morbidity and mortality from infectious diseases worldwide, an intractable epidemiologic shift has occurred. NCDs now account for nearly 70% of all deaths globally; 40 million people die from preventable NCDs each year, and 80% of these deaths occur in lower- or lower-middle-income countries, accounting for a significant proportion of premature mortality.

This high burden represents one of our most urgent and most neglected global crises, with broad effects on political stability as well as public health. Fortunately, potential solutions have arisen, particularly over the past decade, as outbreak preparedness has become among the most salient of global health challenges. Specifically, the infrastructure needed for pandemic response is also relevant to addressing NCD-related challenges.

Current donor aid funding for global chronic diseases is anemic. In 2017, only $51.4 million — 0.14% of the $37.4 billion spent on DAH — was earmarked for health-systems support initiatives targeted specifically toward NCDs globally. When all relevant NCD-type investments (including aid directed toward mental health, tobacco-related illness, and other NCDs) are included, a total of $825.5 million was spent on NCDs in 2017 (2.2% of DAH). The largest single contributor to DAH in absolute dollars, the U.S. government, spent $77 million on NCDs (1% of its total contributions to DAH) and $5.9 billion on HIV/AIDS (48% of total contributions) in 2017.

Global commitments remain low nearly 5 years after the World Health Assembly endorsed the World Health Organization (WHO) Global Action Plan for Prevention and Control of NCDs 2013-2020, a wide-ranging document that prescribed a menu of policy options for member nations to combat the rising global NCD burden. Shortly after that endorsement, the WHO released a set of nine global targets for reducing the prevalence of common risk factors, such as tobacco use and alcohol consumption. The NCD Alliance and other advocacy groups have similarly raised awareness, but donors’ financial commitments have remained unchanged. The United Nations General Assembly will be hosting its third high-level meeting on September 27, 2018, to increase awareness of and political commitment to the problem; two previous meetings, however, have not been followed by significant investments in prevention or control of NCDs.

Sustaining the political will for even current global health priorities has proven challenging, but there is now clear evidence that DAH not only saves lives but affords state-stabilizing dividends. In order to continue to maximize these benefits and ensure the effectiveness of health aid, we believe that DAH’s scope must be urgently and strategically reimagined.

Ensuring that countries meet their commitments to the 2002 Monterrey Consensus, a broad