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Providing Lifelong Support for Pediatric Recipients of Organ Transplants Etsuko Soeda



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VOL.

032

/100

2019.Nov ISSUE

Japanese Color: VIOLET-iro

My Role as a "Lifelong Manager" for 300 Patients

A major difference between transplantation medical care and other types of medical treatment is that the former is never ending. Existing medicine requires transplant recipients to keep taking immunosuppressants for life, yet the medical staff involved in organ transplants are not necessarily always going to be working in the same unit or out-patient clinic where they can keep monitoring the patients. This is where RTC is needed as someone who can provide continual support to transplant recipients. My role is to respond to any patient who reaches out to me, and I have a notebook filled with information on over 300 liver, kidney, and small intestine recipients that I've looked after so far. I'm something of a "lifelong manager" for them.

Organs for transplants can come from deceased persons or living donors. I worked specifically as a coordinator for liver, kidney, and small intestine recipients, and living-donor transplants were overwhelmingly common for the liver and kidney. So I provided support for both the transplant recipient and the organ donor. Living donors are principally restricted to immediate family members and relatives, and these potential donors need to voluntarily agree to donate their organs. Although family members may also feel pressured and obliged to become a donor if others tell them "you are the only person who is compatible"; and even if they agree to be a donor, it's not uncommon for them to feel anxious as the surgery approaches. Having a family member who requires an organ transplantation sometimes also brings to the surface issues the family hasn't been acknowledging. So RTC needs to be sensitive to and aware of the relationships between family members as well.

Experiences in America - An Advanced Nation for Transplants



Associate Professor Soeda during her time studying abroad in America. In the first half of the 1990s, when debate on transplants from brain-dead donors had just begun in Japan, organ transplantation was already in America as an option alongside other treatments. She felt the same resistance toward the idea of organ transplants that many Japanese people had at the time. However, after traveling to America for training and meeting children whose lives were saved by organ transplants, she had a complete change of heart.

Transplantation Medical Care is Never Ending: Caring for Pediatric Recipients is an Issue

The Organ Transplant Law of Japan was enacted in 1997, paving the way for organ donation following brain death.

Since then, transplantation medical care has been gradually expanding in Japanese society.

As more people's lives are being saved thanks to transplant surgery, there are calls for creating social structures that understand and support the actual circumstances, feelings and wishes of the transplant recipients. Associate Professor Etsuko Soeda has worked as a recipient transplant coordinator (RTC) at Keio University Hospital, where she provided medical and psychological support to organ transplant recipients.

She is currently focusing on researching long-term care for patients who received an organ transplant as a child.

How Can We Support the Recipient's Growth After the Transplant?

What if I gave you 10,000 yen? You'd surely be happy to receive it, right? How about if I gave you my organ? Would you be equally as happy to receive such a gift?

The 10-year survival rate of children receiving a liver transplant is currently 80%

or higher, while the engraftment rate^(*) for kidney transplants is over 90%. While it is truly wonderful that many lives are being saved thanks to transplants, the flipside is there will be more children who will live while feeling the weight of having "received an organ." I'm currently researching long-term support for children who have received a liver transplant,

particularly during the "transition period" when the patient moves from receiving medical care as a child to as a teenager and adult.

These children who have received organ transplants face various problems as they continue to grow. They dislike taking certain medication that have adverse effects such as excessive hair growth or hair loss, and once they turn 20, they aren't sure how much alcohol they can drink. There is also a difference in the warmth of the medical staff in terms of how they interact with the patient in the pediatric department, where the child was treated when they had the transplant the transplant, and as an adult patient in the other hospital departments. The reality is there is insufficient psychological and social care to deal with the growth and changes in children after they've received a transplant.

Recently it has become more common to see scenes of organ transplants being performed in television dramas and movies, although they don't really depict the true feelings and struggles of the donor and recipient. I believe some of the issues we need to address in transplantation medical

care are creating more opportunities for transplant recipients to talk about their experiences, and setting up support structures in society for donors and recipients.

* Rate of transplanted organs that are functioning after the surgery.

Fun-Filled Three Days Gives Recipients a Zest for Life

Part of my research includes running an annual camp for patients who received an organ transplant at Keio University Hospital as a child. The participants span a wide age group from 4th year elementary school students to people in their 30s, and includes a man who received the first living-donor liver transplant for a child at Keio University Hospital.

At the camp, we survey the participants

about things such as their psychosocial skills, moral education and physical abilities, and analyze how the children's "zest for life" changes through taking part in hands-on activities. For me though, the primary purpose of running these camps is for the children to have some fun.

Every day these children are faced with the same concerns of kids around them such as study, relationships with friends and love-related issues, as well as the stresses associated with being a transplant recipient including hesitation and discomfort about going on a school trip and having their friends see the post-transplant scars on their body. My most earnest wish is for children who have received transplants to be able to get through these tough times by remembering the fun they had at the camp, and recalling the stories of older kids with the same experiences.

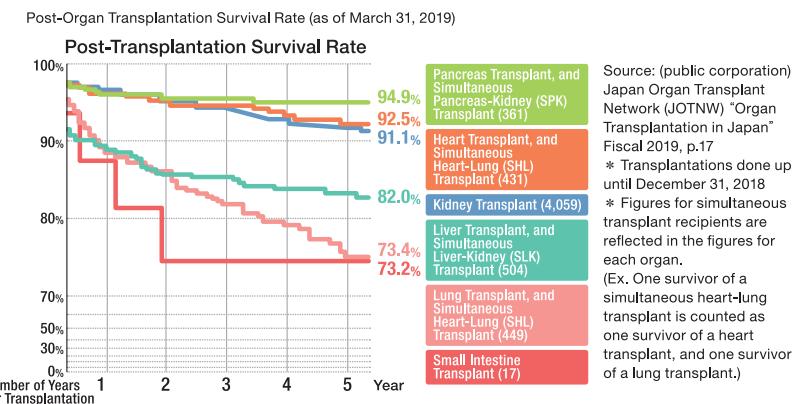
I drew inspiration for this camp from the Children's Hospital of Pittsburgh's summer Camp Chihopi, which I experienced for myself during my time in America. This summer I started the Keio Origami Project to teach origami to children at the summer camp in America, 3 Keio University nursing students and 1 law student volunteered to travel to America with me to assist with the project. Eventually, it would be great if we could make both summer camps a place for interaction and exchanges between Japanese and American children who have received organ transplants.

Profile Etsuko Soeda



Associate Professor, Faculty of Nursing and Medical Care, Keio University. Certified Recipient Transplant Coordinator (RTC). Completed the Doctoral Course at the Duquesne University School of Nursing in Pittsburgh, the United States. She is a board member of the Japan Academy of Transplantation and Regeneration Nursing, and a trustee of The Japan Society for Transplantation. Specializes in pediatric nursing, transplantation nursing, and transplant coordination.

Rising Post-Transplantation Survival Rate



Domestic post-transplantation survival rate from organ donation after death (as of March 31, 2019). Advancements in immunosuppressants have helped to drastically raise the post-transplantation survival rate; however, the number of organ transplants in Japan remains fairly low compared to other countries. This is particularly notable in kidney transplants; although there are about 330,000 artificial dialysis patients, the annual number of kidney transplants is around 1,700. "I'd like more patients to know that transplantation is another treatment option along with blood dialysis and peritoneal dialysis, and to challenge themselves to choose it", She commented.



Camp Gives Children a Zest for Life

Children who have received an organ transplant are having fun at Soeda's camp held at the Keio University Akakura Sanso Lodge. It is also an excellent opportunity for medical staff to see the children express emotions they usually don't while in the hospital, and to check their activities of daily living etc.



Young transplant recipients at the Children's Hospital of Pittsburgh's summer Camp Chihopi are enjoying folding some origami. Soeda and 5 students from Keio University travelled to America to teach the recipients origami as one of the camp activities.



Please visit S-face website for details!

There are more articles and video of Etsuko Soeda.

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Keio Research Institute at SFC
Office of Research Development and Sponsored Projects,
Shonan Fujisawa Campus, Keio University
5322 Endo, Fujisawa, Kanagawa, 252-0882, Japan
Tel: +81-(0)466-49-3436
E-mail: info-kri@sfc.keio.ac.jp

