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Author(s)	YASUOKA, Keiko
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Rebirthable Life: *Narratives of Japanese organ transplantation by concerned parties*

Keiko YASUOKA

Abstract: Japan's first organ transplantation law was established in 1997 and revised in 2010, but only 191 organ transplant operations from brain-dead donors have yet been performed (data to 23 September 2012). Most recipients depend on living donors within their family unit or overseas transplants from foreign donors; as a result, organ transplantation issues are not exclusively medical problems. The objective of this study was to analyze the concepts of life held by people involved in organ transplantation in Japan. Methodologies included interview research and participant observation with concerned parties, who were mostly introduced through the Japan Transplant Recipients Organization. Ten transplant medical workers (seven transplant surgeons, two recipient coordinators and one donor coordinator), seven organ recipients and six donor families were interviewed, and participant observations were performed at related events. The data were transcribed verbatim and analyzed using qualitative research methods and coding methods from the grounded theory approach, paying particular attention to objectivity, reliability and validity. The results reveal that the existence of donors is the most important issue for concerned parties, and that donors' lives can be "reborn" in both recipients' bodies and donor families' minds. Surgeons admire organ transplantation as a new medical treatment but they cannot help feeling guilty about harvesting organs, especially undertaking such procedures as removing a still-beating heart from a donor's chest. Recipients are grateful to donors but have complex feelings about their donors' deaths and the donor families' sadness at losing family members. Donor families may have negative feelings toward recipients but find interpretations that allow them to imagine the rebirth of their family members via their living organs. Further research should inquire into the relationship between emerging medical technology and human responses in the twenty-first century.

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INTRODUCTION

Many important emerging biomedical treatments were discovered in the twentieth century, of which one of the most sensational and dramatic was organ transplantation from brain-dead donors. The first heart transplant was performed by Dr C. Barnard in South Africa in 1967.

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Keiko YASUOKA: mkya11@let.hokudai.ac.jp

Thereafter, various transplantation laws were established throughout the world; these not only saved recipients but also created new issues.

In Japan, organ transplantation has been the most widely discussed medical, legal, ethical and cultural issue since 1968 when Dr J. Wada performed the first heart transplant operation; this became the "Wada Case", as he was accused of murder. The strictest organ transplantation law in the world was established in Japan in 1997, since when only 191 cases from brain-dead donors have been performed (data to 23 September 2012).

These cultural issues surrounding organ transplantation in Japan mean that most cases have an international element. Most of the transplant surgeons I spoke to had gone to the US for training and had experience working in American hospitals. The recipients had often depended on overseas transplantations: while three had received organs in Japan, two received livers in Australia and two received kidneys in the US. Two of the donor families had donated organs in Australia following the deaths of their family members in automobile accidents.

There is a severe organ shortage problem worldwide. In Japan, living donors can only legally be family members, so many Japanese depend on overseas transplants. But the EU has stopped accepting Japanese recipients and the US is reducing the overall number of foreign recipients, so the options for Japanese patients awaiting transplant are greatly reduced, leaving them only able to look toward Asian countries. The issues of ECD (expanded-criteria donors) and NHBD (non-heart-beating donors) are also being discussed by specialists. Some transplant surgeons are keen to embrace the new procedures in order to save more patients but some are concerned about the possible dangers inherent in the new technologies. Furthermore, bioethicists are considering the risks of expanding the range of donors.

RESEARCH QUESTION AND OBJECTIVES

What factors contribute to the infrequency of organ donation in Japan? From 1968 to 1997 depending on living donors was the only option available for kidney recipients in Japan. In addition, overseas transplants via "medical tourism" were the only option available for Japanese heart recipients, and organ transplants from overseas are very expensive. Since 1997 organ recipients' concepts of life have been transformed by many kinds of donors; this study compares their narratives (Kleinman, 1988) to show how they were affected. My research set out to examine the narratives created about organ donation by concerned parties, including seven transplant surgeons, seven recipients and six donor families. The recipients obtained their organs from either brain-dead or heart-dead donors. The donor families included two fathers, three mothers and one wife.

By examining these organ transplantation issues, we may find a better way to preserve patients' autonomy and support their decisions. While paying attention to the unique Japanese organ transplantation situation, it is possible to reflect on organ transplant problems throughout the world. Brain-dead organ transplantation is an emerging medical technology, and can be used to try to understand the new relationship between technologies and humans.

METHODS

The relationships among donors and concerned parties are varied and complex. For transplant surgeons' donors are sometimes their own patients and can be well known, but for recipients the donors are almost always unknown, while for donor families, donors are close family members. In an attempt to take this broad range into account, my research methodologies included both participant observation and formal interview research. Participant observations were carried out at events attended by surgeons, coordinators, recipients and donor families. These were of two types: those concerning treatment and those intended to deepen mutual understanding. In Japan, unlike in the US and Australia, there is no system for providing medical and psychological support for donor families, so such events are set up to enable the families to try to take care of each other. I acted as an interpreter at concerned parties' events including the "Transplant Games", in order to build understanding and rapport. This led to successful interview research through the Japan Transplant Recipients Organization, which introduced members including transplant surgeons, recipients and donor families.

Interview research was conducted with concerned parties in Sapporo, Tsukuba, Tokyo, Osaka, Sakai and Okayama from December 2002 to April 2003. Initial follow-up research was performed from July to September 2006, then a second series of interviews was undertaken in April 2008, Mar 2009, August 2010, July 2011, and March and July 2012. Some follow-up interviews were also conducted. The medical interviewees were seven transplant surgeons, two recipient coordinators and one donor coordinator — many coordinators are former nurses. Seven recipients were interviewed, as well as six donor families who had donated organs from four sons, one daughter and one husband. In total, twenty-three interviews took place.

Data obtained at events were transcribed verbatim and an effort was made to record the atmosphere clearly and objectively, including exclamations and non-verbal input. These data were analysed using both a qualitative research method to find unique narratives — paying attention to quality rather than quantity (Flick, 1998) — and coding methods from the grounded theory approach.

RESULTS: SURGEONS' NARRATIVES

I interviewed seven transplant surgeons, including two heart transplant surgeons, two liver transplant surgeons and three kidney transplant surgeons. Each of them had received both training and work experience in the US. They outlined their experiences of organ harvesting and transplantation as a daily medical treatment. What was their understanding of the "gift of life"?

Kidney transplant surgeon:

> Dying patients recovered dramatically when I put new organs into their bodies ... I can't save such patients without organ transplants — I feel that it's a "miracle". In fact, organ transplantation is one form of medical resuscitation ... a child who was estimated to have a life expectancy of only three months ... the organ arrived for him and he jumped out of his bed like he was skiing after organ transplant surgery!

Heart transplant surgeon:

> Whenever I harvest a beating heart from a brain-dead donor, I feel that I've given him a finishing blow with my own hands ... It's too painful for me as a human. I wonder whether I should first save this donor as a doctor. It's cruel! ... We transplant surgeons are required to harvest a beating heart ... I think organ transplantation from brain-dead donors is a cruel medical procedure for transplant surgeons in Japan now.

This highlights the ambivalent assessments even among organ transplant surgeons about this medical treatment: they continue to face huge dilemmas, and these dilemmas are varied and complex.

Surgeons' Dilemmas

There are various ambivalent interpretations of organ transplantation by transplant surgeons (Starzl, 1992). They encourage the procedure as one type of medical resuscitation treatment and they admire the medical development of organ replacement. Nevertheless, organ transplant treatment requires donors, living or dead, necessitating organ harvesting. This is a unique procedure in medical history, and many surgeons describe it, offering various rational interpretations for their role in the process.

According to my data, organ harvesting is seen as a cruel medical act, causing transplant surgeons to feel guilt and inhumanity toward donors. Some have complex feelings, including guilt toward donors, and try to switch their focus from the donor's death to the recipient's survival. In rationalisation, some surgeons told me that they felt that a better term for the "gift of life" (a term also disliked by donor families because of its implication that the donated organ is purely material) was a donor's "gifts of love" — organ donation seen as a wonderful form of human love from dead donors in the desire to save someone's life (Calne, 1970). Although as medical practitioners they harvested the organs themselves during the surgical process, in defining their roles they expressed that they were just mediators between donor and recipient: they transplanted the donor's human love into the recipient's body through their medical skill (Sharp, 2006) in order to make the recipient's wish to live longer come true.

There remains a paternalistic relationship between most doctors and patients in Japan, but transplant surgeons have deconstructed the traditional relationship and created a new role for themselves, positioning themselves as mediators between donors and recipients rather than authority figures imposing treatment on subordinates.

RESULTS: RECIPIENTS' NARRATIVES

There are also very ambivalent narratives about organ transplantation among recipients. All recipients feel gratitude to the donor and donor's family and for the medical treatment. However, most recipients have complex mixed feelings toward the donor and donor's family: while they are grateful for the organ and for the donor's and donor family's decision to donate the organ, they also feel guilt for the donor's death. Their feelings swing between appreciation and a kind of guilt.

Pancreas and kidney recipient:

I thank my donor and the donor's family from the bottom of my heart. Yes, there are no words other than "thank you" ... I was almost dying at that time, I would surely have died without an organ transplant! I will keep the new organs as long as possible to show my appreciation ... organ transplantation is a precious medical treatment to be grateful for, I really appreciate both my donor and the precious donation. That's my mission!

Kidney recipient:

When I was waiting for an organ in the US, I felt that my death was coming but I couldn't think about the donor at all. I didn't want to die, I just wanted to live! I really want to live. I just didn't want to die at that time, that's all. But as a result, I was waiting for someone's death. It's an unusual medical treatment, one that is dependent on death ... Organ transplantation is a waiting-for-death medical treatment ... with a really heavy heart.

Transplanted Life

"Transplanted life" was named by a heart transplant surgeon in Japan: he explained: "I always say that my patients who receive a heart have to forget about their life before organ transplantation after the operation: patients have to start to living as a heart transplant recipient and not compare their former and present life. That's transplanted life with someone's organ." According to his narrative, a heart transplant recipient's life is divided between the time before the organ transplant operation and after it: between life as a heart patient and as a heart recipient. A recipient's life course from birth to organ transplant operation is called his/her previous life; once "reset" after the operation the recipient should not try to recall it. The new life is called the "transplanted life", and it is the life for a person with someone else's organ so it has become completely different. Transplanted lives are very varied, and there are as many transplanted lives as there are recipients (Fox and Swazey, 2002).

Many recipients express that their transplanted life is not a "gift of life" but a "given life", entailing responsibilities and restrictions as a requirement of the donation rather than acceptance of an unconditional gift. They position organ transplant surgery as a procedure for them to receive "given life" from donors, understanding that it enables them to live only through the donor's organ and the donor's love. Thus, organ transplantation is a procedure of given life from a donor or donor's organ, but not from a donor family.

Most recipients feel their donor's organ and the donor himself/herself inside their body. Their narratives of transplanted life involve sharing life not only with the donated organ but also with the donor as a life partner, whose organ and personality both live inside the recipient's body. Although recipients receive only organs, they have accepted the donor's human love and the donor's life too. Sometimes the donor's life controls the recipient's life; in other words, recipients are obedient to the donor's imaginary existence.

Recipients feel both sorry for the donors' death and grateful for the organ they have received. They feel guilty toward the donor because they are alive because of the donor's organ, but they can't express their appreciation. After struggling with the dichotomy, they often reach the decision to become a donor in return — they plan to donate their own organs at the end of their

life as a kind of reciprocity. However, while they recognize organ donation as reciprocal situation, it is impossible to donate their organ back to their own donor (Fox and Swazey, 2002); this can cause further feelings of guilt.

In Japan it is customary to exchange gifts twice a year, in Otyugen (June) and Oseibo (December). The Japanese have a strong sense of giving and receiving gifts, so even though organ donation is based on altruism, Japanese recipients tend to feel a strong obligation to return a "gift of life" to the donor. In this way, Japanese feel a greater sense of reciprocity than North American recipients (Lock, 2001), but individual personality also has a strong effect, and Fox points out that American recipients also think about how they might "pay back" their received organs (Fox and Swazey, 1992).

RESULTS: DONOR FAMILIES' NARRATIVES

I interviewed six donor families, including two donor fathers, three donor mothers and a donor wife. The differences in narratives between donor parents and donor spouse are interesting: while spouses are connected by their wills or love, making their relationship equal, donor parents' connection to their children by blood is a more fundamental and emotional relationship and it can be difficult to understand their narratives logically as they appear to turn metaphors (such as "my child lives in me") into their own reality. In addition, in Japan the family ties between mother and child are generally much stronger than between father and child.

Donor father:

I decided on organ donation because I wanted my daughter to live, even if it was only her organ in someone's body. I didn't want my daughter to die completely ... she is a missing child, she lives inside a recipient's body. I want to see the recipient and touch the stomach of the recipient with my hand and I want to ask her about the donation ... I need my daughter's forgiveness for donating her organs! That's my wish.

Donor mother:

When my doctor said "There is no hope", I asked about organ donation. I wished to make my son alive in someone else's body to avoid his death. He didn't die at all. He is still alive. I had a feeling that I didn't lose everything. After donation, he is always beside me. He is a part of my body. Actually I'm always with my son. I don't want to hear about donors ... because I'm afraid to hear about a recipient's death!

Spouse:

My husband had a donation will and I thought that I should support his will, because making his wish come true is a wife's mission. We had been fighting his brain tumour together and I informed his doctor of his donation will when it came to the end of his life and I donated his organs: his comrades and I can feel his satisfaction every day!

All the donor family members were keen to disclose the motivations for donating organs.

Five donor families accepted their doctor's offer of organ donation: three parents and the spouse agreed with donation wills, including a father who, when offered the choice by the doctor, felt that this hit upon a way to allow his daughter to live as a donated body part (a kidney); another donor's mother felt unable to refuse the doctor's request for organ donation. Unusually, one donor mother proposed the donation of her son's organs herself to avoid his "complete" death — so that she felt his organs could live forever with her.

Donor Families' Lives

In Japan, the donor family's life is still difficult due to misunderstandings among the public about organ transplantation; consequently, organ donation is still rare. Many donor families are isolated from their communities or are criticized by others. Their lives are not proud ones, and they tend to hide the fact that they permitted an organ donation. They produce their own rational interpretations for the donation. Donor families have faced their family member's death and sought a way to keep a part of the dead family member alive. They have reached the organ donation decision by various routes, often without the donation will or donor card of the dead family member.

In the mothers' narratives, a child's sudden death is an event that is very difficult to endure and their shock is beyond imagination. In one example, a donor mother struggled with sadness about her son's death, but she tried to avoid his "complete" death by donating his kidneys to keep him alive inside someone else's body. For her, organ donation was an egoistic choice: she had no plan to save others' lives. At that time she thought that she could not have the desire to save someone or to do good things for someone else; she just cared about her son's life and avoiding his death. But her feelings changed gradually to the recognition that her son saved two recipients. She insisted that as a result, the donation was a "gift of life". Organ donation is a ritual that allows donors to be reborn to their own families through narrative.

In the fathers' narratives, a child's sudden death in a car accident is very difficult to accept and they think about many ways to keep their child alive, even just as one kidney. But Japanese mothers' and fathers' narratives are a little different and it is easy to see the difference in the relationship between mother and child, and father and child. Mothers tend to believe that their child lives on with the mother herself or that the mother and child will always be together: one mother said: "My son lives inside me!" But the fathers' stance toward their children is more distanced and their interpretation is more objective. One donor father told me: "My daughter lives in someone's body somewhere just like a missing child and I hope that she is fine". So donor families' attitudes to their donations and their lives in terms of the donors are very complex. In some cases, donors can be reborn in donor families' minds as a result of various narratives.

According to my data, all donor families feel the same duty toward donors, but with both positive meanings and negative ones. When donor families are aware of the donation will of a dead family member, they are proud of this decision to make an organ donation. Donor families also make plans to donate their own organs at the end of their lives. But when donor families do not know the donation will of the dead family member, they feel guilt for allowing an organ donation.

Donor parents who donate children's organs without the donation will of their children feel

especially guilty on behalf of their dead children. They feel that they experience their child's situation and beg forgiveness from their organ-donating children. As a result, parents often plan to also become donors as a way of vicariously experiencing and sharing the painful experience of their children. Japanese parents tend to feel guilty for the organ donation of their own children and they feel a duty to experience the same difficulties as their children: they think that they should also volunteer for organ donation to make a sacrifice on behalf of their children who became donors. The relationship between Japanese mothers and children in particular can be much closer than in Western countries: Japanese mothers tend to maintain a stronger relationship with their children, even after they have grown up, and sometimes imagine their organ-donating children still inside their own bodies like foetuses.

DISCUSSION

These data show that while it is possible to say that the organ recipient's and the organ donor's roles in the transplantation process are different — one giving and one receiving life — both equally continue to live among the concerned parties.

Renewable Life (Recipients)

A recipient can renew his/her life and live longer with a new donor's organ(s), but it is a biologically lengthened and limited life. Thanks to organ transplant treatment they avoid imminent death, but they will die when the transplanted organ dies, so they are saved only temporarily and their death is postponed.

Rebirthable Life (Donors)

A donor can be reborn in the donor family's mind through organ donation, but it is an invisible and limitless metaphorical life. The donated organ can live inside the recipient's body as part of their limited biological life, so it will die someday. But the donor's life becomes non-biological and non-existent, created by their family's narrative, so it can live forever in the donor family's imagination. The donor family accepts that the donor's human life has finished, but the donated organs still have biological life inside the recipients' bodies, so the donor family creates the whole-body image of a new type of family member from the donated organ. The donor can gain an endless life in the donor family's mind and grow stronger through their narratives, day by day.

My tentative conclusion is that there is "renewable life" and "rebirthable life" for both recipients and donors. This new concept of lives is ambiguous, complex and changeable, even among concerned parties. The organ recipient's life has changed and his/her organ has been replaced by someone else's organ, so the recipient's body becomes a hybrid (Lock, 2000). In addition, the donor's body is cremated without the donated organ and the donor is legally dead, although his/her donated organ still remains biologically alive. That donated organ can live inside someone else's body until the recipient's death or the donated organ's failure. All donor families are confused by such a life; that is, a mostly dead, partly alive person. But donor families are better able to cope with the loss of a family member with more than just a memory, now that

the donated organ is alive inside someone, somewhere. While the concept of "rebirthable life" is a kind of fantasy, donor families depend on the donated organ and evoke the memory of the new whole body of the donor.

Emerging medical technology has produced this new concept of "rebirthable life" through organ transplantation from brain-dead donors. The concept exists not only among donor families but is also shared by recipients and transplant surgeons, spreading among concerned parties invisibly but powerfully.

CONCLUSION

There is a gap between real-world organ transplantation procedures and narratives about organ transplantation. While the emerging medical technology is focused on the life of the organ recipient, not only the recipient but also the donor, the donor's family and even the surgeons and other medical professionals involved are also touched by the transformation made possible by the donor's "gift of love". Organ transplantation is indeed a wonderful treatment representing the development of medicine in the twentieth and twenty-first centuries, but the more challenging the medical treatment, the more unpredictable the side effects can be; this includes not only medical but also ethical and cultural side effects. New concepts of life, such as "rebirthable life" of donors, are necessary to help concerned parties to adjust to new treatments. Brain and heart death, organ donation and reception, and the existence of limited biological renewable and endless non-biological rebirthable life are the new agents produced by this innovative technology.

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