Changing Minds about Pediatric Organ Transplants

This past July, 2008, Megumi Aihara, a six year-old girl suffering from severe heart disease, had a cardiac transplant operation in the United States. Her parents raised funds to get enough money for the operation, and successfully collected 110 million yen (“First grader Midori,” 2008). This is very delightful news, but this news has clearly posed a serious question to us all. That is: how many families can afford as much as a hundred million yen for an operation for their child?

Taking the specific example of heart transplants, according to the Tokyo Shimbun, from 1997 to mid-2002, in a group of 41 children, 22 were successfully able to receive cardiac transplantation operations in foreign countries. However, 19 passed away either while preparing to travel abroad or after they went abroad (as cited in Onda, 2004). Since it costs an enormous amount of money for the operation, most of the fortunate patients, like Megumi Aihara, have to collect money by conducting fundraising campaigns.

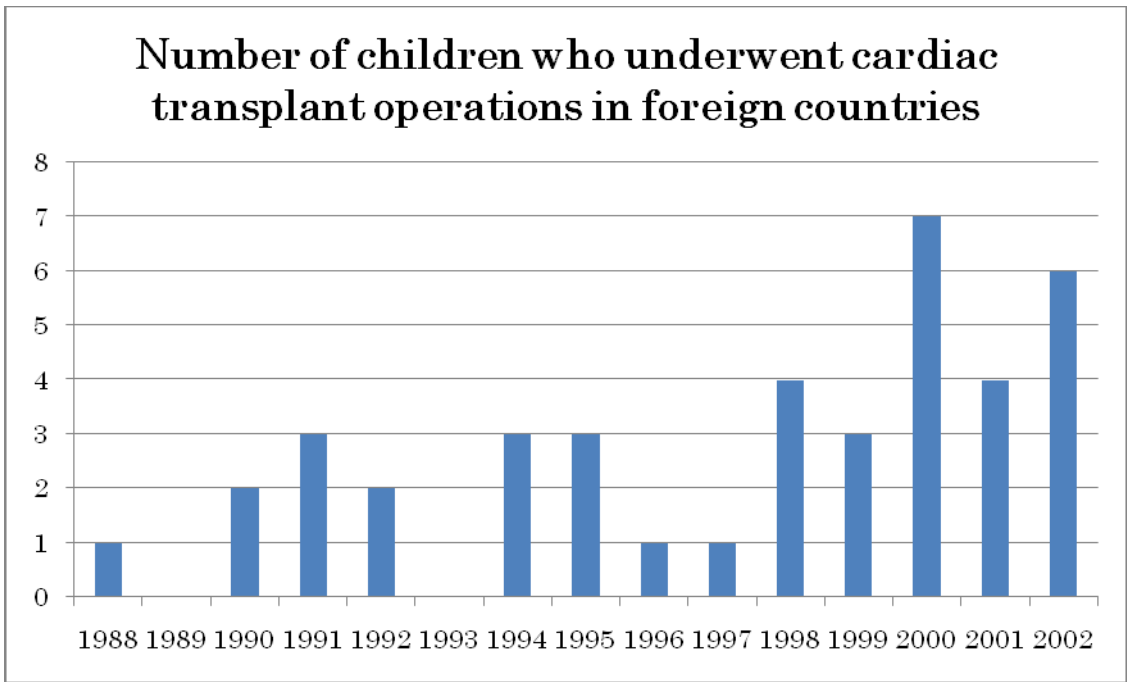

Diagram 1

Diagram 1 above shows that, although the overall numbers are relatively small, there are children who are in great need of special care at home here in Japan. This is clearly a serious problem we have to address. It is not only a financial problem. Most of those children are in severe condition, so they do not have time to wait for their parents to collect money on the streets. The average life expectancy of such children is 6 months, and their one year survival rate is only 32.5% (as cited in Onda, 2004). Therefore, there are some cases where the children become too ill to travel at all.

Also, the great costs involved lead to unfairness in medical treatment. Children whose parents can afford to pay the cost can undergo the transplantation operation. But how will children of less wealthy families fare? It is possible that they will not be able

to have the operation because their parents cannot collect sufficient money despite their best fundraising efforts. In this case, the gap between rich and poor is causing the injustice.

Thinking about these problems, one naturally wonders why those children cannot pursue organ transplantation operations in Japan. Despite the availability of the necessary technology and expertise, the Organ Transplant Law prohibits brain-dead children under fifteen from being organ transplant donors (as cited in “Revising the Organ,” 2006). This means that a child in need might possibly receive an organ from an adult donor, but in the case of cardiac transplants, this has only happened twice (due to the size of the heart needed) (Bagheri, n.d.; Onda, 2004).

There are several reasons why organ transplantation from brain-dead children is prohibited. The first reason is the difficulty in judging brain death. The domestic criteria for brain death, called the *Takeuchi Kijun*, is not adaptive to children under six years old (“Zouki no ishoku,” 2000). More data is needed to either broaden the *Takeuchi Kijun* or to introduce a specific version just for children. Also, Dr. Sugimoto (2003) has pointed out that the pathophysiology of brain death remains to be clarified in children because children can react differently than adults to trauma that leaves their heart uninjured.

Another reason why the Organ Transplant Law bans children from being donors is because of the problem of child abuse. According to research by the Ministry of Health, Labour and Welfare, there are cases of children under six who have become brain-dead because of abuse from their parents (as cited in Onda, 2004). Also, according to other research, 10-40% of all children with head injuries are suspected of being victims of abuse (as cited in Onda, 2004). Given the existence of child abuse, organ donation with only the permission of parents would be a problem in many surgical cases. So, as the Japan Pediatric Society (2003) and the Japanese Society of Child Health Nursing (2004) argue, it would cause a serious problem if organ transplantation from children is allowed without first making a solid system for distinguishing child abuse brain-death cases from non-child abuse brain-death cases.

Another obstacle Japan suffers from is a lack of consensus among doctors and lay people about the need for organ transplant in general. For example, in Christian countries like the United Kingdom, organ donation is accepted as a natural duty. In fact, the Church of England has declared organ donation to be a Christian duty (as cited in "Organ donation a Christian," 2007). Also, two-thirds of the people surveyed by the British Medical Association said the UK should move to an opt-out system, meaning that all citizens are automatically organ donors unless they specifically request not to be

（as cited in “Most back opt-out organ donation,” 2007）.

On the other hand, in Japan, organ transplantation from brain-dead people in particular is not popular. According to a research report by the Japan Organ Transplant Network, only 76 brain-dead people became donors after the Organ Transplant Law was put into force in 1997 (“Data about organ transplant,” 2008). Diagram 2 (below) gives a graphical representation of these statistics.

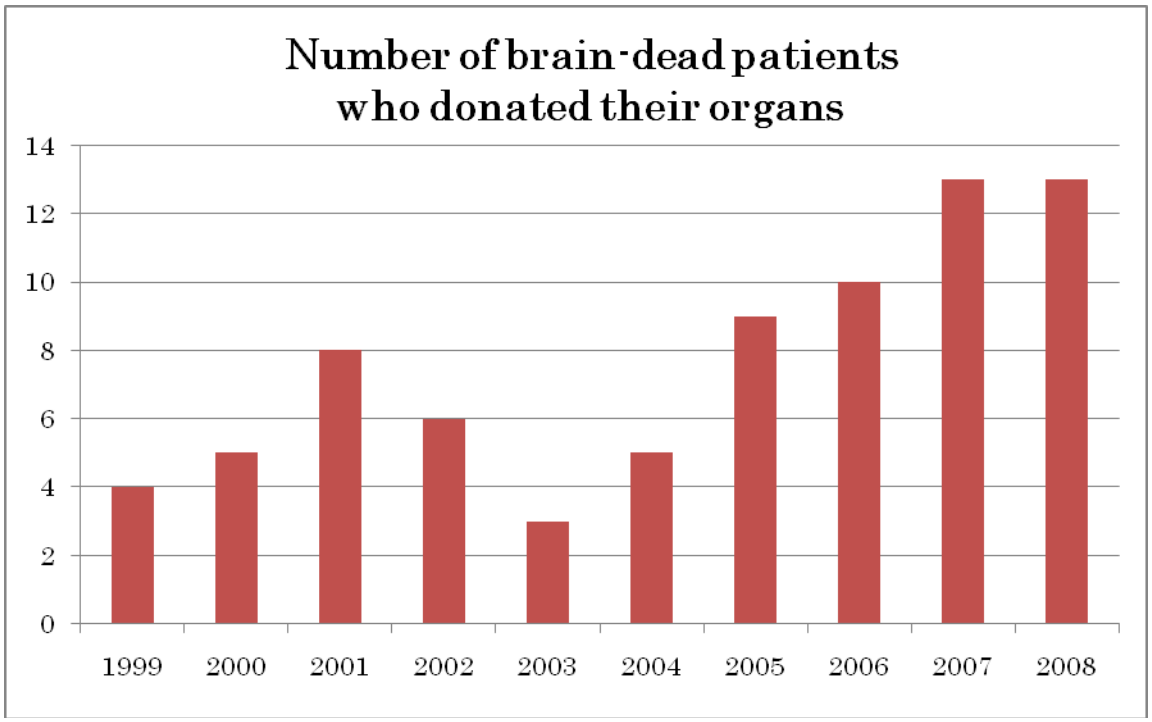

Diagram 2

These data mean that only about 7 brain-dead adults become donors each year on average, while 3000-4000 people are estimated to meet the medical definition of brain death each year (Shimazaki, n.d.) Why can’t organ transplants attain social acceptance and consensus? Alireza Bagheri (n.d.) pointed out that, “the Japanese . . . beliefs

towards life and death had a great role to shape [attitudes].” In fact, some experts have pointed out that traditional Buddhist and Shinto teachings influence Japanese views on death. Dr. Brannigan has argued that many Japanese believe body and soul rest side by side and thus Japanese do not want to tamper with the bodies of deceased loved ones (as cited in Wicks, 2000). That is not to say that the bodies of the deceased people cannot be altered what so ever. Cremation, for example, is common practice in Japan. However, removing part of a body, especially in a surgical procedure behind closed doors, is unacceptable (or just alarming) to many Japanese people.

The cultural issues are, undoubtedly, affecting the current debate on organ transplantation from brain-dead children. Clearly a new proposal is necessary to better inform the public, to revise current laws, and to bring doctors together in a new organization. We do not have any time to waste. This past May (2008), the Transplantation Society adopted the Declaration of Istanbul on Organ Trafficking and Transplant Tourism, which states that, “Countries . . . should strive to achieve self-sufficiency in organ donation . . . .” (The Transplantation Society, 2008). In addition, Dr. Luc Nuel, in charge of transplantation at the WHO, warned members of the Japanese Diet to change the present condition when he came to Japan this June (as cited in Today’s feature, 2008).

As a solution, firstly, organ donation from brain-dead children under fifteen should be allowed. It is true that there are many medical, ethical, and cultural problems, but the Japanese government should undertake to help children waiting for organ transplants. The advantages of introducing child organ donation clearly outweigh the problems. I believe that these problems can be mitigated by establishing a solid system for pediatric organ transplant based on the idea from a proposal by Masahiro Morioka and Tateo Sugimoto (Sugimoto, 2003). They have proposed a revision to the current law. Their proposal consists of two variants, and I strongly agree with their plan for permitting organ removals from children over five. Ideally, children of any age would be eligible organ donors, not just those over five. However, Japan just does not seem ready for this degree of medical change. My proposal is a compromise which hopefully will eventually lead to the ideal solution.

One of the features of Morioka and Sugimoto's proposal is the requirement of donor's consent via a prior declaration plus the prior consent of persons in parental authority. This requirement is similar to the current law for adults, but it is also in accordance with the UN Convention on the Right of the Child (Office of the United Nations High Commissioner for Human Rights, n.d.).

The second part of my proposal is to establish an organization called the Child

Organ Transplantation Management Organization (COTMO) that will register and record organ donors. Currently, the Japan Organ Transplant Network (JOTN) is working as the sole organ transplant network. However, considering the several controversial issues of organ transplant from children, it is necessary to distinguish the current network from the COTMO network.

As mentioned previously, where size is concerned, usually organs from children should be given to children (in very few cases, adult organs may be given to children and vice versa, depending on the size of the adult). Therefore, by establishing a new association which deals only with child organs, it would be smoother to locate organs before an operation.

However, this new organization (COTMO) and the current JOTN should work together seamlessly as a team especially for those times when a child organ fits an adult patient. Also, there will be certain ages that overlap between the two organizations (for example, older teenagers and young adults).

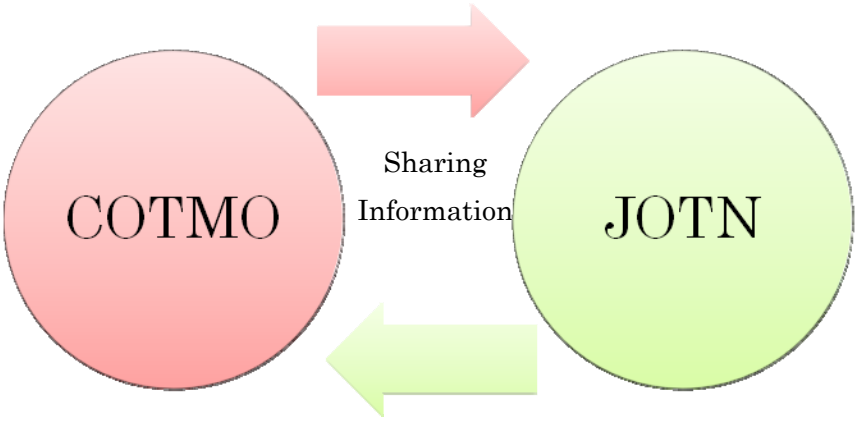

Diagram 3 Relationship between COTMO and JOTN

In my proposal, COTMO will work not only as a network of child organs but an organization which deals with all aspects of child organ transplantation.

First, COTMO would provide pediatric transplant coordinator training. Currently, there are about twenty transplant coordinators working for the JOTN. However, the specialty of the coordinators is related to the non-surgical aspects of organ transplant from adults, not children. Therefore, it would be urgent to educate new child organ transplant coordinators. The coordinators should have special national licenses.

By the same token, pediatric implant surgeons are necessary. The organization should accredit the doctors, and only the accredited doctors should be allowed to undertake child organ transplantation operations. The merit of introducing this system is that these doctors would have specialized knowledge and experience in all aspects of pediatric organ transplantation. For example, these accredited doctors would know enough about child abuse, so that they can distinguish between cases of child abuse and

other cases of brain death. Thinking about the example of the United States, the American Academy of Pediatrics states:

> The medical and forensic investigation of the death of a child attributable to trauma (unintentional or resulting from abuse), SIDS, poisonings, etc, presents unique issues related to organ procurement. Close cooperation between the forensic system, transplant team, treating physicians, and OPO allows . . . successful organ procurement (The American Academy of Pediatrics, 2002).

This quote shows that, although challenging, child organ transplantation can work. It takes cooperation and close oversight by accredited professionals. My proposal, though, does not advocate organ donation from abused children.

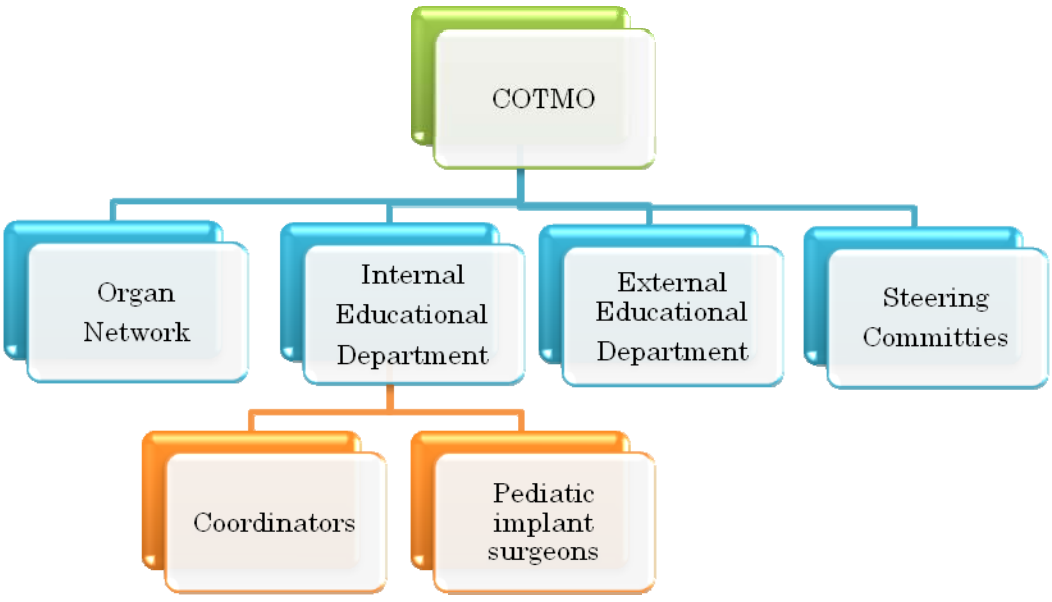

Diagram 4 Image of the ideal COTMO network

In addition to providing training, COTMO should create a steering committee to discuss ethical, medical and cultural aspects of organ transplantation. It will consist of COTMO members including pediatricians, surgeons, COTMO coordinators, ethicists and possibly lawyers. As new discoveries and developments occur concerning pediatric transplants, this committee will be the forum for sharing that information and deciding how to publicize it.

A lot of progress needs to be made in organ donation education in Japan. According to research by the Cabinet Office, only 8 % of the people surveyed had donor cards (as cited in Today's feature, 2008). This number is far too small, but shows a good opportunity for improvement. This is how we should approach the pediatric organ transplant issue. There is good opportunity for improvement in every area. It is important to remain positive about the progress that can be made. Only criticizing the current system will be counter-productive. Just like when a pediatrician treats a child, bedside manner and attitude make the difference between a hospital with a waiting list and a hospital with an empty lobby.

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