

Organ Transplants and Japanese Views of Life and Death: Talking with Living Pediatric Liver Donors

DATE Kiyonobu

Keywords: PLDLT (pediatric living donor liver transplantation), Japanese religion, Organ transplants, Interview

Introduction

The purpose of this paper is to show a few aspects of contemporary Japanese views of life and death through the testimonies of living donors, particularly pediatric liver donors. But first of all, let me present some background information about this study.

From the first enactment of the transplant law in 1997 to July 2010, Japan witnessed only 86 transplants from brain-dead donors, an average of 6-7 donors per year. This figure is very low in comparison with Western societies. And this difference has been attributed to particularities of Japanese religious culture.

However, Japan's organ transplant law was revised in 2009, and the amended law recently went into effect in July 2010. Now, (1) when a patient goes into a brain-dead state without a proper will, transplant surgery can be performed with the consent of a family member, and (2) child-to-child transplants are possible, as the law lowered the minimum age (previously

set at 15).¹ The amended law is expected to increase the number of brain-dead donors anywhere from 30 to 80 per year. At this significant moment, it seems worthwhile getting an insight into Japanese religion and, in particular, Japanese views of life and death.

Although many studies have been done on organ transplants and Japanese religious views of life and death, they have focused mainly on “brain death,” and little attention has been given to living donors’ thoughts on life and death. Moreover, these studies handle “Japanese religion” controversially, depending on a cultural essentialist framework. My proposition is to shift the focus of argument from “religion” to “religiousness” or “religiosity.”

But why have I chosen to focus on pediatric liver transplants? To tell the truth, it is because I myself was a donor for my daughter. This type of personal connection might cause concern for some, but I feel it is a good chance to consider what it means to be a researcher with a personal investment in contemporary academic issues. One might also point out a parallel situation in that some historians of religion have their own faith and attachment to their subject of study.

At any rate, I hope this focus on PLDLT (pediatric living donor liver transplantation) provides a useful opportunity to consider life and death as related to children. And after analyzing interviews with those who have been through this surgery, I have come to recognize there are some “phenomenological characteristics” of liver transplants.

I will start with a critical remark on the framework which has constrained for some time studies on Japanese religious views of life and death as related to organ transplants. I will also review some investigations carried out with donors of LDLT. Next, I will discuss the interview method used and the difficulties involved in conducting these interviews. After this, I will try to shed light on some aspects of contemporary Japanese views of life and death. I am particularly interested in the configuration and function of “religiousness” or “religiosity” in contemporary Japanese society. Of course, it is difficult, even impossible, to perfectly circumscribe this ambiguous concept. Nevertheless, I would like to provide a rough

1. Another amendment came into force in January 2010. Potential brain-dead donors can now give priority rights to their relatives as recipients of their organs.

sketch by indicating the social changes involved in the religious reconfiguration.

Religiosity and Living Donor Transplantations

Against a cultural and religious essentialism

Why has Japan been slow to accept organ transplants from brain-dead donors? While the answers to this question are certainly complex, “religious explanations” have been invoked. Indeed, Shinto animism, Japanese Buddhism, Confucian loyalty, and filial piety may often appear at odds with Cartesian dualism and the Christian volunteer spirit.²

However, while some people’s feelings toward transplantation can certainly be explained by religion, it is unlikely that these conventional religious ideas have determined most Japanese people’s attitudes and behaviors for many years. Instead, the situation seems to be as follows: transplanting organs from brain-dead donors is an advanced Western medical technique, and its association with Western culture (and its Judeo-Christian roots) has caused a negative reaction, as seen in Japanese society. This underlying structure seems to have led to the reconstruction of “uniquely Japanese religious views of life and death.”³

To make my position clear, I do not completely deny a “religious interpretation,” but rather I hope to view it with a more realistic sense of its relative importance. In other words, religion and its artificial categories – Shinto, Buddhism, Confucianism, Christianity, etc. – can yield some insight into attitudes toward brain death and organ transplants, but they cannot explain the situation as a whole.

The conventional “religious interpretation” is based on a cultural es-

2. Takeshi Umehara, “Noushi: Sokuratesu no To ha Hantai-suru (I am against Brain Death as a Disciple of Socrates)” (1990) in Takeshi Umehara ed., *Noushi to Zouki-ishoku* (Brain Death and Organ Transplant), Asahi-Shinbun-sha, 1992, pp.207-236; Makoto Hagiwara, *Nihonjin ha Naze Noushi-Zoki-ishoku wo Kobamu-noka* (Why Japanese reject Brain Death and Organ Transplant?), Shinyo-sha, 1992.

3. Margaret Lock points out that Japanese attitudes toward modern technology “cannot be understood in isolation from interpretations of the relationship of Japan to the West” (*Twice Dead: Organ Transplants and the Reinvention of Death*, University of California Press, 2002, p. 149). I think that Japanese religious “uniqueness” is reconstructed in this scheme.

sentialism, and is not sufficient to explain Japanese attitudes toward transplants. The relationship between religion and medicine in Japanese society is much more complex.

Let us put aside man-made categories of Shinto, Japanese Buddhism, or Confucianism, and try rather to observe how *religiosity* functions. In the medical field, for example, we speak of the authoritarianism of some doctors, which reminds us of “medical clericalism” in the modern West or “feudalism” in old Japan. In this situation, a sort of “religiosity” seems to be in operation. At the level of society as a whole, the Japanese reaction to the Western universality would appear religious for some sociologists of religion for whom “religiousness” regulates the ideas and behaviors of a society’s members.

Living donor transplantation as a Japanese adaptation

Many studies in the social and human sciences have focused on organ transplants from brain-dead donors. But, the previously mentioned difficulties with this type of medical procedure in Japan have led, in reality, to the development of living donor transplants in this country. This alternative clearly involves Japanese views of life and death, but little attention has been given to this point. Living donor transplants are also playing an interesting role in the development of transplants in Japan.⁴

From a medical point of view, the transplant consists of transferring living tissue from a donor to a recipient. The key is to slip this tissue through the recipient’s immune mechanism, finding a balance between “rejection” of the organ and prevention of “infection.”

Analogically speaking, living donor transplants in Japan are like an immunosuppressant drug, controlling the rejection we have seen provoked by “transplanting” brain-dead donor transplants into the “recipient body” called Japan. This Japanese adaptation gives a sense of the history of organ

4. In the USA, about 95 % of liver transplants (some 6,000 cases per year) depend on cadaveric donors; while in Japan, 99 % of liver transplants (some 500 cases per year) rely on living donors. By way of suggestion, in Korea, the proportion of cadaveric and living donor transplant is, respectively, 25 % and 75%. Koichi Mizuta, “Ishoku Iryou to Kodomo no Seitai Kan’ishoku : Genjou to Kongo no Kadai (Medical Transplant and Pediatric Living Donor Liver Transplant: The Present Condition and Tasks for the Future),” *Shouni Kango (The Japanese Journal of Child Nursing)*, Vol.33 No.6, 2010, p.703.

transplantation in this country.⁵

There is another point regarding the difference between investigating cadaveric donor transplants and living donor transplants. A famous immunologist, Tomio Tada, makes a cadaveric donor speak in his Noh play “Mumyô-no-i” (*The Well of Ignorance*, 1992). Needless to say, such a thing is not possible in reality. In contrast to cadaveric donors, living donors have the advantage of being able to talk about their experiences (though not, as I will point out later, in all cases).

This study is based on the testimonies of those who have experienced transplants. Although organ transplant issues have attracted interest over the past few decades, this type of study has lagged behind in Japan.⁶ In the 1980s, the voices of lawyers, journalists, doctors and medical staff were dominant. Studies focusing on donors, recipients and their families, from the viewpoint of care, began to emerge in the 1990s.⁷ Regarding investigations with donors of LDLT, Satomi et al. (2005) carried out a massive survey of 2667 liver donors in Japan, all of whom had donated prior to 2003 in Japan.⁸ Muto (2003) examined several issues concerning care for donors from a family sociology point of view.⁹ Fujita et al. (2004, 2006) focused on the donors’ decision-making process in adult-to-adult LDLT in Japan.¹⁰ Journalists have also reported on the issue.¹¹ However, little is known about how PLDLT donors view life and death.

5. This history is not irrelevant to social articulation of organs. In Japan, for example, prospects for a heart transplant are bleaker than for a kidney or liver transplant.

6. In the USA, there is a classical study by Roberta G. Simmons, Susan Klein Marine and Richard L. Simmons, *Gift of Life: The Effect of Organ Transplantation on Individual, Family, and Societal Dynamics*, Wiley, 1977.

7. I have in mind the studies of Masahiro Morioka, Yoshihiko Komatsu, Shin’ya Tateiwa, etc.

8. Susumu Satomi et al., *Seitai Kan’ishoku Dona ni Kansuru Chousa Houkokusho (Report of Investigations towards Donors of LDLT)*, Japanese Liver Transplantation Society, 2005. http://jlt.umin.ac.jp/donor_survey_full.pdf

9. Kaori Muto, ““Kazoku-ai” no Na no motoni: Seitai Kan’ishoku to Kazoku (In the name of “Love in the families”: Living donor liver transplantation and families),” *Kazoku Shakaigaku Kenkyu (Japanese Journal of Family Sociology)*, 14(2), 2003.

10. Misao Fujita, Brian Taylor Slingsby and Akira Akabayashi, “Three Patterns of Voluntary Consent in the Case of Adult-to-Adult Living Related Liver Transplantation in Japan,” *Transplantation Proceedings*, 36, 2004; Misao Fujita et al., “A Model of Donors’ Decision-making in Adult-to-Adult Living Donor Liver Transplantation in Japan: Having No Choice,” *American Association for the Study of Liver Diseases*, 12, 2006.

11. Especially the work of Masaharu Goto, *Seitai Kan’ishoku: Kyodai Chiimu no Chosen (LDLT: Challenges for Kyoto University’s Team)*, Iwanami Shoten, 2002.

Interview Method

Bias due to Sample Size and Characteristics

I have been conducting interviews with individuals who have or will donate livers to pediatric recipients, as well as their spouses. A donor is normally a parent of the child recipient, and I think both parents can say they are intimately involved with the procedure.

This ongoing study is not statistic-based, but is based on qualitative interviews. Interviewees are not selected by random sampling, but by opportunistic (or snowball) sampling. In other words, these are people I have become acquainted with personally or have met through a third party.¹²

Subjects take part in this investigation as responsible individuals, with their own views of life and death. Furthermore, I don't push anyone to participate who is not emotionally ready for an in-depth interview. For instance, it may be difficult for parents to respond to questions when their child is in poor health. Indeed, one interviewee states, "All that I've said is related to the fact that our recipient daughter is alive. If unfortunately we had lost her, my words could be very different." This statement suggests that one's opinions and feelings can differ, especially in accordance with the child's state of health.

It is clear that these interviewees represent just a tiny portion of organ donors in Japan, and I acknowledge that there is necessarily some bias here. But I hope and believe that their testimonies can shed light on some aspects of contemporary Japanese views of life and death. Through their words, I would like to glimpse changes in social relationships and even in the notion of what a human being is – changes in light of which concepts of religiosity must also be recomposed.

I started my research in March 2010 with a pilot survey, and so far, I have interviewed ten persons for the study proper. Among them, one woman has lost her son. Another woman was waiting to become a donor at the time of the interview. In most cases, a certain period of time has passed

12. On this method for selecting interviewees for a qualitative study, see Takashi Miyajima and Susumu Shimazono eds., *Gendai Nihon-jin no Sei no Yukue: Tsunagari to Jiritsu (Contemporary Life of People in Japan: Solidarity and Independence)*, Fujiwara Shoten, 2003.

since the surgery, and the state of the recipient's health is relatively good.

Most interviewees consider themselves to have no formal religious affiliation (*mushukyo*), but some show an interest in religion or spirituality. One woman (as well as her family) is a member of Soka Gakkai, and another woman tells me her husband and mother-in-law are Christians.

This study's focus on *Japanese* views of life and death requires me to offer a precise meaning for the word "Japanese" (*nihonjin*). I mean "people in Japan" rather than "Japanese people," to reflect the varieties of being Japanese. In our sample, one woman gave birth to her son in the USA before returning to Japan (her husband is Japanese); and another woman is Taiwanese, having spent half of her life in Japan.

Concerning the diseases of the child recipients, one child had fulminating hepatitis, and another child had citrine deficiency. All other cases were biliary atresia (BA is the most representative disease leading to PLDLT).

Regarding the age and sex of our interviewees, women are generally in their 20s to 40s and men in their 30s to 60s. Some generation gaps are observable. There are relatively many women in their 30s, and the reasons for this will be suggested below.

Difficulties in Discussing Views of Life and Death

During each interview, I ask interviewees about their donor experience, their views of life and death, and their opinions on religion, medical techniques, etc.

The nature of the topic constitutes an immediate difficulty. "What is your opinion on life and death?" This question is quite different from "When is your birthday?" or "How do you spend your weekends?" It is not easy to talk about one's views of life and death. And as I have already mentioned, interviewees may not be emotionally ready to speak at all, and what they say can change, depending on the situation.

Another factor is their relationship with the interviewer. If interviewees see you as untrustworthy, they will only tell you the accepted view and will not disclose their real doubts, fears or hopes.

Even when they trust you and are ready to tell you their true feelings, it is often difficult for them to touch the core of the matter with the appropriate words.

In these cases, you may try to help them to express themselves. But this can lead to the trap of supplying them with your own words. Seeing your suggestion confirmed, you believe mistakenly that the words came from them, and don't recognize that you are looking at your own words, in the mirror, so to speak. Thus the subject's "otherness" can slip away.

Finally, when presenting the results of interviews, it can be difficult to reproduce the words and/or meanings of interviewees in a logical, well-organized fashion.

This study may not completely overcome such difficulties, but I believe I have broadened my horizons through these interviews. In what follows, I will try to present some of the testimony of the interviewees I have spoken with so far, and share some of the insights I have gained through these conversations.

Some Landscapes of Life and Death in Contemporary Japan

On the Death of the Child

One interview question is, "Since you learned of your child's disease or the need for a transplant, have you ever imagined the death of your child?"

According to the Gender Equality Bureau,¹³ the child mortality rate in Japan was 16.5% around 1920 and 6% around 1950. Now, the rate is only 0.3%, and in general the death of a child is highly unexpected.

One man speaks of a point beyond which it is impossible to reason:

The elderly die first; this is comprehensible. But it is hard to understand a disturbance in this order. I didn't dare to think of it... Yes, I did, but there was a point beyond which I couldn't go.

In such a situation, a kind of self-defense mechanism may work unconsciously. The man's wife kept telling herself, "This boy is lucky":

13. http://www.gender.go.jp/whitepaper/h17/danjo_hp/danjo/html/zuhyo/fig01_00_12.html

He is our first child, so we didn't know what was normal. His disease could have passed unnoticed. Fortunately, it was detected early. To tell the truth, when he was in my womb, we came very close to a premature delivery. We cleared that hurdle. After the delivery, the bleeding wouldn't stop, and the doctor nearly performed a hysterectomy on me. Again, we overcame another difficulty. He's a lucky boy. So I've never imagined he would be lost... Maybe I don't dare think of it.

But death can occur. The same woman became acquainted with another mother whose daughter had the same disease:

A few days after the transplant, I went to see her mother. At that time, just one year had passed since our case. Showing her my son, I told her that her daughter would be as vigorous as him. I said it to cheer her up. But her daughter died a few weeks later. I lost my voice. The shock continues. My intention to encourage doesn't change. But "he will be better," "she will be fine," I can't say these words any more.

A woman who lost her son told me:

Facing his death, there are really no words... After the cremation, his bones were reduced to powder. He hadn't been well nourished because of his disease. It was such a shock that I don't remember so much what I felt at the moment.

Through my experience of losing a child, I've come to think that no matter what his state of health, I would want my child to live beside me, to touch, to hold, to speak with. Only having his soul to speak with is too painful and heartbreaking.

"Why Me?" "Why Our Child?"

While traditional religions had a slate of answers for those in quest of meaning, the medical industry itself remains silent on such questions. If old spiritual systems provided the means for resolving the problem, we are now in a situation where the "problem remains problematic." Furthermore,

the social conditions of those who puzzle over these questions and who need to be consoled are different. If in the past they were somehow embedded in a local community, now they live in an individualized and global society.

In this context, “why me?” or “why our child?” appear as keen questions of meaning, and these questions can remain as religious elements in a post-religious society.¹⁴

Let us cite the testimony of one man:

I am a serious person and I have spent a modest life. The question, “Why our child?” was all the more acute. I’m ashamed to say this, but our conjugal relations weren’t good for a period. Chagrined, frustrated, I couldn’t figure out why these things happened to me. In the midst of this turmoil, I read *Creation of Meaning for Life* by Iida Fumi-hiko. The author’s words, “We are reborn to mature,” resonated with me and brought me relief. My religious views of life and death have changed. Now I believe in a previous life and a life after death. I don’t absolutely claim this vision as the truth, but I accept its possibility.

Facing the question “Why our child?” a mother is driven by a sense of guilt:

Since his birth, I feel a sense of guilt. [...] I know I shouldn’t blame myself. I hear of this everywhere, but the feeling never disappears.

Disease without a known cause draws religious meaning

As the last example suggests, an unknown cause may draw us toward religious explanations. Here is the testimony of one woman:

In the hospital, there were believers trying to force me into joining their religious organizations. They even told me that lack of faith caused the disease. I myself never reasoned in this way.

14. Cf. Marcel Gauchet, *The Disenchantment of the World: A Political History of Religion*, tr. by Oscar Burge, Princeton University Press, 1999, p.206.

Another woman, who claimed to have no religion but was interested in spirituality, told me:

To tell the truth, my sister is a member of a religious organization. I don't know the exact name of this religion, because if I ask her to explain in detail, she persistently tries to involve me. Anyway, it seems to have a charismatic person making predictions in exchange for donations. My sister recommended this religion to me, when my daughter was diagnosed with a disease of unknown etiology which might require a transplant.

This episode seems significant in that it suggests under what circumstances the "religion machine" goes into action in today's Japan.

In the case of another woman who belongs to Soka Gakkai (her family as well), she confessed that she had resented her mother's religious interpretation of her daughter's disease:

My mother said something to the effect that my daughter was going to sacrifice herself to awaken our religious feelings which had fallen into a rut. At that moment, I rebelled against her. But I've come to accept the idea that disease can develop religious feelings.

Interviewer: Do you know someone whose experience of transplantation led to a belief in your religion?

Not around me. Personally, I'm reluctant to abruptly recommend our belief to those with a serious illness. It's like taking advantage of them. But my idea could turn out to be a cruelty for devout believers. Anyway, I've already told people that our faith has been a great support to me.

The "Otherness" of the Child

Compared to adult-to-adult transplants, it is difficult in pediatric cases to confirm the will of the recipient. If the word "stranger" is not appropriate to describe the relationship between parent and child, the child patient can still appear to be an "other," because it is impossible for the parent to determine exactly what the child feels.

Formerly, from the viewpoint of religious history, this “other” would have been some kind of divinity or God, who transcended humans’ intentions. Now, the child patient is on a human realm, but is somehow beyond our intentions.

The development of medical technology has changed the human condition, enlarging the available options. But the zone of incomprehensibility always remains. It is in facing this enigma as well as the impossibility of exactly representing the will of the child recipient that a parent is pressed for an answer. The decision can appear to be rather a reflex than a choice. Indeed, some donors make their decision to sacrifice a part of their liver for their ill child immediately or soon after learning of this possibility. However, others feel hesitancy, internal or external pressure, even coercion.¹⁵

One of our participants explains her awareness of the problem of seemingly sacrificial consent:

The more options we have, the more I think medical conditions are like fate. Refusing a transplant can be seen as the same thing as intentionally letting the child die. [...] I’m afraid of a situation in which a transplant is almost imposed on us, because of the child’s inability to express his/her wishes.

Reorganization of Family Ties

Transplant experiences are lived out over a long period. They often change the relationships of those involved.

To begin with, let us consider the reorganization of family ties. It is not uncommon to hear that transplantation breaks up the family. Especially the relationship between the mother-in-law and the daughter-in-law seems to be fragile. However, an adverse situation can lead to improved relationships. Here is the example of a Taiwanese woman:

15. Hideo Kawarazaki ed., *Shoni Seitai Kan'Ishoku (Pediatric Living Donor Liver Transplantation)*, Nihon Igakukan, 2010, p.278. Cf. According to the study of Bliss and Stuber, “most mothers were certain at both pre-transplant and follow-up that serving as a donor was the best way they could fulfill their role in relationship to the ill child. [...] Fathers were more likely to have some role conflict.” Aminah Bliss and Margaret L. Stuber, “Giving Life for the Second Time: A Preliminary Study of Parental Partial Liver Donation for Pediatric Transplantation”, *Families, Systems & Health*, Vol.17, No.2, 1999, p.224.

Due to our international marriage, there was hesitation and distance between our two families. However, we all grappled with the transplant in such a close, cooperative manner that ties were deepened.

To tell the truth, I haven't necessarily had such a good relationship with my stepmother. But thanks to the transplant, this bond has been greatly improved.

As for my husband's mother, she is very kind and always helps us. I love her. She is like a true mother.

So in my case, I was first blessed with a child, and then, with two mothers.

In general, a major disease tends to be a problem for the whole family and leads to a reorganization of family ties. In this regard, transplants are no exception.

Communities for those concerned

Transplant networks have, of course, developed among doctors, but also among patients' families. Let us examine this type of social bond.

As for PLDLT, the most commonly indentified disease is biliary atresia (BA). The incidence rate is one in ten thousand. A woman in her late forties who acted as a donor over 15 years ago explained how the BA association saved her:

At that time, we lived in a remote area of Hokkaido. Among those around us, we didn't find any families like us. Available information was limited; the internet hadn't yet come into wide use. So just hearing of the existence of such an association relieved me. I telephoned, applied for membership, and I felt assured. The president said, "I understand how hard things are." These words saved me.

Now many of those affected by PLDLT are expanding their network on the web. A woman in her thirties who acted as a donor a couple of years ago is a member of the PLDLT community on mixi ("mixi" is a Japanese social networking service like "Facebook"). Her testimony shows a change in her

lifestyle and a new sensibility:

Before the transplant, I communicated only with friends I knew. However, after the transplant, my important fellow members became those who have been through it as well. We exchange information and opinions. My mixi daybook has become my childcare diary. It is a great change.

Before, I felt reluctant to communicate with people whom I'd never met. Now, my vigilance is relaxed with those who have been through a similar experience. When a child of my fellow members is ill, even if I haven't met them face to face, I really worry about it.

By the way, this online community is marked by its feminine character. According to the same woman, "My husband dislikes my detailed reports on the health state of these children. He says, 'Don't worry about everything.'"

Another woman says:

[There are] only women. No men. Our community is sort of an extension of housewives' gossip. It's a rude remark, but dealing with children day and night is a mother's task. It is hard for men to exactly appreciate our feelings. When my husband worries about the health of our child, I worry all the more. However, to avoid panicking him, I conduct myself coolly in his presence. The online community is the place where I can release my panicky sentiments.

Medical Literacy of Patients

As online communities are a recent development, the relationship between doctor and a patient's family seems to be changing among the younger generation.

After experiencing the transplant, a couple comes to study about the disease and treatments and run a check on potential doctors. The husband says:

When my mother was ill, my father only repeated, "Please, please

doctor.” If family members show such a reaction, I suppose the doctor cannot speak frankly about the risks and possibilities. So I think it’s necessary for the patient to study.

My father-in-law belongs to an earlier generation and believes in doctors, says his wife. But we see doctors as professionals. After the transplant, the relationship with our regular doctor has also changed. When we needed to have a doctor look at our son’s ear, we checked on the web regarding the careers of doctors we were interested in. It was a great success. I think patients are responsible to convey the necessary information and study to some extent, in order to build a relationship of trust with doctors.

The Articulation of Organs, or the Phenomenological Character of the Liver

While we are healthy, we are not always conscious of our organs working. When one organ becomes diseased, we learn about its impact. Are there some phenomenological characteristics of the liver?

When hearing of the need to donate a part of her liver to her daughter, a woman thought, “No way for the heart, but I could give a part of my liver.”

LDLT makes use of a liver’s capacity for division and recovery of function. Here is the explanation given by one man: “It’s like a lizard sacrificing its own tail (*laugh*). Anyway, the liver grows back, so I think it’s an indispensable organ for life.”

In this regard, LDLT might be seen as an extension of blood donations and transfusions:

Among donations, says a woman, there are blood, bone marrow, and organs. Donating bone marrow is harder than donating blood; and donating an organ is harder than bone marrow.

Another woman has given a part of her liver to her son and feels now her grafted liver is “personalized.” She has declared her will to donate organs in case of brain death, except for the liver:

I have a donor card, I agree with donating organs, but the liver is

exceptional. For me, this organ has had its proper life. When undergoing ultrasound examination, I speak to my liver and my grafted one like this. “Hey, Mister Liver, you are in top form!”

Concluding Remarks

In these interviews, I have asked participants if their views of life and death have changed as a result of the transplant process. Here are some of their answers.

A woman who lost her recipient child told me:

I used to be terribly afraid of death. But now, I feel that after death, I will be able to go where my son is. This idea keeps away the fear of the death.

Another woman testifies (her child’s state of health is good):

My view on life hasn’t changed. However, due to the transplant experience, I think I have had more opportunities to think about what life is. Now, I am living with my daughter, and I never take this fact for granted.

And here is the testimony of another woman (her child’s state of health is relatively good):

We have approached a crucial point of life and death. This experience has made me realize that life is limited. I often think of our limited time, perhaps more strongly than the typical parent. If my daughter hadn’t been ill, I would have left her in a crèche or a nursery school, and I would have had much less time with her. [...] I guess the essence of religion is to give thanks for something which allows me to be and provides support for me. I often remember it, even if I cannot keep it in mind all the time.

I could continue to cite such emotional stories, but in order to close my

argument, it will be necessary here to restrict myself. I would like to just suggest the great variety of experiences. The more the testimony touches upon reality, the more impossible it becomes to compare such testimony with others, because each testimony is rooted in the personality of the one sharing his/her experience.

Nevertheless, it would be fair to say that PLDLT is typically a profound experience for interviewees, changing or deepening their views of life and death, and reorganizing their family ties or social relations. These changes may also be related to conditions of their religious development.

In this regard, let me point out that those who have lived through PLDLT and its most difficult periods often represent these periods as a “heterogeneous time,” in which they continue with the necessities of daily life, but at the same time are involved in experiences, thoughts, and emotions beyond the ordinary. And they live now and will live on with an awareness of this “heterogeneity.” If a religious life can be characterized, in the style of Durkheim’s sociology of religion, by the cycle of the sacred and the profane, then this cycle seems to be represented by this heterogeneity (and ordinariness). Therefore, an aspect of contemporary religiosity in Japan seems to be in operation in the lives of these interviewees.

Last but not least, I wonder if such a religiosity can be attached exclusively to any “typical” aspect of the Japanese character. On the contrary, the voices of the interviewees seem to be viewed with compassion and sympathy by other cultural traditions, including post-religious societies. If the conventional discourse on transplants in Japan tends to emphasize the particularity of the Japanese mentality, then this study proposes to take a more relative point of view through the words of those who have been involved in PLDLT.

Acknowledgements

I am especially grateful to those who took part in my interviews and told me their precious experiences. I hope I have done justice to their accounts. Special thanks go to Koichi Mizuta, Yukihiro Sanada, and Kazue Kobayashi at Jichi Medical University, who helped me with this investigation. I owe also a debt of gratitude to Ken Schmidt and Thomas Marks, who corrected and improved my English.