

Virtual Mentor

American Medical Association Journal of Ethics
August 2014, Volume 16, Number 8: 642-647.

MEDICINE AND SOCIETY

Medical Ethics and the Media: The Value of a Story

Macey L. Henderson, JD, and Jennifer Chevinsky

“Judge Rules Sarah Murnaghan Can Be Put on Adult Donor List” is just one of many headlines about this medical story that filled national news outlets during early June of 2013. A ten-year-old girl being treated at the prestigious Children’s Hospital of Philadelphia for cystic fibrosis was reportedly “dying” while waiting for a lung transplant [1].

Up until June 2014, Organ Procurement and Transplantation Network (OPTN) and United Network for Organ Sharing (UNOS) policy dictated that lungs for children under the age of 12 be strictly allocated in the US on a first-come, first-served basis, unlike lungs for adults and children over 12, which are allocated by an algorithm (Lung Allocation Score) that takes into account factors such as disease progression and life expectancy [2]. What began as one mother’s fight to save her child’s life through medical treatment she believed her daughter deserved quickly transformed into a public controversy about organ transplant allocation policies that was widely broadcast to the American public via television, newspapers, and digital media sources.

Frustrations over the unavailability of suitable pediatric donor lungs for transplant became the central issue of Sarah’s story. Advocates such as Pennsylvania Senator Pat Toomey and Representative Pat Meehan pushed for the expansion of transplant policies to include suitable adult organs [3], but adult donor lungs are themselves a scarce resource. After Sarah’s parents took her story to national media and news outlets, allowing the press an intimate look at her fragile condition while they argued her case in the US District Court for the Eastern District of Pennsylvania, things began to change. “Sarah” became a character in a larger story about the survival of an innocent child, a child who could have been born into any family. One of the arguments presented by the family was that “the pool of lungs donated from adults is more than 50 times larger than the pool of lungs donated from children” [4].

On June 5th, 2013, following an emergency hearing, Judge Michael Baylson directed former Health and Human Services (HHS) Secretary Kathleen Sebelius to issue a temporary suspension of the under-12 rule [1]. In an attempt to provide an ethically appropriate response, the OPTN instated a temporary one-year appeals process, which expired June 20th of 2014, for all children under the age of 12 whose doctors believed they might benefit from adult lungs. In the end, Sarah received two lung transplants—the first, a pediatric lung that failed, and the second, an adult lung that,

on the first anniversary of the transplant, had held up well enough for Sarah to breathe unassisted [5].

During the June 2013 plea to temporarily suspend the rule so Sarah could be put on the adult lung waiting list, former Secretary Sebelius ordered an investigation of the research on outcomes of pediatric lung transplantation for those with cystic fibrosis. Sarah and her parents could not wait, so the suspension was put in place before the review was completed, but data gathered during the suspension has added to the evidence base for forming current organ transplant policies.

A Double-Edged Sword

“We’ve helped a lot of other kids, too. There are about 10 kids listed right now who wouldn’t have been listed for adult lungs and at least one other child that’s gotten a transplant like Sarah,” her mother, Janet Murnaghan, said in a video posted on Facebook that showed Sarah breathing on her own after her successful transplant [6]. It is clear that those who utilize social media for health care advocacy purposes or seek the assistance of the press to tell a story through popular or mass media usually do so to gain support, increase awareness, or change public and professional opinion about their cause. Sarah’s case did just that. “I think that this issue raised awareness that there may be circumstances where children like Sarah ought to be able to request an exception,” said Dr. Stuart Sweet, director of a pediatric lung transplant program and writer of the original OPTN lung allocation policy, in an interview with NBC News [6]. This concept in some ways parallels the recent and controversial “right to try” rules popping up in states such as Colorado, Missouri, and Louisiana, where families have garnered social media support for allowing people with conditions refractory to available medical treatments to have access to pharmaceutical therapies that are still in clinical trials [7].

However, the most effective health policies consider large-scale statistical and public health data in addition to personal narratives. We should not forget that there are scientific and ethical reasons that the under-12 rule was created in the first place. The Scientific Registry of Transplant Recipients (SRTR) reviewed trends over time in deceased-donor lung transplant waitlist mortality and transplant rates. It found that the mortality rates of children aged 0-5 on the waitlist were higher than they were for adolescents (aged 12-17 years) or adults (aged 18 years and older), but the rates among children aged 6-11 years were the same as those of adults [8].

Lung transplantation in pediatric patients is associated with high postoperative morbidity and mortality, which is due largely to the recipient’s underlying comorbidities or medial conditions [9]. Furthermore, lung transplantation for the treatment of cystic fibrosis has been shown in several retrospective studies to have only marginal benefit [10]. Therefore, it is unclear whether allowing children between the ages of 6 and 11 with cystic fibrosis onto the adult lung-transplant waiting list will be a better use of the available organs, or, furthermore, whether it will make the system more just. In fact, it might shift organs away from adolescents

or adults, unfairly giving only children between the ages of 6 and 11 two pools of organs from which they could potentially benefit.

The under-12 rule, like all OPTN/UNOS policies, was originally a result of deliberation and consensus of an expert panel that took account of medical, ethical, legal, and other stakeholder input to craft a rule intended to uphold the ethical values of *justice* and *fairness* that underpin the entire US transplant system [11, 12]. While Judge Baylson and Secretary Sebelius were successful in aiding Sarah, OPTN/UNOS has the legal authority and responsibility to review its policies and procedures to ensure that they reflect the most recent medical and scientific evidence. As a direct result of Sarah's story, The OPTN/UNOS Lung Allocation Policy Review analyzed the effects of the two-tiered lung-allocation priority system which was implemented in 2010 (in which there are two separate systems, one for children 6-11 and one for children over 12 and adults). In this policy review, it was found that a higher percentage of children under 12 on the wait list died within a year of getting listed after the policy went into effect than had beforehand (30 percent, rather than 26 percent of children aged 6-11) [13]. In addition, analysis of recent OPTN/UNOS lung offer data demonstrated that fewer children under 12 received at least one lung offer than did older children and adults [14]. These studies do not suggest that increasing organ offers to children between the ages of 6 and 12 will significantly impact long-term mortality rates, because factors other than organ offers—especially those related to clinical condition—contribute to their outcomes. However, increasing organ offers may decrease *waiting-list mortality* among children, which currently mirrors adolescent and adult rates.

This data must be paired with the aforementioned mortality study, as our nation decides whether the goal of our transplant system should be to further minimize waiting-list mortality, by increasing organ offers to pediatric groups, or to attempt to maximize long-term survivability with organ transplantation, by giving the organs to adolescent and adult groups with overall higher rates of survival. It is also important to remember that more organs in one population pool means fewer organs available in another population pool; in other words, a child with cystic fibrosis who receives an adult organ is obtaining a precious resource that would have otherwise been transplanted in an adult who may have received a greater benefit. Of course this relates the difficult questions that underlie the transplant system: how can we, in an unbiased way, judge the amount of benefit that an individual receives from an organ? If we agree that the length of life lived with the new organ is an important consideration, it certainly seems that policies such as those governing pediatric lung transplantation with adult organs need further investigation and deliberation.

Although a full analysis of reasons for policy change will likely be revealed over the coming months, on June 23, 2014, the OPTN/UNOS board of directors voted to keep the new rule allowing children under the age of 12 to have access to the adult waitlist, illustrating the victory of Sarah's campaign for new lungs [15]. We expect that the rates of lung offers, organ rejection, waiting-list mortality, and long-term

survival will continue to be assessed as the adult waitlist becomes a mainstream option for children between the ages of 6 and 11 years old.

The narrative of Sarah's lung transplant controversy, as framed by the media, had the ability to change the treatment plan for one patient, the transplant options for pediatric patients during the year of the suspension, and US health care policy for the future. Sarah's story illustrates the power of medical narratives to bolster awareness of complex issues in medical ethics for physicians, medical students, and the public by bringing forward an anecdote that is widely relatable.

Mass Media's Impact on Promoting Action in Health Care

A broadly disseminated, emotionally affecting narrative such as the story about Sarah's lung transplant arouses sensitivity to ethical issues in medicine and helps us to experience a situation emotionally, asking questions like: *What if this were my child? What if this were my patient? What if this occurred in my hospital?* Mass media has the ability to promote this kind of reflection and empathy by drawing attention to aspects of medicine and public health from a different perspective than that adopted by dry coverage of legislative wrangling over policy.

Over the last three decades, the term "narrative medicine" has emerged to recognize the importance of patients' stories in helping physicians understand and be moved by patients' experiences of their illnesses. Can media stories of individual patients' experiences be considered part of medical narrative? We think so. Journalism and social media have the ability to accompany patients through the ordeals of an illness, promote the recognition of the impact and burden of diseases, and convey knowledge formerly known only to those who experienced it. Furthermore, as seen through Sarah's story, news coverage often contains the opportunity for moral evaluation, either implicitly or explicitly, of challenges and debates over health care decisions, resource allocation, and the validity of scientific research that informs health policy. The American public responds to the media's ability to shape and impact ethical decision-making—and has been doing so for decades.

Physicians must recognize that these stories are intended to move readers and policymakers toward particular goals. Media narratives help make population-level studies accessible to the public, but not without the risk of replacing necessary large-scale statistical studies with "n of one" anecdotes. Transparency of media coverage of issues of ethical debate in health care can be improved if journalists remain committed to high-quality reporting and data presentation that includes different opinions and promotes dialogue. Recognizing the power a narrative can have in shaping opinions, organizations such as the Association of Health Care Journalists should hold their membership accountable for adhering to the principles of accurate storytelling the organization promulgates [16]. At the same time, it is the responsibility of physicians and the medical profession to weigh in on the clinical efficacy and ethical soundness of those goals, so that evidence- and experience-based stories are a recognized part of the larger narrative.

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Macey L. Henderson, JD, is a doctoral student and associate instructor in the Department of Health Policy and Management at the Indiana University Richard M. Fairbanks School of Public Health in Indianapolis, series editor of SpringerBriefs in public health ethics, and an appointed member of the OPTN/UNOS Living Donor Committee. Her JD is from the Indiana University Maurer School of Law, and her BA is in philosophy and medical humanities. She was a visiting researcher at the Kennedy Institute of Ethics at Georgetown University, where she studied organ transplantation under Robert M. Veatch.

Jennifer Chevinsky is a third-year medical student in the Scholarly Excellence Leadership Experiences Collaborative Training (SELECT) program of the University of South Florida Morsani College of Medicine and the Lehigh Valley Health Network in Allentown, Pennsylvania. She is chair of the student affinity group at the American Society for Bioethics and Humanities and of the American Medical Association Medical Student Section's Committee on Bioethics and Humanities. She has a degree with honors in bioethics in cross-cultural perspectives from the University of Connecticut's combined program in medicine.

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