Moving Boundaries — The Nightingale Twins and Transplantation Science

Stefan G. Tullius, M.D., Ph.D., Julia A. Rudolf, B.A., and Sayeed K. Malek, M.D.

Johanna Rempel and Lana Blatz sat on either side of Dr. Joseph Murray in the reception room of the Transplant Surgery Division at Brigham and Women’s Hospital one May morning in 2011. The 63-year-old identical twins had made the trip from Alberta, Canada, to Boston to meet with the Nobel-honored surgeon who pioneered the field of human organ transplantation. The sisters — then Johanna and Lana Nightingale — had first met Murray in 1960, when he transplanted Lana’s left kidney into Johanna, saving her life. The twins were 12 years old at the time. Today, Johanna is the longest surviving kidney-transplant recipient.

In December 1955, 7-year-old Johanna Nightingale had become very ill with a *Streptococcus pyogenes* throat infection, which soon affected her kidneys, causing acute glomerulonephritis and then chronic kidney disease. Dialysis did not yet exist, and the next 5 years of Johanna’s childhood revolved around the hospital. Johanna was extremely small, weak, and prone to sickness. She spent at least 3 weeks of every month in the hospital, receiving supportive care. In 1960, one of Johanna’s doctors in Winnipeg read that Murray was performing kidney transplantations in Boston and immediately wrote to him about Johanna’s case. Murray responded, saying that as a patient with renal failure who happened to have a healthy identical twin, Johanna sounded like a perfect candidate for transplantation.

Whether 12-year-old Lana should be asked to donate a kidney to her sister was a delicate question. Lana recalls accompanying her mother to a doctor’s appointment and being asked to leave the room and run an errand. When she returned, she overheard the physician and her mother discussing a possible transplantation. Without hesitation, Lana stepped into the room. “Absolutely we’re going to do that,” she said. “No question.”

Lana’s request to donate her kidney was denied by three separate courts, until eventually the twins appealed to the Supreme Judicial Court of Massachusetts. The judge asked Lana what she would do if she were denied again. “I’ll go to a higher court!” she replied. Permission was granted to proceed with the surgery.

On December 7, 1960, Johanna and Lana arrived in Boston for preoperative testing. Skin grafting confirmed that the twins were a compatible match. By that time, Johanna’s kidneys were functioning at only 10%. On December 28, the transplantation was performed.

For the next several months, the twins were kept at the Brigham for monitoring. They became the darlings of the hospital, where nurses entertained them by helping them hook up imaginary IVs to treat their dolls — one of which (see photo) was given to them by President-elect John F. Kennedy on a visit to the hospital.

Today, the twins live 4 hours apart in Alberta, where they both work as bookkeepers. Johanna married in 1966, and although her doctors weren’t sure how pregnancy and childbirth would affect the transplanted kidney, she had three children after uneventful pregnancies. Since the transplantation, Johanna’s kidney function has remained normal and her health has been excellent. She volunteers with the Kidney Foundation of Canada. Lana married in 1967 and has four children. She’s had no side effects from the kidney donation and has her renal function monitored once a year.

The Nightingale twins’ story is more than an inspiring account of modern medicine’s triumph over disease. When the twins underwent surgery in 1960, they were the youngest living kidney donor and recipient to date, and theirs was only the 13th renal transplantation from a living donor ever performed. The operation was in its early years and was fraught with uncertainties and unknowns.1,2 Saving Johanna’s life required courageous actions on the parts of the surgical team, Lana, and Johanna herself. The bravery of the Nightingale twins and of other patients who have been willing to push the boundaries of medical science is one of the key factors that has made progress in medicine possible. Their legacy serves as a reminder that, like the physician-scientists who care for them, patients help in advancing medicine.

Johanna and Lana’s experience also illustrates how medical tech-
nology and medical ethics evolve in tandem. Although the Hippocratic principle of doing no harm has guided the work of physicians since ancient times, and though organ donors are approved only after a thorough evaluation of their medical fitness, the principle of nonmaleficence has been consistently violated since organ transplantation began: living organ donors undergo an invasive medical procedure that carries risk but is not for their own benefit. In this context, Johanna and Lana's story offers an interesting perspective on patient autonomy. The process of obtaining informed consent for donation must take into account both the patient's autonomy to make a well-informed decision and the physician's duty of beneficence to protect the patient's best interests. In 1960, far less was known about the short-term and long-term safety of live kidney donation than is known today; however, Lana's resolve to donate her kidney was absolute. Johanna and Lana were twin sisters and best friends, and in that predialysis era, Johanna would certainly have died without the transplant. It is not difficult to imagine the devastating burden that Lana would have had to bear if the option of donating her organ to her sister had been denied. For the physicians involved in the operation, being truly beneficent to Lana meant considering her emotional and social interests as well as her medical interests.

Organ transplantation, promoted in the early years by a few pioneers, has evolved into an extremely successful treatment for patients with organ failure, with graft-survival rates far exceeding 90%. Like many other areas of medicine, the practice of transplantation operates today under strict supervision and tight regulation. Fifty years ago, Murray and the Nightingale twins made the choice to push the boundaries. As a result, Johanna and Lana have been able to enjoy a lifetime together, and their contributions helped to pave the way for thousands of other patients to receive the lifesaving benefits of organ transplantation. Transplantation has evolved rapidly into an established, and simultaneously intensely regulated, treatment for patients with end-stage organ failure. The importance of careful and purposeful regulation of medical research is not disputed. However, innovation in clinical medicine can be achieved only when the value of progress is recognized in the development of regulations.

Composite tissue transplantation is an example of an area where the frontiers of medical innovation are currently being explored. As the fields of limb and face transplantation evolve, new questions about ethics and policies are arising. These issues should be studied, debated, and examined from all angles, as they have been in the case of solid organ donation and transplantation. Lessons can be learned, however, from the evolution of the solid-organ-donation field, as well as from nonrandomized studies of innovations. There must be a delicate balance among innovation, administration, and execution if we are to avoid a serious decline in the advancement of science and medicine. The story of the Nightingale twins illustrates that bold steps are sometimes necessary in order to blaze new clinical trails.

Disclosure forms provided by the authors are available with the full text of this article at NEJM.org.

From the Division of Transplant Surgery, Brigham and Women's Hospital, Boston.


Copyright © 2012 Massachusetts Medical Society.