

**Heart Transplantation: Its Risks, the Expectations,  
and Cultural Negotiations in Japan**

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## **Abstract**

The aim of this thesis is to facilitate an understanding of the experiences of Japanese heart transplant recipients in terms of how their identities are transformed. The thesis contributes to the discipline by providing an understanding of issues relating to the surgical procedure of heart transplants, the labelling of the recipients by the Japanese government and Japanese cultural factors. This is a qualitative study based on semi-structured interviews, which have been analysed thematically. The thesis sheds light on two major aspects of heart transplantation. One is the experiences of heart transplant recipients, from diagnosis through surgery to recovery. The other is the influence of Japanese cultural expectations about the body and the custom of reciprocal gift-exchange on recipients' experiences. In so doing, this thesis argues that heart transplant recipients face an issue of identity crisis when making a decision to have transplant surgery, and that identity is reconstructed in the post-operational period. In this process, the recipients face social stigma as the result of having a heart transplant. Considering heart transplants as they are viewed by Japanese people in everyday life, the use of an organ for this medical purpose is in conflict with conventional attitudes towards the treatment of the dead body in Japan. In addition, it is difficult for the practice of altruistic organ donation to take root in the modern consumer culture of Japan, where gift-giving has become a quasi-commercial transaction. As a result of these phenomena, anonymous relationships between heart transplant recipients and donors are varied in terms of the gift relationship. It is key how Japanese heart transplant recipients repay their donor. The repayment strategies are impacted by cultural factors.

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## **List of abbreviations**

DCM	Dilated CardioMyopathy
JOT	Japan Organ Transplant Network
NUIH	Nihon University Itabashi Hospital
TRIO	Transplants Recipients International Organization
UNOS	United Network for Organ Sharing
VAD	Ventricular Assist Device
VAS	Ventricular Assist System



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# 1. Introduction

## Aims and background of this thesis

This thesis aims to explore the experiences of Japanese heart transplant recipients so that these may be taken into when planning the future of heart transplantation in Japan. In order to achieve this aim, this thesis attempts to answer the following questions: How do Japanese recipients experience and perceive the process of heart transplantation? What is needed to plan for the future of heart transplantation in Japan?

Initially, the starting procedure of heart transplantations led to wide-ranging discussions in several countries, paying a lot of attention to the issue of brain death (Giacomini, 1997; Lock, 1995; 2002; Nathoo, 2009; Tansey and Reynolds, 1999). In Japan, it has been discussed as not only a medical issue, but also a social issue since the first procedure took place in 1968 (Fukushima, 2004; Komatsu, 1996; Lock and Honde, 1990; Matsuda and Fukushima, 1998; Matsuda and Fukushima, 2001; Namihira, 1990; Nunoda, 1997b; Ohnuki-Tierney, 1994; Umehara, 1992; Wada, 2000). The discussion has been led mainly by the Japanese government, medical experts and the mass media. Chronologically, the discussion has proceeded through three phases, which shall be explained further to set the context.

In the first phase, the first Japanese heart transplant, performed by Dr. Wada and his team in 1968 garnered attention not only in the medical field, but also among the general public (Asahi Newspaper, 1968). The commotion surrounding this transplant surgery continued until 1972 when Dr. Wada was charged with the murder of a donor and recipient (Organ Transplant News Team, 1998).

During the second phase, in the 1980s and the 1990s, the issue of heart transplantation once again became controversial centring on the practice of transplanting organs from patients diagnosed as brain-dead. The main aim of this discussion was to establish whether there was a legal right to perform organ transplants from brain-dead individuals, whether a social consensus permitting such transplantation existed, and whether a legal change should be made to allow this practice in Japan (Akabayashi and Satoh, 2003).

In the third phase, the focus of the discussion moved to amending the Organ Transplant Law that was legislated in 1997, which did not allow children younger than

fifteen years old to donate their organs (Onda, 2004). This discussion was conducted from a viewpoint of how the law would be amended to make it possible to perform such organ transplants in Japan. The law was finally amended in 2009 (Ministry of Health, Labor and Welfare, 2010).

Throughout the second and the third phases, concern was largely focused on how the organ donor could be protected from possible risks. This neglected a number of crucial considerations of the recipient's experience: first, the issues that the patient faces while making the decision to have a transplant; second, risks associated with the operation; and third, lifelong aftercare. Recipients' voices have been marginalised in the debates about heart transplantation in Japan.

Since the 1980s, a number of Japanese heart disease patients who were diagnosed as needing heart transplants went abroad to countries including the U.K, the U.S and Germany to have the transplant (The Japan Society for Transplantation Publicity Committee, 2010; Transplant Communication, 2010). This practice continued even after the introduction of the Organ Transplant Law in 1997, and resulted in more patients receiving heart transplants abroad than in Japan (ibid).

During the same period, public opinion surveys regarding organ transplants showed that Japanese people had become more positive towards organ transplants from brain-dead people. However, in reality, the actual number of people who registered as willing to donate organs, as well as the number who actually donated organs, did not increase in line with the growth in support which public opinion surveys showed (Cabinet Office, Government of Japan, 2008).

In summary, the events from the 1980s onwards, concerning heart transplantation in Japan, show that this medical treatment is not only a medical matter, but also a matter in which the mass media exercises considerable influence. Therefore, a social policy to complement medical policies is required as is greater recognition of the individual's experience, of both donors and recipients.

The introduction of a third party, namely the donor, into the doctor-patient relationship means that the perspective that is applied to the more usual dyadic doctor-patient relationship requires rethinking.

In addition, organ donation raises issues relating to dead bodies and body parts, such as organs, arising from medical and cultural perspectives. In Western medicine, death is often considered to be as a result of a failure of treatment (Chapple, 2010). Medical concerns about the dead body of an organ donor focus on the definition of death, the diagnosis of death and the use of the dead body and its parts. In contrast, a

dead body may raise different issues in the context of a culture influenced by the presence of ritual processes that concern death. In such ritual processes, religion plays an important role in the treatment of the dead body and funerals, including the method of burial, are informed by cultural factors.

Similarly, there is a gap between the attitudes of medicine and culture towards organs. The medical perspective focuses on the function of organs, while the symbolic meanings of organs are important in the cultural perspective. Thus, organ transplantation, which removes an organ from one person's body and implants it into another person's body, is a matter of biological integration in medicine whereas cultural perspectives understand that biological bodily integration could be linked to ideas about identity.

Keeping in mind the different medical and cultural perspectives involved in organ transplantation, an organ transplant recipient experiences the surgical procedure firstly from a medical perspective. However, they also receive information from the mass media and are influenced by social policies, which are all influenced by Japanese cultural factors. In this regard, the experience of having a heart transplant is not merely a medical one; as anthropologically informed studies of the experience in countries other than Japan have indicated, it is also highly related to the issue of patients' identities (Sharp, 1995, 2006).

Most existing studies focus on heart transplant recipients who undergo transplant surgery in their own countries and cultures. There is a lack of an exploration of recipients' experiences in a global context. Information on heart transplants is globally disseminated, and it is possible for the patient to have a heart transplant in another country, where different cultural norms from the patient's country of origin may apply. However, such travel has recently been numerically limited following the Declaration of Istanbul on Organ Trafficking and Transplant Tourism (American Society Nephrology, 2008). Heart transplant recipients who have had heart transplants in cultures other than their own have not been studied. The study reported in this thesis addresses this, using the situation in Japan case as an opportunity to explore heart transplant recipients' experiences in both global and domestic contexts.

### **Outline of the thesis**

This thesis consists of a literature review – Chapter 2, an explanation of the methodology – Chapter 3, and data analysis in Chapters 4-7. The analysis chapters are

divided into two parts. Chapters 4 and 5 examine heart transplant recipients' experiences from diagnosis through surgery to recovery. Chapters 6 and 7 examine their experiences in the context of Japanese cultural expectations about the body and the custom of reciprocal gift-exchange respectively. The final chapter – Chapter 8 summarises the findings of the study. It also provides a theoretical contribution to medical sociology and makes suggestions for future heart transplant planning in Japan.

Chapter 2 begins with a review of the historical background of heart transplantation in Japan and attempts to locate that history in a wider global context. It also identifies individuals who have played key roles in discussing heart transplants in Japan. In doing so, issues that have arisen concerning Japanese heart disease patients and heart transplant recipients will be described. The second half of the chapter provides an in-depth theoretical background by reviewing the literature of chronic illness and identities, and literature relating to the concepts of 'shame', 'body' and 'gift-giving' in Japan. Studies of chronic illness and identities provide perspectives regarding the effects of the chronic condition caused by heart disease and heart transplant surgery on recipients' identities and everyday lives. These perspectives are important for examining recipients' experiences at a micro level. In order to explore the heart transplant recipients' chronic condition in depth, I relate them to the notion of shame in Japanese culture, the Japanese notion of the body and the concept. The second half of the chapter provides an in-depth theoretical background by reviewing the literature of chronic illness and identities, and literature relating to the concepts of 'shame', 'body' and 'gift-giving' in Japan. Studies of chronic illness and identities provide perspectives regarding the effects of the chronic condition caused by heart disease and heart transplant surgery on recipients' identities and everyday lives. These perspectives are important for examining recipients' experiences at a micro level. In order to explore the heart transplant recipients' chronic condition in depth, I relate them to the notion of shame in Japanese culture, the Japanese notion of the body and the concept of reciprocal gift-exchange. Chapter 2 concludes by outlining a conceptual framework to analyse recipients' experiences, and outlines the initial research questions that were proposed.

Chapter 3 is the methods and methodology chapter and provides an overview of the research design, including an account of the sampling and approach to interviewing recipients and others involved in the transplant experience. I also outline the procedures involved in the use of thematic analysis.

Chapter 4 highlights the analysis of the experiences of patients needing heart transplants in the pre-operation period, looking at the process they go through in

deciding to have heart transplants. In this period, a patient's quality of life is diminished due to his or her disease. Charmaz (1983) insists that chronically ill people experience productivity loss, financial crisis, family strain, stigma and a restricted existence and as a result, often experience a loss of self. I argue that in addition to these things, developing heart disease disrupts one's life, and that this disruption causes an identity crisis. At the end of the chapter, I will summarise how the findings help answer two key questions:

- (1) How are heart transplant patients' everyday lives disrupted during the pre-operation period?
- (2) How did this disruption affect their identities?

Chapter 5 explains the analysis of recipients' post-operation experiences. Soon after a heart transplant, recipients perceive an improvement of bodily functions. From a professional medical point of view, within a year after their release from hospital, most recipients return to a life in which it is possible to go to work, school or community activities in society like other people. For example, Osaka University Hospital web-site for heart transplant recipients gives the following advice:

'Heart transplant recipients can return to work in three to six months after the release from hospital as long as the recipient can lead a well-regulated life and the condition of the work place is hygienic. However, it takes a long time for rehabilitation to result in a return to work as the muscles became weak if the patient has experienced a long period of cardiac insufficiency before having a heart transplant. In order to completely return to work, it can take as much time as the time the recipient spent in bed because of heart failure' (Division of Cardiovascular Surgery, Department of Surgery, Osaka University Graduate School of Medicine, 2011).

It is important to notice that no emotional and social problems are indicated. This explanation focuses on entirely medical issues. Heart transplant recipients are apparently released from the physical restrictions associated with their bodily condition. However, it is worth exploring whether their lives remain in some ways disrupted by their bodily condition. For example, recipients will need life-long immune control; as they still have a chronic condition, although it is different from the one before their heart transplant. Also, Japanese health policy defines heart transplant recipients as disabled people who are entitled to receive financial and social support to increase their public participation including going to work, school or community activities in society

(Bureau of Social Welfare and Public Health, Tokyo Metropolitan Government, 2009). The recipients are labelled both from medical and social policy viewpoints, and cannot reject these labels; although they can control to what extent, to whom and how they disclose information in relation to these labels. This chapter explores how the recipients establish identities and cope with these potentially stigmatising labels in terms of information gathering and information control.

Chapter 6 looks at how cultural ideas and norms relating to the body in Japan influence the identities of heart transplant recipients. I review how these norms have entered public debates about heart transplantation in Japan, in particular prior to the passing of the Organ Transplant Law in 1997.

This shows how the body was discussed both from a Cartesian perspective of dualism and in relation to the norms governing Japanese ritual processes such as funerals. In their attempts to legitimise their opinions, people who have engaged in these debates have often invoked historical experiences. Such people insist that past experiences ought to affect current attitudes. However, these perspectives do not pay much attention to ways in which newly emerging factors of consumer culture impact upon attitudes. Images of the body are reconstructed constantly in a consumer culture. At the same time, a person can recognize when the image of their body changes. If the person attempts to attach a new body image to himself or herself, he or she may experience the impact of that new body image. This phenomenology of the experience of the body is an individual experience and is perceived subjectively. Thus, this phenomenological perspective is important in understanding the relationship between the body, self and experiences (Turner, 1996). I will therefore examine how the body is discussed in relation to consumer culture in Japan. I will explain how heart transplant recipients hold both knowledge of the body derived from historical sources, traditional ritual processes, as well as the knowledge derived from modern consumer culture. In order to answer the question addressed in this chapter, the recipients' and doctors' narratives of heart and body will be discussed and compared. This comparison will enhance the understanding of how the medical experts' knowledge of heart transplant contends with popular Japanese attitudes towards heart transplantation.

Chapter 7 explores how the custom of reciprocal gift-exchange, which is firmly embedded in Japanese everyday life, affects the experiences of heart transplant recipients. I will review the literature on the notion of gift-exchange, pointing out that Mauss (1954) provides a framework which can be used to explore issues of organ transplantation, used by several other authors, such as Gill and Lowes (2008), Lamanna

(1997), Lock (2002) and Saher et al. (2003). These studies also show how altruism fits into the organ transplant experience. Moreover, Shaw (2008) explores how altruism associated with organ transplantation is institutionally established in terms of gift-relationships. However, these studies do not examine altruistic gift and gift-exchange in terms of organ transplant in the context of the consumer culture that characterises modern Japan.

In particular, I will explain how the ancient custom of gift-exchange in Japan has been by a modern consumer culture. I will argue that it is important to examine how people perceive a gift which is initiated in a context where exchanges are normally mediated by a market. This chapter therefore shows how the heart transplant recipient perceives and experiences the gift of a heart organ in a consumer culture, exploring this in three stages: the experience of donating a heart organ, of receiving a heart organ and of repaying the donation.

Chapter 8 discusses the results of the study and summarises the answers that are explored in each chapter. It also describes the theoretical contribution of this study to medical sociology. Based on these findings, I make a suggestion for the future planning of heart transplantation in Japan.

### **Clarification of terms**

*Patient and Recipient* – In this study, the expression ‘patient’ is used to refer to a person with heart disease before having a transplant surgery. After a heart transplant, I will describe them as a ‘recipient’ because they have recovered from the conditions of heart disease although they need life-long immune control following the operation. People who have had transplants often reject the label of patient themselves, and prefer to be referred to as heart transplant recipients.



## 2. Literature review

This chapter consists of two main sections: a review of the historical background of heart transplantation in Japan, and a review of literature relating to chronic illnesses and identities.

The first half of this chapter attempts to locate the history of heart transplantation in Japan in a wider global context. It also identifies individuals who have played key roles in discussions on heart transplants in Japan. Finally, it describes issues that have arisen concerning Japanese heart disease patients and heart transplant recipients.

The second half of the chapter provides the theoretical background for what follows. In order to achieve this, literature relating to concepts of 'shame', 'body', and 'gift-giving' in Japanese culture are examined.

Studies of chronic illness and identities provide several perspectives regarding the effects of the chronic condition caused by heart disease and heart transplant surgery on recipients' identities and everyday lives. These perspectives are important to examine recipients' experiences at a micro level. Following the review, I will examine three key concepts of 'shame', 'body', and 'gift-giving' in Japanese culture. I will also investigate the issues faced by Japanese heart transplant recipients, and relate them to the notion of shame in Japanese culture (2.2.3), the Japanese notion of the body (2.2.4), and the concepts of reciprocal gift-exchange (2.2.5).

I argue that heart transplant recipients may be marginalised by Japanese society, not only due to the physical restrictions associated with their condition, but also in being labelled heart transplant recipients. Here, I will pay particular attention to chronic conditions caused by heart disease and heart transplant surgery on the recipients' identities and everyday lives. This chapter concludes by outlining a conceptual framework that will be used to analyse recipients' experiences.

## **2.1 Historical background of heart transplantation in Japan in a global context**

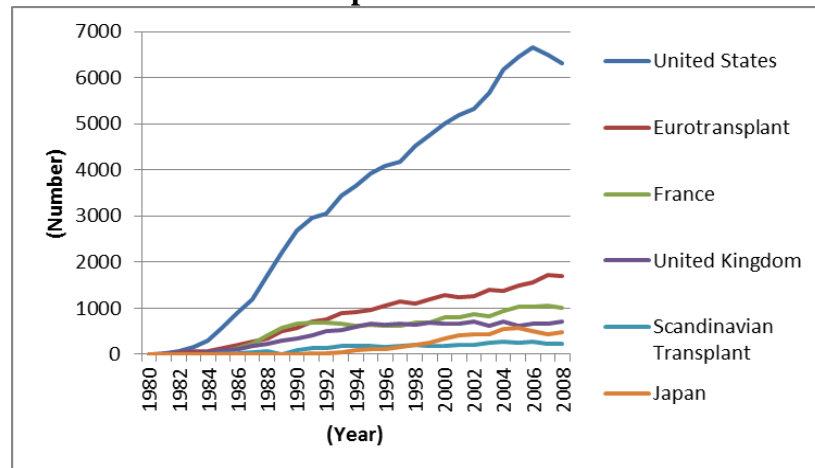
### **2.1.1 Introduction**

French surgeon Dr. Carrel first succeeded in stitching up blood vessels in 1902 (Fridman, 2007). This development of a new surgical skill had important meaning to the field of organ transplantation. This skill would make it possible to stitch up the blood vessels of a transplanted organ with the vessels of a recipient. However, organ transplantation was not successful for another fifty years due to medical reasons such as those related to immunosuppressant drugs. The world's first successful organ transplantation was a renal transplant performed by Dr. Murray and his colleague in 1954 (Fox and Swazey, 2002). In 1963, Dr. Starzl performed the first liver transplant in the U.S. Dr. Barnard performed the first heart transplant in South Africa in 1967 (Fox and Swazey, 2002). Organ transplants were then globally performed.

Looking at the situation surrounding organ transplantation in Japan, in 1956, Japanese surgeons performed a renal transplant in a patient with acute renal disease. As the donor's one kidney was suddenly bleeding, the kidney was extracted in order to improve the patient. The extracted kidney was transplanted to another patient. After for a while, the recipient's condition was improved. In this regard, this kidney transplant was different from the usual kidney transplant. The transplant team used the kidney from a live donor as an alternative for artificial kidney for transplantation (Lock, 2002). In 1964, Dr. Ohmoto and his colleagues performed a true renal transplantation, and the Chiba University Medical team attempted the first Japanese liver transplant (Lock, 2002). The first heart transplant in Japan was performed by Dr. Wada and his staff in 1968 (Lock, 2002).

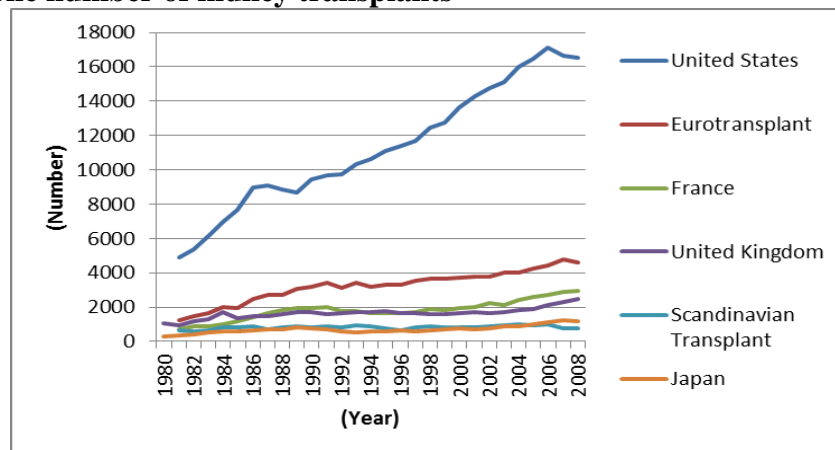
In the 1950s and 1960s, organ transplant surgeries were performed across the globe. Shortly following this period, the excitement surrounding organ transplantation decreased due to the difficulties of immunosuppressant drugs following transplant operations (Fox and Swazey, 2002). This was solved by the development of immunosuppressant drugs in the late 1970s (Fox and Swazey, 2002). The number of renal, liver and heart transplant surgeries increased once more in many countries in the 1980s onwards as Figures 1, 2 and 3 show.

**Figure 1 The number of Liver Transplants**



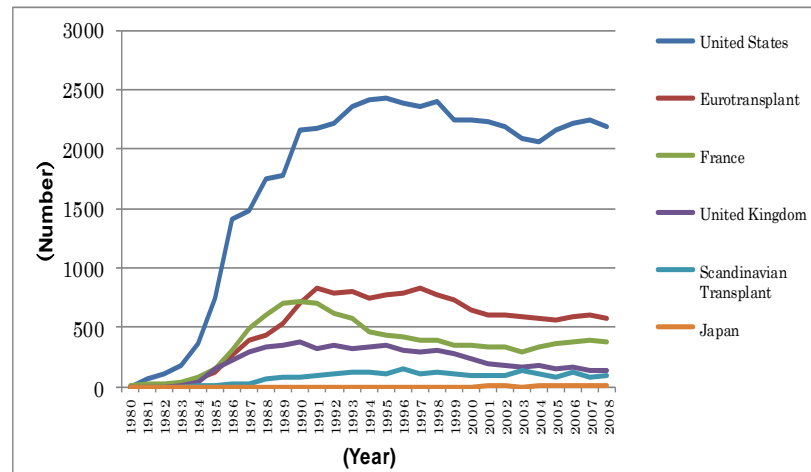
(Sources: Transplant Communication, 2009a; 2009b; The Japan Society for Transplantation Publicity Committee, 2010; United Network for Organ Sharing, 2011b; Organ Donation and Transplantation, 2011b; Eurotransplant, 2011a; 2011b; 2011c; Scandinavian Transplant, 2011)

**Figure 2 The number of kidney transplants**



(Sources: Transplant Communication, 2009a; 2009b; The Japan Society for Transplantation Publicity Committee, 2010; United Network for Organ Sharing, 2011b; Organ Donation and Transplantation, 2011b; Eurotransplant, 2011a; 2011b; 2011c; Scandinavian Transplant, 2011)

**Figure 3 The number of heart transplants**



(Sources: Transplant Communication, 2009a; 2009b; The Japan Society for Transplantation Publicity Committee, 2010; United Network for Organ Sharing, 2011b; Organ Donation and Transplantation, 2011b; Eurotransplant, 2011a; 2011b; 2011c; Scandinavian Transplant, 2011)

Japan's GDP increased in the 1980s onwards (Ministry of Health, Labor and Welfare, 2009). At the same time, the percentage of elderly in the population has increased dramatically. This has seriously impacted on the budget at a nation-state level. The percentage of the budget devoted to medicine and health care has rapidly increased. This percentage nearly doubled from 1980 to 2009. This trend will become more serious in the near future (ibid.).

The budget for medicine and health care has become an urgent issue. This economic context has affected organ transplant medicine in Japan. Haemodialysis has become popular for patients with kidney disease patients, but the cost is high (Ministry of Health, Labor and Welfare, 2009). Renal transplantation represents a less expensive alternative (Ministry of Health, Labor and Welfare, 2009). In addition, after receiving a kidney transplant, the patient does not need to visit the hospital frequently, as is true for patients receiving haemodialysis. In both respects, renal transplantation seems to be a superior medical treatment.

However, the situation is not simple with regard to organ transplantation. This is a unique trend in organ transplants in Japan. Although kidney transplants and liver transplants from living donors have increased, in many countries transplants from a cadaveric donor are still more popular than transplants from a living donor (Ishida and Toma, 2004). These trends suggest that Japanese people are resistant to organ donation from a deceased person. Organ transplants such as kidney and liver transplant are possible from a dead person although there are several difficulties for them. By contrast, a heart donor must be diagnosed as brain dead. In the next section, I will examine the

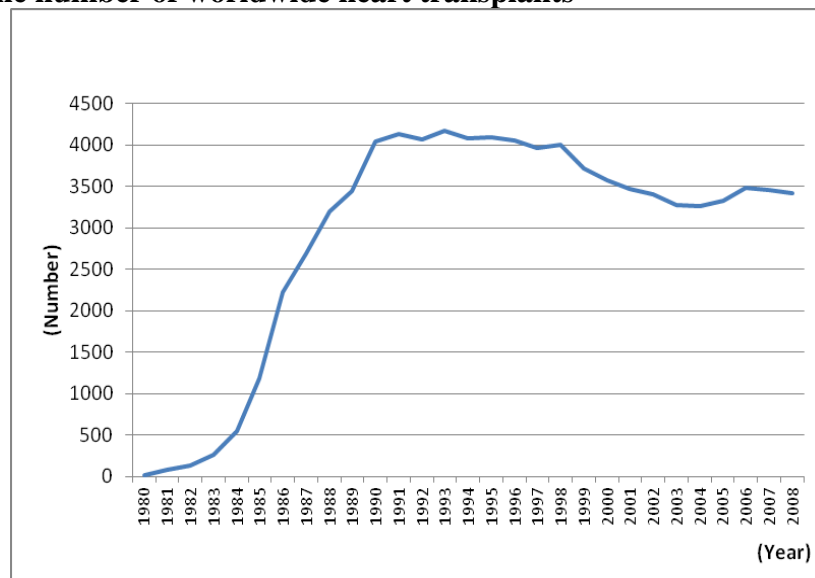
difficulties surrounding heart transplant operations in Japan.

In order to understand the issues with heart transplantation in Japan, I will begin by looking at the number of heart transplant recipients there have been in Japan in recent years. Based on this numerical data, I will survey the situation surrounding heart transplantation in Japan by exploring the following questions: ‘Who has played key roles in discussing heart transplants in Japan?’; ‘What has the trend of the number of heart transplantation in Japan been?’; and ‘How has this trend been affected by global factors?’ I will answer these questions by looking at the discussions of, and actual, heart transplantations in Japan, as well as heart transplantations for Japanese recipients abroad. In addition, I will examine public opinion surveys to enhance an understanding of the public’s attitude towards heart transplantation.

### 2.1.2 Historical background of heart transplantation in Japan from 1968 to 2009

Heart transplantation has been established as a medical treatment for heart disease in many countries since the world first heart transplant in 1967 (Hosenpud, et al. 1998; Taylor, et al. 2009).

**Figure 4 The number of worldwide heart transplants**



(Sources: Transplant Communication, 2009a; 2009b; The Japan Society for Transplantation Publicity Committee, 2010; United Network for Organ Sharing, 2011b; Organ Donation and Transplantation, 2011b; Eurotransplant, 2011a; 2011b; 2011c; Scandinavian Transplant, 2011)

As Figure 4 shows, the number of heart transplant operations has increased worldwide from 1980 onwards. Since 1988, over 3000 heart transplants have been conducted per

annum across the world.<sup>1</sup> However, the total number of heart transplants in the world has declined in recent years. The development of alternative medical therapies has decreased the range of potential recipients (Peck, 2006). Administrative reasons are also sometimes factor: in recent years in the U.K, for example, heart transplant rates have declined due to the small number of intensive care unit beds, while the donation rate has actually increased. (MacGowan, et al. 2011; Triggle 2011).

In Japan, although the first heart transplant was performed in 1968 (Asahi Newspaper 1968; Brannigan 1992), it was not until 1999 that the second heart transplant was performed (Yomiuri Newspaper, 1999b). Since 1999, the number has been 10 or less each year, with the exception of 2008 (Figure 5 in page 43). Numerically there is a huge gap between Japan and other countries, in particular in comparison to the U.S., where more than half of all heart transplants in the world are performed.<sup>2</sup>

This data raises many questions. For example, does this mean that there are more patients who need heart transplants in the U.S than in Japan? The potential number of Japanese patients is estimated between 228 and 670 per year (Matsuda and Fukushima, 1998). Following this estimate, for example, if there had been at least 228 potential patients for heart transplants, it can be assumed that there were 2280 potential patients over ten years. During the ten years from 1999 to 2008, 60 patients had heart transplants in Japan. Less than 2.6 percent of the potential patients therefore obtained the treatment.

Why does this kind of difference occur between countries? In particular, why have heart transplants been performed on such a limited number of patients in Japan? Given that the medical technology for heart transplantation is available internationally, it can be concluded that the numerical difference has been caused by non-medical factors. These might include social, cultural, political and economic considerations. To begin to explore these potential other reasons, in what follows I will therefore examine the

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<sup>1</sup> The table that summarises the number of heart transplant is attached as Appendix 1. This table reflects the data introduced by Transplant Communication (2009a; 2009b), which collected statistical data on organ transplantation. The total number of heart transplant recipients in most years is slightly different from the data introduced by Taylor et al. (2009). Looking at data of the number of heart transplants, Transplant Communication (2009a; 2009b) introduces data of many more countries than Taylor et al. (2009) did. Therefore, I referenced the Transplant Communication's data and combined data from other sources in the table. I also added data of 2009 and 2010 referencing The Japan Society for Transplantation Publicity Committee (2010), United Network for Organ Sharing (2011b), Organ Donation and Transplantation (2011b), Eurotransplant (2011a, 2011b, 2011c) and Scandinavian Transplant, 2011). Apart from the differences in the specific numbers between the two researchers, both researchers show that the number of recipients increased until the mid-1990s, and then began to decline. In addition, Taylor et al. (2009) explains that every heart transplant procedure is not necessarily reported in many countries. They estimate that more heart transplant operations have been performed than those reported in many countries.

<sup>2</sup> Schoenberger (2009) points out that Japan has the lowest rates of organ donation among the countries covered by The International Registry of Organ Donation and Transplantation.

historical background of heart transplantation in Japan.

The world's first human heart transplant was performed by a team led by Dr. Barnard in the Republic of South Africa in December 1967 (McRae, 2007). This surgery became world famous through coverage by the mass media (Lock, 2002; Nathoo, 2009). The first heart transplant recipient lived for eighteen days after the procedure (ibid). Following this operation, heart transplant surgeries were performed in many countries, with about one hundred heart transplants performed in 1968 across the world. However, most patients died less than one year after the transplant due to the inability to control the reaction of the recipients' immune system. As a result, most surgeons stopped conducting heart transplantations in the 1970s (Benjamin and Barnes, 2004; Kahan, 1996; Wada, 2000).

In Japan, the first heart transplant was performed by a team led by Dr. Wada in August 1968, which was the thirtieth such surgery that had taken place to date in the world. The Wada procedure initially produced accolades from the media and was heralded as a dramatic triumph (Brannigan, 1992; Lock, 2002). But in December 1968, Dr. Wada was arraigned on a charge of the murder of both the donor and recipient. The reasons of the arraignment were whether or not the recipient needed a heart transplant operation, and whether or not the donor was correctly diagnosed brain-death. He was eventually acquitted of the charge in 1973, after a six-year legal examination due to a lack of evidence (Organ Transplant News Team, 1998). During this period, the Japanese government set up a consultative committee to discuss organ transplants, beginning in December 1969. However the discussion was disrupted in December 1971. The consultative committee failed to reach a conclusion that would allow organ transplantation in Japan to progress (Akabayashi and Satoh, 2003). Furthermore, in March 1973, Dr. Takemi, the chairman of the Japan Medical Association and a powerful influence in Japanese medicine, made a critical remark about the heart transplant conducted by Dr. Wada. He claimed that the heart organ transplant operation carried out by Dr. Wada had had many problems. Dr. Takemi had such authority that his speech was seen as representing the attitude of the Japan Medical Association. As a result, after his speech, medical experts in Japan did not try to make progress on heart transplantation (ibid.). This meant that, after 1973, heart transplantation ceased to be of interest to the Japanese mass media, with public interest also decreasing (Yonemoto, 1988).

However, in the 1980s heart transplantation returned to the agenda in Japan (Akabayashi and Satoh, 2003; Lock, 2002). There were three main contextual reasons for this. First, an immunosuppressant drug, cyclosporine, was developed. Cyclosporine

made it possible to reduce the activity of the patient's immune system, which was otherwise at risk of rejecting the organ after transplant surgery. Thus, it raised the survival rate of patients who had organ transplant surgery. Cyclosporine was subsequently approved for use in 1983 and heart transplants began to be conducted again in many countries. This led to cyclosporine being imported into Japan (Asakawa, 2008). Second, the number of young physicians who had gone abroad to study new skills for organ transplantation increased (New Heart Club, 1993). Third, Dr. Takemi, who was opposed to heart transplantations and had exerted a powerful influence over Japanese medicine, retired as the chairman of the Japan Medical Association (Yonemoto, 1988). As a result of these social changes, the discussion of issues surrounding heart transplants resumed in the 1980s.

In 1983, the Japanese government began to set up meetings to discuss the ethical issues of heart transplants. As a result, the government brought the issue of brain death to public attention. As I will explore, meetings were conducted by the government between 1983 and 1997, with five different study groups established to discuss the issues vis-à-vis heart transplantation.

First, from 1983 to 1985, the Ministry of Health and Welfare set up the Life Ethical Forum. This forum aimed to examine the ethical issues which would be caused by the development of new medical technologies such as organ transplantation (Nudeshima, 1991). Second, in parallel with The Life Ethical Forum, a Brain Death Study Group, composed of neurosurgeons and anaesthesiologists, was formed at the initiative of the Ministry of Health and Welfare from 1983 to 1985. This study group was chaired by the neurosurgeon, Dr. Kazuo Takeuchi. In December 1985, they published a report which included the definition of death, and the criteria for its diagnosis of brain death became the standard in Japan, becoming called the Takeuchi Criteria (Akabayashi and Satoh 2003). Third, the Japan Medical Association set up the Japan Medical Association Bioethics Roundtable to discuss the relationship between life and ethics. This took place from 1986 to 1988 (Nudeshima, 1991). Fourth, the Japanese government formed the Provisional Commission for the Study on Brain Death and Organ Transplantation from 1990 to 1992. The commission aimed to explore the issues of brain death, organ transplants and ethics (Kimura, 1998; Lock, 2002; Nakayama, 1992; Nudeshima, 1991). Fifth, the issue of the legalisation of transplantation was discussed in Parliament. All the deliberations of Congress were open to the public, as reported through the mass media (Lock, 2002; Nudeshima, 1991).



**Table 1 Key meetings to discuss heart transplantation between 1983 and 1997**

<b>Year</b>	<b>Organised by</b>	<b>Meeting and the aim</b>
1983 – 1985	The Ministry of Health and Welfare	<b>The Life Ethical Forum</b> <b>Aim:</b> to examine the ethical issues which would be caused by the development of new medical technologies such as organ transplantation
1983 – 1985	The Ministry of Health and Welfare	<b>Brain Death Study Group</b> <b>Aim:</b> to define death and to establish the criteria for diagnosis of brain death
1986 – 1988	The Japan Medical Association	<b>The Japan Medical Association Bioethics Roundtable</b> <b>Aim:</b> to discuss life and ethics related issues, which have been newly caused by the development of medical technologies
1990 – 1992	The Japanese government	<b>The Provisional Commission for the Study on Brain Death and Organ Transplantation</b> <b>Aim:</b> to explore the issues of brain death, organ transplants and ethics
1992 – 1997	The Japanese government	<b>Parliament</b> <b>Aim:</b> to discuss the legalisation of transplantation

In these meetings, included in the discussions vis-à-vis heart transplantation were not only medical professionals but also jurists, the mass media and administrative staff. Also, public awareness was increased through several publicised symposiums and through mass media reports (ibid).

In order to find out the trend of mass media reporting on heart transplantation until the passing of the Organ Transplant Law in 1997 in Japan, I searched newspaper articles on heart transplants, using the Asahi newspaper database, a broadsheet paper in Japan that started to archive issues in August 1984. This is the oldest newspaper archive amongst newspapers in Japan. Articles were searched using combinations of the words ‘heart and transplant’. Other word combinations ‘should be possible to thoroughly search articles dealing with heart transplantation. After attempting several patterns of word combinations such as ‘organ and transplant’, ‘heart, transplant and recipient’, ‘brain death and transplant’, I used the combinations of ‘heart and transplant’ to explore how frequently newspaper articles on heart transplantation were conveyed. As a result of searching the period between 1984 and 1997, the number of articles was as follows: 1984 (51), 1985 (101), 1986 (57), 1987 (90), 1988 (140), 1989 (241), 1990 (241), 1991 (225), 1992 (195), 1993 (144), 1994 (173), 1995 (84), 1996 (20), 1997 (384). As the database started in August 1984, I look at the year 1985 onwards here. These numbers show that the newspaper covered heart transplantation intensively between 1990 and

1992, with a next peak was 1997. In parallel with the media coverage trend, it is possible to assume that the public had more opportunities to listen to the news of heart transplantation, regardless the degree of their interest on heart transplantation. This increased opportunity might stimulate the interest of the public, although this point needs further study in future research.

It was in 1997 that the Organ Transplant Law relating to brain death was passed in Japan (Bagheri, 2003; Lock, 2002; The Ministry of Health and Welfare, 1999). Prior to this, the Japanese government did not allow heart transplantation. The new law requires donors to be over fifteen years of age and to have previously declared formally that they wish to become organ donors. Only those who previously declared this wish formally could be subject to diagnosis of brain death, which is fundamental for the extraction of a heart organ (The Ministry of Health and Welfare, 1999). It also means that people younger than fifteen years old cannot be donors. This age limit is related to the fact that Japanese law does not allow these young people to sign a living will. As young people cannot be donors, only a few heart transplants have been performed on children. This is due to problems between body and organ size: because an adult's heart is too large for a child, and a difference in size brings risk for the heart transplant recipient (Onda, 2004). Due to the situation among Japanese patients, more than twenty years after improvements in immunosuppressant drugs for heart transplant, and more than ten years after the enactment of the law, heart transplantation is still a controversial matter (Crowley-Matoka and Lock, 2006).

The discussion to amend the Organ Transplant Law returned to a political debate in 2008. This involved a discussion of the possibility of conducting heart transplants for people younger than fifteen years old. There was a strong sense of urgency, because of the release in May 2008 of the 'Istanbul Declaration' by The Transplantation Society and International Society of Nephrology (American Society Nephrology, 2008). This declaration stated that each country should provide for the transplant needs of its citizens from within its own population (ibid), in part to discourage people from going abroad to have an organ transplant. This influenced the need for a political discussion to amend the Organ Transplant Law in Japan. In July 2009, the government achieved an agreement to amend the law (Japan Organ Transplant Network, 2011a). The two major amendments were first, that a person can demonstrate his or her wish to prioritise his or her spouse, parents and children as the person who should receive his or her organs. This was enforced in January 2010. The second is that removal of an organ became possible with the agreement of the donor's family, without the donor himself or herself

having to have officially signed a donor card. Before the amendment of the law, this had been fundamental (Yomiuri Newspaper, 2009). Under the new law, if a potential donor did not declare their wishes in writing, his or her organ may be used for transplants, if their family agree, even if the donor is under fifteen. Therefore this amended law made it possible to perform transplant surgery for children, as long as parents' permission had been granted. This law was enforced in July 2010 (ibid).

To sum up, the current discussion regarding organ transplant law revolves around an amendment that will legalise organ transplants from a person who is brain dead. The discussion lacks a broader perspective on organ transplantation in general. Nudeshima (2012) explains that this situation reflects the strong resistance of the Japanese towards organ transplantation from a person who is brain dead. As a result, organ transplantation from a live donor is more popular than the one from a brain dead person.

Reconsidering the trend along with the process for the enforcement of the transplant law and the amendment, Japanese society has legally accepted organ transplantation, although the actual situation vis-à-vis organ transplantation from a brain-dead person still has many issues that need to be resolved. Aita (2012) points out that the understanding of brain death in medicine has changed since the first definition by the Harvard Ad Hoc committee in 1968. Aita (2012) found that the condition of brain death is not always precisely diagnosed in adherence to the brain death criteria. Furthermore, the President's Council on Bioethics in the U.S. uses the term 'total brain failure' instead of 'brain death' (President's Council on Bioethics, 2008). Thus the understanding of brain death has changed since 1968.

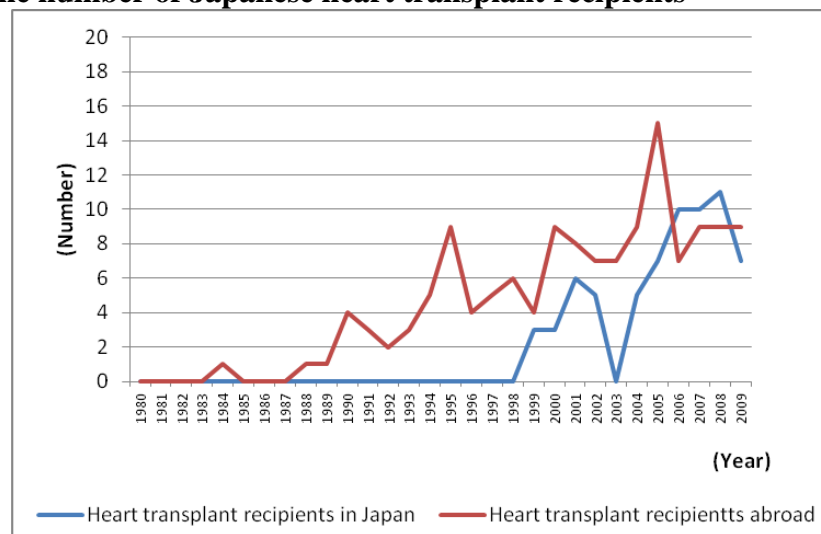
How can it be possible to understand brain death? Aita (2012) explains that the precise diagnosis of brain death means that the person cannot recover from the condition. Here, the problem is whether the patient should be given further medical treatment when the patient's family requests it. The answer to this question is varied (Aita, 2012). In Japan, the patient's family often wishes to continue medical care after the diagnosis of brain death (Aita, 2008a; 2008b). However, this type of care is medically inappropriate (British Medical Association, 2001). I argue that these opposing attitudes reflect the patient's relationship with family members.

In the next section, in order further explore how the Istanbul Declaration has affected the regulation of transplantation in Japan; I will explore in more depth the situation of those Japanese patients requiring an organ transplant from a brain-dead person.

### 2.1.3 History of the Japanese heart transplant patients abroad

As mentioned above, the Japanese government did not legally allow heart transplants to be performed until 1997. This is despite heart transplants being performed world-wide since 1980 as a result of improvements in immunosuppressant via the drug Cyclosporine (Brannigan, 1992; Nunoda, 1997b). Thus, during this period Japanese patients wanting a transplant had to seek heart transplants abroad. Furthermore, this pattern has continued even since the lifting of the ban.

**Figure 5 The number of Japanese heart transplant recipients**



(Source: The Japan Society for Transplantation Publicity Committee, 2010)

As Figure 5 shows, the number of Japanese patients who travel abroad to undergo heart transplant operations has been increasing over the last twenty years. These patients have tended to visit the U.K, Germany and the U.S to have their operations (Nunoda, 1999; Sono and Akasaka, 1999). Eighty-four Japanese patients had heart transplants abroad between 1999 and 2008, many more than in Japan (The Japan Society for Transplantation Publicity Committee 2010). Looking back further to another ten-year period between 1989 and 1998, no Japanese patients had a transplant in Japan and forty-two patients had the operation abroad (Nunoda, 1999). How did it become possible for these Japanese patients to have a heart transplant abroad? To answer this, I will explore the social background to this practice. This will also enhance an understanding of the likely future impact of the Istanbul Declaration upon Japanese patients.

In a global society, it is physically possible for patients in need of medical treatment to travel abroad. Nevertheless, in Japan, public discussion of heart transplantation (as

examined in the previous section), was conducted within the cultural framework of the Japanese nation-state. Very little attention was paid to global discourses. Therefore, understanding the experiences of Japanese heart transplant patients abroad will help me to complete an important missing element of the research into the issues surrounding heart transplantation in Japan. In particular, as I will show, the fact that more people have had heart transplants abroad (supported by fund-raising activities) means that many Japanese support patients by donating money. This fund-raising has shaped a part of Japanese support for heart transplantation. Thus, exploring this further will enhance the understanding of relevant attitudes, beliefs and social relations in relation to heart transplants among the Japanese.

**Table 2 The number of Japanese heart transplant recipients by countries from 1984 to 2008**

US	107
Germany	14
UK	7
Canada	1
France	1
No data	5
<b>Total</b>	<b>128</b>

(Sources: The Japan Society for Transplantation Publicity Committee, 2010  
Yomiuri Newspaper between 1984 and 2008)

As Table 2 shows, overseas heart transplants for Japanese patients have mainly taken place in the U.S. These heart transplants were often publicised through the mass media. Therefore, it can be assumed that public awareness of transplantation also increased through this media coverage. This also led to these patients receiving a high degree of attention. Another important factor for these patients was a young generation of physicians who had been abroad to study new skills relating to organ transplantation. Several of these physicians had set up networks between hospitals in Japan and those abroad (Hew Heart Club, 1993). These networks included connections being established between: Kobe City Hospital and Harefield hospital (U.K), Kofu Hospital and University of Utah hospital (U.S); Osaka University Hospital and Texas Heart Institute (U.S); Tokyo Medical Women’s University Hospital and UCLA Hospital (U.S); Saitama Medical University Hospital and German Heart Center (Germany); Kobe City Hospital and Sharp Anniversary Hospital (U.S); National Cardiovascular Center and Pittsburgh University Hospital (U.S); Japan University and German Heart Center (Germany). After

returning to Japan, what was happening was that these physicians were effectively sending some of their patients to these hospitals abroad to have heart transplants (Hachida, et al., 1996; Nunoda, 1999).

There exist no social systems in Japan for patients wishing to go abroad to undergo heart transplants. Individual connections between health professionals in Japan and hospitals abroad thus remain important in such cases. As this process is not systematised in the Japanese medical system, health professionals have to spend considerable time preparing for patients to be sent abroad for heart transplants. This includes holding meetings with airline companies: medical equipment is needed on board the aircraft which, in turn, requires specialised knowledge to set-up. Health professionals undertake this work in addition to their usual work within the hospital (Dodo and Isoda, 2006).

The mass media often conducted campaigns to raise financial donations to support patients going abroad for their heart transplants (ibid). As Table 3 demonstrates, 61.4 percent of the patients needed support by fund-raising. This is because the surgery has not been covered financially by the Japanese medical insurance system.

Before 1996, the Japanese government did not have any data about patients who went abroad to have heart transplants. The government thus did not record how many patients went abroad to have heart transplants and how these patients had managed to organise their surgery. Also, if problems occurred with the heart transplant surgeries abroad for these Japanese patients, the patients and their families would have to resolve these problems without recourse to the Japanese medical care system. This meant that, although these patients needed social support on returning to Japan, this was not feasible in a situation where the Japanese authorities had no data regarding these patients. Additionally, the lack of data being collected meant that the Japanese government did not understand the urgency of establishing a medical system within Japan for providing heart transplantations.

**Table 3 The number of Japanese heart transplant recipients who acquired fund-raising support from the public between 1984 and 2008<sup>3</sup>**

	Total	Own expense	Fund raising	% who fund raised
US	81	9	72	88.8%
Germany	13	0	13	100.0%
UK	7	5	2	28.6%
France	1	1	0	0.0%
Canada	1	0	1	100.0%
<b>Total</b>	<b>88</b>	<b>34</b>	<b>54</b>	<b>61.4%</b>

(Sources: The Japan Society for Transplantation Publicity Committee, 2010; Yomiuri Newspaper between 1984 and 2008)

As figure 4 shows, by the mid-1990s, the number of these recipients was increasing. However this data was not available, even for Japanese health professionals. In order to improve these recipients' prospects for receiving medical treatment after returning to Japan, researchers Hachida et al. (1996) and Nunoda (1999) respectively sent a questionnaire to hospitals in Japan to collect data on Japanese patients who had undergone a heart transplant abroad. Hachida et al. (1996) clarified the number of such recipients and key demographic information, as well as researching recipients' quality of life following their transplant, focusing on seven recipients. Following such research, data regarding Japanese heart transplant recipients abroad began to be collected and shared among health professionals (Fukushima, 2006; Hasegawa, 2006; Kobayashi, 2006; Koyanagi, 2001; Shinozaki, 2006). Nunoda (1999) and Hachida et al. (1996) recognised that a heart transplant was an effective treatment if the patients were in good enough health to endure the long trip. The costs of a transplant abroad and the subsequent lifelong medical treatment are two major issues for these patients.

Nunoda (1999) focused on child recipients, and recognised the same issues in their cases. In addition, he found that psychological care for these recipients is also significant after transplantation (Nunoda, 1999). The issues Japanese patients and their families experience in the process of obtaining a heart transplant abroad are also discussed by Sono and Akasaka (1999) as well as Sezai and Minami (2006). These

<sup>3</sup> The information of 108 cases out of 128 cases between 1984 and 2008 were available from Yomiuri Newspaper between 1984 and 2008. 19 patients who went to the U.S to receive a heart transplant and 1 patient who went to Germany to receive a heart transplant were not covered in the mass media. One possible reason is that these patients were not covered as they did not seek fund-raising support from the public. The table that summarises the profile of the Japanese heart transplant recipients abroad between 1984 and 2008 is attached in Appendix 2.

studies enabled Japanese health professionals to better understand the actual situation among heart transplant recipients from a medical viewpoint. The patients and their families still experience issues of the costs to have a heart transplant abroad, the subsequent life-long medical treatment, and psychological care, which have not improved yet.

It is also important for the Japanese government to understand the problems faced by Japanese patients who go abroad to have heart transplants. These patients come from the national insurance system in Japan, and, in order to have surgery and aftercare, they have to arrange the whole process (with help from health professionals), including their travel arrangements (Dodo and Isoda, 2006). In other words, since these patients are not served by the Japanese medical system, the government has a responsibility to improve the Japanese medical system so it is able to protect Japanese heart transplant patients from any risks which may arise. Thus, it is important for the Japanese government to learn more about the experiences of these patients.

These cases have also demonstrated tensions between Japanese national culture and the global medical cultures, which do not share the same definitions of death. This is partly because people can travel and communicate easily with each other with the advent of globalisation. Also, with the rise of the internet, it has become easy to discern information about what is going on in other countries at the touch of a button. This helps to develop a shared understanding of what is going on in other countries. This has meant that people in Japan have started thinking about how things are done in Japan and how this is different to what occurs in the rest of the world. Heart transplantation is therefore a case study of some of the acute tensions brought about by the process of globalisation, with it being interesting to explore the experiences of people who are caught between a national culture that conflicts with the global medical culture.

Looking carefully at heart transplantation in Japan, the situation surrounding patients is filled with contradictory attitudes. Japanese people financially and mentally tend to support patients who needs heart transplants abroad. There is an underlying reason behind the limited chances for these patients to receive heart transplants in Japan. Due to the Japanese legal constitution, children had no chance to receive a heart transplant unless it is performed abroad. Although Japanese people find it possible to accept organs from brain dead donors abroad, they simultaneously feel reluctant and negative about accepting them. This ambivalence means that there are contradictory attitudes towards heart transplantation among Japanese people.

Fukushima (2012) explains that this contradictory attitude is an ethical issue which



needs to be resolved. He argues that people should consider organ transplant from a brain dead donor without distinguishing between whether the transplant occurs in Japan or abroad. Fukushima (2012) argues that such attitudes show that Japanese people consider only the situations of Japanese patients without being equally concerned about the situation of patients abroad. The contradictory attitude identified by Fukushima will be explored further in my thesis.

To summarise, in a global society, health professionals are able to establish networks between hospitals in Japan and hospitals abroad, allowing patients to use this network for medical treatments including heart transplantations. However, discussions of heart transplantation have tended to be conducted within a framework of the Japanese nation state. As a result, patients who travel abroad have been outside the Japanese medical system and outside government consideration. Yet in reality, global factors such as the Istanbul Declaration have had an impact upon the domestic Japanese medical system. Issues of heart transplantation in Japan therefore need to be examined in relation to a global context.

#### **2.1.4 Public opinion polls**

In this section I will review the results of opinion polls concerning organ transplantation in order to understand Japanese public attitudes. Public support is necessary to establish the legal and medical system for organ transplantation. In addition, because of the reliance of transplantation on voluntary organ donation, public acceptance is important. Therefore, it is important to understand the public's attitude towards organ transplantation in order to be able to plan for the future. In this regard, opinion poll surveys provide a significant insight into people's attitudes.

Before the passing of the Organ Transplant Law in 1997, the government had conducted opinion poll surveys twice, in 1987 and 1991 (Yomiuri Newspaper, 1987; Yomiuri Newspaper, 1991). The mass media have also conducted their own surveys from time to time. After the passing of the Organ Transplant Law, the Cabinet Office, the government of Japan, conducted opinion polls about organ transplantation every two years. These surveys have been conducted six times from 1998 to 2008. In addition, some surveys sampled, for example, only medical school students. In this section, I will focus on the surveys undertaken by the government and the Yomiuri newspaper. The Yomiuri newspaper has been chosen because this newspaper company has conducted significantly more opinion surveys on organ transplant-related issues than any other

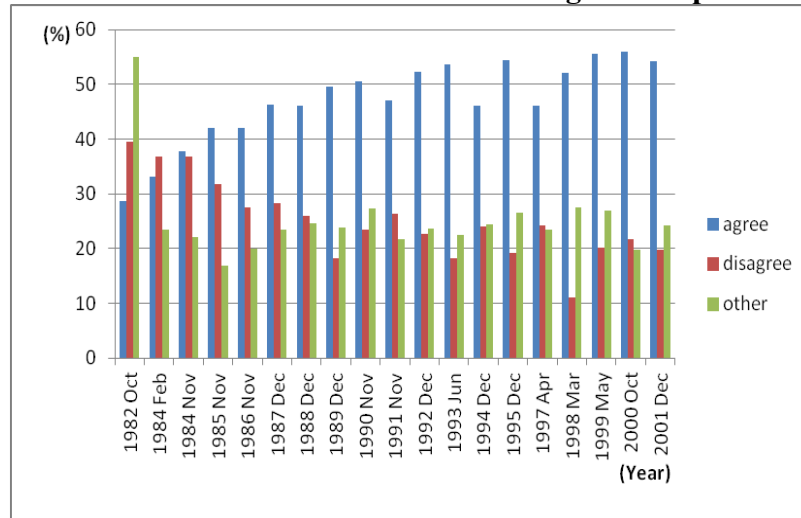
mass media organisation. This comparative way of reviewing the results of these surveys should identify any differences in survey results. I also will examine the reason behind those differences.

#### **2.1.4.1 Yomiuri Newspaper opinion polls**

First I will examine the surveys undertaken by the Yomiuri newspaper, which has conducted surveys on heart transplantation since 1982. Its sample size is always 3,000 people, selected at random. The method used was home visit interviews. Some of the same questions have been asked in most of the surveys; others, however, have been less constant. I focus here on results of a question about whether people agree with organ transplantation using organs from a brain-dead person. In relation to this question, I have also looked at a question about whether people agree with brain death as a criterion for death.

The question about brain death appeared in the surveys taken between 1982 and 2001. The question and possible answers are worded as follows: ‘I will ask you about brain death. Currently, in Japan, there are two types of idea: “if his brain is dead, then a person can be diagnosed as dead” and “even though his brain is dead, a person should not be diagnosed as dead until his heart completely stops beating.” If a person’s brain is dead, do you think it can be diagnosed as a person’s death, or it cannot be diagnosed as a person’s death?’ The answer choices are: (1) it can be diagnosed, (2) it may be possible to diagnose, (3) I am not sure, (4) it probably cannot be diagnosed, (5) it cannot be diagnosed, or (6) no answer. Of these, (1) and (2) reflect an attitude that accepts brain death as the diagnosis. On the contrary, (4) and (5) reflect an attitude that does not accept brain death. This question was not asked in the survey after 2001. Figure 6 summarises these results.

**Figure 6 Public attitude towards brain death as a diagnosis of person’s death**



(Sources: Yomiuri Newspaper, 1994; 1997; 1999; 2001)

As shown in Figure 6, more than fifty percent of respondents chose the answer ‘I am not sure’ or ‘no answer’ in the 1982 opinion poll survey. However, the percentage of respondents choosing the answer ‘I am not sure’ or ‘no answer’ decreased by the next survey in 1984. Instead of choosing these answers, people began to show their attitude towards brain death as either ‘agree’ or ‘disagree’. Since the survey in November 1984, people who choose ‘agree’ have become the majority in these surveys. In 1988, the percentage of people choosing ‘disagree’ and the percentage of people choosing ‘other’ were close to being equal. In 1989 and 1990, there were more people who chose the answer ‘other’ than people who chose ‘disagree’. This trend repeated itself in the four years from 1992 to 1995. Then, in 1998, after passing the Transplant Law in 1997, the percentage of people who chose ‘disagree’ dropped; the percentage of these people was less than half of the people who chose the answer ‘I am not sure’ or ‘no answer’.

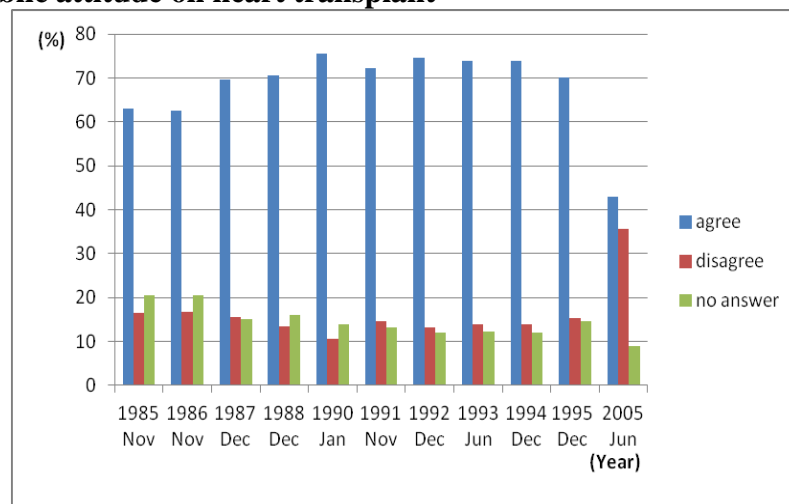
I assume that the result of the 1982 opinion poll survey reflects the situation of brain death not being a popular topic for the public, and the public did not have many opportunities to know about brain death. Therefore, this can be a reason why more than fifty percent of people chose ‘I am not sure’ or ‘no answer’.

As reviewed in the previous section, social situations surrounding organ transplantation and related issues including brain death have changed. For example, the Japanese government formed the Provisional Commission for the Study on Brain Death and Organ Transplantation from 1990 to 1992. The aim of this commission was to explore the issues of brain death, organ transplants and ethics. It was at that time the issue of the legalisation of transplantation began to be brought to Parliament. Along

with such governmental situations, the press began to focus on organ transplantation. As reviewed in the previous section, the press conveyed the news of heart transplantation intensively between 1990 and 1992, and the next peak was in 1997. I assume the public had more opportunities to listen to news of heart transplantation, regardless the degree of their interest in the matter. Reconsidering the result of this public opinion poll survey, the governmental moves and the trends of the press, I argue that the government and the press did not work enough in order to make people have a clear understanding towards brain death.

Next I will examine a question about heart transplantation. The question and answer are as follows: ‘Different from kidney transplants, heart and liver transplants need donations of organs from brain-dead people. Do you think that it is acceptable to perform heart transplants in Japan?’ The answer choices are: (1) okay to perform, (2) should not be performed, or (3) no answer. Figure 7 summarises the results.

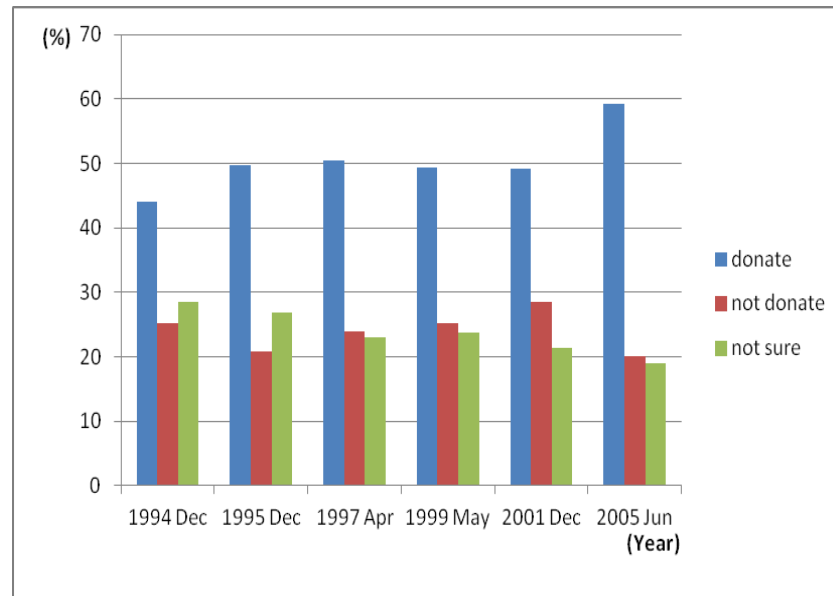
**Figure 7 Public attitude on heart transplant**



(Sources: Yomiuri Newspaper, 1994; 1997; 2005g)

Related to the above question, I looked at the responses regarding organ donation. The question is as follows: ‘If you were diagnosed as brain-dead, would you want to donate your heart and liver, or not?’ Figure 8 summarises the results.

**Figure 8 Public attitude towards heart organ donation**



(Sources: Yomiuri Newspaper, 1994; 1997; 1999c; 2001j; 2005g)

These results seem to indicate that more people have consistently had positive attitudes towards transplantation than have opposed it.

#### **2.1.4.2 Opinion poll surveys by the Japanese government**

So far, I have been reporting on surveys done by the Yomiuri Newspaper. The government's opinion poll surveys on brain death were initially conducted in 1987 (Cabinet Office, Government of Japan, 1987) and 1991 (Provisional Commission for the Study on Brain Death and Organ Transplantation, 1992). In parallel with the adoption of the Organ Transplant Law in 1997, the Japanese government began polling individuals regarding their opinions of brain death and organ transplantation. These surveys showed results that differed from the surveys taken by Yomiuri Newspaper.

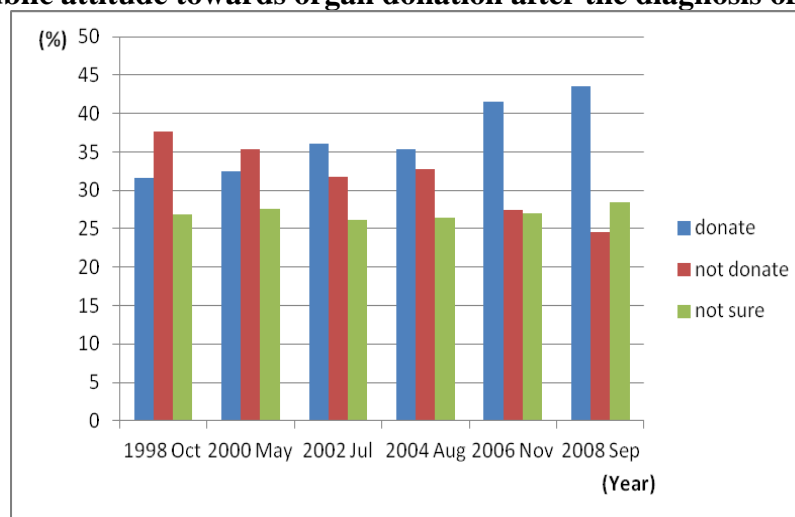
A survey on brain death was conducted in 1987 by the Japanese government as part of a larger survey concerning health services and medicine. This was the first time a question regarding brain death had been included in a public opinion survey. This government's first survey, in 1987, randomly sampled 5,000 people via home visit interviews. One of the questions that the survey asked was, 'Do you agree that brain death should be used to diagnose a person's death?' The results were as follows: (1) 36.7% answered that it depends on the person's wishes or that of their family, (2) 24.1% answered that they could not agree it was a death until the heart stopped beating, and (3)

23.7% answered that they could accept brain death as a means to diagnose a person's death. Then I looked at the answers to the question about organ donation after brain death: (1) 51.9% answered that the decision should depend on the patient's wishes or that of their family, (2) 17.8% answered that they would donate their organs, and (3) 13.5% answered that organs should not be donated by brain-dead people (Cabinet Office, Government of Japan, 1987).

The second survey, in 1991, was carried out by Provisional Commission for the Study on Brain Death and Organ Transplantation. This was an ad hoc commission set up by the Japanese government to research and consider issues surrounding brain death and organ transplantation. They worked on these issues for two years, between 1990 and 1992. For the survey in 1991, the government randomly chose 3,000 people. Similar to the previous survey described above, this one used home visit interviews and asked the same questions as the previous survey, regarding people's attitude towards brain death and organ donation. Regarding brain death: (1) 44.6% agreed with brain death being used to diagnose a person's death, (2) 24.5% disagreed and (3) 30.9% answered that they did not know. Regarding the question of organ donation: (1) 55.5% agreed with accepting organ donations from brain-dead people and (2) 13.5% opposed it (Provisional Commission for the Study on Brain Death and Organ Transplantation, 1992).

Since passing the Organ Transplant Law in 1997, the Japanese government has been carrying out surveys on organ transplantation. For each of the surveys, undertaken from 1998 to 2008, the government randomly chose 3,000 people. The method these surveys used was also home visit interviews. The sample size, the sampling method and the survey method are the same as previous opinion poll surveys by Yomiuri Newspaper and the previous survey by the government. Some questions were asked by all the surveys; however, others were not. Of those that were shared, I focus here on the responses to a question about whether or not people agree with accepting organ donations from a brain-dead person. In these surveys, conducted after the Organ Transplant Law's 1997 passing, they did not ask respondents about the validity of brain death as a definition of death. Rather, the surveys focused on the public's perception of, and behaviour relating to, organ transplantation. I have summarised the responses to the question, 'If you were diagnosed as brain-dead, would you want to donate your organs?' in Figure 9. The surveys by the mass media showed a more positive attitude among people towards organ transplants from brain-dead donors than the surveys conducted by government.

**Figure 9 Public attitude towards organ donation after the diagnosis of brain death**



(Source: Cabinet Office, Government of Japan, 2008)

According to the Japanese government survey in 1998 (Cabinet Office, Government of Japan, 2008), 31.6% wished to donate their organs after the diagnosis of brain death and 37.6% did not wish to do so. Negative attitudes towards organ donation were thus more popular than positive ones. The trend regarding organ donation has changed. In 2002 more people had a positive attitude than a negative attitude. In the latest survey in 2008, 43.5% were willing to donate and 24.5% were not. Looking at the differences among generations in this survey, the number of older people willing to donate their organs was lower, with people in their sixties onwards showing a negative attitude towards organ donation. Positive attitudes towards organ donation were higher for those in their twenties and thirties. People in their forties tended to answer ‘don’t know’. The differences between generations show the significance of considering which factors influence attitudes about organ donation (Cabinet Office, Government of Japan, 2008).

It is also important to look at the data about the dissemination of organ donor cards to understand people’s actions. The percentage of people who hold organ donor cards was less than 10% in 2008, which is still a low rate. Furthermore, less than 5% of the population signed the cards in 2008 (Cabinet Office, Government of Japan, 2008). If a person held the card without a signature, the card is not authorised to show that the person will donate his or her organs. The survey by the Cabinet Office, Government of Japan (2008) looked at the reasons why people did not hold an organ donation card. The two top reasons according to the research in 2008 were first that people did not know how to acquire a donor card and second that people had negative feelings towards organ

transplantation. In other words, one of the reasons was a physical problem of lack of information and another was a psychological objection to organ donation.

Regardless of the person's attitude towards organ donation, as I will explore, the main reason why people had not signed an organ donation card was that people were not able to make up their mind whether they would donate their organs or not. Results show that although organ transplantation has been discussed for a long time, nevertheless not enough information to assist individual decision making about organ donation may have been disseminated. This can be seen from the results of data which relates to receiving information about organ donation. More than 80% of the people answered that, even in 2008, they have not acquired enough information about organ transplants. These people answered that they wanted more information about organ transplantation including the security of this medical procedure, the costs and data about the actual number of patients (Cabinet Office, Government of Japan, 2008). This result suggests that organ transplantation is not widely perceived as a secure medical procedure. In addition, basic information about actual transplants to date is not widely known.

To sum up, looking at the desire for organ donation, the public attitude seems to have changed. The survey by the mass media showed a more positive attitude towards organ transplants from brain dead people among the people than surveys by the government. However, the actual number of people willing to donate has not changed very much, and public understanding of organ transplantation has not increased. The Organ Transplant Law has been passed and the medical system to perform transplantation has also been established, nevertheless, what actually happens to potential recipients is not understood by the public. This means, as Bagheri (2009) points out, that it is imperative that efforts are made to address the related sociocultural issues to increase public acceptance of organ transplants from brain dead donors.

How can we explain the co-existence of negative views about heart transplantation with the support given in practice by Japanese people to patients who seek funds to travel abroad for heart transplant procedures?

Looking at the situation surrounding heart transplantation, as we have seen, recipients and their families cannot necessarily avoid the complicated social situation in which organ transplantation is still a controversial issue in Japanese society. As we have seen (Figure 4), more than half of the Japanese public agrees with organ transplant from a brain-dead person; nevertheless, as we have already discussed in the previous section, the actual number of organ donations in Japan has not increased as expected since 1997 when the Transplant Law was passed. In Japanese society, patients who seek



fund-raising support to travel abroad are, in practice, financially supported by the public.

Here, the question raised is: ‘What is the factor that causes a negative viewpoint about heart transplantation?’ Parisi and Kats (1986) argue that an altruistic attitude and greater knowledge establish a positive attitude towards organ donation, while less knowledge and the fear of organ donation tend to influence a negative attitude towards organ donation. The authors also argue that religion and cultural factors impact both positive and negative attitudes towards organ donation. In particular, knowledge about organ donation is a significant factor, whether or not that knowledge is based on a greater or lesser degree of information; therefore, it is possible to have a hypothesis that medical practitioners should have a more positive attitude towards organ donation than the public, because physicians have more knowledge about organ transplantation than the public does.

In order to find the differences in attitudes towards organ transplantation and brain death among the public and medical practitioners, Uryuhara (2011) reviewed the results of public opinion surveys and surveys of medical practitioners by comparing surveys conducted in Japan and surveys conducted in the European countries.<sup>4</sup> She notes that, in terms of the public, the results between Japan and European countries were more or less the same. In contrast, there was an obvious difference between Japanese emergency physicians and emergency physicians in European countries. Emergency physicians have more opportunities to encounter patients who are diagnosed as being brain dead, than other medical practitioners. Japanese emergency physicians had negative attitudes towards organ transplantation and brain death compared to emergency physicians in European countries.

In summary, while Japanese health professionals hold a similar background in terms of medical knowledge of organ transplantation, Japanese health professionals, especially Japanese emergency physicians, show a different attitude towards organ transplantation and brain death than European health professionals. In this regard, I argue that the attitudes among these medical practitioners may be a factor that negatively impacts views about heart transplantation. In other words, in Japan, the

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<sup>4</sup>She referenced a study by Roels et al. (2010) and referred to the data that noted, for example, that 44.8% of Japanese emergency physicians are in favour of organ transplantation following brain death. The percentage of supportive attitudes among Japanese emergency physicians was almost the same as the percentage among the Japanese public. In Austria, 33% of the public are in favour of organ transplantation following brain death, while 82.9% of emergency physicians in Austria showed a supportive attitude towards organ transplantation following brain death. Similarly, in other European countries, about double the number of emergency physicians are supportive towards organ transplantation following brain death, as compared to the public (Uryuhara, 2012).

quantity (greater or lesser) of knowledge about organ transplantation and brain death has a limited impact on the attitude towards organ transplantation and brain death and, finally, the attitude toward heart transplantation. Applying the studies conducted by Parisi and Kats (1986), an altruistic attitude, religion and cultural factors are important elements that contribute to the attitude towards heart transplantation in Japan.

### **2.1.5 Conclusion**

In conventional medical treatment, the main actors are health professionals and patients. However, heart transplants require another entity: a dead person diagnosed as brain dead. This reality forces us to consider a new type of relationship between health professionals and patients. It has become clear that this new medical treatment, heart transplantation, needs a social consensus. In other words, heart transplantation is not only a medical issue, but also a social issue. The key actors in both the transplant programme and the discussion of transplantation in Japan have been transplant health professionals; in particular, those who have studied or worked abroad. In addition, the Japanese government, legal and life ethics experts, social scientists and the mass media have tried to reach a social consensus on heart transplants. A strong influence on this situation has come from outside Japan, in the form of the Istanbul Declaration. However, this discussion in Japan has remained contested for more than thirty years. This means that heart transplantation has become more of a social issue than a technical medical matter. In the meantime, as a result, many Japanese patients have been abroad to get a heart transplant. During this same period, public opinion surveys have shown that the Japanese people's opinion on heart transplantation has changed. However, their actual behaviour, as revealed in rates of organ donation, has changed little. The domestic discussion of heart transplantation has not proven able to change the actual conduct of these surgeries. What underlying reasons have kept the ambivalent attitude of the Japanese towards organ donation so dominant? In the next section I will review the discussion that there has been relating to this question.

## **2.2 Chronic illness, identity and body in relation to heart transplant recipients**

### **2.2.1 Introduction**

This thesis addresses the relations between a surgical procedure, the body and Japanese identity among heart transplant recipients. As already stated in the Introduction, the research questions of this thesis are: (1) How does the recipient experience and perceive the process of heart transplantation? (2) What is needed to plan for the future of heart transplantation in Japan? This chapter aims to review studies of chronic illnesses, body image, and gift exchange theories in order to develop an analytical framework to explore the experiences of heart transplant recipients at both micro and macro levels.

There are two key factors which influence the shaping of the identity of Japanese heart transplant recipients: undergoing the surgical procedure and the way in which the Japanese government labels the recipients. Heart transplant surgery is a recognised clinical procedure suitable for patients with certain forms of heart disease. This type of surgery exerts a number of changes on the recipient, including physical, physiological and psychological (Bialystok, 2006; Kaba, et al., 2005; Sanner, 2001; Sharp, 1995 and 2006). The body plays a role in the establishment of a person's identity (Turner, 1996), and changes to a body that arise from undergoing a heart transplant influence this identity.

In relation to the recipients' experiences, health care services provide support for the recipient until they have had their heart transplant. The Organ Transplant Law (1997) provides regulations to help the patients who need an organ transplant. After the procedure, the recipients are labelled as 'disabled' by the local government because of their relatively greater medical needs of post-heart transplantation (Bureau of Social Welfare and Public Health, Tokyo Metropolitan Government, 2009).<sup>5</sup> These social and health care services are organised on the assumption that the recipients are vulnerable because they need on-going medical and surgical treatment. The health care system labels them as 'heart transplant recipients', rather than considering them as individuals with identities separate from this label.

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<sup>5</sup> Detailed information regarding criteria for the certification of heart transplant recipients as disabled is publicised by each local government.

Therefore, although the physical bodily changes that result from the heart transplant are invisible (in being hidden under clothing), it may be possible for other people to identify heart transplant recipients as a result of the 'disability' label imposed on recipients by the Japanese government. With this in mind, this study explores how the identity of heart transplant recipients is established and how Japanese culture influences the experience of heart transplant recipients.

Being labelled as heart transplant recipients, both as individuals and as a distinct group, results in two problems in relation to recipients' identities. First, as a group, they are viewed according to prevailing stereotypes. Second, as individuals, the 'heart transplant recipient' label results in personal character traits being deemphasised. As reviewed in a previous section, the number of surviving heart-transplant recipients in Japan is small. Comparing Japan with other similarly developed health care systems reveals that it undertakes fewer heart transplantation procedures than other countries. Therefore, because these procedures are so infrequent, heart transplant recipients gather public attention, with the 'heart transplant recipient' label becoming prominent in Japanese society. As I will explore, this results in social marginalisation. However, the current social and health care system does not recognise these effects.

This marginalisation is brought about by the relationship between the distinguishing characteristics of heart transplantation as a treatment and how this is understood in Japan. Heart transplantation requires a third party: a recently dead donor. It is therefore impossible to perform a heart transplant based solely on a joint decision between a health professional and a patient. In Japan, this has resulted in an intense controversy, not only because of the obvious complication of having a third party involved in the transaction, but also because of cultural discomfort about the act of transplanting an organ from a dead body into a living body. One effect of this is to contribute to a disproportionate amount of attention being focused on a minority group: heart transplant recipients.

In Japan, as public opinion surveys show, many individuals do not accept brain death as an acceptable diagnosis for death. This has an impact on understandings of heart transplantation, causing it to be considered by many as 'unnatural.' For those who oppose heart transplantation, some have demonstrated negative feelings towards heart transplant recipients and their families. By contrast, many others recognise that there is great need to increase the supply of donor hearts, with these individuals often signing an organ donor card. Through fund-raising activities, some have also financially supported patients who need to have transplant surgery. There have also been numerous positive

expressions of support towards the recipients and their families (Cabinet Office, Government of Japan, 2008). As a result of the discussion of these competing arguments, the recipient becomes a subject of public attention, with negative attention tending to outweigh the positive.

Thus, heart transplant recipients tend to be socially marginalised. Therefore, it is necessary to understand their experiences at a micro level, i.e. to explore their individual experiences with their chronic condition. Along with this perspective, it is also necessary to understand them at a macro level, i.e. to explore the cultural impact of their chronic condition on their experiences in a social context. In what follows, I will review studies of chronic illnesses and identities (2.2.2). These studies provide several perspectives regarding the effects of the chronic condition caused by heart disease and heart transplant surgery on the recipients' identities and their everyday lives. These perspectives are important to examine the recipients' experiences at a micro level. Following the review, I will examine three key concepts of 'shame', 'body' and 'gift-giving' in the Japanese culture. I will also investigate the issues faced by Japanese heart transplant recipients, and relate them to the notion of shame in the Japanese culture (2.2.3), the Japanese notion of the body (2.2.4), and the concepts of reciprocal gift-exchange (2.2.5).

### **2.2.2 Chronic illness and identity**

Heart disease patients who are diagnosed as needing heart transplant surgery experience severe chronic conditions, as symptoms show that transplant surgery is the only way to recover from the disease. After surgery, transplant recipients need life-long medical treatment to control their immune systems. In this regard, recipients still experience chronic pain and distress with their bodily condition, and they are labelled as 'disabled' by the Japanese government (Bureau of Social Welfare and Public Health, Tokyo Metropolitan Government, 2009).<sup>6</sup> Heart transplant recipients experience a sort of chronic diseased condition for their entire lives. How does this chronic condition, caused by heart disease and heart transplant surgery, affect recipients' identities and their everyday lives?

Regarding the impact of chronic illness on patients' identities, Bury (1982) argues that the condition of developing a chronic illness disrupts patients' everyday lives. The

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<sup>6</sup> Detailed information regarding criteria for the certification of heart transplant recipients as disabled is publicised by each local government.

author interviewed patients diagnosed with rheumatoid arthritis (RA) in order to explore their experiences. He found that RA patients not only experience a painful and disabling condition, but also disruption in terms of their relationships with other people. Bury (1982) insists that the experiences caused by RA come to undermine the patients' self-concepts.

Charmaz (1983) argues that pain and suffering caused by chronic illness diminish the self-concept through the experience of losing one's self-image. She also argues that chronic illness raises issues of loss of productive function, financial crisis, family strain, stigma, and a restricted existence. As a result, individuals often experience a loss of self. These studies show that chronic diseased conditions physically limit patients' everyday lives and, at the same time, have an impact on individuals' self-concepts.

Does a chronic disease state always affect patients' identities? Pound et al. (1998) provide another insight to answer this question, which is the issue of the predictability of the disease. The authors point out that Bury (1982) focused on younger patients with RA. In the study by Pound et al. (1998), they researched how working-class elderly East Enders in London understand and experience stroke in their later lives. Pound and her colleagues found that these patients with stroke did not think that their disease disrupted their lives. Rather, these patients saw their strokes as a feature of ageing. This finding indicates that patients do not tend to consider predictable disease as a disruptive event in their lives.

Sanders et al. (2002) focused on older patients with osteoarthritis (OA). The study provides a different perspective from that of Pound et al. (1998). On one hand, these patients consider OA a disease that is inevitable in older age. At the same time, these patients narrated how OA disrupted their everyday lives. As it were, OA is a biographically anticipated disease that physically disrupts everyday lives among the patients.

Both studies argue that the chronic conditions caused by diseases such as RA and OA are predictable. However, whether the disease disrupts the individual's everyday life depends on the individual's perception and understanding of disease.

In addition to these perspectives, in terms of the impact of the predictability of disease on the patients' attitudes, Carricaburu and Pierret (1995) provide another insight through a study of HIV-positive men. In their study, they explored two different groups of patients: homosexual men and haemophiliac men. Homosexual men were infected through gay sex, and haemophiliac men were infected through medical treatment. Regardless of the reason for these patients' infections, Carricaburu and Pierret (1995)

found that these two groups of people describe and depict their experiences with HIV differently from each other. The more important finding is that these HIV positive men tend to reinterpret their individual and collective experiences in the past, and then they reconstruct their reinterpreted experiences by connecting to the current situation. Carricaburu and Pierret (1995) see the process of reinterpretation and reconstruction as a process that reinforces their identity as patients with HIV, in addition to the fact that these patients' everyday lives are disrupted by HIV infection.

From a perspective in which illness and diseased condition disrupt patients' everyday lives, Faircloth et al. (2004) point out that 'illness as a discursive resource can be used in a variety ways, resulting in myriad meanings of the illness itself depending upon the respondent's everyday life' (256). They suggest a notion of 'biographical flow'. For example, they explain that an illness such as stroke can be connected to socially contingent events in many ways when patients construct their biographies. The authors argue that this constructing process is not limited by time and space; i.e., the process flows broadly across time and space. Many factors surrounding these patients affect their biographies.

These studies are mainly concerned with chronic illness's initial impact on patients' lives. However, they are less concerned with the way in which patients change the narration of their chronic condition along with the passing of time.

Hyden (1997) insists on the significance of looking at situational factors when patients narrate their experiences. The disease state may change, and the situational condition for the patient to talk about his/her condition may also change. Along with these changes, the patient reconstructs his/her narratives in a new discourse that reflects the changing diseased condition and situational factors.

In terms of a perspective on situational factors, Clark and Mishler (1992) point out that patient-physician communication impacts patients' narratives. They found that authoritative attitudes on the part of physicians led them to talk with the patient about the biomedical aspects of the disease, while the patients tended not to narrate their experiences as a story with coherence. On the contrary, if physicians maintained passive attitudes, patients tended to talk about their experiences with the disease as a story with coherence.

It is Lawton et al. (2007) who explore in detail how situational factors impact on patients' biographies and self-concepts. They explored narratives about diabetes in a comparison between Pakistani and Indian migrants in Britain and white British patients. Lawton et al. (2007) found that Pakistani and Indian patients narrated their diabetes

experiences as a result of an accumulation of external circumstances in society such as socio-economic conditions. By contrast, white British patients tended to perceive their diabetes as ‘a sign of individual failure’ (902). The differences found in this study show that individuals’ chronic disease state is influenced by rhetoric and social value in society. Therefore, cultural factors are also a key perspective to explore patients’ narratives in terms of their experiences and self-concepts.

In sum, studies of the influence of chronic disease on self-concept raise the following issues: (1) whether the chronic condition is predictable for the patient; (2) whether the patient considers the chronic condition as a disruption in their lives; (3) the way in which the chronic condition impacts the self-concept of the patient along the passage of time; and (4) how situational factors such as cultural factors impact on the patient’s self-concept.

In the case of heart disease patients who are scheduled for heart transplant operations, it is important to examine their condition both before and after receiving the transplant surgery; i.e., in terms of the decision-making process and post-operational experiences respectively. Patients will find their pre-operational experiences, as patients would not have predicted they would have such severe heart disease. Regarding their post-operative experiences, patients learn how their lives will be altered by their receiving the transplant surgery. In this regard, the experiences of heart transplant recipients consist of both unpredictable and predictable conditions.

In addition, the transplant recipient needs to maintain immunosuppressant drugs for the rest of their lives; i.e., this is a chronic condition supported by lifelong continuation of medication. Therefore, when examining the influence of the chronic condition on transplant recipients, it becomes important to consider the impact of contingent events in the recipient’s life, along with the passage of time and different places, such as situational settings.

In order to develop a framework to examine such impacts on Japanese heart transplant recipients, I will focus on three key concepts in terms of situational/cultural factors: the concept of ‘shame’ in Japanese culture, the notion of the body, and the concept of gift-giving. I will review all these perspectives in the following sections; in the next section, I will begin to shed light on the concept of ‘shame’. As Benedict (1946) suggests, ‘shame’ is an important aspect of culture. She explains the Japanese culture in terms of the notion of ‘shame’. By reviewing this conventional notion, I will explore the role of the cultural factor ‘shame’ in a heart transplant recipient who accepts new medical technology, i.e. heart transplant surgery.



### 2.2.3 'Shame' in Japanese culture

Benedict (1946) suggested that there are two types of culture, one influenced by the idea of 'guilt', the other by 'shame'. For Benedict, that shame is seen as a particularly important feature of Japanese culture. She explains, 'The primacy of shame in Japanese life means ... that any man watches the judgement of the public upon his deeds' (Benedict, 1946: 224). In a society where there is a shame culture, people are very sensitive about how other people think and respond to them, with Benedict defining shame as a response to criticism by others (Benedict, 1946). It is important to clarify the meaning of shame. What is shame? In what situations do people feel shame? How do they react to others after experiencing shame? Answers to these questions will vary according to the respective culture (Lu, 2008).

Benedict's classification has been criticised for its simplicity. Yamada (2008), for example, refers to Sakuta's (1967) discussion. Sakuta (1967) argues that 'shame' needs to be examined from two different perspectives. One perspective relates shame to others' responses, i.e. the gaze of others and their evaluation of an individual's behaviour results in shame. But Sakuta argues that shame is also a response to one's own internal voice, i.e. related to an individual's values and an evaluation of his or her own behaviours, which in turn results in a feeling of shame. Benedict (1946) considered only the former point (Yamada, 2008). However, despite this criticism, I nonetheless assert that it is worthwhile to examine the character of shame in Japanese culture, but without simply accepting Benedict's definition.

For, in the case of heart transplantation, a culturally specific understanding of shame does seem to influence the experiences of Japanese heart transplant recipients. There are two factors to be considered here. First, heart transplants always require a donor. This donor is a third party, whereas conventional medicine is fundamentally conducted between a health professional and a patient. In this regard, the heart transplant is necessarily influenced by the decision of this third party as well as others to whom the donor has an association. A heart transplant can only be performed under the condition that the donor agreed to donate his or her organ before death, that his or her family agreed to donate the organ, and that the heart is in a transplantable state. Second, the issue of heart transplantation has been discussed in Japan since the first procedure in 1968. The medical and social systems have now been established to enable heart transplants to be performed in Japan, and public attitudes in Japan have not wholly been negative. However, one problem is that heart transplants are not a popular medical

treatment (as is reflected in the limited number of heart recipients). In other words, heart transplants attract attention and are therefore still controversial operations in Japan.

For these two reasons, it is important to explore how Japanese people perceive shame, and how the notion of shame influences the experiences of heart transplant recipients. In particular, this study focuses on how transplant recipients perceive people's responses to them and how they disclose information about themselves and their heart transplant to others. In addition to these perspectives, it is also important to explore how heart transplant recipients themselves perceive shame and how the notion of shame influences their experiences. By so doing, the notion of shame in Japanese culture will become clear in relation to recipients' own experiences.

Benedict (1964) points out another important aspect of Japanese character. She argues that what is understood as 'self-sacrifice' in the United States, for example, is considered reciprocal exchange in Japanese culture (Benedict, 1964). In Japan a father might raise his son in the early part of his life, with the expectation that the son would look after him later in his life. Thus, the father does not consider that he is sacrificing something in raising his son. The important point is that this is a reciprocal exchange between them. This sort of reciprocal exchange in everyday Japanese life can be considered similar to a business contract (*ibid*). This 'contract' works on the presumption that a person returns the same quantity or quality or 'value' of things to the 'giver'. Benedict (1964) explains this as follows:

'The sanction behind services to others in Japan is of course reciprocity, both in kind and in hierarchal exchange of complementary responsibilities' (Benedict, 1964: 232).

If we accept this argument, a person feels shame when he or she cannot return something to the person who gave to him or her. Unable to carry out the duty of reciprocity, the person feels a sense of dishonour and therefore shame.

Regarding the heart transplant, the recipient cannot return an equivalent thing, a heart organ, to the donor. Firstly, as the donor has already passed away, the recipient does not have a person to whom he or she can offer reciprocal exchange. Secondly, even if it were possible, the recipient could not return something of an equivalent value (to the donor's heart). Thirdly, the recipient interferes with the reciprocal exchange relation between the donor and the donor's family. Procurement of a heart from the donor may cause discomfort among the donor's family during the funeral process. This is because the funeral process is an important part of the appropriate completion of a reciprocal

exchange relation between the living and the deceased. In the next section, I will examine the way in which the feeling of shame, in relation to heart transplant, is reflected in ‘the notion of the body’ and ‘reciprocal gift exchange’ respectively.

## **2.2.4 The notion of the body and ‘shame’ in Japanese culture**

### **2.2.4.1 Notion of the body in Japan in discussions and studies of organ transplantation**

From the 1980s onwards, anthropologists (Lock and Honde, 1990; Namihira, 1990; Ohnuki-Tierney, et al., 1994) and philosophers (Umehara, 1992; Takatsuki, 1999) began to study organ transplantation, showing how significant cultural aspects of organ transplantation are in Japan. In particular, they have focused on how conventional understandings of the body amongst Japanese people become obstacles for the promotion of organ transplantation.

The philosopher Umehara (1992), for example, relates this to the concept of Cartesian dualistic thinking, which sees the body as separate from the soul and the mind. He argues that that there in Japan there exists a non-Cartesian, holistic understanding of the body. In Japanese culture, he argues, the human body is thought of as a totality, not as the integration of fragmented organs and body parts. He concludes that organ transplants, taking from one human body and placing into another, were therefore seen as part of ‘unnatural’ medicine. The Japanese, not liking ‘unnatural’ actions being performed on the body, thus feel a strong resistance to organ transplantation.

From an anthropological perspective, Namihira (1988) examined understandings of, and attitudes towards, the dead body among the Japanese, focusing on families who were bereaved as a result of a devastating airplane crash in 1985. She concluded that the dead body was not regarded in Japan as merely inanimate material and that this could be explained culturally. The Japanese perceive death as a process from life to death rather than a single event. It is a process that needs to be witnessed by the close friends and family of the dying individual – as many as possible. The condition of the dead body is understood as having an impact on not only the life of the soul after death, but also the life of the bereaved family. Therefore, it is thought that the dead body should not be damaged in any way. Organ procurement for transplant inevitably results in damage to the dead body. Namihira concluded that, for this reason, organ transplantation was difficult for Japanese people to accept.

However, as Deguchi (2001) points out, neither Umehara's nor Namihira's studies examine attitudes towards the dead body and death rituals in other cultures, despite the fact that these have an important relationship to culture. In this respect their studies are of limited value in explaining the peculiarity of the Japanese attitude.

The most notable point in these discussions concerns whether Japanese understandings of the human body are dualistic (body and mind are separate) or monistic (body and mind are part of a whole). However, this debate does not reflect on real people's attitudes in order to clarify this. As the Japanese anatomist Yourou (1996) has pointed out, conceptions of the body in Japan have changed historically, as well as varying according to an individual's social situation. Thus, contemporary attitudes cannot simply be assumed to be similar to those that applied in past historical moments, nor are they likely to be universally held. Therefore, in addition to a historical understanding, it is important to explore what kind of attitudes people in contemporary society have towards the body. In this case, it is important to consider people's attitudes in the period after the Second World War. This is because first, heart transplants were available to people born after the war. Second, such medical treatments, influenced by other countries' regulations, were developed after the war. Thus, the medical and social systems relating to heart transplants were also developed after the war. In what follows, I will proceed to examine people's attitudes towards both the dead and the living body.

#### **2.2.4.2 The dead body and ritual process**

Twigg argues that 'Corpses are never simply treated as garbage: all cultures have taboos and rituals concerning their management' (Twigg, 2006: 83). This becomes obvious at the time of the funeral (Gennep, 1960; Hertz, 1960; Metcalf and Huntington, 1991). The existing studies by Gennep (1960), Hertz (1960) and Metcalf and Huntington (1991) point out that the rituals that surround death are a way of conveying the symbolic meanings associated with both the soul and the dead body, although the particular processes are culturally varied. Different from medical perspectives which focus on the physical rather than the social meanings attached to the body, funeral rituals reveals the social meaning of the dead body. We may thus understand people's attitudes towards the dead body by exploring these processes.

Nudeshima (1991) examined how dead bodies were treated by Japanese people in a study of a series of ritualistic funeral ceremonies. He pays attention to those who are engaged in the process, and the relationship that exists between these people and the

dead body. His findings show that, first, funerals have historically been conducted within the community to which the person belonged. The community mostly overlaps with the location where the person lives, often meaning their village. Second, the funeral serves to give a dead person a new type of identity *as* a dead person. Third, the rituals allow people in the community to recognise the death of the individual. Further, whatever religion people believe in, it is considered important to complete the funeral ritual process appropriately. Otherwise, there is a concern that the dead person might cause misfortune to their family, to the community where the person belonged to, or the place where the person may have accidentally died. This idea is still shared by people in Japan<sup>7</sup>, despite the fact that both the funeral ceremony has varied historically and the form of burial has changed.

How do attitudes towards the dead body, revealed through the funeral process, influence donations of bodies to medicine? Since it was legalised in 1983, donating a body to medicine has been unpopular in Japan, although the number of people opting to donate their body to medicine has increased. Hoshino (1991), who explores the reasons why many people do not donate their bodies and those of their family to medicine, has identified six reasons. He suggests that when people imagine donating the dead body to medicine, (1) they feel compassion for the dead body, (2) they worry that the dignity of the person after death may be damaged, (3) they feel that the dead body may experience loneliness, (4) people feel uncomfortable imagining body parts preserved in formalin after death, (5), there is a concern that the pride of the dead person is damaged by medical use and that the dead person may feel shame (an individual's shame becomes shame for his or her whole family), (6) people worry about how other people might perceive their decision to donate a member of their families' dead body to medicine, as such a donation is unpopular in Japan.

Reasons (1) to (4) reflect people's feelings, because they sympathise with the dead body/mind after death. That is to say, these feelings reflect what people think about a person's identity after death (the idea of the dead person's identity is discussed in the section pertaining to the funeral process). Reasons (5) and (6) reflect the notion of shame in Japanese culture. To use the dead body for medicine and to treat the dead body

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<sup>7</sup> A Japanese mystery novel, *Yatsuhakamura* (Yokomizo, 1971), depicts how a dead person can cause a curse if their dead body does not receive appropriate funeral rituals. In the novel, a group of people are killed in a small village; later, 'evil' things happen in that village. The people in the village think that these events are curses imposed by the people who had been killed, so the survivors perform funeral rituals to placate the evil souls. Following that ritual, peace returns to the village. This novel inspired films, television dramas and cartoons, with the story being very popular in Japan.

in unconventional ways might bring shame on the family. Others' views are important when an individual is making a decision as to how the dead body should be treated. Therefore, choosing to treat the dead body in an unconventional way may result in a stigma being attached to the person. To explore this further, while bodies generally do not receive conscious attention in everyday life, dead bodies make people reflect on the meaning of their own bodies. In the next section, I will explore the attitude towards the living body.

#### **2.2.4.3 Attitude towards the live body**

A person has an awareness of the body through everyday senses such as seeing and hearing. These are individual and internal physical experiences impacting on one's perception or understanding of the body. When considering the body in a wider context rather than through physical experiences, we recognise that the body is connected to cultural and historical factors. These are two different perspectives through which to consider the body. One is based on an individual's perception, while the other places an emphasis on cultural and historical factors. The latter, attached to cultural and historical meanings, is fluid. In addition, the two are not always contiguous. As a result of this gap, a person may experience an internal conflict between the individual experience of his or her body and social perceptions of it. In order to attempt to reduce this conflict, a person reconstructs the notion of his or her body.

Focusing on the fluid character of the body in Japan in order to explore its designation after the Second World War, one of the main factors to consider is Japan's economic development. Immediately after the war, in Japan, it was important that the body worked. Therefore, bodies which could be relied on to be hardworking were very important. In parallel with the improving Japanese economy, the body has also become important in relation to consumption. In Japanese society, people are regularly encouraged to enjoy sports, and the number of people taking part in various sports in their leisure time has increased (Kondou, 1999). As a result, people pay more attention to their own bodies, with a particular emphasis on the ideal body shape. Kondou (1999) explains that, because of environmental problems and the development of new medical technologies, there is a fear of damaging the body and mind. Therefore, people's attention towards the body has increased.

These attitudes mean that the ideal image of the body has constantly been reproduced. Why have people absorbed these images? It is argued that, given people's

fear about their body and mind being damaged, people have accepted this ideal. Thus, not having an ideal body and the denial of body image are understood as potentially related to a body and mind that are damaged.

### **2.2.5 Gift-exchange in relation to heart transplantation in Japan**

The 'Gift-exchange' theory proposed by Mauss (1954) has frequently been focused in the discussion of organ transplantation. Mauss (1954) researched gift exchange in tribal societies, that is, gift culture in non-market-oriented societies. His study was the first study which systematically focused on the custom of gift-exchange. He provides two important insights to understand the issue of gift exchange. One involves the role of the gift itself; another is how the process of gift exchange holds the meaning between two entities.

The first relevant point to note here is that, in the societies Mauss (1954) studied, people expected to share fortune and redistribute wealth through the exchange of gifts. This meant that a 'gift' was not merely an object. The giver attached meaning, related, for instance, to the giver's nature and 'spirit', to a 'gift'; therefore, the gift bore important meaning for the receiver. The second thing to note is that the gift holds a social meaning intended to help maintain social order within the society in which it is given. As a 'gift' is believed to hold the attributes described above, it works to govern peoples' relationships.

Mauss (1954) outlines three major concepts in the exchange process he studied: the obligation to give, the obligation to receive and the obligation to repay. The act of giving a gift may bring a sense of indebtedness to the receiver. The receiver is then obliged to reciprocate to the giver (Mauss, 1954). This is a reciprocal gift-exchange system. As pointed out above, the gift reflects receiver's spirit. If the giver did not send the gift or the receiver rejected to receive the gift, the spirit attached to the gift is destroyed. To refuse a gift was unusual, because to refuse meant that one was clearly fearful about being unable to repay the giver. This fear was considered a loss of dignity and power in these societies. This social pressure attached to the custom of gift-exchange exposed people and helped establish and reinforce social relations.

As Mauss (1954) focuses on a specific culture of gift-exchange, his study does not consider gift-exchange mediated by a market. Nevertheless, the gift theory suggested by Mauss can be applied to an examination of organ transplantation and used as a framework to understand it in the context of gift culture in contemporary

market-oriented society. It is important to consider to what extent Mauss's gift theory is applicable to the case of organ transplantation from cadaveric donors. Sque and Payne (1994) maintain that organ transplantation has similar characteristics to forms of gift giving and receiving. They argue that organ transplantation consists of several norms which structure the feelings and behaviours of donors as well as recipients. In this regard, organ transplantation is the same as other forms of gift exchange. Sque and Payne (1994) also point out that it is important to respond to expectations of the constant obligation to give for donors, as well as important to receive and repay for recipients. 'Failure to live up to any of these expectations produces disequilibrium and social strain that affects the giver, the recipient and those closely associated with them' (Sque and Payne, 1994: 47).

So far, I have reviewed arguments of gift theory by Mauss, and I also reviewed how his gift theory is applicable to an examination of the social dynamics of organ transplantation. As of giving, receiving and repayment, in particular, the matter of repayment in the process of organ transplantation has become an issue for both donor and recipient. It was Fox and Swazey (1974) who first discussed this matter.

Fox and Swazey (1974) studied how innovation in biomedicine influenced American society. They were requested to do so by Dr Mesthene, then director of the Program on Technology and Society at Harvard University. Through this study, Fox and Swazey (1974) point out two major themes, those of uncertainty and gift exchange, by exploring the issues around dialysis and transplantation. In order to explore these themes, Fox and Swazey agreed to focus on new and nascent biomedical innovation by examining cases of organ transplantation and chronic haemodialysis. Fox and Swazey (1974) regard transplantation and dialysis as constituting a paradigmatic case that exemplifies the attributes and processes of therapeutic innovation, presenting virtually the whole range of medical and social phenomena that characteristically accompany biomedical research and its clinical application. In addition, they point out that transplantation and dialysis have themselves generated certain new phenomena that may have an impact on future medical developments.

In their literature survey they noted that medical literature tends to focus on psychiatric strains and characteristic defence mechanisms in terms of transplantation, while mass media tends to more pay attention to the heroic, sacrificial and scarce nature of the gifts in relation to organ transplantation.

Through interviews and participant observation in this study, Fox and Swazey (1974) noticed that organ transplantation and dialysis share similar characteristics with



the gift-exchange theory introduced by Mauss (1954). They found that both donors and recipients begin to feel transcendent obligation to each other in the process of the transplantation. More significantly, they found that ‘recipients tend to exhibit what psychiatrists have termed “ambivalent dependency” in the following form: “It’s a debt that can’t be repaid.”’ (Fox and Swazey, 1974: 26). A transplanted organ is, as it were, a gift which the recipient cannot reciprocate.

### **2.2.5.1 Heavy repayment**

How has the issue of the repayment for recipients been resolved? Sque and Payne (1994) argue that many organ transplant recipients feel psychological obligations which cause them to want to reciprocate the gift from a donor. However, the gift of an organ cannot actually be paid for in terms of financial reimbursement in developed countries. Fox and Swazey (2002) explain this phenomenon as the ‘tyranny of the gift’.

There are, however, some studies which insist upon the possibility of the repayment of the ‘gift’. Gill and Lowes (2008) review the discussion on repayment in terms of psychological perspectives. They review a study by Siminoff and Chillag (1999) which focuses on letters of thanks from recipients to their donor families. Many recipients anonymously send a letter to show their appreciation to donors and the donors’ families, a process normally mediated by health professionals. In addition to this, Gill and Lowes (2008) also review studies which examined the impact of these anonymous letters on donor families. They report that ‘donor families greatly value such gestures, as it often helps them to come to terms with their loss (Gill and Lowes, 2008: 1609).

Gill and Lowes (2008) explored the possibilities for resolving the issue of ‘repayment’ in organ transplantation. However, their study provides evidence that, ‘given the nature of the “gift”, some recipients may find this expectation potentially overwhelming, particularly as failure to “respect” the gift may have a detrimental effect on the recipient’s health and also affect the donor’s feelings’ (Gill and Lowes, 2008: 1614). They point to psychosocial problems that recipients may experience.

The issue of ‘repayment’ initially explored by Fox and Swazey (1974) thus seems still to be a problem which needs to be addressed. In addition, it is important to examine whether there are any differences on this issue between live organ transplantation and cadaveric organ transplantation. Recipients are not able to repay donors who are dead,

while they may think about their relationship with their donors after other kinds of transplant surgery, such as kidney transplantation.

### **2.2.5.2 Live organ transplantation**

Fox and Swazey (2002) examine the possibility of what sort of counter gift would be adequate if recipients attempted to repay their donors. As stated earlier, they found that some recipients tend to feel indebted to donors. In addition, recipients may feel guilt, disequilibrium, and have problematic relationships with their donors in their everyday lives post-transplant.

However, some other studies argue that relationships between donors and recipients do not always become a problem for either party post-transplant (Simmons et al, 1977; 1987). These authors point out that there are recipients who maintain the same relationship with their donors, and some have better relationships with donors (Simmons et al, 1977; 1987; Buroughs et al., 2003).

Fox and Swazey (2002) show that recipients attempt to express gratitude to donors, which is a means for recipients to deal with their sense of obligation; this is a form of reciprocation which is not 'material'. They argue that this is important in live transplantation in order to respond to donors' expectations. Even though donors do not expect the recipients to express their gratitude, this kind of attitude on the part of recipients seems to be important to donors. If recipients do not show a humble and grateful attitude, donors may feel angry or used (Simmons et al., 1977; 1987).

Nevertheless, it is still too early to conclude how important it is that recipients express their gratitude to donors. Findings from a study by Gill and Lowes (2008) show that 'showing some degree of appreciation is not the only, nor the most significant, form of non-material reciprocation'. The gift of an organ is never reciprocated in an economic sense; however, the 'joy of giving' is the most important non-material reciprocation for donors, and makes donors recognise that their donation was worthwhile.

Gill and Lowes (2008) also point out that humble attitudes on the part of both donors and recipients may best serve their relationship, i.e. recipients minimise their gratitude when expressing their feeling to donors, and donors also refer to the organs they have donated in a humble manner. Gill and Lowes (2008) insist that these attitudes may be similar to those found in contemporary gift culture. In this regard, this type of gift relation is slightly different from the one outlined by Mauss (1954).

### **2.2.5.3 Cadaveric organ transplantation**

In cadaveric organ transplantation, as the donors are dead, recipients cannot personally repay them even if they want to do so; for example, they cannot express their gratitude to donors. If a recipient wishes to express gratitude to a donor, he or she can do so only to the donor's family. This is done, for example, through writing a letter of thanks to the donor family. Because the recipient cannot establish any relationship with his/her donor, Gill and Lowes (2008) insist that 'cadaveric transplants cannot constitute a "true Maussian gift"' (Gill and Lowes, 2008: 1609).

Nevertheless, I argue that the gift theory developed by Mauss (1954) is still applicable to cadaveric organ transplantation. Mauss (1954) focused on the meaning attached to a gift, rather than on the gift as an object. He also pointed out the relationship between the giver and receiver is mediated by the gift. Considering these findings, I argue that his gift theory is applicable to cadaveric organ transplantation even if certain circumstances need to be altered to apply to cadaveric organ transplantation.

In cadaveric organ transplantation, there are more entities than just giver and receiver involved in the process. A donor shows his/her will in the matter by signing a donor card. In fact, in order to donate organs in Japan, a donor must also have his or her family's consent when the actual opportunity for transplantation arises; families must give consent before organs can be taken from a donor's body. In this regard, the situation in which a recipient receives an organ transplant involves both the donor and the donor family's will. Furthermore, anonymity is also a fundamental principle between a recipient, and a donor and his/her donor family. In addition, the process of organ transplantation is always mediated by medical practitioners. These medical practitioners play the role of gatekeeper, in this case one who arranges for the organ transplant surgery.

To summarise, in cadaveric organ transplantation, a gift giver (here, the organ donor) is dead by the time the gift is given. The donor's family is a key entity in ensuring that the gift is sent in response to the donor's will. There is therefore a gatekeeping system for sending and receiving the gift. Additionally, in terms of 'repayment', such as a letter of thanks sent to show the recipient's gratitude, this gatekeeper is often also a mediator who oversees the process.

As discussed, the issue of a gift which the recipient cannot repay has not been resolved yet. Nevertheless, the globalisation of transplant medicine has progressed, and the issue of reciprocation has become more complicated for the recipient. Therefore, a

new framework is needed to examine organ transplantation in terms of reciprocity by applying a gift theory. Looking at the situation surrounding organ transplant recipients, there are three classes of recipient according to place of the operation and the financial background to the case. A recipient may receive a transplant (1) in his/her own country or (2) in other country funded by him/herself or (3) in other country by receiving fundraising support from the public.

It can be considered that the entities engaged in the process of organ transplantation are altered according to whether the recipient falls into one of the three groups above. In particular, attitudes towards repayment of the gift will be different for each group. This can be summarised as follows if we are to explore the relationship between recipients and other entities in terms of gift theory.

In the process of heart transplantation, in Japan, all entities who engage in the process are generally Japanese. The donor is an anonymous Japanese person. In cases of recipients who undergo self-funded heart transplant surgery abroad, the recipients receive medical treatment both in Japan and abroad, i.e. the recipients commute between hospital settings in two countries. The donor is an anonymous non-Japanese person. In these two cases, the recipients consider repaying the donor by building a gift-exchange relationship, although they are respectively in different situational and cultural settings. In contrast, the recipients who receive a heart transplant abroad usually receive fund-raising support from the public and consider repaying both the donor and the public by building a gift-relationship with them. In summary, the entities considered for the repayment may depend on the situational and cultural settings surrounding the recipients.

### **2.2.6 Conclusion**

In conclusion, situational and cultural factors are keys to understanding the chronic condition of heart transplant recipients. I have pointed out the three key concepts of this study: 'shame', 'body' and 'gift-exchange'. The studies of the notion of shame provides a perspective on how the Japanese people perceive their relationship with others in everyday life, and how others' gaze is given due importance. The discussion of the notion of body shows that an individual's body image is constantly reconstructed, influenced by the individual's image of the ideal body, according to which they adapt their own physical body. The discussion of the concept of gift-exchange elucidates the relationship between a recipient and a donor in terms of organ transplantation. However,

these studies have not solved the most important issue: how does a recipient repay a donor for their enormous gift? Therefore, this study will analyse the recipients' experiences in terms of their chronic condition and consider their attitude towards the gaze of other individuals. I will, then, explore their experiences with respect to the reconstruction of their bodily image. Based on these, I will explore the recipients' experiences in terms of gift-exchange, and I will finally investigate the manner in which the recipients manage their emotions in relation to the repayment.

## **Chapter 3 Methods and methodologies**

This chapter provides an overview of the research design. In the previous chapter, I reviewed the literature on heart transplantation in Japan and concepts related to Japanese heart transplant recipients' experiences. Key concepts were 'shame', 'body' and 'gift-giving' in the Japanese culture. These concepts are interrelated. In reviewing the literature, I found that two important perspectives were missing in existing studies of transplant recipients' experiences. One is a perspective that views their experiences in both a global context and in a local context. Another is to focus on heart transplant recipients; experiences of other types of organ transplant recipients, such as kidney transplants, have been studied more extensively. Thinking about the inadequacies of existing studies allows me to develop a different way to understand the relationship between a surgical procedure, the body and Japanese identity using qualitative methodologies. The methods used to gather and analyse qualitative data that will develop the conceptual framework explained in Chapter 2 are explained in this chapter which consists of three main sections: data collection, data analysis and validity of this study.

### **3.1 Methods for data collection**

In order to collect data about the experiences of heart transplant recipients, I decided to interview the recipients using semi-structured interview techniques. In addition, I interviewed a number of different people who were involved in heart transplants such as transplant surgeons, heart transplant recipients' families, donor families, patient support group organisers and family members whose families passed away before having a heart transplant operation. Other types of organ transplant recipients and some of their family members were also interviewed in this study for comparative purposes, but in this study, the main focus is on heart transplant recipients. Their experiences as a heart disease patient and also as a heart transplant recipient are influenced by plural factors in their everyday life, which consists of the decision making process to receive the transplant operation and their lives after receiving the transplant. In this whole process, needless to say, they cannot ignore their relationship with medical professionals. Rather, it can be assumed that the recipients would establish and manage the relationship with their medical professionals in terms of the medical need for immunosuppressant drugs

following their heart transplant operation. In this regard, in order to understand the experiences of heart transplant recipients, it is important to listen to their voices, which are subjective voices, and also to listen to the voices of their medical professionals, because they add different views to the recipients' perspectives. By examining both the voices of the recipients themselves and key people around them, I argue that it would be possible to understand the recipients' experiences in a wider context of their everyday life. This will be a strength in this study.

On the other hand, it was not always possible to interview every medical practitioner who had direct contact with the recipients that I interviewed in this study. This may be a weakness of the sampling in this study. Considering the difficulties I could have faced when asking the donor recipients to introduce me to their medical practitioners for this research, as their relationship will have been established for the purpose of improving the recipients' health condition rather than for partaking in any study, I individually contacted the key medical practitioners instead.

Ethical approval for the study was initially granted in 2008 by the research ethics committee in the sociology department at Goldsmiths College. The study also received approval from Queen Mary's research ethics committee in 2009. In the early stage of this study, I planned to conduct this research using archival data in newspaper articles and interviewing clinicians, journalists and members of patient support organisations. I did not plan to interview transplant recipients and their families. Imagining the situation surrounding the recipients and their families, which I knew only through the media coverage, I was pessimistic when it came to approaching transplant recipients and their families. I had assumed that most of them would hesitate to disclose their experiences publicly, and that this would include me. As a plausible alternative method, I planned to delve into heart transplant recipients' experiences by examining archival data and interview data from people who communicated with the recipients such as clinicians, journalists and members of patient support organisations.

However, during my early field research after the initial ethical approval in late 2008, I recognised the importance of collecting the actual voices of organ transplant recipients directly. Therefore, I re-applied to the Queen Mary's ethics committee in order to be granted permission to carry out this type of field research. The study received approval from this committee in 2009. In this section, I provide an overview of the interview technique, archival data search of newspaper articles, ethical issues, selection criteria and the sampling process.

### **3.1.1 Overview of semi-structured interview technique**

In order to collect data from transplant recipients and people who engage in transplantation including health professionals, I decided to use a semi-structured interview. Attempting to discuss the character of in-depth interview method, Legard et al. (2003) describe interviewing as ‘conversation with a purpose’ referencing Webb and Webb (1932). The advantage of a semi-structured interview is that interviewers are able to go in-depth with the interviewees and ask complex questions (Bloch, 2004). I expected that, using a semi-structured approach, my interviewees would voice ideas on transplantation that they might have otherwise hesitated to express, or not had the opportunity to talk about. I assumed that, from these ideas, I would be able to discover the factors that influenced opinion on heart transplantation in Japan, which has been controversial for the past forty years. Therefore, a semi-structured interview could make it possible to garner these ideas, which were necessary in order to gain an in-depth understanding of heart transplant recipients’ experiences.

The questions I designed which are included in Appendix 3 for reference provided the interviewees with space to explore and analyse their viewpoints on heart transplantation. A set of interview questions gives the interviewees some space for open discussion. In this regard, as Warren (2002) explains, a qualitative interview is a kind of ‘guided conversation’.

Due to the fact that many of the interviewees in this research were heart transplant recipients, and it was the first time that these informants had been interviewed by a social science researcher, these interviews gave interviewees an opportunity to voice their opinions and express their thoughts in a private and confidential space.

One of disadvantages of using qualitative methods such as a semi-structured interview is that it takes a long time to do each interview. Studies using this method cannot involve hundreds of people without becoming very expensive. Another limitation of this study is that it was time-limited. Geographical coverage is therefore limited. The interviews were conducted in Tokyo and the west part of Japan, and only one interview was conducted in north of Japan. If I have time – perhaps a future research project – it will be very interesting to expand my research into different areas of Japan in order to understand experiences of heart transplantation in different regions of Japan. Some patients may have less accessibility to receive a heart transplant. Also, heart transplant recipients in Tokyo may have different post-operational experiences from those in other cities. Factors such as living expenses, labour, behaviour and ritual



processes in everyday life vary in different cities throughout Japan. These differences at a local level may have an impact on the experiences of the patients and recipients. However, there are no data on the relationship between their experiences and geographical impacts.

Another concern about the semi-structured interview is to what extent an interviewer is able to strictly adhere to a previously prepared interview guide. Each interviewee has a different style in terms of communication. Interviewers need to carefully consider how to elicit responses to all questions from interviewees without distracting from the overall coherence of the interview. It is also important to properly guide the interviewee when he or she begins to digress (Flick, 2002).

In order to address the limitations of face-to-face semi-structured interviews, I also used e-mail interviews which allowed me to explore further the themes of the semi-structured interviews. By using e-mail interviews, I had the opportunity to expand my knowledge of the themes I had discovered. E-mail interviews also provided interviewees with the freedom of time and space to provide longer answers. At the same time, however, email replies are less spontaneous and this is different from face-to-face interviews (Hunt and McHale, 2007). However, the time interviewees took to compose their thoughts before responding by email was likely to produce more thoughtful answers. In addition, I experienced other difficulties with the e-mail interviews relating to technology. First, there are two main styles in terms of e-mail communication: PC and mobile phone. Every participant used a mobile phone, while only some participants used a PC. When the participants used only a mobile phone for e-mail communication, due to the small size of the screen, it seemed that replies tended to be shorter than the ones sent through a PC. Second, participants were not necessarily happy to write down their feelings and opinions; some of them preferred talking to writing e-mails.

### **3.1.2 Archival data search**

Initially, newspaper articles were collected by using archival data. I planned to analyse them in order to understand heart transplantation in Japan and the recipients' experiences. As the research method was changed to qualitative interviews, the newspaper articles were switched from being the target of the analysis to being a supplemental resource in this study.

The targeted newspapers are the three largest broadsheets in Japan: the politically left wing (*The Asahi*), the right wing (*The Yomiuri*), and the liberal (*The Mainichi*).

Archival data was searched for between August 1968 and December 1972, and between September 1986 and December 2008. After the first Japanese heart transplant surgery in 1968, heart transplantation was often a focus of the mass media, and the trend continued until 1972. After the quiet period in the 1970s, when there was a lack of attention to heart transplantation in the mass media, the media began again to convey the issue of heart transplantation in the early 1980s. In addition, the archival database of the newspapers improved. Those three newspapers' articles have been digitalised; *The Asahi's* electronic archive dates from August 1984, *The Yomiuri's* from September 1986, and *The Mainichi's* from January 1987. Newspaper articles before the digitalisation need to be collected by using reduced sized editions of each newspaper. Considering the historical background of heart transplantation and the practical reason to digitalise newspapers, in the initial archival search, I targeted the periods between August 1968 and December 1972, and between September 1986 and December 2008. Along with collecting newspaper articles for these periods, I began to contact heart transplant recipients themselves to request interviews. I obtained first-hand knowledge from the recipients, which exposed me to more aspects of their experiences that had not been fully covered by the newspapers. Eventually I decided to analyse the interview data and use newspaper articles as supplemental information.

### **3.1.3 Ethical issues**

The main ethical issues in relation to this project were informed consent, data protection and confidentiality. As organ transplant recipients were interviewed about their experiences, the information acquired through interviews was related to their privacy. Additionally, interviews with health professionals, recipients' families and members of patient support organisations sometimes uncovered information which was also related to recipients' privacy. It was possible that interviewees, in particular organ transplant recipients and their families, might feel distress at having this information shared. However, I was able to assure the interviewees of organ transplant recipients and their families that I would maintain their anonymity. I also demonstrated the importance of the study by explaining the lack of existing research into Japanese organ transplant recipients; in particular, heart recipients. In this way, the interviewees were encouraged to give their opinions in the certainty that the information was appropriately handled.

In order to conduct interviews in an ethical way, all interviewees were fully informed about the reason for this study and the requirements of interviewees.

Interviewees were given information about this project both verbally and through an information sheet (Appendix 4). The information sheet was written using simple language and did not contain specialist jargon. Written consent was provided through a consent form signed by the participant and the researcher. Two copies were signed, one kept by the researcher and one by the participant. All information identifying an individual was removed from the interview transcripts. In order to promote confidentiality, on a practical level, the data was secured in a computer with a password. Back-up data was stored on a hard disk drive and hard copies of the interview transcripts. These backups, together with hard copies of the consent forms, were kept in a locked filing cabinet.

### **3.1.4 Selection criteria**

Regarding transplant recipients (heart transplant recipients, lung and liver transplant recipients, liver and lung transplant recipients), I only interviewed people aged 20 and over where more than one year had passed since the operation. Recipients of organs are at risk of infection and so most are under intensive immunosuppressant drugs by health professionals during the period immediately after surgery. Intensive control usually continues for about six months to one year after surgery with the period of time dependent upon each recipient's condition. After this, they are able to return to work, school or community activities in society. By waiting until this period was over, the potential transplant recipient interviewees in this research were in a condition that enabled them to respond to my request for an interview without compromising their immunosuppressant drugs.

Organ transplant recipients' families were also interviewed once their family members met the conditions mentioned above.

Health professionals were recruited by considering their specialities and their general attitude towards heart transplantation, whether proactive or negative towards transplant medicine. There were two groups of transplant surgeons. One group consisted of transplant surgeons; the other group consisted of health professionals of internal medicine.

Regarding the members of patient support organisations, I recruited people who were members of the organisation supporting patients who needed heart transplants. I also requested interviews to journalists at broadsheet newspapers who reported on heart transplantation.

### **3.1.5 Initial sampling**

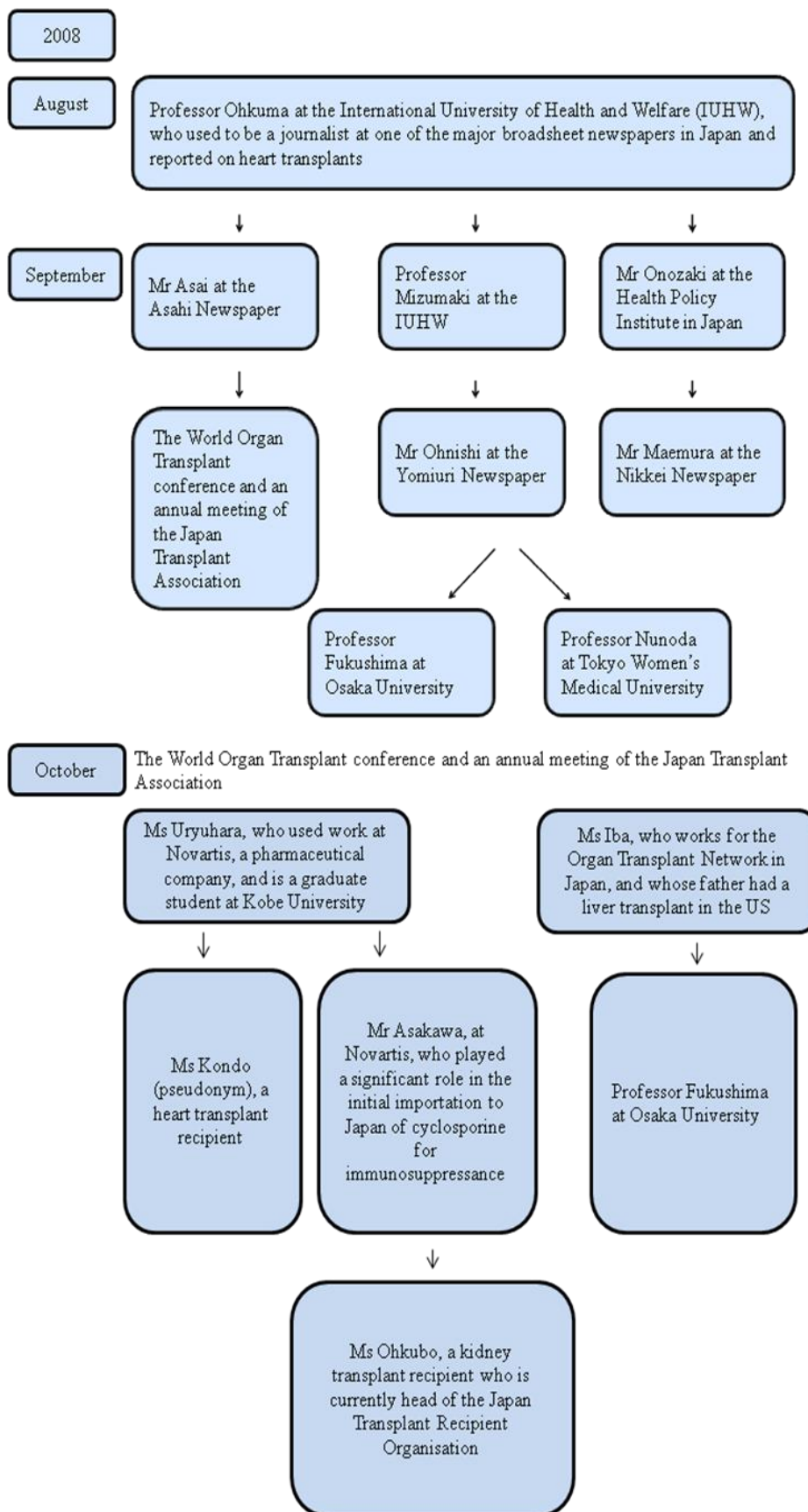
I planned to use ‘snowball’ sampling to recruit interviewees. As Figure 10 shows, my first contact was Professor Ohkuma Yukiko at the International University of Health and Welfare (IUHW), who was previously a journalist at one of the major broadsheet newspapers in Japan and reported on heart transplants. In August 2008, she introduced me to a journalist, Mr. Asai, who works for the Asahi newspaper. Mr. Asai was the first interviewee in this study. He advised me to attend the World Organ Transplant conference and an annual meeting of the Japan Transplant Association in October 2008, which was held one month after I met with him. I attended the conference.

Professor Ohkuma then introduced me to Professor Mizumaki, also a professor at the International University of Health and Welfare (IUHW). Professor Mizumaki used to be a medical journalist at the Yomiuri newspaper, another major Japanese broadsheet. Following this, Professor Mizumaki introduced me to a medical journalist at the Yomiuri newspaper. This journalist, Mr. Ohnishi, was the second interviewee in this study. He advised me to contact Dr. Fukushima at Osaka University and Dr. Nunoda at Tokyo Women’s Medical University. These two health professionals are leading heart transplant surgeons in Japan who are treating Japanese heart transplant recipients in both Japan and abroad. They also collect data on Japanese heart transplant recipients.

Professor Ohkuma introduced me to Mr. Onozaki, who is a research fellow of the Health Policy Institute, Japan. He introduced me to a journalist, Mr. Maemura, who works for the Nikkei newspaper and has a strong interest in children’s organ transplantation. I conducted an interview with him.

These contacts developed further contacts for interviews and eventually to heart transplant recipients. In the following, I shall elaborate further on how I established contacts for interviews from September 2008 to March 2010.

**Figure 10 Flowchart showing how interviewees were recruited**



October

Transplant Game in Japan

Mr Ohkubo, head of the Japan Transplant Recipient Organisation

Mrs Mazawa, who donated her daughter's organs in other countries, and started the Donor Family Club in Japan

Professor Fukushima at Osaka University



Organ transplant recipients

A symposium organised by the Japan Society for Heart Transplantation 27 October

Professor Nunoda at Tokyo Women's Medical University

Mr Kato (pseudonym), whose son and daughter both had heart transplants

Mr Miyamoto (pseudonym), a heart transplant recipient

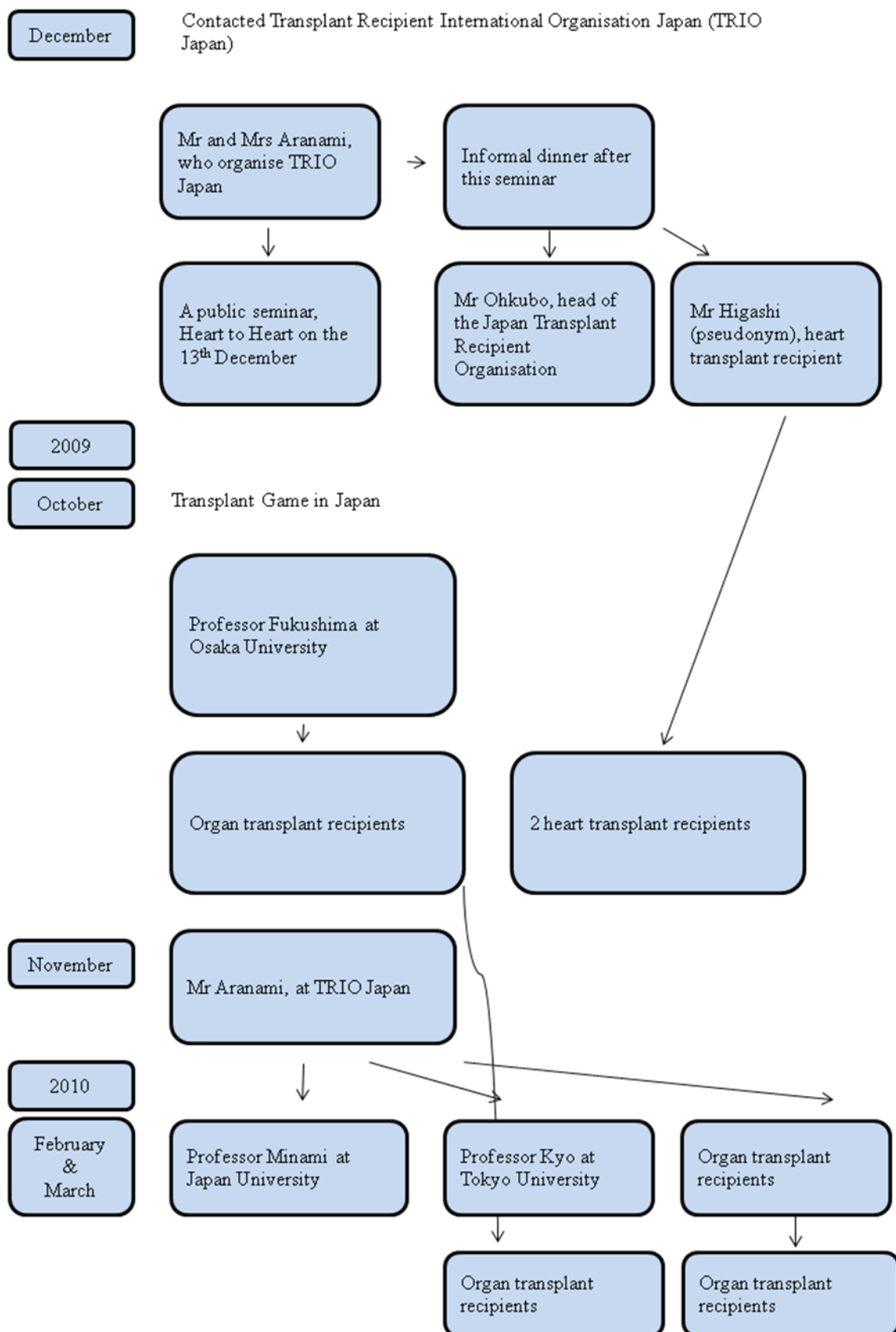
November

Reading *A Story in the Harefield*, which is written about Japanese doctors and heart transplant patients in the UK

Dr Sono, who edited this book, and the first Japanese doctor to have been to Harefield Hospital to learn about heart transplantation.

Dr Akasaka, who was the second Japanese doctor to visit Harefield Hospital to learn about heart transplantation

Mr Toda (pseudonym), who is a heart transplant recipient and a director of a patient support group



### **3.1.6 Establishing contacts for interviews from September 2008 to March 2010**

After interviewing the three journalists mentioned above, Mr Asai, Mr Ohnishi and Mr Maemura, I travelled to Osaka to attend the World Transplant Conference and the annual meeting of the Japan Transplant Association for three days. During those three days, I was able to establish contacts for further research purposes. Among them, the following three people are key people in my field research. Heart transplant recipients' names have been changed for anonymity.

It was important to meet Ms. Uryuhara. She previously worked for Novartis, a pharmaceutical company, and was a graduate student at Kobe University. She had worked on a research 'action programme' for organ donation that had been established in Spain and medical experts in Japan wanted to learn about that programme with the view to promoting transplantation in Japan. Ms. Uryuhara established contact between myself and a heart transplant recipient (Ms. Kondo)<sup>8</sup>, and also between myself and Mr. Asakawa, an executive at Novartis. In the early 1980s, Mr. Asakawa played a significant role in the initial importation to Japan of cyclosporine for immunosuppression.

The medical world, in particular the field of organ transplantation in Japan, is not an open community in terms of the expertise. It consists of medical experts, people who dedicate to the field such as staff at pharmaceutical companies and patient support organisations, as well as patients and their families. People who attend these kinds of conferences and meetings usually know each other to some extent. During those three days, I was 'new' to them. I did not know anyone on the first of day of the conference. I attended many workshops and seminars to listen to presentations, and I enjoyed discussing the issue of organ transplantation with other participants. During each break between seminars, I also enjoyed asking questions of people who had given presentations. Ms. Uryuhara had observed me, and talked to me. During our conversation, I briefly explained my research project, and she suggested I should meet a heart transplant recipient (Ms. Kondo). I was subsequently able to establish contact with this recipient.

People who had attended the conference included medical experts on organ transplantation, people from pharmaceutical companies, transplant recipients, organ donors, donor families, staff members from patient support organisations, journalists, social scientists and members of the public. These people are related to organ

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<sup>8</sup> Ms Kondo is a pseudonym.



transplantation in some way, or at least, are interested in it. It seemed that people observed each other in order to recognise each others' backgrounds. It was not so difficult for me to recognise what each person did, mainly based on their way of dressing. I assume that this was not difficult for other participants as well. In addition, people used the conference as a way to communicate with others. This kind of communication seemed to be usual for them.

I met Ms. Iba, who works for the Organ Transplant Network. Her father had a liver transplant in the U.S. After hearing about my research, she became interested in telling me about her experience with her father's transplant. She promised to have a meeting with me in Tokyo. She introduced me to Dr. Fukushima at Osaka University Hospital, who is one of Japan's leading heart transplant surgeons.

I had contact with Dr. Fukushima. On that day, I introduced myself and my research, and made an appointment for a future interview in Tokyo.

The following day, Ms. Uryuhara had a chance to talk to Mr. Asakawa, who was her ex-boss at Novartis, and was an interviewee in this study. He became interested in my research, and I received an e-mail from him asking to make an appointment to meet with me. At the meeting that followed, he suggested that I should meet Mr. Ohkubo, a kidney transplant recipient who is currently head of the Japan Transplant Recipient Organisation. He was also an interviewee in this study.

At that time I also attended a symposium organised by the Japan Society for Heart Transplantation, at which I established contact with Dr. Nunoda at the Tokyo Women's Medical University; Mr. Kenmoku, whose two children had heart transplants in the U.S, and is currently a member of a patient support organisation; Mr. Kenmoku's daughter and son, who are both heart recipients; and another heart recipient, Mr. Miyamoto (pseudonym). I later interviewed Mr. Kenmoku, however I did not have a chance to interview Mr Miyamoto due to his work schedule and a private matter.

Dr. Sono was a leading figure in establishing a network to send Japanese patients to Harefield Hospital in the U.K in the late 1980s. He edited a book, *A Story in the Harefield*, which is about his experiences and those of his colleagues and patients. This was the first book to focus on their experiences. I attempted to contact Dr. Sono and others who had contributed to the book. I wrote to Dr. Sono, and then to Dr. Akasaka, who was a transplant surgeon and the second such person to have visited Harefield Hospital to assist a Japanese heart transplant recipient. Dr. Sono had retired from surgery because of his age. However, he called me soon after he received my letter, and told me that he could talk to me about his experiences and his opinion on transplant

medicine. I visited him the following day.

Dr. Sono was helpful because he had established a heart transplant recipients' network, the New Heart Club. I contacted the New Heart Club's office and Mr. Toda,<sup>9</sup> who is the director of the New Heart Club and the oldest Japanese heart recipient, agreed to be interviewed.

Dr. Akasaka works at the Wakayama Prefectural Hospital, and had already left the field of transplant medicine when I tried to meet him, although he works in the hospital. His secretary called me to explain that he is not in a position to talk about heart transplantation.

The TRIO Japan is an organisation that works to disseminate information about transplants in order to improve the situation in Japan. They also help patients who need extra support outside the hospital; for example, they are able to give patients information about raising the funds to have an organ transplant abroad. In order to understand the situation of Japanese transplant recipients abroad, I contacted them and visited their office in Tokyo several times. They introduced me to three heart transplant recipients and one heart transplant recipient's family to conduct interviews with.

A further event that proved useful was a public seminar, Heart to Heart, on the 13th December 2008. This was an event organised by Japan University to enhance public understanding about organ transplantation. However, most of the participants at this event were people who were already engaged in transplants in some way. At the end of this half-day event, there was a small casual reception. I noticed that there were no donor family members at the reception.

Following this event, a representative of the Japan Transplant Recipient Organisation, Mr. Ohkubo, invited me to an informal dinner. At the dinner, there was a transplant surgeon, Dr. Fukushima; other members of patient-support organisations; some medical journalists, a recipient's mother; and a heart recipient, Mr Higashi.<sup>10</sup> All of them have attempted to amend the Organ Transplant Law (1997) to make it possible for more transplants to take place in Japan.

Through this dinner, Mr. Higashi became a key person in my studies by telling me about his experiences as a recipient and by introducing me to his 'fellow heart recipients'. He received a heart transplant in the U.S. in 1995. I observed that his surgeon is proud of Mr Higashi's health condition, because he is in quite good health more than ten years after the surgery. Mr. Higashi seemed to be a sort of leader among

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<sup>9</sup> Mr. Toda is a pseudonym.

<sup>10</sup> Mr. Higashi is also a pseudonym.

the heart transplant recipients. Therefore, he was happy to describe his experiences and analyse the transplant situation in Japan. In the end, he suggested that I meet his fellow heart recipients and introduced me to three of them.

### **3.1.6.1 Transplant Games and afterwards**

Another interesting event I became involved with was the Transplant Game in Japan. The Transplant Game is an annual gymnastics event held by the Japan Transplant Recipient Organisation. Organ recipients, their families, donor families, health professionals and even some organ recipients from foreign countries and their families come together each year for this event. Volunteer staff members also assist in the organisation of the event. The volunteers are recruited from the city where this event is held. The event has about between one hundred and fifty and two hundreds participants in total each year including the volunteer staff.

The Transplant Game aims to enhance communication between organ transplant recipients each other, and also assists in facilitating communication between organ recipients, organ donors, donor families and health professionals (Japan Transplant Recipient Organization, 2006). This event serves to publicise the organ transplant as a marvellous medical achievement because the recipients are able to show how they enjoy sports, and this is then seen by the mass media.

As some participants are from other countries, the organisers of this event need several interpreters during their stay in Japan. They recruit volunteer interpreters. Therefore, I attended the game both in 2008 and 2009 as an interpreter. During the event, I had the wonderful opportunity to talk to many other participants.

During the October 2008 event, held in Ohtawara, Tochigi prefecture, I acquired the contact details of Mrs. Mazawa, who donated her daughter's organs in the U.S., and started the Donor Family Club. Her husband is currently a representative of this organisation. I also had a chance to talk to Mr. Ohkubo, and since then, I have had several meetings with him. Furthermore, I acquired several other transplant recipients' contacts.

Many participants had already attended this event several times in the past. A number of these participants live in different cities; therefore, this event is an annual meeting for most of them. It seems as though they enjoy the meeting, and take part in a lot of conversations with their friends.

I found that these participants asked firstly whether the person was an organ

recipient or a recipient's family member. Then, their second question was which organ was transplanted. If they were not a health professional or a local volunteer, most participants were categorised according to whether they were an organ recipient, a family member, or part of a donor family. They immediately started the conversation with these questions. One lady, whose husband had a liver transplant in the U.S, told me that her husband seemed to enjoy the atmosphere of the event because he could talk about his transplant experience without hesitation, which was different from daily life. By contrast, I did not frequently see communication between the recipient and their families and donor families, even in this casual atmosphere. Although it may have happened, I did not witness it.

I also attended the Transplant Game in 2009, held in Fukuoka, Fukuoka prefecture. Prior to going in 2009, I exchanged e-mails with some participants who had attended the games in 2008 and would join again in 2009. Through these e-mail exchanges, I was able also to contact some of the heart recipients. Soon after arriving at the venue for this event, I enjoyed chatting with some of the participants again after a one-year gap. This allowed me to talk to their friends as well. It was not difficult to join their conversation.

On the first evening, there was an informal buffet style dinner, and people either walked around or had seats by the wall. The total number of attendees was about one hundred. There were many small groups there. I noticed that each group was similar, consisting of organ transplant recipients and their families. The next evening, there was a gala party that began with a table dinner. Health professionals and donor families sat at the main guest table. Everyone else sat at smaller separate tables. I saw a sort of order among people, indicating who should be most respected. I perceived an invisible wall between organ recipients and donor families. I got the impression that this table allocation reflected the actual relationship between recipients and donor families in Japan.

After the Transplant Games in 2009 in Fukuoka, Japan, I emailed Mr. Aranami at the TRIO Japan (in November 2009) to ask for help in recruiting interviewees. He talked to several organ transplant recipients and their families between December 2009 and January 2010, and then introduced me to five more heart transplant recipients and one liver transplant recipient. In addition, he suggested that I consult Dr. Minami at Japan University and Dr. Kyo at Tokyo University. He established contacts with them for me. One heart transplant recipient, to whom I was introduced by Dr. Fukushima at the Transplant Game in Fukuoka, introduced me to a further two heart transplant recipients who I interviewed in February 2010.

During my field research in Japan between February and March 2010, interviewees themselves put me in contact with more heart transplant recipients and their families. I interviewed them before returning to the U.K.

### 3.1.6.2 The interviewees

In total, I interviewed nineteen Japanese heart transplant recipients and thirty-four other people who had been involved in heart transplants as well as other organ transplants. Table 4 profiles participants who were heart transplant recipients and their family members who took part in the study. Appendix 5 contains more detailed information about each interviewee. As participants who were health professionals, members of patient support groups and journalists have not been anonymised in this study, their detailed profiles are contained in Appendix 5.

**Table 4 Characteristics of heart transplant participants and family members who took part in the study**

#### *A. Gender*

Male	Female
12	7

#### *B. Age*

Age	Number
20 – 29	8
30 – 39	5
40 – 49	2
50 – 59	3
60 >	1

### *C. Characteristics of family members*

Relationship with recipient	Number
Father	2
Mother	6
Husband	1
Wife	4
Fiancé	1

I also interviewed two people who had received other organ transplants and their relatives, in one case a man who had received liver transplant, his wife and his daughter, in the other a woman who had received a lung transplant.

One point that requires consideration is the method of making appointments for interviews. By using the snowball sampling method, one participant introduced me to the next participant. When contacting the next participant, I used e-mail to request an interview following another informant's introduction. I first introduced myself as a social scientist investigating issues around people's experiences of heart transplantation in Japan. I found that potential interviewees would like to know who I was and what I thought about transplants. Therefore, I started exchanging ideas with them via e-mail prior to the face-to-face interviews. This is the process in which the participant decided whether responding to the interview would be a positive rather than negative experience. This was also an evaluation of me, the interviewer, by the participants. I argue that their attitudes at this point reflected their sensitivities about disclosing personal information, because they were not familiar with responding to interviews and they also may have experienced stigmatisation in society. As the theme for the interview is closely related to delicate and private matters for interviewees, the communication before the interview meeting enhanced the positive atmosphere during the face-to-face interviews.

### 3.1.6.3 Interview format

As shown in Table 5, the e-mail interviews were conducted with nine heart transplant recipients, three heart transplant recipients' families and one lung transplant recipient.

**Table 5 Interview format**

<b>Face-to-face interviews</b>	<b>Face-to-face interview + E-mail interviews</b>
<p><b>36 participants</b></p> <p>10 heart transplant recipients</p> <p>11 heart transplant recipients' families</p> <p>4 Surgeons</p> <p>3 people from patient support group</p> <p>3 journalists</p> <p>1 liver transplant recipient</p> <p>2 families of liver transplant recipients</p> <p>1 donor family</p> <p>1 representative of a pharmaceutical company</p>	<p><b>13 participants</b></p> <p>9 heart transplant recipients</p> <p>3 heart transplant recipients' families</p> <p>1 lung transplant recipients</p>

Soon after the face-to-face interviews, I sent e-mails to all the participants to express my appreciation for their response to my interview requests. At this stage, I did not send any further questions. Some of the participants replied with further information that they wanted to add to what they had told me during the interview. Two of the heart transplant recipients sent me their diaries, which described how they had been feeling during the waiting period and the days soon after the operation. Based on these additional e-mail replies, I felt it acceptable to send further questions by e-mail. These follow-up questions were specific to each individual participant. Eventually, I conducted both face-to-face and e-mail interviews with nine heart transplant recipients, three heart transplant recipients' families and one lung transplant recipient. I conducted only face-to-face interviews with the remainder of participants in this study.

## **3.2 Data analysis**

### **3.2.1 Data management**

All interviews were recorded by using an IC audio recorder. Most interviews lasted about one to two hours. Three interviews were about five hours long. All were transcribed into a simple text. Due to using this interview technique, through the transcription process, some relevant information such as facial expression and tone of voice were not reproduced in the final written transcription. This information was important to understand interviewees' facial expression. In order to minimise this problem, I supplemented notes which described those non-verbal characteristics. At this stage, all the recipients and their families were given pseudonyms for anonymity.

All interviews were conducted in Japanese, which is not the language that has been chosen for reporting the study. Two interviews were fully translated from Japanese into English so that they could be discussed in more detail with my supervisor, who did not read Japanese. As for the rest of the interview transcripts, only extracts were translated into English. Some words cannot be translated literally from Japanese to English. In these cases, I explain the meaning of the word instead of giving a direct translation. Another difficult point in translation was the sentence order. Because of grammatical differences, direct translation does not necessarily provide the proper meaning. Because of a particular characteristic of the Japanese language, the conclusion, or sometimes the main point, is not clearly expressed until the end of sentence. In addition, conversational styles were sometimes very casual; some participants suddenly jumped to a different topic. Therefore, when translating interviews, I put the priority on expressing clear meaning.

All the transcriptions, including the translation, were imported into MAXQDA, which is a computer program used for qualitative data analysis. Using MAXQDA, it was possible to attach codes on a computer screen, and it was also possible to attach extra information which would be important for analysing themes later. The advantage of using computer software for data management and coding is the ability to rapidly retrieve information from large amounts of interview data. In addition, it was very helpful when refining coding schemes.



### 3.2.2 Thematic analysis

In order to analyse interview data I chose thematic analysis. Thematic analysis is a method of analysing qualitative data based on themes (Benner, 1985). It has been described and applied in interpretive qualitative data analysis (Butcher. et al., 2001; Hunt, 1999; Laitinen, 1996; Park et al., 2004; Schommer, et al., 2009). However, there is no clear agreement about the pragmatic process of thematic analysis (Aronson, 1994; Attride-Stirling, 2001), therefore the actual process used for thematic analysis varies. Thematic analysis shares many procedural aspects with content analysis and grounded theory. While content analysis de-contextualises themes from a dataset, thematic analysis does not do so (Joffe and Yardley, 2004). Unlike grounded theory, thematic analysis does not aim to create a theory, but rather discovers meaningful terms in data and enhances the understanding of the data (Benner, 1985). The ambiguity of the definition of thematic analysis is often claimed to be a weakness of the method (Braun and Clarke, 2006). Nevertheless, I argue that the flexibility of thematic analysis is its advantage as a method, because ‘the thematic framework is used to classify and organise data according to key themes, concepts and emergent categories’ (Ritchie et al, 2003: 220). This study aims to enhance the understanding of the experiences of Japanese heart transplant recipients, which should take into account both global and local contexts. Moreover, the field of the experiences of Japanese heart transplant recipients lacks studies; so the process of finding themes in the data is a combination of inductive and deductive approach. For these reasons I propose that thematic analysis is a suitable method for this study.

In order to develop and clarify how thematic analysis is used in this study, applying the process which was introduced by Rosenthal (2004), Attride-Stirling (2001), Spencer et al. (2003) and Ritchie et al. (2003), I conducted the data analysis as follows.

First, I coded the interview data which involved listing patterns of experiences. This was a systematic coding process. The codes were based on both theoretical interests and recurrent issues in the interview text. In the initial coding process, I coded the interview data along with the recipients’ experiences in a chronological manner. Many common codes appeared in both before and after receiving a heart transplant. In addition to codes relating to their experiences, codes regarding recipients’ views on heart transplantation and related issues. The initial codes are as follows (Table 6 Coding stage 1).

**Table 6 Coding stage 1**

Internal self-conflict
Health condition
Gathering information of heart transplant
Conversation with family and others
Talk about other recipients
Received information and recipient's thoughts about heart transplant
Restrain activities
Establish network for fund-raising (pre-operational experience)
Information gathering for the medical treatment (pre-operational experience)
Sharing information (pre-operational experience)
Money (pre-operational experience)
Notification of heart transplant (pre-operational experience)
The moment to be notified to have a heart transplant (pre-operational experience)
Waiting period (pre-operational experience)
Side effect experience (post-operational experience)
Narrative to return to society (post-operational experience)
Press
Death
Thoughts about organ transplant
Thoughts about medical system
Thoughts about health professionals

Reciprocal gift-exchange
Thoughts about donor family
Thoughts about the organ
Thoughts about the donor

Secondly, I went through the coded data, and classified and organised them. This was the process used to abstract themes from the coded text segment by exploring common or significant themes in the coded segments. Simultaneously, finding that several coded segments were too broad or narrow, I renamed those codes, combined segments or broke them down into smaller categories. They are summarised into the following table (Table 7 Coding stage 2).

Next, I identified how each coded segment related to the others as shown in the following table (Table 7 Coding stage 3). These segments were allocated into four categories: pre-operational experiences, post-operational experiences, experiences influenced by notions of the body and experiences influenced by the idea of gift-exchange. These categories emerged from the literature review.

Interview texts were analysed by describing themes and patterns characterising the themes in each category. At this stage, further related concepts emerged, and then the newly related literature was examined.

**Table 7 Coding stage 2 and 3**

Coding stage 2			Coding Stage 3
Internal self conflict	Identity, Stigma		Stigma
	Personal experiences		Personal experiences
Health condition	Identity, Stigma		Stigma
	Personal experiences		Personal experiences
Gathering information of heart transplant	communicatio n	Health professionals,	Communication

		Other medical practitioners, Families, Friends, Press, Patient support organisation	
Conversation with family and others	master status	Experience of not having master status Experience of having master status	Master status
	information control	Covering, Passing, Dissemination of feeling , Before heart transplant, Information disclosure	Information control
Talk about other recipients	Identity		Personal experiences
Received information and recipient's thoughts about heart transplant	Thoughts about discussion regarding body and soul		Body and soul
	Thoughts about body and soul		Body and soul
	Thoughts about discussion regarding a		Heart

	heart organ		
	Thoughts about a heart organ		Heart
	Thoughts about the influence of religion to the people's attitude towards heart transplant		Religion
Restrain activities	Identity, Stigma		Stigma
Establish network for fund-raising	Experience of fund-raising		Finance
Information gathering for the medical treatment	communication	Health professionals, Other medical practitioners, Families, Friends, Press, Patient support organisation	Communication
Sharing information	communication	Health professionals, Other medical practitioners, Families, Friends, Press, Patient support organisation	Communication
Money	Self-payment		Finance
Notification of heart transplant	Personal		Personal

	experiences		experiences
The moment to be notified to have a heart transplant	Personal experiences		Personal experiences
Waiting period	Stigma		Stigma
	Personal experiences		Personal experiences
Side effect experience	Identity, Stigma		Stigma
	Personal experiences		Personal experiences
Narrative to return to society	Identity, Stigma		Stigma
	Personal experiences		Personal experiences
Restrain activities	Identity, Stigma		Stigma
	Personal experiences		Personal experiences
Press	Description of media's enthusiasm		Media
	Thoughts about the mass media		Media
Death	Thoughts about people's attitude towards death		Death
Thoughts about organ transplant			Organ donation
Thoughts about medical system	Medicine		Organ donation
Thoughts about health professionals	Doctor-patient relationship		Communication

Reciprocal gift-exchange	Appreciation of the gift of a heart		Appreciaton of the gift of a heart
	Repayment of the gift		Repayment of the gift
Thoughts about donor family	Organ donation		Organ donation
Thoughts about the organ	Organ donation		Organ donation
Thoughts about the donor	Organ donation		Organ donation

Based on the detailed exploration, I summarised the main themes which characterised the recipients' experiences. The coding frame can be summarised as shown in Table 8 below.

**Table 8 Coding frame**

<b>Pre-operational experiences</b>	
Master status	-
Information control	Information disclosure
	Dissemination of recipients' feelings
	Gathering and sharing information about medical treatment
Communication	The Own
	The Wise
	The Public
	Social pressure
Stigma	Felt stigma
	Enacted stigma
Personal experiences	The moment of being notified of the need for a heart transplant
	Describing health condition
	Internal self conflict
Organ donation	Thoughts about the donor
	Thoughts about donor family
Medicine	Thoughts about health professionals
	Thoughts about medical system
Media	Description of media's enthusiasm
	Thoughts about the mass media
Finance	Experience of fund-raising
	Self payment

<b>Post-operational experiences</b>	
Master status	-
Information control	Information disclosure
	Dissemination of recipients' feelings
	Passing
	Covering
	Gathering and sharing information about medical treatment
Communication	The Own
	The Wise
	The Public
	Social pressure
Stigma	Felt stigma
	Enacted stigma
Personal experiences	Describing health condition
	Internal self conflict
	Thoughts towards the life plan
Organ donation	Thoughts about the donor
	Thoughts about organ
	Thoughts about donor family
Medicine	Thoughts about health professionals
	Thoughts about medical system
Media	Description of media's enthusiasm
	Thoughts about the mass media
Finance	Experience of fund-raising
	Self payment
<b>Notion of body</b>	
Body and soul	Thoughts about discussion regarding body and soul
	Thoughts about body and soul
Heart	Thoughts about discussion regarding a heart organ
	Thoughts about a heart organ
Religion	Thoughts about the influence of religion to the people's attitude towards heart transplant
	Thoughts about his or her own religion
Death	Thoughts about death
	Thoughts on the other people's attitude towards death
<b>Gift-exchange</b>	
Appreciation of the gift of a heart	Thoughts
	Action
Repayment of the gift	-



### **3.3 Validity**

In addressing the issue of validity there are three main considerations in relation to this study. The first concerns the sampling procedures, in particular the sample of organ transplant recipients and their families. Due to the sensitivity of the issue and the fact that the number of recipients is limited, I had assumed that there would be difficulties in recruiting interviewees for this study. In order to solve this I chose the snowball sampling technique. However, snowball sampling might have recruited only certain people who belong to a single network, which may not represent the general recipients and their families. This concern was addressed by using several intermediaries to enter the network of recipients, rather than relying on a single entry point. As I proceeded, it became clear that these various intermediaries often pointed to the same people, suggesting that the actual network of recipients is relatively small and self-contained. Nevertheless, it remains possible that my interviewees represent people with better interpersonal links, and that I did not interview people who had become socially isolated.

The second concern has to do with how to construct a coherent, credible account with representative quotations from interview narratives. I have attempted to quote extracts from interview narratives as evenly as possible. This was not easy because some interviewees narrated more experiences than other interviewees. Nevertheless, I found that the detailed information contributed by some patients helped my understanding of other recipients' experiences when they referred to the same theme.

The third concern relates to the way in which interview data was coded. In order to clarify my coding procedures I have summarised the coding framework and then also added examples to each code (Appendix 6). This makes it possible for the validity of my coding to be assessed by other researchers.

In this chapter, I have explained my research design, starting with sampling and then explaining my approach to thematic analysis. I have clarified issues which may threaten the validity of this study, and have discussed ways in which I tried to solve these issues.

## **Chapter 4 The pre-operation period of transplant recipients**

### **4.1 Introduction**

This chapter is an analysis of Japanese heart transplant recipients' experiences in the pre-operation period, with the aim of exploring how they decided to have heart transplants. Throughout the decision-making process, patients typically experience physical and physiological pain, and psychological distress (Bailystok, 2006; Kaba et al., 2005; Sanner, 2001; Sharp, 1995, 2006). Therefore, to examine the decision-making process is to look at how the patients manage such pain and distress. The harsh reality is that it takes time to register on the waiting list for heart transplants. Patients are often forced to wait for more than three years to do so (The Japan Society for Transplantation Publicity Committee, 2010), and only a limited number of patients have the opportunity to have the transplant surgery. Heart disease patients who require a heart transplant, therefore, experience chronic pain and distress. In this regard, the chronic condition that these patients experience is compounded by such situational factors. Bury (1982) argues that the condition of developing a chronic illness is conceptualised as an event which is disruptive to everyday life. Chronically ill individuals have aspects of their lives disrupted which had been taken for granted. Charmaz (1983) argues that pain and suffering caused by chronic illness diminish the self-concept through the experience of losing one's former self-image. She also argues that chronic illness raises the issues of loss of productive function, financial crisis, family strain, stigma, and a restricted existence. As a result, individuals often experience a loss of self.

I agree that developing heart disease disrupts a person's life, and that this disruption causes an identity crisis. When a patient makes the decision to have a heart transplant, he or she hopes to recover from the disease. This means that the patient hopes to overcome the issue of an identity crisis as well. In this chapter, I examine how the patients' everyday lives in my study were disrupted during the decision making process. I also explore the way in which this disruption influenced their identities.

I will review the trend of heart transplant recipients in Japan from a statistical viewpoint. Then, I will examine patients' initial responses to a heart transplant diagnosis. This will be examined from a perspective involving their thoughts about having a heart transplant once they were informed that surgery was required. Next, I will examine how they perceived other patients, who are themselves facing similar experiences of having a

heart transplant, which is so called ‘the Own’ by Goffman (1968), and people around the patient whose close knowledge of – and often sympathy for – the individual facing heart transplantation comes from the fact that they are the family, friends, neighbours, health professionals and other medical staff who have personal relationships with the person; or are journalists and others who have made a special study of the experience and have therefore acquired wisdom about it. They are so called ‘the Wise’ by Goffman (1968). I will examine the responses of ‘the Own’ and ‘the Wise’ to the decision to have a heart transplant. This will mainly focus on face-to-face communication with the patients. I will also focus on the experiences of patients who had transplants abroad; in particular, I will examine how these patients experienced the process of raising fund to have a heart transplant abroad. This will focus on the relationship between the patient, ‘the Wise’ and the general public. The communication involved in this research was conducted at times through mass media, so patients’ responses to this will also be discussed. I will examine how implanting a Ventricular Assist Device (VAD) influences the patients’ identities. Finally, I will examine the patients’ experiences once informed that they could have a heart transplant.

## 4.2 Statistical perspective concerning heart transplant recipients in Japan

This section reviews statistical trends in Japanese heart transplant recipients in order to increase understanding of the impact of gender and socio-economic factors. Data on Japanese heart transplant recipients who had the operation abroad are not collected by any particular organisation, though data on recipients who had the operation in Japan are published by the Japan Organ Transplant Network (JOT). This means that information from patients who went abroad to have the transplant has not necessarily been shared among the Japanese medical community. In order to grasp the statistical trend of the recipients who travel abroad to have a heart transplant, I referenced the data which was published by The Japan Society for Transplantation Publicity Committee. They introduced the number of recipients who have travelled abroad for the transplant without detailed information. In order to acquire more detailed information, I referenced newspaper articles, which provide profiles of recipients, in particular, those people who solicit fund-raising support from the public. Referencing this information and follow-up data from newspaper articles, I review the statistical trend.

Focusing on a gender balance, as Table 8 shows, there are more male than female recipients.

**Table 9 Gender balance of the Japanese heart transplant recipients in Japan and abroad**

	Male	Female	No data	Total
1	26	9	0	35
2	47	38	8	93
3	43	17	0	60
<b>Total</b>	<b>116</b>	<b>64</b>	<b>8</b>	<b>188</b>

1. Recipients abroad between 1984 and 1997 before the passing of The Organ Transplant Law (1997)

2. Recipients abroad between 1997 and 31 December 2008, after the passing of The Organ Transplant Law (1997)

3. Recipients in Japan between 1997 and 31 December 2008

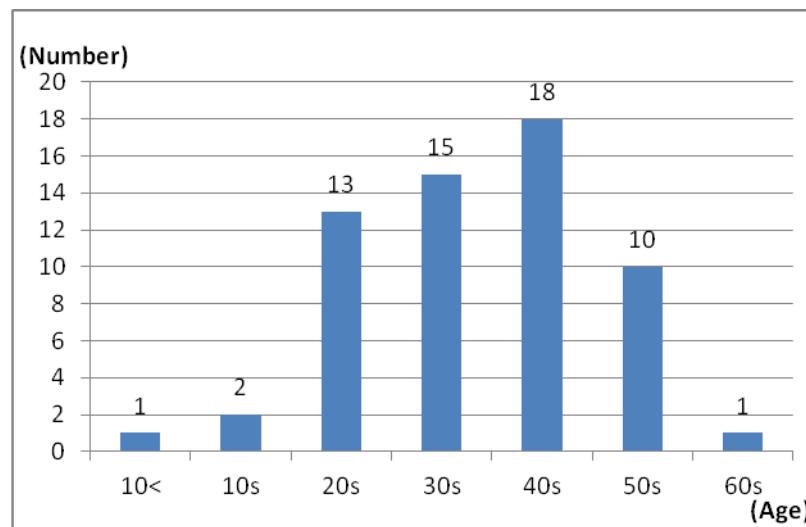
(Sources: The Japan Society for Transplantation Publicity Committee, 2010; Yomiuri newspaper between 1984 and 2008)

The JOT (2011b) regularly updates how many patients have registered on waiting lists to have heart transplants. According to the recent data by the JOT (2011b), which was updated on 31 May 2011, one hundred seventy-three heart disease patients have registered. Of these, one hundred twenty-five are male and forty-eight are female

patients. It seems that the gender balance of the recipients roughly reflects the gender balance of patients who register on a waiting list for heart transplants. However, as Table 8 shows, there are missing data regarding the recipients who travelled abroad after 1997. Regarding the gender balance of the Japanese recipients abroad, further exploration is required to determine whether this data is similar to recipients in Japan.

Next, looking at the data of the recipients in Japan from an age perspective, as Figure 11 shows, the majority of the recipients are in their thirties and forties.

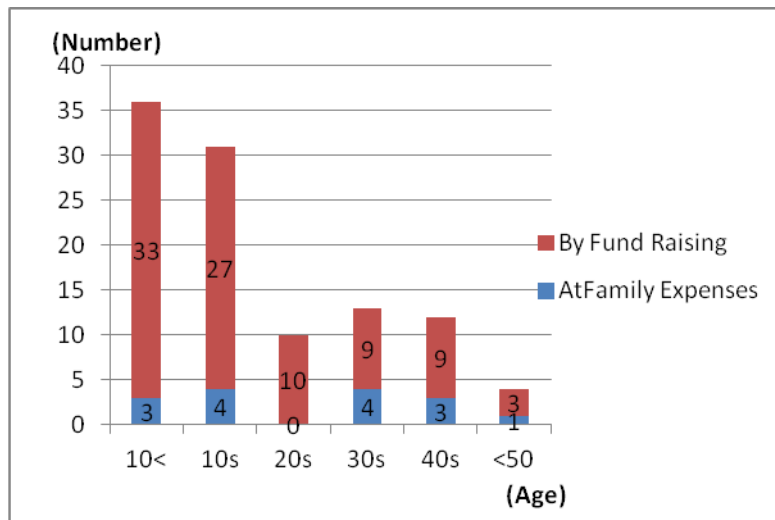
**Figure 11 Age of Japanese heart transplant recipients who received their transplant in Japan between 1997 and 2008**



(Sources: The Japan Society for Transplantation Publicity Committee, 2010; Yomiuri newspaper between 1984 and 2008)

Moving attention to the age of Japanese recipients abroad, as Figure 12 shows, the majority of recipients are younger than the recipients in Japan. This reflects the situation in which children did not have the opportunity to receive a heart transplant in Japan until 2009, which was discussed in Section 2.1. This graph also shows that younger patients seem to be more likely to benefit from fund-raising support from the public. Aranami (2008) explains that one of the background reasons is that it is easier for children to gather attention and sympathy to raise money from the public than for elderly patients. This may reflect the idea that people think that elderly individuals should be responsible for saving a sufficient amount of money to support themselves. If they do not have enough money for the surgery and ask people for financial assistance, the patient loses honour in society.

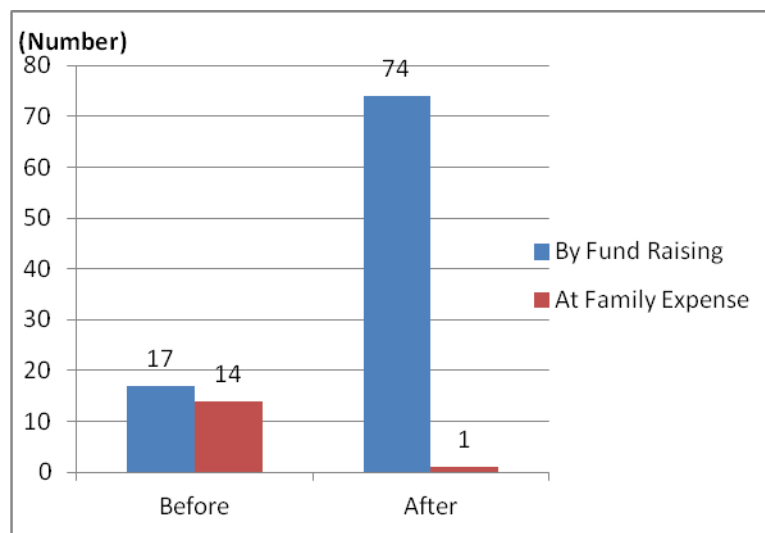
**Figure 12 Heart recipients transplanted outside Japan: their ages and sources of family funding between 1984 and 2008 <sup>11</sup>**



(The Japan Society for Transplantation Publicity Committee, 2010; Yomiuri Newspaper between 1984 and 2008)

In Figure 13, I look at the same data from a different viewpoint by comparing data on transplants before the passing of The Organ Transplant Law in 1997 to transplants after it.

**Figure 13 Heart recipients transplanted outside Japan: their ages and sources of family funding between May 1984 and 2008 (before and after The Organ Transplant Law 1997)**



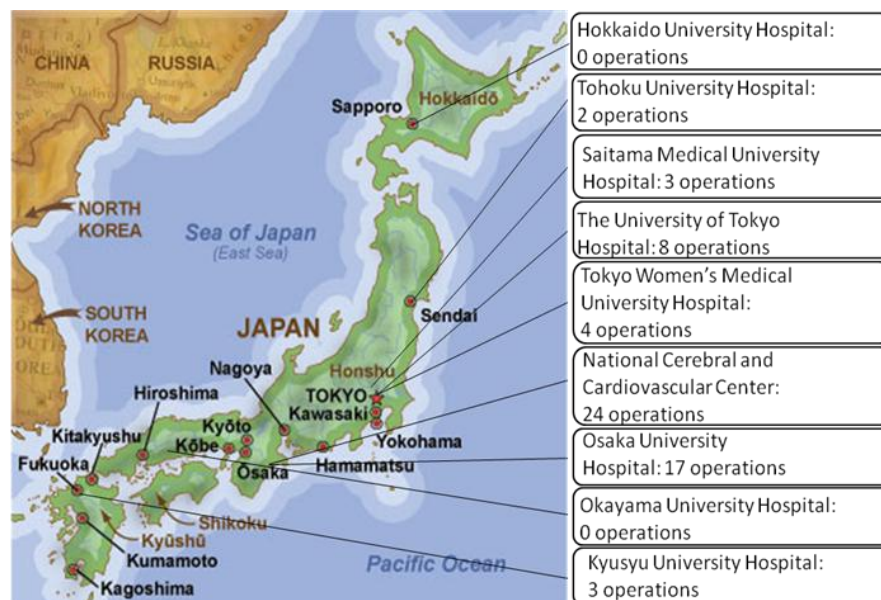
(The Japan Society for Transplantation Publicity Committee, 2010; Yomiuri Newspaper between 1984 and 2008)

<sup>11</sup> This figure is based on data from The Japan Society for Transplantation Publicity Committee (2010) and newspaper articles. The Japan Society for Transplantation Publicity Committee (2010) provides information regarding the number of Japanese heart transplant patients abroad; however, it does not give detailed information. Therefore, detailed information concerning their age is supported by the information gleaned from newspaper articles. This information was available for 106 of 128 cases between 1984 and 2008.

This shows that fund-raising has become more common in recent years. It can be considered that the organisations which support the patients to send them abroad have gained more support. In other words, sending patients to have a heart transplant has become more of a public issue. Another point is that, in the early years, it was more common for rich people to have transplants. This was due to a lack of fund-raising support for heart transplant patients.

The geographical location of hospitals which are authorised to perform heart transplants is another important factor when considering the hospital's accessibility to the patient. Nine hospitals are able to perform heart transplants in Japan as can be seen in Figure 14<sup>12</sup>. All hospitals are located in major cities such as Tokyo, Osaka, Sendai, Fukuoka and Sapporo (Japan Organ Transplant Network, 2011c). Many heart transplants in Japan have been conducted mainly in the Osaka area. The geographical condition may impact on patients' chances to have a heart transplant and also their quality of life, both during the waiting period for the transplant and following the transplant. The lack of data regarding where the recipients are from, the relationship between hospital locations and the patients' accessibility to the hospitals has not been explored further at this stage.

**Figure 14 Heart transplants at hospitals in Japan**



(Source: Japan Organ Transplant Network, 2011c)

\* The number given for operations in Figure 12 reflects the ones performed by December 2008.

<sup>12</sup> Seven hospitals have performed heart transplants in Japan. Hokkaido University Hospital and Okayama University Hospital were certified for performing heart transplant surgery in 2010, but they have not performed heart transplant surgery yet (Japan Organ Transplant Network, 2011c).

### 4.3 Patients' initial responses to a heart transplant diagnosis

In this section, I examine the heart transplant recipients' initial responses when they were diagnosed and informed that they needed heart transplants. I examine their reaction to being told that having a heart transplant was the only available treatment. I also examine whether there are differences in responses depending on age and family background.

Of my interviewees, two recipients, Ms. Kato and Ms. Kondo, who both had heart transplants during their childhood. Eighteen years has passed since Ms. Kondo's surgery when she was seven years old, she is now twenty-five years old. It has been fifteen years since Ms. Kato's when she was eight years old, she is now twenty-three years old. Ms. Kondo was six years old when she was diagnosed with needing a heart transplant. She does not remember first-hand how she responded to her physician's explanation, but was informed by her mother.

(Ms. Kondo) 'According to my mother, I responded to the physician's explanations in the following manner: "I want to go anywhere – even to the opposite side of the earth if I get a chance to recover from the illness." I assume that I had made up my mind to undergo the heart transplant. I don't remember what I told them when I made the decision. I assume that, although I was merely a child, I understood the heart transplant in my own way.'

As noted above, Ms. Kondo did not remember her responses at the time of her diagnosis. However, this extract shows that she clearly expressed her wish, in spite of being a small child aged only six years old.

Another recipient, Ms. Kato remembered how she felt when she was told that she would need a heart transplant. Prior to her heart transplant, her brother had one when he was 11 years old. Sometime after her brother's heart transplant, she was diagnosed with heart disease, and she recognised that her health condition was worsening. In the end, she had a heart transplant about six months after her brother's transplant operation. She described that she was not devastated so much with the diagnosis, when she was informed about her heart transplant. Instead, upon finding out, her reaction to the diagnosis was that she was worried about her parents' feelings.

(Ms. Kato) 'One day, my parents told me that I had the same heart disease as my brother; therefore, I needed heart transplant surgery. I think that my



parents were sure that I would have a chance of having a heart transplant. Without any hopes, I think, they couldn't tell me about it. Generally speaking, I am very sensitive to how others feel under certain conditions, and I try not to put any extra pressure on them. At that time, worrying about my parents, I behaved as if I had already predicted this situation of a heart transplant.'

Ms. Kato's case is completely different from that of Ms. Kondo in relation to one important issue. She knew that her brother had successfully undergone a heart transplant. In the interview, she described that she had understood a heart transplant surgery not as a special surgery; therefore, she could accept the diagnosis without a lot of concerns.

As mentioned above, both Ms. Kondo and Ms. Kato were below ten years of age when they had heart transplants. Therefore, their parents were the primary decision-makers. As these two recipients' description about the understanding of a heart transplant show, these recipients understood a heart transplant in their own way; they then expressed their decision to receive a heart transplant. In this process, I assume that their daughters' positive responses towards a heart transplant encouraged the parental decision.

Four recipients in this research had heart transplants when they were teenagers. They all had their heart transplants abroad, and three of them had the surgery during their high school days. In contrast to the recipients who had the surgery during earlier childhood, they clearly remember how they felt about having a heart transplant.

Ms. Kasai had been suffering from heart disease since birth. The surgeon explained to her parents that she would need a heart transplant in the future. In the meantime, she had several heart surgeries and did not perceive her condition as special or extraordinary.

(Ms. Kasai) 'In my life, I haven't thought about my condition of having a heart transplant as unique or extraordinary, because I have had this heart disease since childhood. Taking medicine, having a machine inside of my body, experiencing surgeries...all of them are ordinary matters for me. Therefore, I have talked about these experiences to my friends without hesitation.'

She internalised her heart disease as part of her identity. Charmaz (1983) explains that the disruption happens when the former self-image is corrupted by the diseased condition. Ms. Kasai's experience shows that a chronically ill condition may not necessarily disrupt an individual's identity. As her own self-image had been established by a chronic condition of heart disease, she had no self-image without the

disease. If she compares her self-image, she may compare it with people who do not have chronic conditions. In this regard, I assume that the experience of hearing her diagnosis of needing a heart transplant was the beginning of her comparison of her own identity to others.

As her condition became worse, she was hospitalised when she was thirteen years old. During the hospitalisation, she was told that she would need a heart transplant when she was a secondary school student. Subsequently, she began to read books and documents about heart transplantation. Through collecting information about heart transplantation, she began to wonder why everyone was not able to have a heart transplant. She also knew that many patients waited in vain for heart transplants. She began to internalise the heart diseased condition, and did her best to learn about the condition from other people until the decision was made to have a heart transplant.

During this time, her mother began to voluntarily work for a patient support organisation for people whose families suffer from heart disease. As a member of this organisation, her mother actively appealed to the Japanese government to amend the law to make it possible to perform heart transplants for children in Japan. Ms. Kasai began to communicate with the people her mother thereby established relationships with. This period of her life was therefore spent usually with ‘the Wise’ such as the family, health professional and sympathetic friends. It also involved establishing a new network with ‘the *New Wise*’ who were added to the existing network by her mother’s activities. By getting to know other patients who needed heart transplants, she was also able to perceive them as ‘the Own’. She focused on this aspect rather than on being anxious about having a heart transplant at the initial stage.

Ms. Hamada, another teenage recipient, experienced a sudden change in her health caused by heart disease, at the age of sixteen years old. Initially, her symptoms were similar to the flu. After undergoing a medical test, her heart disease was diagnosed, requiring a heart transplant. For some time, her condition worsened. A Ventricular Assist Device (VAD) was implanted when she lost consciousness. When her consciousness returned, she realised that a VAD had been implanted. She also received an explanation that she needed a heart transplant abroad because of time constraints. She describes learning of this as follows:

(Ms. Hamada) ‘If I waited for a chance to have a heart transplant [in Japan?], I was told that it would take three years to have the chance. My blood type is A, which is the [same as the] majority of patients who are waiting for a heart transplant in Japan. ... I thought that I could not wait for three years. I was

terrified by the truth, which was that I would die if I did not go abroad for the surgery. I was really in a dangerous condition.'

However, she did not disclose this fear and anxiety to anyone, even to her parents. After some preparation in Japan, she went to the U.S to wait for the opportunity to have a heart transplant. Through this process, she had positive experiences, as she was able to believe that a heart transplant was becoming increasingly possible. During her waiting period in the U.S, she again began to feel anxious.

(Ms. Hamada) 'If I have a heart transplant, I may die or I may survive. I have one of these possible outcomes. I began to feel anxiety related to the possibility that I might not be helped by the surgery. ... Although I couldn't tell anyone of this anxiety to anyone, I felt it.'

This extracts shows how this recipient experienced different types of anxiety towards a heart transplant. She tended to close her fear and anxiety off from other people.

When Mr. Oda was sixteen years old, he was diagnosed as having Dilated CardioMyopathy (DCM). Once this was explained by a surgeon, he was able to understand what the disease was and what would happen to him in particular, because his mother had been diagnosed with the same condition. During the initial two years after his diagnosis, his heart condition was relatively stable. However, during his last year of high school, the condition again became worse. He was temporarily hospitalised. After graduating from high school, he began to work at a company. However, he was forced to take time off due to his health condition, and finally, he had to leave the job after one year. Then, he completely lost any wish or hope of recovery.

(Mr. Oda) 'When I lost the job, I felt that I no longer had anything to protect. Experiencing severe symptoms from the heart disease, I didn't want to suffer pain from a medical treatment. ... Prior to having this symptom, a surgeon had explained that I would need to be implanted with a VAD. I remember this: I didn't want it to be implanted.'

In the meantime, his condition declined, and he understood that the implantation of VAD would result in a heart transplant in the future. VAD can assist the patient only for limited years due to the limitation of VAD, because its long term use may trigger a blood clot which seriously damages the body. However, he did not want to have a heart transplant.

(Mr. Oda) ‘I didn’t want to think about living by receiving someone’s life. I thought that nothing positive would happen to me. I told my mother, “having a heart transplant means that someone will die. Why do I need to live without deep concern for another life? Until recently, heart transplants were not available as medical treatments. Everyone having this disease was destined to die. There are many diseases like mine. I don’t want to be saved by a machine and another human being. I don’t want live bearing someone’s life and their suffering.’”

This extract illustrates three main points. Firstly, Mr. Oda’s perception of a heart transplant is not simply receiving a heart as a medical treatment; rather, he perceives it as ‘receiving life’. Secondly, he draws attention to the fact that a heart transplant is not a popular medical treatment, and it was not until recently that patients could think about or imagine surviving by receiving a heart transplant. He seems to face a difficulty in accepting a new way of medicine. This reflects the discussion about the notion of the body in Japan. Thirdly, he does not want to be saved by a machine. This may mean rejecting the integration of a machine within the body. This relates to the discussion about the notion of the body in Japan. When facing a situation in which he needs a heart transplant, he recognises his idea of the body, which he consciously thinks about in his everyday life. While Mr. Oda was negative about receiving a heart transplant, his mother tried to persuade him to the treatment. However, it was not easy for him to change his mind, as he still felt very negative.

(Mr. Oda) ‘Mom, if you really loved me, please accept that I will die. This is the only thing that I expect from you. You will suffer from my death; please bear the suffering. You ... my only parents, will be sad about my death. I am sorry about this, but just consider this. If you accepted my idea, I would be rescued from my current suffering.’

This extract illustrates his negative attitude towards having a heart transplant. He understood that he needed a heart transplant to survive. For him, this also meant accepting a new way of thinking about the body, because, as was shown in the previous paragraph, he recognised that he was keeping a view of body that was highly influenced by the views of Japan. However, rejecting a heart transplant did not require him to change his ideas towards the body, which he seemed to share with the majority of the Japanese.

In addition to this, he referred to his feeling that he was not important to anyone. The disease disrupted his life, and, as he became sick, his life became increasingly limited. He was unable to attend all of his classes in high school. He had to give up his

job. He was often hospitalised for treatment and his life was limited by the heart disease, and he began to think that his life was unimportant. Different from Ms. Kasai's case, Mr. Oda faced an issue where self-image is disrupted by a chronic condition related to the heart disease.

He expressed this belief to his surgeon as well, when they explained the heart transplant procedure to him. The surgeon told him that he could not help him learn to live with a heart transplant if he held to the belief that his life was not important. When he listened to the surgeon's explanation, he was glad, because the surgeon understood how he felt. He struggled with his physical pain and mental resistance to having a heart transplant.

Mr. Uchida, at the age of eighteen, experienced symptoms which were initially similar to the flu, and soon after, he went to a local hospital. However, his condition rapidly became worse, and he was taken to a university hospital for medical treatment. Soon after being hospitalised, he was implanted with a VAD. He was not conscious during the procedure, and he did not remember what happened until he woke up after the VAD implantation operation. Finally, he was informed of the name of his disease, and was told about the VAD and the necessity of a heart transplant in the future.

(Mr. Uchida) 'A heart transplant wasn't so popular at that time; it wasn't often reported on TV.<sup>13</sup> I understood what a heart transplant was. However, I couldn't perceive it as something that would happen to me. To replace a heart. ... A heart is a special organ, different from other organs, such as lungs. I understood how important the heart is. Therefore, I was very anxious about having a heart transplant. I began to not believe in anything. ... I didn't want to talk about the heart transplant and my anxiety at all.'

Due to the fact that his condition was deteriorating so quickly, he did not have the chance to consider whether he would have transplant surgery or not. When he became conscious after his VAD surgery he was simply presented with the truth: he would need a heart transplant.

Summing up experiences of heart transplant recipients who had transplants as small children, and people who had them as teenagers, reluctance to receive the transplant is shown by several teenagers, but not by the two younger children. The younger children

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<sup>13</sup> Mr. Uchida had a heart transplant in 2008. As The Transplant Law was passed in Japan in 1997, 60 heart transplant operations had been performed in Japan, and more patients had received the operation abroad (The Japan Society for Transplantation Publicity Committee, 2010).

were perhaps not old enough to realise the huge implications of having a heart transplant. By contrast, it seems that for teenagers, accepting their new identity is more difficult. I argue that once the self-image is established and the disease progresses, the condition disrupts the self-image and the disruption may lead the patient to experience identity conflicts.

Next, I will focus on the older recipients who had heart transplants in their thirties or later. All of the interviewees in this research meeting this criterion are married, except one who is engaged to be married.

Mr. Makabe is one of the recipients who had their transplant in the early period of heart transplantation, as his surgery was in 1995 when he was forty-six. Before the passing of the Organ Transplant Law in 1997, if patients required heart transplants, they were forced to travel abroad. Mr. Makabe decided to have a heart transplant when he was informed that he needed either a VAD implant or a heart transplant. When he was initially diagnosed with heart disease, he waited one year until having heart surgery. During that year, he read books about heart surgery and asked other surgeons for a second opinion. When he finally had the surgery, his heart condition was serious. He regretted postponing the surgery. Following this experience, he made the decision to have a heart transplant abroad without a further waiting period. After his decision, his surgeon gave him two books that provided information about heart transplant surgery. Thus, he began to prepare himself to have the heart transplant. Nevertheless, he continued to worry about the transplant. He did not disclose this concern to his wife, and his anxiety soon reduced upon being exposed to other heart transplant recipients.

(Mr. Makabe) ‘Mr. Ozaki [another heart transplant recipient who had the transplant in the U.S before Mr. Makabe] visited me when I was hospitalised. He told me how his health condition improved after having a heart transplant. ... By seeing him and talking to him, I understood how I could recover from the heart disease by having a heart transplant. ... At that time, I hardly moved on the bed in a hospital, had problems even breathing and was connected to many tubes. It was about 2 weeks before flying to the U.S. Seeing him encouraged me a lot.’

Another recipient, Mr. Noguchi, had a heart transplant in 2006 in Japan when he was fifty. At first, he was unable to consider a heart transplant as a realistic medical treatment, even after the Organ Transplant Law was passed in 1997. Then, a surgeon explained that he could only be saved through a heart transplant, but that the likelihood of receiving a heart one was lower than winning the lottery. After hearing this, he

believed that he must prepare for death. Therefore, he told his wife, who had also heard the surgeon's diagnosis, not to share this with any other family members and relatives.

To summarise, before the treatment recommendation, a patient does not expect that a heart transplant will be necessary. Then, anxiety is caused among the patients and his or her family. The initial anxiety is caused by the fact that the majority of patients do not have a chance of receiving a heart transplant. In reality, patients do not always have this chance, although they may yearn for it. Another recipient, Mr. Watari, expressed his experience regarding this situation:

(Mr. Watari) 'I thought that it was cruel to have hope. I may be able to recover from the illness by having a transplant, and I can step forward towards the new life. However, I can't predict when I will have that chance; no one can. I can only perceive it as a minor possibility in the distant future, which is torture. If I was unaware of the possibility of heart transplants, I may be able to think about my odds of living in a more simple way.'

In this extract, the harsh reality of having a heart transplant is condensed. Although the patient decided to receive the transplant, the chances of having a heart transplant are still controlled by other factors such as the donor's wishes.

There is another commonality among the patients. It was common to avoid expressing anxiety related to having a heart transplant. For example, Ms. Okamoto described how she felt when she knew about her disease and that she would need a heart transplant:

(Ms. Okamoto) 'I didn't know anything about Dilated CardioMyopathy (DCM). As surgeons and my family had tried to keep it [my disease] secret from me, I tried to find out about what my actual disease was. I attempted to collect information about DCM on the internet. It was a kind of online medical dictionary that I searched. According to the web-page information, the survival rate for DCM is quite low. It also gave information about the survival rate after three years and five years. It said that DCM causes sudden death to some patients. I was almost in a panic. I felt, 'What's happening to me?' ... I stopped searching for information on the internet, because I didn't want to be depressed by this kind of information. ... I didn't tell anyone what I searched for on the internet.'

Why did she not tell anyone what she found about her disease, DCM? She continues:

(Ms. Okamoto) '...until a surgeon explained DCM, I hadn't said anything like, "I read about DCM on the internet" to my family. I suppose that my family sought a chance to tell me about my disease DCM, however, it wasn't easy for

them. At Nihon University Itabashi Hospital (NUIH), Dr. Minami explained about DCM to me. My family said, “We feel relieved as he explained DCM to you.””

Ms. Okamoto and her family knew about her heart disease of DCM through different channels. This extract gives an interesting insight into the relationship between a patient and family members. Her family members should be ‘the Wise’ for her. Nevertheless, neither the patient nor her family shared information in the early period after the diagnosis of her disease. Before agreeing with each other that the patient’s family should be ‘the Wise’ for the patient, both needed some time. This means that it takes time to become ‘the Wise’, i.e. being ‘the Wise’ needs the approval of the patient and cannot happen without this approval.

A surgeon had explained the condition to her family, and Mrs. Okamoto researched information on the Internet. Due to the fact that DCM is quite difficult to treat, neither Mrs. Okamoto nor her family could avoid imagining that she might pass away. Mrs. Okamoto did not tell anyone what she researched about DCM on the internet in order to avoid bringing the issue of death into a conversation with her family. At least it can be said that she postponed it, and by doing so, she acquired time to find the right moment and setting to discuss DCM and death with her family. Her attitude may reflect the fact that the topic of death is a taboo in family conversation in everyday life in Japan.

She hid her true feelings and acted as if she were not concerned about her illness. She tried to put on a certain persona as a patient. In the next section, I examine how these patients communicate with ‘the Own’ and ‘the Wise’ in relation to anxiety.



#### **4.4 Patients' relationship with 'the Own' and 'the Wise'**

In the social networks of people who have heart transplants, it is possible to distinguish, as explained by Goffman (1968), two important groups of people: 'the Own', who are others facing similar experiences of having a heart transplant, and 'the Wise', who are people whose close knowledge of – and often sympathy for – the individual facing heart transplantation comes from the fact that they are the family, friends, neighbours, surgeons and other medical staff who have personal relationships with the person, or are journalists and others who have made a special study of the experience and have therefore acquired wisdom about it. There are two channels through which patients can know their 'Own' and 'the Wise'. One is through face-to-face communication, and another is through the mass media. I will examine the narratives from interviewees about people whom they considered to be their 'Own'.

As discussed in the previous section, patients experience anxieties over having a heart transplant during the decision-making process; these anxieties remain, even after their registration on a waiting list. As the majority of the recipients narrate, to see other heart transplant recipients ('the Own' in Goffman's terms) can reduce these patients' anxieties. Mr. Higashi describes how he felt when he met another heart transplant recipient:

(Mr. Higashi) '... Receiving explanations about a heart transplant, I had the impression that a heart transplant would bring many negative things to the patient. I heard that heart transplant recipients would be restricted in their lives in many ways, and that they had to take medicine for the rest of their lives. ... At that time, heart transplants were prohibited; health professionals in Japan were not familiar with heart transplants. However, heart transplant recipients whom I met looked really fine. I was really amazed by how fine they were. Having had chances to meet them, I made a decision to have a heart transplant.'

Mr. Higashi worried that his life would be greatly restricted by a heart transplant; he could not imagine the positive aspects of the transplant before seeing an actual recipient. However, Mr. Higashi saw these positive aspects once he had met a heart transplant recipient. He saw the possible future for himself that he might not be subject to a restricted everyday life. In his case, the role of the hospital and his surgeon were as intermediates allowing him to meet others who had received transplants.

Even though the number of Japanese heart transplant recipients has increased and heart transplants have become more popular than before – whilst remaining fewer in number than in other countries – the number of heart transplant recipient are limited in Japan compared to patients who receive other medical treatments. This leads heart transplant recipients to continue to play the same role of showing the possibility of a future after having a transplant.

Mr. Makabe also reduced his anxieties by getting to know other recipients. He made a decision to go abroad to have a heart transplant in spite of his anxieties. This decision was made with his wife. Even though Mr. and Mrs. Makabe made a decision to go to the U.S for the heart transplant, they also had anxiety over having the surgery. When he was hospitalised in Japan to prepare to go abroad for the surgery after his condition became worse, a journalist visited him with an article that reported another heart transplant recipient who had returned from the U.K. The journalist also explained to them how the recipient had been before the surgery, which was quite similar to the condition of Mr. Makabe. Knowing the result and the current condition, their anxieties were overcome to some extent. In this case, the journalist was the intermediary who let him know about other recipients.

These cases show that by seeing and knowing other recipients, patients can cultivate an image of how they wish to be. The actual recipients gave the impression that they had been released from a previously restricted and socially isolated life. In this regard, the actual recipients are role models for the potential heart transplant recipients, and they therefore have considerable power to influence new patients towards the decision to have the surgery. Regardless of the patients' age and gender, this was a common experience among patients. These other recipients might be considered 'the Own', as they are facing the same heart problem.

Next, I will focus on relationships among the potential heart transplant recipients before they have the transplant. Mr. Sano, who was a self-funded patient, had been hospitalised at Tokyo University Hospital before going to the U.S. During this period, two other patients were hospitalised in the same room and they each established a good relationship with Mr. Sano. One of the patients passed away before having the chance of a heart transplant. After that, Mr. Sano had the opportunity to go to the U.S. However, he felt he could not disclose this to the other patient until just before his leaving, because he was self-funding his trip to the U.S, and he knew that this was not possible for every patient. Although, prior to the hospitalisation, he had agreed with health professionals that he would be hospitalised for a while, and then go to the U.S, and he

had good communicative experiences with other patients, he was always sensitive about what information to disclose to others. After returning from the U.S, Mr. Sano knew that another patient, who had been in the hospital with him, had a heart transplant in Japan. As his case shows, chances to have a heart transplant for the patients are influenced not only by the medical factors, but also by the socio-economic conditions of each patient.

By contrast to self-funded patients, patients who support their operation by fund-raising from the public have more communications with other patients. After learning that she needed a heart transplant, Ms. Kasai began to find out about heart transplantation. She was fourteen years old when she was diagnosed. The more she studied, the more questions she had as to why children could not have heart transplants in Japan. Then, she and her mother started a group to change this situation, which consisted of patients and their families (Kouda, 2010). When she went to Germany, other patients whom she had met through the group presented her with some special memento items (called *Omamori* in Japanese), which people buy at Shrine when they go to pray. She kept these Omamori with her, even when she went to the operating room for a heart transplant. So, Ms. Kasai perceived their special relations through the Omamori, as she was always reminded that there were many patients who were waiting for organ transplants, including other types of organ transplants. In reality, her everyday life was physically isolated, particularly, during her hospitalisation, and her activity became more restricted due to her health condition. However, as she established relations with other patients, it seemed that this network relieved her from her feelings of isolation because the Omamori became symbolically important to her.

Finally, I focus on some aspects of the relationship between patients and ‘the Wise’ during this period. Some patients, in particular those who receive fund-raising support from the public, experience difficulties in reconciling the feeling of appreciation and the feeling of being sorry that they required fund-raising support. Mr. Oda struggled a lot with internal self-conflict prior to going to Germany using money from fund-raising. One day, two of his friends recognised his conflicts.

(Mr. Oda) ‘Prior to leaving for Germany, two of my friends came to see me and told me, “Other friends are doing everything they can to help you. We have decided not to do anything for you. We’re really sorry about this. However, you might have some complaints that you cannot express easily to other people. You can express such feelings to us whenever you need to. We want to be your friends; therefore, we won’t give you any funds.” When they told me so, I didn’t understand why they told me like that. However, I appreciate that they didn’t help the fund-raising for me.’

To attempt fund-raising to go abroad to have a heart transplant puts a certain social pressure on the patient and their family. In most cases, it costs more than 100 million yen (£700,000) (Cabinet Office, Government of Japan, 2008). These friends worried that as Mr. Oda owed a lot of money to the public, he may have felt pressure to express only appreciation to other people. He may have felt that his social standing had suffered because he had asked others for money. This feeling was likely to last until such time as he could repay those who had financially supported him. Therefore, these two friends told Mr. Oda that they did not help the fund-raising in order to keep the same status as friends. After some time Mr. Oda came to appreciate their attitudes more.

So far, I have examined the relationships of patients at this time with ‘the Own’ and ‘the Wise’, focusing on patients’ anxieties. This has been analysed in terms of the relationship between (a) heart disease patients and heart transplant recipients, (b) the relationship among the recipients, and (c) the relationship between the patients and the people who have sympathy for them. I will now summarise what emerged from this exploration.

First, even though the number of heart transplants has increased, heart transplant recipients have an important role in that they show other patients, through both face-to-face communication and through the mass media, the future that is possible by having a transplant. In particular, in the early 1990s, the recipients sometimes played the role of convincing other patients to have the surgery. Second, the patients have had more chances to communicate with other patients before having their transplants. On the one hand, the growing relationship with other patients makes it possible to share information and anxieties with them; on the other hand, patients face the fact that, for medical and socio-economic reasons, not everyone has the chance of having a transplant. Third, the patients’ relationship with ‘the Own’ and ‘the Wise’ was initially enhanced by health professionals who played the role of intermediaries. Others including journalists, patient support groups and the patients themselves have taken on the role of the intermediaries and the network has grown. Because of this, the ‘label’ of being a heart disease patient who needs a heart transplant and the ‘label’ of being a heart transplant recipient has become more prominent in society. In the next section, I will examine further aspects of this relationship, considering in particular the patients’ experiences of stigma.

#### **4.5 Responses of ‘the Wise’ to the decision to have a heart transplant**

Upon making the decision to have a heart transplant, and upon disclosing this decision to other people, patients usually experience a number of different responses, both positive and negative. Some of these are included to illustrate the reactions to their decision.

Before going to the U.S, Mr. Makabe’s friends visited him in hospital. At that time, none of his friends believed that he would have a successful heart transplant. Mr. Makabe’s friends told him their feelings when he was recovering from the disease. He said, for example, that several had said things like this:

(Mr. Makabe) ‘My friend told me, “At that time, I thought that it was the last time that I would see you, because I didn’t believe that you would be healed by having a heart transplant. I couldn’t imagine that you would be fine like you are now.”’

Mr. Makabe did not hear these types of negative opinions directly from other people before going to the U.S. In contrast, these friends and also some health professionals, revealed their sceptical thoughts about recovery to his wife. His wife went to a bank to discuss a loan of money, just in case. In the discussion, the bank officer repeatedly asked her whether Mr. Makabe’s life would really be saved by a heart transplant. Mrs. Makabe assumed that the person at the bank did not completely believe that a heart transplant would save Mr. Makabe. Yet Mr. and Mrs. Makabe thought that their only hope was a heart transplant in the U.S. At the end of this discussion, the bank person suggested to Mrs. Makabe that, when she needed the loan, the bank would offer the loan to her husband’s company, instead of offering it directly to her and her husband for his heart transplant. This means that the bank had concluded that a recovery from the heart transplant was in doubt, so that if Mr. Makabe died the bank would be able to recover the money from his company.

Before leaving for the U.S, Mr. Makabe was hospitalised at Osaka University Hospital for a while. In order to safely travel to the U.S for his transplant, it was essential that Mr. Makabe’s condition be improved during this hospitalisation. His condition was not good, as he could not breathe well and was sleeping poorly. He became nervous. Therefore, he was moved from a group room to a private room, which incurred an additional payment. Regarding this, a nurse asked Mrs. Makabe:

(A hospital nurse at Osaka University Hospital) ‘You’re very optimistic, aren’t you? Do you understand how much it will cost to have a heart transplant?’

Being told these things like this, Mrs. Makabe often cried in the hospital restroom. In reality, Mrs. Makabe was under terrible pressure, being anxious about her husband having a heart transplant as well as worrying about financial matters. Mentally, she almost reached her limit. Yet she consciously tried to show no pessimistic attitude to her husband during his hospitalisation. When the nurses saw her attitude around Mr. Makabe, they sometimes told her that she was too easygoing. Through these experiences, Mrs. Makabe recognised that some nurses were not necessarily positive about heart transplants, even though this was one of major hospitals for heart transplant patients in Japan.

The experiences of Mr. and Mrs. Makabe highlights that medical practitioners, such as nurses, expect certain behaviour from the heart transplant patients’ families. In this case, the nurses, in particular those who were negative towards heart transplant expected that Mrs. Makabe would show a pessimistic attitude, and would try to save as much money as possible. In the early period, heart transplants were a controversial issue, even among medical practitioners (Watanabe and Abe, 1994). There were no hospitals that fully supported the sending of patients abroad to have heart transplants; the process of sending the patient from a hospital in Japan to a hospital abroad was often arranged by individual surgeons (New Heart Club, 1993). For example, a recipient told me during the interview that his surgeon in Japan used his holiday time to bring this patient to a hospital abroad because the hospital in Japan did not consider this to be its obligation. This shows that there existed a negative attitude towards transplants among some medical practitioners in the early 1990s. Furthermore, it seems that the boundary between what medical staff had to do and what they were expected to do was sometimes ambiguous. It could be the case that this kind of negative connotation also extended to patients and their families.

In trying to understand why this happened, it may be useful to reflect on the paternalistic relationship between a health professional and a patient. There may exist an idea in which, as health professionals do their best for their patients, the patients have to appreciate their help by expressing appreciation with obeisance. Ueno (2011) indicates that the paternalistic tradition between health professionals and patients in Japan has restricted patients’ chances to receive the medical treatment they need. In the

paternalistic relationship, patients tend to be passive. As patients are still familiar with this passive attitude, the majority of them are not trained to express their needs during medical treatment. Similarly, the majority of health professionals are familiar with this type of relationship (Murphy, 2008; Ueno, 2011). Under this paternalistic tradition in the Japanese medical field, heart transplant surgeons may have brought a new wave of change to this paternalistic relationship. In this regard, not only potential heart transplant patients but also heart transplant surgeons are outsiders from the traditional Japanese medical field. Thus, Mrs. Makabe's experience can be considered a reflection of the conflict between the paternalistic medical practitioners and the outsider. It can be considered that they experienced such stigma in their communication with medical practitioners in the hospital because Mr. Makabe had a heart transplant abroad in the early period. This kind of stigmatising experience is not found among more recent patients. This is because the procedure has improved to the point where more people now survive.\_

The responses from 'the Wise' were not always negative. As mentioned in the previous section, Ms. Kasai was fourteen years old when she was informed that she needed a heart transplant. Due to legal regulations, she was too young to undergo a heart transplant in Japan (The Japan Society for Transplantation Publicity Committee, 2010). Nevertheless, Ms. Kasai wanted to wait for the law to change so as to have the chance for a transplant in Japan, because she knew that there were many patients who were waiting for heart transplants in Japan. However, her neighbours and local people asked her:

(Ms. Kasai's neighbour) 'Why don't you go abroad to have a heart transplant soon? ... You should do so.'

Ms. Kasai explained what her mother would say to the people who said things like this, as follows:

(Ms. Kasai) 'However, my mother explained to these people why we were waiting for a chance in Japan, and she asked them to join the street sign-in campaign and to sign the petition to change the law.'

Ms. Kasai expanded her network with 'the Wise'. Unlike Mr. Makabe's case, Ms. Kasai's case occurred after the passing of the Organ Transplant Law in Japan in 1997. Ms. Kasai had also disclosed the personal issues of her heart disease and the transplant

to her friends and neighbours by starting a patient support group and a petition. This public aspect of her status as a heart disease patient may have been helpful in avoiding the negative responses from other people regarding having a heart transplant. In other words, Ms. Kasai tended to behave as a patient who was constantly sensitive towards others' responses.

In the early period, in particular in the early 1990s, which was before the Organ Transplant Law was passed in Japan (1997), people tended not to consider heart transplantation as a realistic medical treatment. Therefore, some of the patients' friends said, after their return to Japan, that they had not imagined that they would see them again. As they had seen these patients as dying people. However, as time has passed, people's responses have also changed. People have recognised that a transplant can help patients. The problem is that only a limited number of patients have this opportunity. This limitation may stimulate peoples' jealousy toward patients who were able to have heart transplants, especially considering that some patients received negative responses from others.



## 4.6 Recipients abroad and the fund-raising process

In this section, I will examine the way in which the experience of fund-raising influences heart transplant recipients' identity. In other words, this section considers the issue of identities among recipients in terms of the relationship between the patient and the anonymous public. Nine out of nineteen heart transplant recipient interviewees in this research had heart transplants abroad with the help of varying amounts of fund-raising support, rather than being wholly self-funded. The typical process of fund-raising is as follows: firstly, the patient's family members officially set up a support team which aims to conduct the fund-raising. The head of the team is usually one of the family member's close friends or in a close relationship with the family. Secondly, the family member and the patient, if the patient's health condition permits, give a press conference at a local government office which is the centre of each region government. These conferences are often introduced on the local TV news, and announced through the local newspaper (Aranami, personal communication, 12 December 2008). Thirdly, the team starts fund-raising; the team members regularly ask the public for donations. Fourthly, the team creates a website as well. Five out of nine recipients in this research had websites.<sup>14</sup> Three other recipients had their transplants in the 1990s, when using websites was not as popular as it is now. One did not have a website, in spite of having a transplant at a time when this was available.

At the starting point, there are several variables which impact upon whether the fund-raising goes smoothly. The patient's profile, such as age and gender, has an impact. As we have seen in section 4.2 (Figure 11), younger patients are more likely to have used fund-raising to have heart transplants abroad compared to older patients.

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<sup>14</sup> Hiromi-san wo sukuu kai [A support group for Hiromi-san] (2004); Junpei-kun wo sukuu kai [A support group for Junpei-kun] (2007); Karu-chan wo tasukeru kai [A support group for Karu-chan] (2008); Misato-san wo sukuu kai [A support group for Misato-san] (2008); Miyuki-san wo sukuu kai [A support group for Miyuki-san] (2008).

**Table 10 Recipients of heart transplants abroad by age and source of funds between May 1984 and June 2008**

Age	Fund-raising	Own expenses	No data	Total
<10	33	3	4	40
10-19	27	4	1	32
20-29	10	0	3	13
30-39	9	4	1	14
40-49	9	3	5	17
<50	3	1	1	5
No data			7	7
Total	91	15	22	128

As for the ninety-one patients who used fundraising support, thirty-two are female and thirty-nine are male. Data for twenty patients out of ninety-one was missing. There is not a huge difference between female and male patients in terms of opportunity, as reviewed in the previous chapter.<sup>15</sup> Ms. Hamada, who had a heart transplant when she was seventeen years old, explains her fund-raising experiences as follows:

(Ms. Hamada) ‘In my case, we struggled a lot to reach the target amount of fund-raising money. I was not a small kid, although I heard that it was easier to reach the target amount if the patient had been a small kid. In addition, I live in Tokyo.’

As Tokyo is the capital of Japan, there are several key hospitals in relation to heart transplantation, and people can access these hospitals more easily than in other cities. However, these geographical advantages do not seem to necessarily benefit fund-raising.

What do patients actually experience in relation to fundraising? Furthermore, what do they think about the fundraising? I explore these questions here. Mr. Oda describes what he felt when he was told by his mother to go to Germany to have a heart transplant, as follows:

(Mr. Oda) “‘Germany? How are we able to pay for the cost?’” I heard that

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<sup>15</sup> These data are also based on information from The Japan Society for Transplantation Publicity Committee (2010) and newspaper articles. The Japan Society for Transplantation Publicity Committee (2010) publishes information on the number of Japanese heart transplant patients abroad; however, it does not give detailed information.

some people had already told my parents to help the fund-raising. I said, “How can I repay them? Who will help me?” I thought that I didn’t have any friends at all to help me. I felt miserable when thinking of it.’

He continued:

(Mr. Oda) ‘Imagining that people are in the street to ask the public for fundraising to have a heart transplant abroad for me, I felt ashamed and miserable at the thought of fund-raisers in the street asking the public for money so I could have a heart transplant abroad. I saw them on the TV news and felt even more miserable. I took my frustration out on my parents, and I told them, “I don’t need help like that.”’

To ask for public fund-raising reduced his dignity. This feeling was enhanced by the fund-raising on TV. However, as discussed in the earlier section, he gradually came to accept his situation and finally became positive about having a heart transplant. Thus, he went to Germany. Once, in Germany, he needed to regularly update his website with photos to show his progress. This website played a role in helping him inform the people who had helped to send him to Germany of his situation. At the same time, the website gave more anonymous donors the chance to learn about his situation. Another patient, Mr. Uchida, responded more positively to the mass media interest:

(Mr. Uchida) ‘When we were told that I could most likely be accepted by a hospital in the U.S., we needed to prepare the money for the deposit for the hospital. Without money, this chance to go to the U.S. couldn’t proceed. Therefore, I appeared on TV as many times as possible to ask for fundraising. When appearing in TV programmes, I attempted to introduce my disease and how it was. I thought that the public’s understanding of my disease was fundamental prior to asking for fundraising.’

By appearing in TV programmes, he began to receive responses from the public:

(Mr. Uchida) ‘I began to receive letters and emails from people who watched me on TV. For example, one person wrote to me: “knowing about you, I felt my problems seemed very small, therefore, I’ll do my best in life”. I received many other similar messages a lot. I was surprised that I was told “thank you” by someone else, because I was hospitalised.’

Through communicating with the public by TV, letters, and e-mails, his dignity began to return to him. Ms. Sakata had similar experiences:

(Ms. Sakata) ‘Receiving letters from the anonymous public, and listening to

how an anonymous person gave fundraising money on the street, I was encouraged by them. I thought that now wasn't the moment to hesitate to step forward to have a heart transplant. On the contrary, I still wondered whether my survival was worth using a lot of money. After experiencing these internal self-conflicts, I gradually began to think that it wasn't worth thinking about whether there was value or not, and I have to live'.

Initially, patients' lives are disrupted by having heart disease, and they are isolated from their previous lives. In addition, patients sometimes feel 'ashamed' to ask for public fundraising money. Through communication with the public, especially if members of the public send messages of support and encouragement, the feeling of 'shame' can be reduced. However, it cannot be concluded that the isolation is also reduced. When the public knows the person as a 'patient-in-need', the patient responds to the public as a 'patient-in-need'. Through these kinds of communication, patients acquired a stronger identity as patients.

## 4.7 Identities of patients with implanted VAD

Five out of nineteen heart transplant recipients who were interviewed for this research had received a ventricular assist device (VAD) implant prior to having a heart transplant. A patient who receives a VAD is in a severe condition and cannot live without it. Although a VAD can save a patient's life, such everyday life is physically limited by the implantation, and the VAD has a limited duration of use.

Mr. Ono received a VAD implant, which was still in the experimental stage, at Osaka University Hospital in 1995, before the passing of the Organ Transplant Law in 1997. Because he was implanted with the VAD, he could leave the hospital and live at home while waiting for a chance to have a heart transplant. Soon after the implant surgery, his surgeon explained to him that he was unsure how long the VAD would work properly in Mr. Ono's body. Thus, Mr. Ono was given a chance to live with the VAD and wait for a heart transplant. Not only was his present life influenced by the VAD, but also he could not envision his future either. As a result, after receiving his VAD and after the Organ Transplant Law was passed, he registered on a waiting list for a heart transplant. However, this brought him and Mrs. Ono tough times. Mrs. Ono describes how they felt during their wait for a heart transplant:

(Mrs. Ono) 'Before getting into the worst condition of the body with VAD, we even thought to ask further help of a surgeon, and go to the U.S. to have a heart transplant. We did have a strong hope to live. ... We experienced depression during the 1,000 days.'

Under the pressure of time, not knowing how long the VAD would work properly in her husband's body, Mrs. Ono strongly wished that her husband might somehow survive with the help of VAD until his chance for a heart transplant, and experienced depression. Mr. Ono wanted to understand what a heart transplant is:

(Mr. Ono) 'I met some heart transplant recipients to listen to their experiences. They gave me a lot of information about the transplant. Nevertheless, I couldn't smoothly digest it.'

One thousand days after receiving his implant, he underwent heart transplant surgery in Japan.

Once having received a VAD implant, the body is connected to a device by a hose.

The majority of patients think their body's appearance with the hose makes them different from others, particularly from their friends who have been with them.

Mr. Oda did not initially experience restrictions on his life even after being diagnosed with DCM. But his life was restricted by his being implanted with a VAD, and he also experienced social isolation. He returned home for a while after the implantation. Before his parents took him to Germany for his heart transplant operation, they prepared a fund-raising activity that was reported on television. Soon after, his friends began to visit him at home. However, he declined to see them because he did not want them to see him with the VAD.

Mr. Uchida, another recipient, had a similar experience to Mr. Oda. Mr. Uchida received a VAD implant when he was teenager, as did Mr. Oda. After the implant surgery for the VAD, Mr. Uchida shut out his friends and did not see anyone because he did not wish to show himself with the hose. He gradually began to accept some of his close friends' visits. Mr. Uchida describes this experience as follows:

(Mr. Uchida) 'Some worried about my situation with a hose. However, my close friends didn't refer to my heart disease. They talked to me the same as before. I was very pleased with their attitudes. I didn't want to be treated as a diseased person. For example, one said "pass the cup to me." This means that this friend treated me as if I was not a diseased person. I felt that I was still the same as before with them.'

By referring to an example of communicating with his friend, Mr. Uchida attempts to describe how his friend did not treat him as a vulnerable patient. He did not have a problem passing a small mug to his friend even in a condition in which his body was connected to VAD with a hose. Mr. Uchida worried that his friend who saw his condition might help his every movement. Even after seeing his condition, his friend attempted to behave as though he was interacting with the 'usual' Uchida, rather than a diseased, vulnerable person, i.e. in this example Mr. Uchida preferred that he could hold onto the self-image which he had had before the hospitalisation. In contrast, Mr. Hamada felt ashamed that he had a VAD:

(Mr. Hamada) 'I felt bad going out with a VAD, because I felt that being with a VAD was inferior to other people. It took time to make my decision to go out, which would be to be seen as a person with a VAD.'

The experiences of these patients show that all had a certain unconscious image of the 'ordinary' body. Their friends also had ideas of the body. Having a VAD meant not only

physical but mental isolation from friends. This was an experience of identity crisis for the patients. They had to accept that their body image had changed, and was an image different from that of their friends. In other words, they lived in a different social category from their friends. In addition, in order to ask for fund-raising money, they had to disclose information to their friends and the public about having a VAD and waiting for a chance for a heart transplant. While possessing these internal self-conflicts, they experienced isolation from society as a whole and from their former personal relationships. At the same time, they experienced psychological isolation, but this problem was often gradually solved, as Mr. Oda shows. Immediately after the implant of the VAD, Mr. Oda did not see anyone; however, he began to slowly accept his friends' visits and even began to enjoy the time spent with them. This changed his attitude towards having a heart transplant.

(Mr. Oda) 'How can I say ... instead of expressing directly how I felt ... a feeling that I shall return to see them was bigger than a feeling of worry.'

He began to re-recognise himself as important to his friends, and his friends as being important to him. In spite of this change, Mr. Oda had a lot of concerns regarding what would happen in order to have a heart transplant, and what medication he would need in the future.

(Mr. Oda) 'I started not to care about these things [medical information along with a heart transplant]. All I thought about was getting back to my friends.'

In the case of Mr. Oda, his relationship with his friends made him realise the importance of being positive when waiting for a heart transplant while having a VAD. We can consider this process as a re-establishment of his identity. Mr. Oda's life was first disrupted by heart disease, and this disruption became visible to others after he received his VAD implant. Yet after realising that he was accepted by his friends as before, he was released from his psychological isolation and his identity entered a more secure phase.

## **4.8 The moment of being informed that a heart transplant can occur**

To be informed you are about to actually have a heart transplant means the end of the waiting period for the patient. The moment is very sudden for patients. Although patients are expecting the news and accrue information about heart transplants, including the risks, during their waiting period, patients experience individual situations which might be different from what they have anticipated. In this section, I examine how patients feel about having a heart transplant just before the surgery. In particular, I focus on how they perceive the assumed risks of heart transplant, and the expectations regarding having a heart transplant. Then, I examine the way in which these feelings influence their identities.

Narratives of patients' feelings about having a heart transplant just before the surgery are varied. Ms. Kasai describes at the moment of receiving the news as follows:

(Ms. Kasai) 'When I was told that a donor appeared, my mind went blank. I came to Germany to have a heart transplant. Nevertheless, I thought about a donor and his or her family, first of all. I was just thinking about how the donor's family were now. Thinking about how someone had passed away, I felt terribly sad, and cried. A nurse was with me and she told me, "You don't need to cry, nobody died for you."' "

Until that moment, she had already been hospitalised in Germany for more than two years, and she had experienced dangerous conditions during her hospitalisation. She had waited for this moment for a long time. Nevertheless, she could not help thinking about the donor's death and the donor's family, rather than thinking about her own surgery, or the possibility that she too might die.

After the notification of the upcoming heart transplant, she had one hour before having the operation. During that hour, she made several phone calls to her aunts, uncles, grandparents and a representative of her fund-raising support organisation in Japan to let them know what was about to happen. Everyone was glad to know that she would finally have a heart transplant. Through conversations with them, she began to calm down.

(Ms. Kasai) 'The donor's family suddenly lost their family member. Thinking about how they made a decision so quickly to agree to donate their family



member's organ, I was amazed by their having made the decision in their deep sadness. Thinking about this donor family, I could become positive about having a heart transplant, as if fog had lifted.'

During this one hour, she thought about the donor's death, the donor family's sorrow, and the feelings of her own family, relatives, and friends. After contemplating and experiencing these feelings, she could somehow manage them.

Another recipient, Mr. Sano, experienced fear about having the transplant when he heard that a heart was available:

(Mr. Sano) 'I felt fear when I was informed I was having a heart transplant. Nobody knows what will really happen during the operation, do they? A transplanted heart might not work. I may die. I feared the operation. However, I tried not to show my fear to others; I attempted to behave as usual. Otherwise, my wife would be upset if I was beside myself ... Of course, thinking about the situation; I couldn't reject the heart transplant because of my fear. To be or not to be, this was the only way at that time.'

His fear was that he may die during the operation. In his case, he overcame the fear by pretending that he was OK.

Ms. Okamoto experienced her heart transplant being cancelled. Many patients experienced transplant cancellation after the notification due to medical reasons. In her case, prior to the cancellation, she had a catheter inserted for the operation, which was terribly painful.

(Ms. Okamoto) 'I wasn't sure how I would be in the process of having the heart transplant. From the previous experience, I was scared of having the catheter inserted. I easily got sick during the medical treatment because of the 'contrast agent' and the tubes. I wasn't sure what kind of pain I would experience. During the anaesthesia, I would be OK, however, I would feel pain. People told me that such pain doesn't matter, but... I also thought, "Can I return home? OK, I need to make a bit more effort, and I can return home." I did my packing talking about these feeling with my mother.'

Her fear was about the physical pain. Whatever people said to her, she was traumatised by the painful experience of the catheter insertion. However, she found a strong hope that she could return home after a heart transplant.

Another patient in my research, Mr. Uchida, experienced the transplant operation without any notice being given to him:

(Mr. Uchida) 'One day, I was brought to a room, which was like CCU or ICU.'

I understood that the room was for patients just before having an operation. I was wondering whether I would have transplant surgery. However, nobody told me anything. ... A medical staff member and an interpreter were in the room. The interpreter told me that the staff wasn't sure whether I would have a heart transplant. After a while, I was brought to an operation room. My father assumed that I was in an X-ray room, and he wasn't told that I was being brought to an operation room. Therefore, I didn't have any chance to talk to my father. Soon after being brought to the operation room, I was given anaesthetic. When I woke up, the heart transplant was done.'

In his case, he did not have a chance to think about fear, pain, and donors, like other patients did.

Prior to heart transplant surgery, patients generally collect and study information about heart transplants. This means that they mentally simulate what a heart transplant is going to be like. Nevertheless, patients tend to experience fear just before having heart transplants regardless of their expectations; at the same time, they tend to shut out the feeling of fear. The main reasons to shut out this feeling are that they do not want to make their family worry, and they do not want to be seen as showing a loss of their self-control. To summarise, it is important to them to maintain a certain image and behaviour in relation to their families and friends.

How do these emotional experiences influence patients' identities? By simulating what a heart transplant is going to be like, patients construct a self-image of the recipient with reference to other recipients. This is a process of assimilating one's own self into other recipients. Despite the simulation, patients experience fear of having a heart transplant. They try to control their behaviour in order not to express fear, particularly in front of their families. In these circumstances, they attempt to maintain the identity that their family is most familiar with, and not the identity of a heart transplant recipient. In other words, this is the moment in which the existing identity is mixed with the new identity of a heart transplant recipient. Thus, underneath the fear of having a heart transplant, patients emotionally struggle to accept their new identity.

## 4.9 Conclusion

This chapter has examined patients' experiences during their pre-operative periods, focusing on how patients manage feelings, relationships, pain and distress during the process of deciding to have a heart transplant.

From being given the diagnosis of heart disease, from which having a heart transplant is the only way to recover, patients usually experience intense anxiety. The initial anxiety is due to a lack of adequate access to necessary information about heart transplantation. The anxiety is reinforced by the truth that the majority of patients do not have the chance to receive a heart transplant. Nevertheless, several patients tried to avoid expressing anxiety about having a heart transplant to their families, friends and health professionals, and rather acted as if they were not concerned about it. This means that they assumed a certain persona as patients in relation to those close to them.

In this regard, the patients' lives are disrupted in two different ways. Firstly, the disease physically disrupts their lives. Secondly, they are disrupted in terms of the switch to new identities as patients who need heart transplants, something that is not always easy to achieve. Their identities as patients are influenced by social and economic factors such as age, gender, geographical location, family background and the time of the heart transplant. In addition, the patients are categorised into three groups: patients who had heart transplants (1) in Japan, (2) abroad by self-funding, and (3) abroad by fund-raising. The patients in each category established relationships in different ways with other people and I have focused on three groups: 'the Own', 'the Wise', and the public.

Regardless of the categorisation of when and where patients have a heart transplant, there is a common process among the patients during the pre-operative period. Following the recommendation that they need a heart transplant, patients experience negative emotions, such as fear and anxiety. They collect information and simulate in their imaginations the process of what a heart transplant will be like. They struggle with the conflict of holding on to their old identity and accepting the new identity of a heart transplant recipient. The patients face this issue of having an identity that will differentiate them from others, such as their friends. In this regard, a heart transplant is a transformation of the self into a new person.

The differences between the recipient and other people become more prominent

with patients who are implanted with a VAD and ask for fund-raising support from the public. Patients who are implanted with a VAD experience suffering as a result of their changed body image, because the presence of a VAD is highly visible to others. Patients who seek to raise funds also experience being publicly recognised as heart disease patients, and as being different from most members of the general public. There exists a gap between the self-image, which the patient may want to hide from others, and the image that other people hold of the patient. The patient does not want to be differentiated by being seen as a vulnerable patient, as VAD visibly exaggerates these aspects, while other people may easily hold an image of the patient as very diseased. Therefore, patients experience stigma as a result of making the decision to have a heart transplant.

From my data analysis, it seems likely that the experience of stigma was stronger in patients who had transplants during the early period of the transplantation programme. If this is true, it could be that in more recent times, stigma has been experienced in particular by patients who go abroad for their surgery rather than having it in Japan.

In the early period, people tended to consider a patient who had a heart transplant as a dying person, and heart transplantation was not widely believed to be a realistic medical treatment – as Mr. and Mrs. Makabe’s interview showed. In addition, those in the Japanese medical field considered both the transplant surgeon and the patient outsiders. More recently, heart transplants have become accepted as practical treatments. Still, only a limited number of patients have had the opportunity to have a transplant; due to this low number, patients risk becoming targets of jealousy from the public. This is because the majority of people in Japan have similar lifestyles, in particular after the Second World War, and the majority believe themselves to have a similar quality of life, culturally and economically, to others around them. This equalisation, more or less, has been encouraged at a nation-state level. Health care support is a part of this. Therefore, to be different or to be prominent compared to others tends to give one a negative reputation in Japan; within this socio-historical background, having a heart transplant goes against one’s virtue.

In the next chapter, I will examine the way in which the patients re-establish their identities after the heart transplant. It will become clear that the chronic condition of patients during the pre-operation period does not stop even after having heart transplant. Patients experience a different type of chronic condition, largely dictated by the need to maintain lifelong immune system control. This has profound consequences for both their identity and their relationships with others.

## Chapter 5 Experiences after heart transplant surgery

### 5.1 Introduction

This chapter explores the experiences of heart transplant recipients after their heart transplant surgery. Before having surgery, the patients are isolated from society due to heart disease. The heart transplant releases patients from social and physical isolation. From a medical standpoint, most cases take about a year to return to a life in which it is possible to return to work, school or community activities in society like other people (The International Society for Heart and Lung Transplantation, 2010a; The International Society for Heart and Lung Transplantation, 2010b; The Japan Society for Transplantation publicity Committee, 2009). From the viewpoint of social policy, heart transplant recipients are regarded as disabled for the rest of their lives (Bureau of Social Welfare and Public Health, Tokyo Metropolitan Government, 2009).<sup>16</sup> The heart transplant recipient returning to society has to cope with many changes. For example, they have to gain access to medications and learn how to take them in a way that is integrated into the rest of their daily lives. In order to qualify for formal social and financial support from the Japanese welfare system, they have to become officially registered as disabled. These things are new challenges. In order to cope with such changes, it is important for recipients to acquire information. For the heart transplant recipient this process of gathering information is an experience of the ‘reflexive-self’ as a heart transplant recipient.

Here, I will explore the issue of self-identity for the recipients, in terms of information gathering and information control. Their experiences will be examined chronologically. Firstly, I will focus on the recipients’ experiences of returning to work, school or community activities. This section will explore the way in which the recipients experience a body condition with a transplanted heart in the returning process (5.2). Secondly, I will examine the doctor-patient relationship after the recipients return home (5.3). Thirdly, their experiences after returning to social activities will be explored in terms of their experiences of stigma (5.4).

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<sup>16</sup> Detailed information regarding criteria for the certification of heart transplant recipients as disabled is published by each local government, and there are no differences regarding the criteria among local governments. Heart transplant recipients are certified as grade one which is assigned to a person who is the most severe health condition. However, there are some differences between each prefecture what kind of services a disabled person receives.

In the analysis, the recipients are categorised into five groups:

- 1) recipients in Japan
- 2) self-funded recipients abroad before 1997
- 3) self-funded recipients abroad after 1997
- 4) recipients abroad before 1997 for whom funds were raised
- 5) recipients after 1997 for whom funds were raised.

## **5.2 The experiences of returning to work, school or community activities in society: experiencing a new body condition with a transplanted heart**

### **5.2.1 Experience of having a transplanted heart**

In their narratives, heart transplant recipients describe how they experience their new body condition. Before their heart transplant, most recipients experienced severe health problems, which forced them to give up their jobs or education, and some were near death. However, after the transplant surgery, even while still lying in bed in the Intensive Care Unit (ICU) and soon after waking up from the anaesthetic, they recognised how much better they felt than before the surgery.

The narratives of their perception of their body experiences upon regaining consciousness, which is the first moment after their heart transplants, indicate no differences between the recipients abroad and the recipients in Japan. No differences were revealed when employing the variables of gender and age. Not only recent recipients but also those who had heart transplants more than ten years ago described clearly the details of their experiences, which suggests that the experience strongly affected them, and the memory has stayed clear in their minds since then.

Different patients focused on different aspects of their experiences. Mr. Makabe described his pulse.

(Mr. Makabe) ‘Before having a heart transplant, I had arrhythmia. The rhythm of my pulse was like “tatta, tatta, and then tattatta”. ... After the transplant surgery, I recognised how the rhythm of my pulse was regular’.

Having experienced arrhythmia before the transplant, he perceived how the body condition was improved through the rhythm of his pulse. The rhythm of the pulse was a sign for him at this stage through which he recognised his body condition, and it was a symbol for him of his life. Ms. Kasai referred to other physical experiences.

(Ms. Kasai) ‘Although I understood that I was lying on the bed, I felt like my body was swaying. As the transplanted heart beat strongly, I felt that the beating heart made my body shake’.

Ms. Kasai had heart disease from birth. Thus, it was the first time she had experienced

her heart beating without the assistance of a device. Therefore, this experience impressed her greatly. Another recipient also described the feeling of the transplanted heart in her body.

(Ms. Hamada) ‘I felt that the transplanted heart strongly pushed my body from the inside. I had never experienced such strong pressure before.... I was confused by this heart beating. I also felt temperature in my body. I was confused about what I could do. However, I didn’t tell this feeling to anyone’.

Like Ms. Hamada’s narrative, several other recipients’ experiences were not described to health professionals and their families immediately after the surgery. In other words, these narratives show how the initial experience with the transplanted heart soon after the surgery was a personal and somewhat private matter. They talked about their body perception. At this stage, they focused on thinking about their body, and they did not pay much attention to the body as a social entity, or feel the need to share their inner thoughts.

### **5.2.2 Hospitalisation after heart transplants**

In every case, the interviewees’ perception of their body with a transplanted heart was different from that before the surgery. The fact that rehabilitation programmes began very soon after the transplant was important in helping them realise how different their bodies had become. The recipients abroad were usually discharged from hospital one to two weeks after surgery. They then began to live in an apartment for six months, and to visit hospital regularly to monitor and possibly control the immune rejection as necessary. The six-month milestone is important from a medical viewpoint because during up until that point, immunological rejection of the transplant may be diagnosed. Finally, the recipients returned to Japan. By contrast, recipients in Japan stayed longer in hospital after the transplant surgery. The average period of hospitalisation after a heart transplant in Japan is, and was for all interviewees, three months (Division of Cardiovascular Surgery, Department of Surgery, Osaka University Graduate School of Medicine, 2010).

I will now focus on the narratives of the experiences of the recipients in Japan.

(Mr. Noguchi) ‘Interestingly, in my mind, there was a huge gap between being in ICU and returning to a general room in the hospital. Even though the general room was specially organised as a bio-clean room, this move made me



feel better. I felt that I was recovering from the surgery’.

This extract shows how the hospital environment affected the recipient’s perception of his progress. Although he was still isolated from his everyday life, the return to his room raised his hopes. Other recipients expressed similar feelings. In particular, a positive atmosphere in the hospital was described when the recipient was the first heart transplant case for the hospital, as Mr. Hoshino’s mother expresses:

(Mr. Hoshino’s mother) ‘My son’s heart transplant surgery was the first case at this university hospital. As this transplant surgery was successful, everybody was happy with the outcome. The health professionals seemed to be excited by this success; therefore, they enjoyed taking photos of both him and us, even in the ICU on the second day after the transplant surgery.’

It seems that there was an atmosphere of celebration of their achievement in the hospital. This elation might be similar to the atmosphere in the early period of heart transplantation in the late 1960s (Nathoo, 2009). In this warm atmosphere, in which they took photos – although the recipient’s prognosis was still not an optimistic one – the situation did not resemble a paternalistic doctor–patient relationship. In this atmosphere, the recipient was treated as ‘special’ in the hospital.

(Mr. Hoshino’s mother) ‘As this was the first case at this university hospital, you [Mr. Hoshino] were carefully and specially treated by health professionals, weren’t you? This was really nice.’<sup>17</sup>

Thus, the whole process of having the transplant and the surrounding atmosphere made him feel like a special heart transplant recipient. The following extract gives us more information about how the relationship between the recipient and nurses in a hospital could develop.

(Mr. Watari) ‘After the surgery, I could do more. For example, before the surgery, a nurse brought my meal to my bed, I had the meal on the bed, and a nurse came to the bed to collect my empty meal plates. I was really uncomfortable with this situation. I wanted at least to carry my meal plates myself. However, I couldn’t, because I always had oxygen bottles, and, in reality, my body condition wasn’t strong enough. After the surgery, my body

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<sup>17</sup> Mr. Hoshino and his mother were interviewed together. As Hoshino has a speech problem as a side-effect of his heart transplant operation, his mother stays with him as much as possible. During the interview, she sometimes talked to him and responded to me (interviewer).

was stronger than before. ... A nurse told me that I didn't need to do so.'

In this extract, this recipient expressed how happy he was with his recovery. His experience shows that a patient in a hospital perceives his recovery in relation to the extent of the help given by nurses.

This personal experience is related to his identity as a transplant recipient in a conversation with a nurse.

(Mr. Watari) 'I said to a nurse, "I have to recover very well, as I am the first heart-lung transplant recipient in Japan. I have to be very fine as soon as possible. The nurse told me, "As you are the first case, you shouldn't behave in a way that may put pressure on future recipients. What is more important for you at this stage is to learn the way of taking medicine to control the immune system." ... I understood what she said to me. Nevertheless, I was thinking that my condition would be recorded as data, for example: I walked in how many days after the surgery. This record would be used when health professionals explained my case to others. Therefore, I did my best to get well as soon as possible.'

This extract indicates that this recipient had a distinct sense of his social identity as a heart-lung transplant recipient and felt certain pressures as a consequence. In the conversation between the recipient and the nurse, both focused on what a heart-lung transplant recipient should be or should not be. In other words, they were discussing the identity of the recipient in the conversation. Furthermore, as the extract shows, this recipient considered how he would be perceived by others, such as health professionals. He then decided what would be appropriate behaviour for a heart-lung transplant recipient. This process was therefore influenced not only by immunosuppressant drugs and other biomedical markers, but also social factors revealed through conversations with medical staff.

In these two cases (Mr. Hoshino and Mr. Watari), it was considered that sharing in the pioneering work of the health professionals was an important factor in the creation of recipients' identities. Ms. Hoshino and Mr. Watari were the only interviewees to make that point. Other recipients in Japan confined their reflections to describing how they learned what they had to be careful of in everyday life after returning home, and the experience of living with a transplanted heart.

(Mr. Hamada) 'Before my discharge from the hospital, a nurse explained to me what I had to be careful of in everyday life. She also explained to me about meals, what I should and should not eat and drink.'

Every recipient is given these tips before being discharged from hospital. If the recipient does not follow these instructions they will face severe medical problems. In this regard, these tips are very important for the recipients. From a viewpoint of self-identity, their lives are framed by these medical instructions. By obeying these new rules, the recipients acquire new life styles, which help establish and reinforce their new identities. The new regime constantly reminds them that they are recipients. Although the life-style changes may be burdensome, the recipients may not perceive it in a negative way because they understand the need for them and they are always surrounded by people who support recipients, ‘the Wise’, with whom recipients are in close relationships. ‘The Wise’ show their sympathy to the recipients, and respect their life styles.

I will now move to the narratives of Japanese recipients who had transplants abroad. The recipients abroad are isolated from their everyday lives until they return to Japan. In the following section, I will focus on their narratives of the recipients about the time between their heart transplant surgery and their return to Japan. This period includes time before and after their discharge from hospital in the other country.

Compared with the narratives of the recipients in Japan, which referred to their experiences during the period before discharge, the recipients abroad did not talk so much about their time in hospital. In practice, as the recipients abroad described with surprise, the period of hospitalisation was shorter than in Japan, and the recipients had to regularly go back to the hospital as out-patients for medical check-ups following the heart transplant surgery. In this situation, their lives, which consisted of regaining consciousness after surgery, experience in a hospital, and life in the other country before returning to Japan, were isolated from the society around them. What did they say about their experiences during this socially-isolated period?

Their narratives are categorised into four themes: the process of returning to everyday life; the emotional challenge of accepting a transplanted heart; communication with ‘the Wise’ and ‘the Own’; and the impact of fund-raising.

### **5.2.3 The process of returning to everyday life**

When these recipients talked about the time after the transplant surgery, they described – often in a monotonous voice – how many days before they were discharged from hospital, how many months before they returned to Japan and so on. Among them, a recipient who had the surgery in the mid 1990s said how surprised he was to be

discharged from the hospital one week after the transplant surgery, which was sooner than expected. This recipient's wife was also very surprised at this. Most recipients were discharged from hospital about one to two weeks after the surgery, unless they had any problems with rejection of the transplanted heart. However, in the narratives of the recent recipients, they did not express that they had been surprised at this short stay in hospital. These new recipients had already known the schedule in advance. Mr. Makabe described his feeling when he was discharged from a hospital.

(Mr. Makabe) 'I was scared to be discharged from hospital. As only one week had passed after the surgery, the surgery wound hadn't even healed'.

The day after his discharge from hospital, he rested in the apartment, where a surgeon visited him. The recipient's wife described the visit as follows:

(Mrs. Makabe) 'When we were in the apartment, a surgeon visited us and told him to go walking, not to stay home all the time. I was surprised and asked him whether he would go walking. He told us that it was better to go walking than staying at home. .... He could return to **usual life** very soon' (the researcher's emphasis).

These extracts show that there was a difference in expectations between Mr. and Mrs. Makabe, and the medical staff. Both Mr. and Mrs. Makabe perceived Mr. Makabe to be a still vulnerable patient. As the wound was not healed yet, it is understandable that they thought so. Therefore, he attempted to continue his life as a patient in a way that was consistent with his image of a recent heart transplant recipient. In contrast, the advice from medical staff, which was given from a medical viewpoint, was different from Mr. Makabe's assumption. At this stage, the gap in perception between the heart transplant recipient and the medical staff did not cause any problems. Instead, the recipient and his wife changed their views as a result of the advice from medical staff. Therefore, at the end of this extract, the recipient's wife talked about returning to 'usual life'. Considering that she used this expression, it was obvious that she differentiated the days as a patient in a hospital from everyday life.

A recent recipient of a heart transplant abroad, Mrs. Sano, clearly expressed her feelings, which were in contrast to those of Mrs. Makabe after her husband's transplant abroad.

(Mrs. Sano) 'When an electrocardiogram was removed from my body [after

the transplant surgery], I strongly felt that I would be able to move around. When I was hospitalised in Japan, I thought that I would not have any chance to go out from this room. However, at that time, I really thought that I could go out from this room.’

Her description suggests that she saw her life in hospital to be isolated from society and from everyday life outside the hospital.

The recipients began to have a clear image of their everyday lives outside the hospital. In other words, for the recipients not only their health condition but also hospital itself is a symbol of their social isolation. The narratives, which focused on the process of returning to their everyday life, show how the recipients began to understand life as a transplant recipient outside hospital. This was different from their views as patients. Also, the meaning of hospital changed. Although hospital was perceived as helping the recipients, they began to recognise the hospital as a symbol of their social isolation; therefore, they felt happy to be released. In this regard, the transitional period changed their relationship with the hospital.

#### **5.2.4 The emotional challenge of accepting a transplanted heart**

Heart transplant seems not to be merely surgery. Many heart transplant recipients in the 1960s and the early 1970s experienced depression and psychotic reactions to the transplanted heart during the post-operative period. Therefore, the transplanted heart disturbs the stability of the recipient’s self (Castelnuovo-Tedesco, 1973). However, it is not certain whether recent heart recipients experience similar psychological difficulties. Bunzel, et al. (1992) argues that many heart transplant recipients tend to confront emotional stress. By doing interviews with 44 heart transplant recipients, Bunzel, et al. (1992) found that heart transplant recipients reduce the emotional stress in their own ways.

Ms. Kasai had heart disease from birth; therefore, she had not experienced how her body condition was without a device to assist her heart such as a pace-maker. Before having a heart transplant, she had developed her own idea of her heart.

(Ms. Kasai) ‘I often thought that my “Ms. Heart” was trying to work very hard, therefore I had to do my best. Even now, I have the same idea with the transplanted heart. ... I have had a feeling that my heart had its own self since childhood, or the heart is like another person [who lives in my body]. I have had this kind of feeling, instead of feeling that I was a heart disease person. I can’t explain to you this feeling about my heart well. ... My heart is like my

partner. When my body condition wasn't good, I thought that I have made my "Ms. Heart" work too much'.

She had perceived her heart as more than an organ. When she talked about a heart, she often called it 'Ms. Heart'.<sup>18</sup> Her diseased heart had often disrupted her everyday life; and this heart condition was beyond her control. In other words, her everyday life was very much controlled by the heart. Under this condition, she developed her own way of understanding the situation with her heart. Another question arose here. Why did she develop this kind of story, even though a health professional gave her a medical explanation about her heart? I assume that, first of all, she is very sensitive about her body. In other words, as she had a heart problem from birth, she unconsciously developed a kind of sensor to understand her body's condition. It might have been that her own understanding of her body, particularly her heart, was not necessarily explained by the medical explanation. As a result of her sensitivity about her body and insufficient medical explanation, it could be possible to consider that she established the story to cope with her heart condition. She describes the way of the communication with her heart as follows:

(Ms. Kasai) 'My "Ms. Heart" often cheered me up. For example, when facing a difficult situation, I thought that I shouldn't be mentally depressed, because my heart was trying to help me. I have always had this kind of feeling.... I have the same feeling about my transplanted heart. ... As this transplanted heart used to have another "owner", which is the so-called "donor", I feel a sense in which this transplanted heart is different from my previous "Ms. Heart"'.<sup>19</sup>

This recipient talked about how she perceived the relationships with her previous heart and the transplanted heart. When thinking about the transplanted heart, she also considered the relationship between the transplanted heart and the donor, which is 'another owner of the transplanted heart' in her expression.<sup>19</sup> In her mind, her body, her previous heart, the transplanted heart, and the donor, are independent of each other.

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<sup>18</sup> She used an expression of 'Shinzou-san', which means Mr. or Ms. Heart. In Japanese, 'san' means both Mr. and Ms. The gender is interpreted from the context. Although, in the interview, she did not describe the gender of her heart, I interpreted it as a woman for the English translation.

<sup>19</sup> Other recipients also reported similar attitudes towards their transplanted hearts. They perceived the transplanted heart as more than merely a heart organ. For example, Ms. Ishida wrote a poem after her transplant. In the poem, she seems to be talking to her transplanted heart. Music was composed for the poem by a Japanese transplant surgeon. This music, with him singing, has been produced as a CD (Ibukuro, 2008 [audio recording]). Another heart transplant recipient, Mr. Kiuchi, states that he thinks that the transplanted heart helps him and gives him the opportunity to say what he wants to say (Kiuchi, 2009).

These independent entities were integrated through the heart transplant surgery, and then her self-identity was established. In her case, this integration was done in the early period after the transplant surgery on an individual level, and she had not yet considered how this self-identity would relate to society.

### **5.2.5 Communication with ‘the Own’ and ‘the Wise’**

Some recipients focused on their experiences with ‘the Own’ who are other heart transplant recipients, and ‘the Wise’ who are in a close relation with the recipient and have sympathy for them. Mr. Higashi talked about his experience of attending a party in the hospital before returning to Japan.

(Mr. Higashi) ‘A Christmas party was organised in the hospital. This party also celebrated the tenth anniversary of heart and lung transplants. Many lung transplant recipients and heart transplant recipients came to the party. I didn’t know any of these recipients. At the reception, we were passed a numbered card, which showed the order in which each recipient had had a heart or lung transplant at UCLA so far. Mine was 530 or 530 something. It means that I was the 500 something recipient in the hospital. Everybody was dressed up, and some wore dresses that showed a lot of skin! Other attendees looked as if they often attended this kind of party.’

This occasion was the first time for him to meet many other heart transplant recipients. Besides, it can be considered that this party made an impression on him because it was the start of socialising with people. Considering the timing of this party, which was just before returning to Japan, it will have been a symbol of the end of his hospital treatment in the U.S, and also the beginning of returning to everyday life. In addition, he was twenty years old, which means he was an adult in the Japanese legal system. When people in Japan reach the age of twenty, they experience a social ritual to celebrate this special age. However, as he was hospitalised and he did not experience this ritual because of his heart disease and the heart transplant. Therefore, when he described the experience of attending the party, he referred to his age as follows:

(Mr. Higashi) ‘It was a very enjoyable time. I took many photos of other recipients. Many photos were taken of me by other attendees.... I was impressed that there were many people who had had transplants.... In total, I think, there were about 100 attendees including recipients, their families, and medical staff.... I was almost the youngest among the adult recipients, as I was twenty.’

Mr. Higashi could finally experience being a member of adult society.

An older recipient, Ms. Okamoto, described her experience with ‘the Own’ and ‘the Wise’ in a different way from that of Mr. Higashi. When she talked about it, she focused on the communication with her daughter and volunteer staff there.

(Ms. Okamoto) ‘I went walking, although I could cycle. I went to a city centre by bus. My daughter was surprised seeing me. ... First of all, I couldn’t hold her in my arms before. She asked me, ‘may I ask you to hold me in your arms?’ I was really happy with this. When doing rehabilitation, a surgeon asked me, ‘will you try climbing steps?’ Then, I tried to climb to the 3<sup>rd</sup> or 4<sup>th</sup> floor. As I wasn’t out of breath, I was surprised myself.’

This extract shows that she regained her identity as a mother, which was very important to her. In addition, she began to think about what she would be able to do as a heart transplant recipient.

(Ms. Okamoto) ‘When we left Germany, Mr. and Mrs. Cotei<sup>20</sup> told me that we should do our best to improve the situation surrounding heart transplantation in Japan. They told me to disseminate my opinion of heart transplantation in Japanese society. ... I think that western people have different national identities from us. We Japanese hold Samurai’s soul.’

As this extract shows, not only did she begin to consider her own role as a heart transplant recipient but she also began to consider her role in the Japanese cultural context. In other words, she began to explore ways to establish her identity as a Japanese heart transplant recipient. Her Japanese identity, which she had before having the transplant, was reconsidered through the experience of the transplant.

By exploring these narratives, we can see that age should be a variable which impacts upon the recipients’ identities after the transplant. As people age, society attaches roles to them more than it does to younger people. The more that people are socially labelled by social roles, the more the recipients need to reconsider their social role in the new situation of having received a heart transplant. It seems likely that younger recipients are able to establish a relationship with people more readily. In contrast, older recipients more often need to add the essence of a new identity to the previous one. The next extract shows another recipient’s perspective:

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<sup>20</sup> Mr. and Mrs. Cotei have voluntarily supported many patients including Japanese heart transplant recipients in Germany. Every Japanese patient who has been to NRW Herz und Diabetes zentrum in Germany to have a heart transplant has met them.



(Mr. Oda) ‘With rehabilitation, I eventually was able to sit on the bed. I could pee on the bed using a medical glass for pee. One day, a nurse put the glass for pee in a different place than usual. I couldn’t reach it from the bed. I pressed a button to call a nurse; nobody came. Then I fell out of the bed and hit my head and fainted. While half-conscious, I attempted to call a nurse. Nobody noticed me. When I woke up, I was still lying down on the floor, nurses and health professionals all around me, and the health professionals were very angry with the nurses. This doesn’t happen in a hospital in Japan. It was a really terrible situation. ... I believe that nurses in Japan are the best in the world.’

Based on this experience, he compared nurses in Germany and nurses in Japan. We can see that he used the framework of Germany and Japan, not individual nurses, when explaining this experience, which means that he consciously assigned labels of national identities to the nurses. More or less, both consciously and unconsciously, he thought about Japanese identity; although it is not clear from this extract how he integrated the Japanese identity into his self-identity. The following extracts more directly express the negative feeling about being a patient in another country.

(Mr. Uchida) ‘I felt both physically and mentally very exhausted to live in the U.S [even after having a heart transplant]. Since before the surgery, I had kept in contact with a surgeon in Japan. I asked the surgeon to arrange my aftercare medical treatment in a hospital in Japan as soon as possible, because I almost couldn’t stand to live in the U.S.’

He frequently talked to surgeons in Japan about his concerns relating to his disease and the medical treatment. However, he could not establish such a relationship with surgeons and other medical staff in the U.S that was like his relationship with the surgeons and nurses in Japan. A possible reason is the language issue. In addition, in the U.S his status as a patient was different in terms of the relationship with health professionals. In Japan, both health professionals and patients are outsiders because of the relative unpopularity of heart transplants. In contrast, in the U.S, although the patients are well treated, transplant recipients are treated as part of a routine hospital process. In this situation, this recipient focused more on his relationship with health professionals in Japan. As a result, it can be considered that he came to perceive and value his Japanese self.

### **5.2.6 The impact of fund-raising**

The recipients who used fund-raising from the public tended to garner the media’s

attention, particularly in the early period. Ms. Kondo describes her experience of the media at the airport when she returned to Japan.

(Ms. Kondo) ‘Before going to the U.S., my parents told the mass media to leave us alone. ... She then explained to the press that we would be ready for interviews after the heart transplant succeeded and I recovered. She requested them to leave us alone until then. As a result, we didn’t have to give any media interviews before the surgery. ...As soon as we got back to Japan, the press organised a press conference at the airport. The television channel may still have a recording of the interview. My face was like a moon, which is so called ‘a moon face’ ... what is it in the airport, ah...’

Ms. Kondo’s mother promised the press an interview after the heart transplant was successfully performed. She thought that it was her obligation to respond to the many people who supported the transplant. In fact, as the media came to the airport, and Ms. Kondo attended a media conference with them. It can be understood that this media attention, in particular at the airport, made her particularly aware of her new identity as a heart transplant recipient. She experienced how others looked at her, and their attention served to establish her identity as a recipient. In reality, after returning to her home, she began to recognise how the people in town looked at her through communication with them in everyday life.

(Ms. Kondo) ‘It was in such times that I recognised that my life was not just mine to live as I pleased. I gradually took it upon myself to ensure that I always looked fine, and had a smile for everyone to prove it. I began to play this role with the earnestness of doing a duty. However, I soon began to feel a form of pressure and stress. I guess I may have subconsciously adjusted to, and even helped create, an identity as a heart transplant recipient during my junior high school days. So, even as I live my life in the most normal terms, people nevertheless look at me as a transplant recipient. The reactions of people around me may have influenced my ideas about how I ought to live, in my situation as a transplant recipient. These were my set of thoughts and experiences during my junior high school days.’

The ‘gaze’ of others can construct and reflect the social construction of identity. This is a reflexive process, in that a person perceives the gaze of other people and tries to adjust his or her behaviour to their expectations. This adjustment process is constantly going on between the person and other people in society. As the other people see how the person change their behaviours, their evaluations of the person also changes as time passes (Giddens, 1991). Although Ms. Kondo might have not clearly recognised the nature of people’s expectations as to how she would behave as a recipient, she

experienced the media's expectations of her at the press conference. In this regard, the press conference at the airport was the time and place in which this recipient's existence was mingled with the media's assumptions about a heart transplant recipient, which was still a new category at that time.

During the interviews, it became apparent that the mass media pay a great deal of attention to those recipients abroad whose heart transplant surgeries were supported by fund-raising. Media interest in these patients has increased in recent years. This trend by the mass media seemed to be stronger than before. Patient support organisations, such as the TRIO Japan, have developed a way to support these patients including information and fund-raising. In addition, the internet has made it possible for the public to access web sites. On the one hand, these factors help to increase opportunities to have heart transplants abroad; on the other hand, they open more channels of information about heart transplants between the recipients and the public. Japanese recipients who travel abroad have become public entities, which seems to have been enhanced by the passing of the Organ Transplant Law in Japan (1997). The recipients not only talked about their feelings when arriving at the airport, but also began to express their feelings to the mass media waiting for them there. Mr. Oda described his feeling when arriving at the airport as follows:

(Mr. Oda) 'I felt a sense of superiority to something... I can't describe the feeling well... I was satisfied that I had been able to achieve my aim. In my mind, I was like a Napoleon... "returning in triumph", this expression represents the feeling.'

His web-site still shows photos that were taken at the airport (Kenichi-kun wo sukuu kai [A support group for Kenichi], 2009). Looking at these photos, we can see that many people came to the airport to celebrate his return. As some of the photos show, members of the mass media were also there and interviewed him. Such attention is typical when recipients return to Japan. Mr. Uchida described his feeling as follows:

(Mr. Uchida) 'When I arrived at the airport, TV people were also there. I had a press conference at the airport. As my arrival was late in the evening, it was raining, and it was a week day, I didn't expect many people would be waiting for me at the airport. In reality, there were more than 100 people waiting for me. Therefore, I was almost crying because I felt very happy to see them.'

He was glad to see so many people, including the media. This response was opposite to the feelings of recipients in the early period who were surprised to have media attention.

Since then heart transplant recipients have become accustomed to having media attention. In other words, media attention has become a factor in establishing the recipients' identities. However, this media attention does not simply stop after the initial media impact. Later I will show that the media also have an impact on recipients' experiences after some time has passed.

To summarise, during the period after transplant surgery until discharge from hospital, the recipients experience how quickly they recover from the heart disease and the exhaustion from the surgery. Though how long each recipient spends in hospital after the transplant surgery depends on the health condition of each recipient and on the hospital; every recipient positively experienced how the body's condition was different from its previous condition. The recipient quickly perceives that he or she has recovered from their heart disease in this early period. Simultaneously, this period is the beginning of the process of acquiring a new identity as a heart transplant recipient.

The way in which the new identity is acquired can be explained as follows. The recipients who had the surgery in Japan are treated as very special patients in the hospital, due to the fact that heart transplantation is not a popular medical treatment and there have been fewer surgeries in Japan compared to some other countries. In this situation, not only the patient, but also health professionals, consider heart transplant as special. Therefore, the recipient's identity as a heart transplant recipient is reinforced by the health professionals. This relation is characterised by both the recipient and the health professionals being in the 'same boat in a new sea'. In contrast, recipients abroad do not experience health professionals treating them as such 'special' patients. The patient's experience is similar to that of a person being placed in a 'new boat launched onto a new sea'. Therefore, the recipients' experiences in this period are more private experiences than the experiences of the recipients in Japan. In these private experiences, the recipients begin to have relationships with others outside the hospital. This trend was most obvious in the experiences of the recipients who were supported by fund-raising.

After these experiences, the recipients slowly return to society by returning to work and school. In the next section, I will explore how the recipients negotiate their identity as a recipient in this returning process. In particular, I will focus on the differences between their relationships with people who know that they are heart transplant recipients, and their relationships with those who do not know.

### **5.3 The doctor-patient relationship after returning home**

Three models of doctor-patient relationship described by Szasz and Hollander (1956) suggest an appropriate doctor-patient relationship for each model, depending upon each patient's condition. These authors describe their three models as follows: activity-passivity, guidance-cooperation and mutual participation (Freidson, 1970). The mutual participation model assumes the patient has a chronic illness (ibid). Heart disease patients are not released from the status of having a chronic condition by having a heart transplant, but the nature of the chronic condition changes after receiving the transplant, because they require life-long medical treatment, including immunosuppressant drugs. In this regard, their condition, in terms of medicine, can be still considered as chronic. Therefore, when looking at the doctor-patient relationship, in terms of heart transplant patients, the mutual participation relationship model can be applied with regard to their need for life-long medical treatment after the transplant. Now, I will explore the relationship between transplant surgeons and heart transplant recipients, referencing this model.

In the early 1990s, while there were still a small number of Japanese heart transplant recipients abroad as reviewed in Section 2.1.3, both health professionals and patients had less information than they do now. In this situation, patient support organisations for transplant recipients began to be established by health professionals, patients, and patients' families. Toward this end, the New Heart Club was established in 1991, which was the first organisation for heart transplant patients from among these support organisations (New Heart Club, 1993).

(Dr. Sono) 'After returning to Japan [from the UK], each surgeon at a local hospital, who were also physicians before going to the UK, treated these heart transplant recipients. These surgeons had anxieties about whether their way of treating heart transplant recipients was right. Therefore, we established the New Heart Club in order to exchange information regarding patient aftercare for transplant recipients, including immunosuppressant drugs. The New Heart Club consists of heart transplant recipients, their families and surgeons, and we support each other by exchanging information.'

As he noted, not only the recipients, but also the health professionals needed mutual support in order to provide appropriate treatment to the recipients. Recognising the demand from both recipients and health professionals, Dr. Sono established the New

Heart Club with other health professionals, heart transplant recipients and their families. In this regard, this organisation introduced the demand for multiple participation of health professionals, the recipients and their families; rather than mutual participation by health professionals and patients. Looking at the character of this organisation which initially aimed to exchange information among the members, the organisation was opened only to the members. The organisation gradually expanded their activities. The members of the support organisation have committed to heart transplants as a social policy. The members who were recipients and their health professionals began to make social appeals about the importance of conducting heart transplant surgery in Japan.

(Dr. Sono) ‘After returning to Japan, he [Mr. Aoki] said that he would do his best to change the situation surrounding heart transplants in Japan. I expected him to talk about heart transplantation as a recipient. At that time, the Japanese government had set up a meeting to discuss brain death. In a meeting, organised by the Provisional Commission for the Study on Brain Death and Organ Transplantation (Rinji noshi oyobi zoki isyoku chosa kai) [another transplant recipient], Ms. Notoh talked about heart transplants from the point of view of being a recipient’.

The number of Japanese heart transplant recipients is very limited. Some of them have been brought into the political discussion regarding heart transplants. The health professionals and the recipients have thus been united by their political aims. This trend of mutual participation has been expanded, and is clearly defined in the following sentence, presented by the Heart Transplant Support team, which was established in 1994 (Nunoda, 1997a):

‘In order to enlighten people regarding heart transplant and organ donation in Japan, it is important to involve not only medical professionals, but also non-medical professionals and the general public. This is because those who have the greatest potential for becoming a donor are not found among medical professionals’ (Nunoda, 1997a: 254-255).

Before the passing of The Organ Transplant Law in 1997, these patients who were diagnosed in need of a heart transplant and the heart transplant recipients cooperated with their surgeons to make it possible to legally perform heart transplants in Japan. The patients and the recipients also cooperated with health professionals in order to enhance the public’s understanding of heart transplants. Looking at the relationships formed through patient support teams, such as the New Heart Club and the Heart Transplant Support Team, the patients and health professionals seemed to have developed mutually

positive relationships. However, Ms. Kondo describes her experiences and feelings as follows:

(Ms. Kondo) ‘Although I wholeheartedly supported this patient organisation [Heart Transplant Support team], the organisation didn’t help me at all. In the organisation, I haven’t had any chance to express my feelings. I have been wondering about exactly who this organisation serves. Does it not exist solely for the patients? It should exist for the patients’.

She continues:

(Ms. Kondo) ‘I am a member of one of the latter types [heart] of organisations. This patient organisation has meetings twice a year which are held by health professionals. At the assembly, we patients also view presentations made by health professionals, though the content is aimed at health professionals. Following these presentations, everybody prepares for a tea party. In the tea party, patients – instead of being encouraged to communicate among each other – are forced to speak about how they feel. Another patient organisation for heart transplant patient aims to create awareness regarding heart transplantation’.

This seems to show the presence of a somewhat paternalistic doctor-patient relationship, where the mutuality of the participation is sometimes in doubt. Both the health professionals and the recipients attended this meeting. Ms. Kondo felt that the meeting was helpful for the health professionals, since they could gather information about the heart transplant and the recipient’s condition. By contrast, the meeting did not allow the recipient to receive information from health professionals or to exchange information with other recipients, so that recipients had no control over the meeting. It may be that in the early days of establishing patient support organisations, both health professionals and patients set aside such a paternalistic relationship, developing a cooperative relationship for managing the chronic condition. However, as the Heart Transplant Support Team grew, paternalistic elements appear to have come to the fore.

Nevertheless, recent recipients probably have more channels to communicate with other recipients, health professionals and patient support organisations than recipients in the early days. These channels of communication have been enhanced by events that disseminate information about heart transplants to the public. Under these situations, in which the information channel is increasing for transplant recipients, how has the doctor-patient relationship changed?

(Mr. Oda) ‘I asked other heart transplant recipients about their experiences. ... As a transplant recipient needs another person’s organs, I think the combination of the recipient’s body and the transplanted organ brings about a different body condition after the transplant. Therefore, it is important that each recipient explores what is best for his or her body. I think that this character of the transplant is good, otherwise recipients may stop making the effort, and as a result, the recipients may forget to appreciate the donors.’

(Ms. Okamoto) ‘Mrs. Sakata, who is a very slim lady, told me she had experienced these side-effects for a long time. Having listened to issues of these side-effects, I thought that I would have the same side-effects. However, I didn’t have the same experience as she did. Mr. Matsuda [another heart transplant recipient] told me that he wasn’t swollen so much. Each recipient has different rules for diet. This restriction of diet may cause different side-effects of medication. ... I always try to find the best way for me, through trial-and-error.’

These extracts show that recipients have more chances to exchange information about life after their transplants. In addition to information from health professionals, information from other recipients is also important for recipients. Furthermore, as they said ‘making efforts and ‘trial-and-error’, they do not think that there is only one way to live their lives after the transplant. Rather, they consider themselves as participants in finding the right way that works best for each recipient. This shows how the mutual participation model works for the recipients. Mutual participation can be seen not only as the relationship between health professionals and recipients, but as an information exchange with other recipients; the trials based on it are added into the original mutual participation.

In addition to the individual levels of communication between recipients, transplant patients have more opportunities to communicate through such avenues as the Organ Transplant Game, which is held annually in Japan, as well as through public seminars about heart transplantation (Japan Transplant Recipients Organization, 2006).

(Ms. Hamada) ‘I usually don’t go to public seminars to bring my opinions about heart transplant. However, like a transplant game in Fukuoka the other day, it is helpful to attend such an event to know other recipients and exchange the information with them.’

These kinds of events present the positive aspects of organ transplants to the public. In addition, it seems to be important for health professionals to see and record the recipients’ conditions. During the events I attended in 2008 and 2009, I saw health professionals who took photos and recorded a film of transplant recipients doing



exercises and attending sports. These public events are places where health professionals and recipients can exchange information; in addition, recipients can share with other recipients and health professionals can share with other health professionals. Thus, we can see ‘multiple participation’ among people who are engaged in heart transplants.

Moreover, closely looking at how the recipients consider the health professionals, it can be seen that recipients want to be supportive of health professionals in order to change transplant medicine in Japan.

(Mr. Oda) ‘Dr. Minami really has power to attract people. Once attracting people, and showing his medical skills, and then patients are fascinated by him. ... I would like to do something for him whatever I can.’

(Ms. Nakata)<sup>21</sup> ‘I attended activities that aimed to amend the Organ Transplant Law. The reason why I could do my best, as much as possible, was to repay Dr. Fukushima. He really helped us, [although my son passed away before having a heart transplant in the end]. Therefore, I wanted to do my best for him. This was the biggest motivation for me.’

These extracts show how the recipients and their families trust the health professionals. Besides, they seem to have particular opinions that are more than just a sense of trust in health professionals based on medical knowledge and skills. How did they come to have such strong opinions? These extracts show what the relationship is like between a health professional and a patient (and their family). When considering medical treatment such as a heart transplant, a health professional’s professional (medical) knowledge and skills are important for a patient; i.e., professional knowledge and skills are key factors in determining the relationship between these two entities. In these extracts, patients consider their health professional’s personality, which is a concept beyond their medical and professional knowledge and skills. I propose that these extracts show that trust consists of medical knowledge, skills and the health professionals’s personality. The most important point in relation to the health professional’s personality is how the health professional’s personality and behaviour is perceived by a patient and his or her family. These trends can be found among the recipients, and their families, who had

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<sup>21</sup> Ms. Nakata brought her son to the U.S to have a heart transplant. However, her son passed away before having the chance to get a heart transplant in the U.S. Throughout the entire process from the initial diagnosis to the end of her son’s life, she communicated with Dr. Fukushima. In the interview, she described how she not only established her thoughts about the transplant issue in Japan, but also grew as a mother through her communication with Dr. Fukushima.

heart transplants abroad. The trend seems to have been stronger than before the transplant took place. Both health professionals and recipients have begun to think of one another as partners to change the situation regarding heart transplants.

Recipients who had heart transplants in Japan see this partnership in a different way. They also view the doctor-patient relationship in Japanese hospitals in a different manner. Even the recipients, who had heart transplants abroad, once they start their medical treatment in a hospital in Japan after returning to Japan, must adjust to the realities of the situation in Japan.

As Japan's heart transplant recipients are limited in number and anonymous, transplant surgeons in Japan support the establishment of a network that connects heart transplant recipients and patients awaiting a transplant. A surgeon often plays an intermediary role by introducing a heart transplant recipient to a patient awaiting a transplant. The recipients also introduce other heart transplant recipients to these patients. Furthermore, networks among recipients and potential recipients are established via hospitals. As is clarified from interviews conducted with the recipients, this kind of networking is encouraged by health professionals. Mr. Noguchi refers to this networking by considering how it affects the potential recipients emotionally.

(Mr. Noguchi) 'Health professionals and nurses suggested that I come to the hospital as much as possible in order to show how well I am doing after having a heart transplant. They tell me that they feel rewarded by seeing me, and potential recipients can feel hopeful about having a heart transplant. I think that this may be cruel to a patient who is waiting for a transplant, because it is not easy to have the actual chance in reality. The patient may cry after seeing me and other recipients.'

This networking suggests the reconsideration of traditional models regarding the doctor-patient relationship (Freidson, 1970), in a manner that is similar to the reconsideration prompted by the experiences of recipients abroad. Through this networking, the recipients are expected to show positive aspects of heart transplants to the medical staff and patients. Moreover, the recipients are expected to play not only the role of patients to health professionals but also as people who provide medical information to other patients. In this regard, the recipients are categorised both as consumers of medicine and suppliers of medical information. In the relationship between health professionals and patients awaiting heart transplants, the health professionals consider the recipients as part of the process of dispensing medical information about heart transplants. It can be said that heart transplantation suggests

considering the plural and transitive roles of patients, and reconsidering the relationship between health professionals and patients. In addition, heart transplantation also suggests further consideration regarding the relationship among medical staff in a hospital including health professionals, heart transplant recipients and patients.

During this period when returning to work and school after discharge from hospital, through establishing the aforementioned networks, the recipients expand their relationships with each other. In this process, not only medical advice from health professionals but also conversation with other recipients will help the recipients determine how to return to work and school. In addition, the recipients exchange ideas about how they should behave as recipients. By looking at the recipients' conversations and ideas on each other's behaviour, we will know how the recipients perceive their identities.

(Mr. Noguchi) 'I sometimes think that a younger recipient such as Jiro [pseudonym] seems to depend on other people too much. If he expressed how he felt severe pain in his body, the people around him would tell him that he should depend on other people and take a rest. Getting the balance right between how much he really needs help and how much he does not need the help, is important. However, I sometimes see that he depends on other people, which is more than right for him. When I find that he is too dependent, I tell him that he should not behave as such.'

In this quotation, Mr. Noguchi describes his belief regarding how a heart transplant recipient should relate to other people. Although he perceives that a recipient sometimes needs help from others, due to the recipient's health condition, he thinks that they are not released from the responsibility of maintaining a social role. This idea can be thought of as reflecting the concept of the 'impaired role'. The discussion of the 'impaired role' suggests a perspective from which the impaired are expected to behave on the basis of what they are physically able to do. In this regard, their roles are different from the non-disabled people; however, they are not released from bearing a social responsibility (Larsen, 2009; Varul, 2010). By contrast, Mr. Noguchi sees that other recipients have different ideas regarding how recipients should behave. He is critical of Jiro's behaviour because Jiro sometimes depends on other people, which is more than is right for Jiro. Mr. Noguchi sees this behaviour as Jiro wanting temporarily to put aside his responsibility to have a social role. Thus Jiro's attitude can be explained by seeing that he has failed to exit the 'sick-role' (ibid). In the sick-role, a person who has an illness does not need to bear the responsibility of a social role (ibid). Mr.

Noguchi feels that Jiro mixes these two roles (the sick role and the impaired role) in an unsatisfactory manner, and that other transplant recipients should be wary of following his example.

In addition to the recipients' perception, not only recipients, but also people who have sympathy for recipients – called 'The Wise' – have similar ideas as Jiro's towards recipients. Therefore, through the communication between the recipients and 'the wise', the recipients' identities move between the 'sick role' and the 'impaired role'.

## **5.4 Stigma experiences**

Having returned to work, school or community activities in society, heart transplant recipients attempt to adjust to society. They need life-long immunosuppressant drugs and because of this, they are formally classified as disabled by local government agencies. In addition, due to the prominence of their status as heart transplant recipients in terms of the limited number of recipients, they face a situation in which they need to consider the status of heart transplant recipient as a part of their identity. It seems that this identity is often somewhat stigmatised. In this section, I will examine how the stigma experiences of transplant recipients intersect with their identities. In order to explore these experiences, I will focus on ‘enacted-stigma’, in which the person actually experiences being discriminated against by others, and ‘felt-stigma’, which refers to the person’s fear of this type of discrimination (Scambler and Hopkins, 1986).

### **5.4.1 Perspectives of health related stigma**

Heart-transplant recipients may be considered as a marginalised minority group. Through this marginalised position, heart transplant recipients may often experience stigma. Thus, the concept of stigma is one of the keys to understand the identities of heart transplant recipients.

Stigmata – in the sense of identifying marks – were used to brand slaves and criminals in Ancient Greece, and since then, in western societies, the word ‘stigma’ has been used in the context of everyday life (Seale, 1996). Regarding stigmas associated with disability, Goffman explores how ‘disabled people’ communicate with ‘normal people’ who do not hold such disabilities. In particular, he focuses on the stigma that disabled people possess and are encouraged to possess. Goffman describes a stigma as ‘an attribute that is deeply discrediting within a particular social interaction’ (Goffman, 1968: 13). He conceptualises a framework to study this stigma at a micro-sociological level and studies the particular way in which the handicapped people are stigmatised. This is, then, an exploration of how the process of stigmatisation develops. In this regard, his study of stigma offers a perspective on how stigma influences face-to-face personal communication, and an individual’s identity.

Goffman explores this further as follows: ‘An attribute that stigmatizes one type of

possessor can confirm the usualness of another, and therefore is neither creditable nor discreditable as a thing in itself' (ibid). In other words, a stigma is brought about through someone's negative response to the condition which another person has. Goffman (1968) examines stigma by categorising identity into three kinds: social identity, personal identity, and ego identity. I will critically examine these respective identities and related key concepts.

While Goffman (1968) raised the issue of how stigmatised individuals experience ambivalent feelings at a micro-level, Scambler and Hopkins (1986) developed a broader perspective on how their feelings of stigma relate to both distress and discrimination. Through sociological research into epilepsy, Scambler and Hopkins (1986) introduce the ideas of the 'enacted stigma' and the 'felt stigma.' Enacted stigmas are those stigmas that are discriminated against by others. Felt stigmas involves a person's fear of this type of discrimination (Jacoby, 1994; Scambler and Hopkins, 1986, Scambler, 1989).

Their perspective on 'felt stigma' and 'enacted stigma' stimulated more research into stigmas experienced by disabled people. Steward et al. (2008) further developed the 'hidden distress model' through research into people with stigmas relating to HIV in India. In addition to the concepts of 'felt stigma' and 'enacted stigma', Steward and his colleagues argue that subjective awareness amongst the stigmatised people refers to a belief about how people in the local community develop their stigmatising attitudes or to what extent stigma is perceived as 'normative'. These perceptions may influence an individual's behaviour (Steward, et al., 2008). Stigmatised people may become sensitive about disclosing their condition because they wish to avoid an enacted stigma.

They argue that when a stigma is internalised by the non-stigmatised majority, it leads to prejudice, which may cause a stigma to be 'enacted'. Similarly, when stigmas are internalised by those who are stigmatised, it leads to 'self-stigma' (Steward, et al. 2008). This model makes it possible to explore the detailed way in which stigma-related information affects stigmatised people.

Although the concept of stigma has been explored further, these studies of stigmas tend to focus on personal tragedies (Scambler, 2004; Scambler, 2009). Therefore, they analyse stories at a micro-level, without paying sufficient attention to macro-level issues.

Following these studies, sociological approaches have developed more macro-level perspectives. Link and Phelan (2001) suggest that stigmas emerge as a result of convergence of interrelated components: (1) labelling, (2) stereotyping, (3) separating, (4) status loss and discrimination. They also argue that social, economic and political

power is highly related to these components, and affect processes of stigmatisation. Their focus on power is different from the perspective of Goffman. Looking at the issue of power, Link and Phelan (2001) explain that discrimination is not an individual but an institutional issue. In order to examine these institutional influences, they look at four different aspects of the people who confer stigmas on other people, drawing on the four components mentioned above. They examine whether these people have the power to (1) enact human difference, (2) affect how people perceive this difference, (3) maintain the existence of these differences, and (4) control stigmatised people's access to core institutions (Link and Phelan, 2001).

In addition to these perspectives, which encourage attention to be diverted from 'the labelled' to 'the labellers,' there is another point to be considered with regards to 'the labelled.' This is the issue of the feelings of stigmatised people. In order to critically examine this aspect, Scambler and Hopkins (1986) suggest focusing on a person's emotions. They find that people with the stigma of epilepsy felt and experienced their own self as 'being imperfect'; therefore, the person feels ashamed for 'being imperfect.' Based on this research, in order to examine the role of emotions in this context, Scambler (2004) suggests that stigmas should be differentiated from deviances. He explains that a stigma is ontologically established in a society and it is this ontological grounding that makes a person feels ashamed of their stigma. Deviances, however, are related to criminal acts. This criminal behaviour is seen as immoral and socially unacceptable, meaning that it is a form of deviance blamed on the reactions of other people.

Yet many perspectives on stigma and deviance consider only the cases in which a person is labelled with either a label of stigma or an identity of deviant, and do not focus on how a person responds to their labels. In other words, they do not look at the possibility that a person may reject this labelling by others in a society. Scambler and Paoli (2008) note, for example, that a person does not always internalise a stigma or deviance, but may reject it.

These detailed understandings of stigma are useful in exploring the issue of heart transplant recipients' experiences.

#### **5.4.2 Enacted stigma experiences**

Heart transplant recipients sometimes experience social discrimination by others. In the early period of the Japanese transplant programme, some recipients suffered direct

attacks from others. These negative stigma experiences among the recipients were described by a surgeon.

(Dr. Sono) ‘A recipient, Mrs. Natoh, told me that her child was bullied by being told, “Your mom is a Zombie.<sup>22</sup>” ... As children are innocent and cruel, they said so. Thinking about why they said so, I think that this is a reflection of a society in which some people hold this sort of idea about people who have had heart transplants’.

Dr. Sono pointed out that there was a negative image towards people who have had heart transplants among the public. Heart transplants were beyond the imagination of what counted as typical medicine among the public. In the early days it was as if a heart transplant recipient was an entity in fiction. In addition, there were some media articles and TV programmes which raised concerns about heart transplants. They discussed that brain death might not be diagnosed with accuracy, suggesting that a person might still be alive after the diagnosis of brain death (Tachibana, 1991). This image may have still existed in Japan; therefore, the above recipient and her child received this negative response. Even if it had been true to some extent, what was the reason behind this happening among these children? I assume that some people think that the body of a heart transplant recipient is different from other people. In other words, people tend to categorise other people in terms of the body itself. Then, when they find any differences, in particular, when these differences are not consistent with their existing ideas, people attempt to find a way to understand the new idea and express their feelings. In this case, the children’s understanding of a heart-transplanted body and their feeling about it were integrated into a negative word, ‘Zombie’. This kind of experience was not found in recipients’ narratives where the speaker had received a transplant more recently. At least, this kind of expression was not reported to have been expressed directly to the recipients and their families.

Another point about this extract is that this experience was narrated by a recipient to a surgeon, instead of talking about such experiences to other people. No heart transplant recipients in the early period told me such experiences during the interviews. I propose four possible explanations for this. Firstly, perhaps the recipients did not experience such a negative response from people. Secondly the recipients may have hidden such experiences from other people, including an interviewer, such as myself.

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<sup>22</sup> The expression ‘Zombie’ is used in Japan to describe living-dead bodies such as Frankenstein’s monster.



Thirdly, the recipients may have talked about such experiences to health professionals, but not to others. Fourthly, the recipients may have talked about such experiences to other recipients, and the other recipients reported them to a surgeon. Considering that no recipients told me directly about such experiences of discrimination, it is possible to assume that the recipients did not want to be recognised as people who experienced such responses. This means that their relationship with others and the perception of their identities by other people are important for them.

Another ‘enacted stigma’ experience narrated by the recipient to a surgeon is described below:

(Dr. Sono) ‘If using fund-raising support from the public, some neighbours said, “Why did they ask for charitable support to have a heart transplant in spite of having savings? They still have a car.” I heard that, in particular in the countryside, the recipients and their families are more likely to experience these negative reputations.’

This extract shows how people pay attention to heart transplant recipients and how people’s observations are important for the recipients. They are under surveillance in a community. The stigma attracted by those who relied on fund-raising support was often reported, but only recent recipients told me such stories. For example:

(Ms. Okamoto) ‘I seldom go shopping around here. I only do grocery shopping and small shopping for my daughter. ... I don’t buy my clothes here, and don’t even go window-shopping. For example, I earned a negative reputation even for window-shopping at a watch shop. Therefore, I don’t buy anything for me and my husband.’

It seems that the public keep paying attention to the recipients. People expect a certain form of behaviour from them, containing ideas about how the charitably supported patients should behave. Fund-raising for the recipients involves the negotiation of a bond between a recipient and the public. Usually a support team is established in order to conduct the fund-raising prior to going abroad to have a heart transplant (Aranami, 2008).<sup>23</sup> This is initiated at the recipient’s request. This support team grows as a community to financially help the patient who needs a transplant. In this process, both the recipient and people who support the recipient – which consists of the public and

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<sup>23</sup> This process was described by most heart transplant recipients who sought fund-raising support from the public, and the process was more or less the same. Some of the Japanese transplant surgeons suggest that patients contact Mr. Aranami at the TRIO Japan when they need charitable support (Aranami, 2008).

members of a support team – become members of the same community. Because the recipient is in need of help, there is support, but after the transplant, while acknowledging that the recipient is unlikely to be able to repay in financial terms, certain behaviour is expected from the recipient. This means that the public scrutinises the recipient and this surveillance impacts on actual behaviour in the recipient's everyday life.

What is behind this idea? It seems that there is a need to be perceived as a normal member of the community, it is necessary to have a body that is 'normal'. However, a heart transplant allows people to imagine that a person's body is not normal, and this can then lead to rejection from community membership. In this regard, there is a common idea between the enacted stigma experiences in the early period and those among the recent recipients. Even though people do not use the expression 'Zombie', they seem to think about whether the recipients' bodies are still the same as those of people.

Organ transplant recipients tend to have fewer chances to get jobs than other people (Sezai and Minami, 2006). Some recipients experience being rejected at work and school.

(Mr. Oda) 'Before starting a new job, I wanted to get a part-time job in the meantime. When sending my CV, I didn't include the fact that I'm a heart transplant recipient. However, during the job interviews, I always needed to explain it, and I never got those jobs. Therefore, I began to write in my CV that I was a heart transplant recipient. After that I often failed to get jobs for medical reasons.'

Sezai and Minami (2006) point out that organ transplant recipients generally tend to have fewer chances to get jobs because of people's lack of understanding about organ transplant recipients' health condition and whether or how much they can work (Sezai and Minami, 2006: 2114-2115). However, the opposite was found in the case of one interview subject in this study. Ms. Kato, who had received a heart transplant in the U.S., started her career at Sony in 2009 after graduating from a university in Japan. Sony employed her as a disabled member of staff. In the interview, she commented on the advantage to her employer of regarding a heart transplant recipient as a disabled member of staff.

(Ms. Kato) 'Employing me [a heart transplant recipient categorised as disabled] is an advantage for SONY, because I can work the same amount as

other staff and the company do not need to provide special care for me. Nevertheless, they still satisfy a regulation in Japan which states that companies have to employ disabled people; otherwise they have to pay penalties to the government.’

This was the only example in interviews in this study in which a participant described her positive enacted stigma experience. Enacted stigma experiences were mostly related by participants with negative experiences. In addition to these professional experiences, children also experience discrimination about their chance of receiving an education.

(Mrs. Aida, a recipient’s mother) ‘Prior to my daughter’s entrance into a nursery school, the school’s president told me, “If your daughter encounters any problems, we won’t take any responsibility for her. Even though parents agree with this idea, I know that many of them try to make us bear the responsibility if something happens to their children. Therefore, we cannot accept your child into our school.”... Prior to my daughter’s entrance into an elementary school, a similar thing happened to us. The school’s president told me, “We can’t accept your daughter into this school unless you sign a document in which you promise to be responsible for whatever happens to her.”’

The experiences of ‘enacted stigma’ were mostly narrated by the recipients who had heart transplants abroad. By contrast, the self-funded recipients abroad did not describe such experiences as their personal experiences, instead talking about other recipients’ experiences of discrimination. This means that they are aware that such discrimination happens to heart transplant recipients. They did not need to disclose information about themselves, unlike the recipients who needed fund-raising. Therefore, they may be able to control the information disclosure to avoid having ‘enacted stigma’. The recipients who had heart transplants in Japan did not talk about such enacted stigma experiences either. They are anonymous as the recipients in Japan. Therefore, they have less chance of facing the situation of being discriminated against by the public.

It needs to be considered what enacted stigma confined to people who raised money to have transplants abroad? As discussed, by disclosing information, the label of a heart transplant recipient is reinforced among other people such as neighbourhoods and the public. Other people expect the recipients to engage in certain behaviours. In addition, considering the above extracts, it seems that other people are unhappy when heart transplant recipients take further advantages in society. I argue that this reflects the public understanding of the privilege of receiving a heart transplant. People may be jealous of a person when he or she acquires further advantages. The un-described

feeling among the public affects the recipients' experiences of stigma.

### **5.4.3 Felt stigma experiences**

In a situation in which the recipients receive both positive responses and social discrimination, they attempt to avoid actual acts of discrimination. This is called 'felt stigma' (Scambler and Hopkins, 1986). Recipients reported more felt than enacted stigma. Being prominent in a group, in particular at school among teenagers, often causes negative responses from friends. Children try to be the same as their friends in terms of their behaviour and appearance. These attitudes have been usual in Japan. Under these circumstances, Ms. Kato wanted to behave like her friends, although she understood that she should not do physical exercise to the extent that her friends did.

(Ms. Kato) 'I wanted to behave as a "normal person" like other friends as much as possible. Therefore, one day, I tried to sprint, although I understood that I didn't have enough stamina to fully attend the gymnastics class, and I should not try it... In reality, I developed anaemia after the gymnastics class.'

As this extract shows, she has an idea how a 'normal person' should be. In her mind, a 'normal person' can fully attend classes without limitation. As far as a student without any physical problems is seen to behave in classes, the student is categorised as a 'normal person'. Looking at this idea carefully, it does not matter whether or not Ms. Kato has a physical problem in terms of attending classes. The important thing for her is whether she is perceived as a student who can attend classes like other students. The impression of her physical performance among other students was most important for her. In other words, the gaze of others is the key. Among children at school, the gaze often has a strong power to control recipients' behaviours. Ms. Kondo has met many school children who are heart transplant recipients who have such problems.

(Ms. Kondo) 'Some children are unable to tell their friends the truth that they have undergone heart transplants. I then asked them if they managed to take their medicines privately, to which they answered that they do so in a restroom. This was completely new and surprising to me as I used to have my medicines in front of my friends, and they would often make casual, inoffensive remarks such as "Wow, amazing quantity" and I would respond in a similar fashion, "Isn't it?"'

Ms. Kondo herself is a heart transplant recipient; she used to disclose to others that she

is a recipient. By contrast, the children whom Ms. Kondo met are inclined to hide the fact that they are recipients. In order for their differences not to be seen by their friends, when they take medicine, which is very important to control their immune system, they go to a place which is unseen by their friends.

These children's experiences in relation to their friends tell us how the gaze of other students shapes their lives at school. Deviance becomes stigma to them; therefore children struggle not to have the stigma attached to them by trying to seem normal. We need to consider that, even if these recipient children succeeded in hiding the truth of their status as heart transplant recipients, they still have to obey the medical regime which controls their health condition. In their minds, it can be considered that their identities are differentiated from their friends. Often the more they hide the truth, the more they make their identities as recipients stronger in their minds. It seems that these experiences were common among children at school to some extent, regardless of whether they were self-funded recipients or fund-raising recipients. Felt stigma was also experienced by older recipients, and I will now describe this.

Adult heart transplant recipients belong to more social groups, such as workplaces, local community groups, their children's schools and so on, than children. The more the recipients belong to communities, the more they receive responses from other people. Some recipients describe this situation as being under 'surveillance', as Mr. Oda expresses:

(Mr. Oda) 'For two years, I rehearsed in my mind simulations of how I would repay people. Although they had helped me financially to get a heart transplant abroad, I began to fear that I would be under their constant surveillance.'

Mr. Oda imagined the intensity of the surveillance he would be under even before having a heart transplant. This surveillance was actually experienced by recipients, as Ms. Okamoto describes.

(Ms. Okamoto) 'In this city of Yokote, for example, in the station and on the streets, I have often been asked by others, "You're Mika, aren't you? I'm happy for you..." [Under this circumstance,] I feel more tension than encouragement. I know that some heart transplant recipients and their families move to different cities... Recipients and their families often experience negative reputation after a transplant, too. Some are unable to stand the atmosphere in order to keep living in the same city.'

As she said, recipients seem to feel tension in their relationships with other people. When they can't stand the tension, some are forced to move to different cities where people generally don't recognise them as recipients. Mr. Oda also expresses having heard of the same issue regarding other recipients:

(Mr. Oda) 'Some patients and their family members move to a different city. Some others began to go to a hospital where they don't see anyone who knows them.'

The geographical move is the recipients' action to avoid having enacted stigma. When the recipients have relationships with other people who belong to the same communities, it becomes important for the recipients and their families to retain the balance of information disclosures about themselves as recipients. In this regard, the significance of the gaze of others is still the same as the experiences among children. Although many recipients can control disclosures of information about themselves, recipients who are self-funded for the transplant may have different experiences. Recipients who had paid for themselves did not need to disseminate information about their heart transplants to so many other people, seeking only to explain to some people at work and in the community. Nevertheless Mrs. Sato, whose husband had a self-funded heart transplant, expresses her experience as follows:

(Mrs. Sato) 'I felt that people thought and saw us with a negative idea about having a heart transplant abroad, such as "Why do you want to live even using such means of heart transplant?", "You don't need to try it", or "A heart transplant will be merely a life extension". But nobody directly told us these things.'

As the recipient and as the recipient's family, these people also experience felt stigma. As they did not ask for financial support from the public, the public may consider their decision as a private matter for the recipient. In other words, the family of a self-funded recipient feels less pressure from the public. By contrast, once the recipient asks for financial support, the community becomes larger than the family. Therefore, the recipient may feel more pressure in the community.

Looking at the experiences among recipients who had the surgery in Japan, a sense of stigma was not directly described in their narratives. The most likely reason may be that they are anonymous in Japan. Although some people around the recipients know about the transplants, the number of people who know the recipients' identities should

be small compared to the case of the recipients abroad. Recipients have controlled the disclosure of their information as heart transplant recipients. At the same time, this means that the recipients assume that they may experience enacted-stigma when they experience any discrimination. Mr. Watari describes this possibility:

(Mr. Watari) ‘I don’t agree with perspectives in which the disability brings positive experiences to a person’s life. This is my very honest feeling. However, it was really good to have had this surgery for me. I have come to think so. At the same time, other heart transplant recipients told me that I would gradually know social discrimination by having the transplant. ... So far, I have only been with people who have sympathy for me. I don’t think that this situation will continue’.

I found that the recipients in Japan carefully observe how Japanese people perceive heart transplant recipients. Although they do not directly report any negative comments in most cases, the recipients are very sensitive about avoiding possible discrimination.

These experiences reflect the relationship between a community and the recipient. Finally, I will examine the relationship between a recipient and an individual. Ms. Kato talks about a relationship with a boyfriend as follows:

(Ms. Kato) ‘When thinking about my future partner, ideally, I want to see a person who knows that I’m a heart transplant recipient.’

She explains the reason why she wants a boyfriend from among ‘the wise’ as follows:

(Ms. Kato) ‘I am always scared that I may be rejected by a person because I’m a heart transplant recipient. Therefore, I can’t be so positive about going out with someone.’

Although she did not clearly describe being rejected by telling the truth that she is a recipient, she understood that people might think that the identity of the recipient is undesirable. She has come to have this idea that she may be rejected by someone.

This section has explored the way in which stigma experiences among the recipients relate to their identities. The perception that the bodies of recipients are different from ‘normal’ members of the community appears to be fundamental here. The recipients’ bodily changes are generally invisible to the glances of others; once people know the truth, that a person is a heart transplant recipient, they tend to categorise the recipient as someone who is different from the rest of society. Even though these people are not sure what the difference is, and even though they cannot explain the difference,

they may pay a great deal of attention to it. Because of this exaggeration of the recipient's difference, the recipient sometimes experiences enacted discrimination and more often experiences felt stigma. Therefore, it becomes important for them to control how they will disclose their status as a heart transplant recipient. In order to control the disclosure of this information, recipients are often forced to change their behaviour in the community to which they belong.

To summarise, heart transplant recipients become very sensitive to how others in the community perceive their body image, even though the fact that a person is a heart transplant recipient is not apparent to the public. Through observing others closely, recipients find ways to respond to others' expectations in order to reduce the chance of conflict.



## 5.5 Conclusion

This chapter has explored the experiences of heart transplant recipients after their transplant surgery. During the period immediately after the transplant surgery and before being discharged from a hospital, a recipient begins to acquire a new identity as a heart transplant recipient. The way in which this new identity is acquired depends on the location of the surgery: in Japan or abroad. Recipients in Japan experience their new identities as recipients to be more exaggerated than the identities of recipients whose surgeries are performed abroad. The difference between the experience of patients in Japan and those abroad is caused by a difference in the doctor-patient relationship. Due to the fact that heart transplantation is still not a popular medical treatment in Japan, and the number of operations has been limited compared to some other countries, heart transplant recipients tend to be treated as very special patients in the hospitals in Japan. In contrast, heart transplant recipients in hospitals abroad are not treated by health professionals as such special patients. Health professionals' attitudes towards heart transplant highly influence the patients' identities. Another important point is that the recipients do not necessarily experience negative feelings about being labelled 'a heart transplant recipient' in their relationship with health professionals at this stage.

Throughout the process of returning to work, school and social activities, the doctor-patient relationship, which is a relationship of 'mutual participation', tends to develop into a paternalistic relationship. This change in the doctor-patient relationship was mainly found to occur in instances among the recipients who had the surgeries abroad, in particular through activities of patient support groups. By attending a meeting, in particular one that is formally set up by health professionals, heart transplant recipients can interact with other recipients and health professionals. However, the meeting is not necessarily a place for the recipient to freely exchange information and express their feelings, even though they may hope and expect to do so at first. After all, they do not have many chances to do so in their everyday life. In terms of how the meeting is conducted, however, this situation is a reflection of the power balance between health professionals and patients; as it is a situation in which health professionals control the meeting, more than the patients, and can be seen as a reflection of the paternalistic relationship between them. While the relationship between health professionals and heart transplant recipients, particularly in the early period, under the

best conditions should develop towards a mutual relationship, in practice it tends to develop into a paternalistic one.

Recipients gradually perceive and establish their new identities in relation to other people. In this process, there are two key concepts that are important when exploring the recipients' behaviours: a 'sick role' and an 'impaired role'. The key character that differentiates between these two roles is whether or not, under a certain health condition, a person is released from bearing a social responsibility. In most cases of illness, a person is assigned an 'impaired role', which is often attached to disabled people, and does not involve release from social responsibilities (Larsen, 2009; Varul, 2010). Following the definition, a heart transplant recipient is more often expected to have an 'impaired role' than a 'sick role'. Looking closely at the recipients' narratives, they tend to alternate between these two roles. In this light, a recipient may value or devalue another recipient's behaviour in terms of the role. Each recipient considers not only his or her role, but also that of other recipients as well.

Findings in which the recipients felt more stigma than was actually enacted by others do suggest that Japanese people tend not to directly express their negative feelings to recipients. It seems that the pressure of 'felt stigma' makes the recipients sensitive to other people's responses, both through face-to-face communication and in a public space. In face-to-face communication, the recipient observes how the person encountered communicates with him or her after learning he or she is a heart transplant recipient. In a public space, a recipient often imagines a situation in which another person who knows him or her as a recipient observes his or her behaviours. Imagining such a situation seems to be important for the recipient, because the observation may lead to a certain evaluation of his or her behaviour as a recipient. In such cases, this may cause him or her to experience social discrimination later on.

Lastly, heart transplant recipients often experience thoughts that describe a heart-transplanted body as not normal or as different from the bodies of others. By acknowledging these thoughts, the recipients come to consciously perceive that the reason for the discrimination they experience lies in this difference in their body. Therefore, a recipient's bodily image is very important for establishing his or her identity in a community. In the next chapter I will examine how the notion of body in Japan influences recipients' identities.

## Chapter 6 The impact of the Japanese cultural perception of the body on the experiences of heart transplant

### 6.1 Introduction

This chapter explores how the notion of the body in Japan influences heart transplant recipients' identities. In order to explore this topic, I will focus on how recipients and those who have been involved in heart transplants, including health professionals, perceive the body, in particular when death occurs. Dealing with heart transplantation is totally related to the dead body, which is not merely a physical object. In ritual processes, it is considered by many that the soul and spirits inhabit the body. This becomes obvious at the time of the funeral (Gennep, 1960; Hertz, 1960; Metcalf and Huntington, 1991).<sup>24</sup> By contrast, the medical perspective on heart transplantation emphasises the functional aspect of body parts, which makes it possible to perform transplant surgery (NHS choices, 2011). A representative expression here is that the 'heart is a pump'. Interviews with heart transplant recipients reveal a mixture of ritual experiences of body and the medical perception of body. The recipients are forced to consider these views through the experience of heart transplantation.

First of all, I will explore recipients' narratives about the heart. The narrative will be examined focusing on the recipients' perception of the heart organ and their experiential knowledge of living with their received heart: how the recipients perceive the heart organ, and how they describe their experiences with the transplanted heart. In this exploration, I will try to discover what each interviewee's perception of a heart and the body is, particularly whether they see it as a machine or a material object, as opposed to a symbolic object (6.2). Next, I will compare the recipients' ideas with the ideas of health professionals and family members (6.3). Then, I will examine how their perceptions of a heart and the body influence their concepts of heart transplantation, and how these concepts influence the transplant recipients' experiences (6.4).

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<sup>24</sup> These studies show that many cultures have their own ways of treating the soul and the dead body separately. The ritual process is a place to convey the symbolic meaning of the soul and the dead body, although the detailed processes vary in each culture. Nevertheless, this perspective gives us a framework to explore the ritual process in contemporary Japan. The attitude which differentiates the soul from the dead body in the ritual process can be found in current Japan. For example, Metcalf and Huntington (1991) developed an understanding of 'body politic' and 'body natural'.

## 6.2 Narratives of a heart by the recipients

In this section, I will explore recipients' narratives about the heart itself. Firstly, I will focus on how the recipients perceive the heart organ. This will provide insights into the way in which the recipients think about and understand the heart and body. Secondly, I will examine how the recipients describe their experiences with the transplanted heart. This will show the recipients' knowledge based on their experiences of the transplanted heart and the body.

### 6.2.1 Recipients' perception of a heart

Discussions of whether the Japanese notion of human body is dualistic, separating body and mind, or monistic, have become popular (Lock and Honda, 1990; Namihira, 1990; Ohnuki-Tierney, 1994; Umehara, 1992; Deguchi, 2001). Consensus on this question has not yet been reached. Rather, the notion of the body in Japan has historically changed and reflects one's social situation (Yourou, 1996). An exploration of how recipients describe the heart and the body in relation to heart transplantation will provide further insights into this.

Looking at what recipients said about hearts, it is clear that they tend to describe the heart as a special organ.

(Ms. Okamoto) 'The heart is a centre of the body. The heart is one of the most important parts of the body.'

(Ms. Hamada) 'The heart is a special organ, because I understand that one can't live without a heart. ... I don't think it [mind] lives in a heart.'

(Mr. Uchida) 'I thought that, different from lungs and other organs, a heart is more important than other organs. Therefore, I felt a great anxiety to replace my heart by transplant surgery.'

These extracts show that the recipients hold the view that the heart is a 'special' organ. Here, it is important to notice that the recipients look at the heart as a body part. In other words, they have a view which considers body parts individually rather than the totality of the body. Then, the recipients differentiate the meaning that each organ holds. Another important point is that each recipient differentiates his or her own heart from

the hearts of others. Focusing on Mr. Uchida's description above, it is assumed that he considers that his body consists of his existing body parts from the time of his birth. To undergo a heart transplant causes disruption to this harmony of body parts for him. Therefore, he felt anxious about such a disruption. Why did he feel this anxiety in spite of having a new, healthier heart? If he were only to consider the functionality of the heart organ, he would think that a healthier heart would be in a better condition. Nevertheless, he experienced anxiety. The problem for him was that it was someone else's heart. His description of this feeling shows that he differentiates his heart from other's hearts. He did not simply think about the heart's function. Therefore, it can be concluded that he considers that the organs of the body form a person. One person is differentiated from another person by the 'body'; the body establishes the self of each individual, as it were. Therefore, his fear might reflect a fear of the disruption of his self. Further evidence of the perspective which puts a boundary between his or her heart and another's heart, Ms. Kasai develops a similar interpretation of the heart.

(Ms. Kasai) 'In my mind, neither my previous diseased heart nor the transplanted heart is a machine, or stuff. I feel that both are another person. You may feel strange with my idea of a heart. However, a heart is like "Ms. Heart" in my feelings.'

Through the experience with her diseased heart and then with the transplanted heart, Ms. Kasai has always had the situation where she is highly aware of the heart in her body. In addition, she has developed her own way to personify the heart, as I have explored in section 5.2.4. I assume that she needed to find a way to integrate the transplanted heart at a psychological and emotional level, which is a different medical integration process from a heart transplant. In order to accomplish this, she may have started communicating with the heart by personifying it (e.g. 'Ms. Heart'). Narratives of a heart organ provide us with the insight that a heart transplant recipient needs to integrate the transplanted heart at a psychological and emotional level, beyond the medical integration by a heart transplant surgery and immunosuppressant drugs.

### 6.2.2 Memory with a heart

Does a person's heart hold memories when transplanted from one body to another? *A Change of a Heart* (Sylvia and Novak, 1997) describes a heart transplant recipient's experience – one that medicine and science cannot explain. This book describes Claire Sylvia's post heart-lung transplant experiences through which she inherited her donor's memory. After the surgery, Sylvia acquired a new personality, which she believed was inherited from her donor who she met in a dream. Despite not knowing any specific information about her donor prior to her surgery, Sylvia learned about her donor, including the donor's name, through dreams and she eventually met her donor's family (ibid).

This kind of story tends to be considered unbelievable. In modern society, however, some people have suggested that these stories are true. Pearsall (1998) assumed that the heart holds the mind. He explained that the heart not only has functional aspects as an organ that sustains life, but also has a relationship with the mind, the latter is not yet proven. Nishihara (2002) understands Sylvia's experience as true and then attempts to prove how each organ controls a human emotion. These studies, though, do not adequately validate Sylvia's experience. Whether true or not, there are several other stories like hers,. In view of this, I will explore what the recipients said in their interviews.

Most recipients know that some recipients have talked about experiencing their donor's memory through a transplanted heart. The recipients also know that people are curious about whether this is true because some people asked the recipients if they have seen any of the donor's memories after the transplant. Mr. Ohashi, a heart transplant recipient, does not deny that these sorts of things happen to some recipients.

(Mr. Ohashi) 'I relatively believe in supernatural phenomenon, and so I assume that some heart transplant recipients have experienced it [donor's memory after having a heart transplant].'

By referring to supernatural phenomena, Mr. Ohashi describes the heart transplant experience as one that cannot always be explained by the recipient and medical experts. Mr. Higashi, another transplant recipient, has the opposite opinion to Mr. Ohashi.

(Mr. Higashi) 'Prior to a heart transplant, an organ coordinator asked me

whether I would have a heart transplant from a death penalty prisoner. ...I am not sure now whether it [heart transplant from a death penalty prisoner] was real or just an assumption. At that time, the coordinator asked what I thought about it. My answer was that I considered the heart as just an organ. As I think of things in a realistic way, I do not believe in supernatural phenomenon. Although there is a neuro-system in the transplanted heart, I don't think that a heart is something special or more than an organ. After I answered, the coordinator did not continue to discuss my ideas. The coordinator told me that she understood my fundamental idea about a heart. When depicting a heart, we use a heart shape ♥. In Japanese, the kanji [a Chinese ideograph used in Japanese writing] of *kokoro* [mind] is used to represent a heart. We also tend to put more meaning into a heart than only looking at its function.'

Similarly to Mr. Higashi, Ms. Okamoto's surgeon discussed with her whether a donor's memory was transplanted along with the heart organ.

(Ms. Okamoto) 'When Dr. Minami explained about a heart transplant he told me, "Some people say that donor's memory is also transplanted with the donor's heart. However, it's not true. The heart is merely a pump, and it just works to circulate blood in the body. The heart is different from the brain, and the heart organ itself cannot think. Therefore, you don't need to worry about those rumours." ... As he is a surgeon, he told me that this story is ridiculous. I also thought so.'

So, Ms. Okamoto agreed with her surgeon's explanation about the heart being only an organ. At first glance, it seems that there are two opposing ideas about the relationship between hearts and memories among transplant recipients. However, this interpretation is too simple. Despite Ms. Okamoto's agreement with the functionality of a heart, she referred to a TV commercial of cornea donation in Japan as follows:

(Ms. Okamoto) 'In the commercial, there are several messages such as; "I didn't want give any damage to my daughter's body. However, she wished to donate her cornea. Therefore, we did... She used to love cherry blossom. I think that her eyes enjoy cherry blossoms from someone's body".... This is a wonderful way of thinking. However, it's difficult to have such a view. I think that less people think that organs from a dead person will live in someone else's body, and these organs will acquire new lives.'

This TV commercial provides two important messages. One point is to note the damage to a dead body by extracting an organ. Another point is the assertion that a donor's cornea can live in someone's body after the donor has died. On the one hand, Okamoto denies the idea that each organ carries the donor's memory to a recipient. On the other hand, she agrees with the idea that each organ holds a life even after being removed

from a body. In other words, this attitude towards an organ reflects the idea that a person's biological life remains even if only in a body part.

Another recipient describes his views about the relationship between a heart and the donor's memory unambiguously. Mr. Noguchi changed his behaviour after the transplant:

(Mr. Noguchi) 'My wife told me that, unlike before, I began to scold people. It may be impolite to my donor if I said that this change was caused by a heart transplant. My donor was a woman in her 40s when she passed away, although I was not given her exact age at that time. For example, if she had been 49, she might have been in menopause. This characteristic might have been transplanted into me via her heart. One day, I spoke about my experiences to a health professional who was studying this theme [how a person's character changes after having a heart transplant]. He explained that there is no scientific evidence to support my experience. Nevertheless, he mentioned that there was not a zero possibility of this happening to recipients.'

When Mr. Noguchi talked to one of his surgeons about his thoughts and that the transplanted heart might have changed his character, the surgeon did not deny the idea. Mr. Noguchi's surgeon explained it to him as follows:

(Mr. Noguchi) 'For a long time, the heart has been called "an organ of mind" [heart is *shin-zou* in Japanese: *shin* means mind and *zou* means heart]. Therefore, the surgeon told me that it might be possible that the recipient's character is affected by the donor.'

Mr. Noguchi seems confident in expressing his experience and ideas in the knowledge that even a health professional does not deny a relationship between the heart and a donor's memory. In addition, according to Mr. Noguchi, a health professional at the hospital where he had his heart transplant is conducting research about the relationship between a transplanted heart and the donor's.

These narratives show that heart transplantation includes explanations from a medical perspective and from an opposing cultural viewpoint. In the medical explanation, the fundamental idea behind performing a heart transplant is that the 'heart is a pump' (McRae, 2007). The narratives that referred to a donor's memory and life carried with a donated organ reflect cultural matters. Here, people tend to consider organs as something more than their functions but still accept the idea of body parts being used for transplant surgery.

The tradition of animism in Japan may more widely support this kind of attitude



which says body parts carry lives on and contain memories. Moreover, in relation to heart transplantation, these animistic ideas may be disseminated by the mass media which has introduced stories in which heart transplant recipients claim to have experienced memories after a heart transplant. In order to understand the experience of heart transplant recipient, we need to deal with these ideas – either conscious or unconscious – along with the dualistic perception of the body prevalent in Western medicine.

### 6.2.3 The ‘Relay of Life’

The idea that the heart is involved in a ‘Relay of Life’ is a way in which people maintain the idea that life inhabits organs. This metaphor has been disseminated in Japan (Sasaki, 2008), while metaphor of ‘gift of life’ has been more widely disseminated in the U.S.;<sup>25</sup> this is the opposite of the idea that a heart is a pump or that an organ is an object. Here is one interviewee expressing this.

(Ms. Sakata) ‘I don’t exactly remember whether it was Mr. Matsuda, or Mr. and Mrs. Cotei, who told me, but one of them told me that, here [in Germany], having a transplant doesn’t mean the person’s life ends with donating organs. The donor’s life is taken over by another, and this is considered “the relay of life”. Therefore, the transplanted organ continues surviving in someone’s body. ... This explanation encouraged me a lot during the time when I waited for a heart transplant.’

Why does this idea give encouragement to the patient and the recipient? I assume that heart transplant recipients can look much more at the donor’s life rather than the donor’s death by seeing the transplant as a relay of life. First of all, death tends to be considered taboo in Japanese society (Nudeshima, 1999). Therefore, the death-related ritual process of funerals has a role in managing this social taboo. However, the recipient cannot be involved in the donor’s death ritual process. Thus, the recipients do not have any chances to manage the taboo on the donor’s death. However, by contrast, if the transplanted heart represented the donor’s life, the recipient would be released from any concern about a taboo on death. A relay of life explanation will reduce the anxieties of

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<sup>25</sup> Sasaki (2008) explains that the cultural notion of a gift in the U.S is different from that in Japan. While gift-giving and receiving between anonymous people are accepted by people in the U.S, Japanese people are not familiar with exchanging gifts with anonymous people. Therefore, she explains, an expression of ‘relay of life’ is preferred in Japan. The perspective of gifts and transplants is examined in Chapter 7.

the recipients, because the recipients accept, not ‘death’, but ‘life’, as it were. There may be similar anxieties among the public, including among health professionals. This expression may reduce their broad anxieties. However, the idea of ‘relay of life’ through heart transplants is not simply accepted by the public. Here, the complicated atmosphere is narrated by a recipient.

(Ms. Okamoto) ‘Heart transplantation is called a “relay of life”. I know that some people criticise the use of this expression. Whatever some people say, I know that a heart transplant saves another person’s life.’

Referring to actual situations including her own transplant experience, Ms. Okamoto attempts to emphasize a person’s life. Some directly refer to life through heart transplants without using the metaphorical expression. Dr. Sono introduces one of his patients’ experiences in terms of the idea, ‘relay of life’.

(Dr. Sono) ‘One of my patients, Sachiko-chan, received a heart transplant in the U.K. It was a domino-transplant. [Her donor received a heart-lung transplant from a brain dead-donor for her lung disease. As this patient’s heart did not have any problems, the heart was transplanted to Sachiko-chan.] Therefore, Sachiko-chan and her parents often saw her donor and the donor’s family in the hospital. Unfortunately, Sachiko-chan’s donor passed away soon after the operation. When the donor passed away, the parents told Mr. and Mrs. Ishida [Sachiko-chan’s parents] that they were happy that their child’s heart had helped their daughter. Mr. and Mrs. Ishida told me about this experience.’

In this extract, the expression of ‘relay of life’ is not used. Instead, the donor’s parents narrate the functional aspect of a heart organ. Both attitudes focus on the same thing. Comparing them, it seems that the direct expression of ‘the child’s heart helped your daughter’ seems more powerful than the metaphorical expression of ‘relay of life’. In particular, an expression of ‘help’ gives a stronger impression than ‘relay’.

But some do not go along with the idea of ‘relay of life’. A heart transplant recipient’s family member, Mrs. Sano, explains here why she simply does not agree with this idea of a relay of life.

(Mrs. Sano) ‘I don’t think that having a heart transplant does mean receiving a life from a donor. I believe that brain death means ... one’s death. An organ from a dead person doesn’t represent part of the donor’s life.’

She describes organs as merely objects. Similarly, her husband, who is a heart

transplant recipient, considers a heart to be stuff, rather than a life.

(Mr. Sano) ‘People in the U.S. say that they give an “organ”. In a similar situation, Japanese people say that they give a “life”. So, there is a difference in the description of the same thing, between people in the U.S and the Japanese.’

Mr. and Mrs. Sano’s ideas regarding the heart organ do not reflect the idea of ‘a relay of life’. However, they do not simply consider the transplanted heart as an object.

(Mr. Sano) ‘I heard that [an] organ donor’s DNA is detected in [the] tongue. It should be possible, because [the] tongue holds tissues. In any case, I assume that two people’s DNA should be somewhere in my body, as a heart was transplanted.’

In this extract, they pay attention to DNA, which distinguishes an individual from another. They refer to an example which DNA is transplanted to the body with the heart from a brain dead donor; they seem to insist that the recipient receive not the donor’s life, but the information of the individual through the transplant. Their way of thinking about heart transplantation proves that medical data works to minimise a perspective which gives symbolic meaning to a heart organ.

#### **6.2.4 Ownership of the body**

Is a heart the owner of the body? Is the body the owner of the heart? As explored in the previous section, in particular 6.2.1, some recipients have a view which considers body parts individually rather than through the totality of the body. In addition to this, recipients develop their thoughts about the relationship between the transplanted heart and their own body.

(Ms. Hamada) ‘I don’t feel that this [transplanted heart] is mine. ... At the same time, I don’t feel that I am borrowing this heart from someone.’

Why does Ms. Hamada not think about the transplanted heart as hers? She describes her idea of heart as follows:

(Ms. Hamada) ‘The heart is a special organ. Without a heart, one cannot live, regardless of any medical treatment. Thus, I feel that to receive a heart organ has a tremendously special meaning.’

She described the special nature of a heart from a medical perspective, which perceives the function of a heart being to sustain life. Mr. Uchida described how he experienced discomfort with the transplanted heart and how he got used to it.

(Mr. Uchida) ‘Soon after having a heart transplant, I recognised that the transplanted heart did not fit to my body well. Even when I felt sleepy, the heart strongly beat. I felt that I wasn’t getting along well with the heart. Thus, I worried whether I would be fine with the transplanted heart. ... A health professional told me that I would get used to the heart. As health professionals have adjusted me with pills [to control the immune system], I have gradually got used to the heart. Now, I don’t feel discomfort with the heart.’

His narrative shows how medical adjustment makes it possible to integrate the heart into the body. Both Ms. Hamada’s and Mr. Uchida’s narratives demonstrate how heart transplant recipients can experience the transplanted heart as something separate from the rest of their body. In other words, these recipients experience a process in which the body is divided into parts and then integrated with a new part. Another recipient, Mr. Oda, more clearly differentiates the transplanted heart from his body.

(Mr. Oda) ‘I have the idea that I gave my body to the heart. “Live in my body, and I will do my best with you”, I said to the transplanted heart.’

As this narrative shows, Mr. Oda seems to be in two minds when it comes to the transplanted heart as to whether the heart is the owner of his body or whether the body is the owner of the transplanted heart. Here, the transplanted heart becomes an entity to which the recipient communicates by personifying the transplanted heart.

As seen thus far, although every recipient shares the same idea about a heart, the recipients perceive the heart not merely as a heart, but as the ‘transplanted’ heart. In other words, some recipients clearly differentiate the transplanted heart from the heart that previously resided in their body. The time spent thinking about the transplanted heart is when recipients integrate the transplanted heart into their body and into their minds. In this process, the transplanted hearts have an impact on the recipients’ activities. Mr. Oda, who had the idea that he gave his body over to the care of the new heart, began to have a new custom after the transplant:

(Mr. Oda) ‘I go to a church on the 10<sup>th</sup> August every year. ... I’m a Buddhist. I’m not sure about whether my donor was a Christian. ... It’s possible that the

donor was a Christian [because I had a heart transplant in Germany]. By a curious coincidence, the 10<sup>th</sup> of August is a day for the heart. In order not to forget about him, I go to church, and talk to him. ‘How was last year?’ ‘Are you enjoying your life?’ This is very important for me.’

Mr. Oda creates the image of his donor’s personality through the heart. In his idea, the heart has another self, and Mr. Oda communicates with this imaginary donor. This creation actually affects his behaviour. The transplanted heart controls not only his body functions to survive, but also influences his behaviour in everyday life. Another recipient, Mr. Toda, describes how he thinks about his donor as follows.

(Mr. Toda) ‘I heard that my donor was a Christian. When being released from a hospital after having a heart transplant, I bought a cross. ... I have always put it on since then. ... When washing my face, brushing teeth... I always remember my donor. ... Looking at this cross, this cross reminds me that this heart was given by a donor. I recall many things through this cross. ... I strongly think that it would be nice for other recipients to have something which reminds them of their donor.’

Unlike Mr. Oda, Mr. Toda knew that his donor was a Christian. He bought a cross to remember his donor. The cross represents his donor in his mind, as it were. Moreover, he insists on the positive benefits of holding onto this charm in remembering the donor. Thus the transplanted heart performs not only functions for his body, but also reminds him of the donor’s self.

Both Oda’s and Toda’s explanation show how some recipients perceive the transplanted heart. More precisely, the transplanted heart is not experienced merely as a ‘pump’. Therefore, the recipient may need a different story to understand the transplanted heart in the body.

So far, it has become clear that heart transplant recipients do not all think that the heart is either just ‘stuff’ or a ‘pump’, but may instead apply a cultural interpretation to this organ. In these interpretations, the body is an integrated entity. The body defines the self. Heart transplantation disrupts the body, because a heart that belonged to another self is removed from another body, and the removed heart is transplanted into the recipient’s body. When a heart is taken from a body, the organ is potentially made anonymous. The heart is destined from a medical perspective to find the recipient body that medically fits the donor heart. However, many recipients apply a cultural interpretation to the heart, and do not simply consider a heart as a pump.

To summarise, many recipients share the medical idea that perceives the body as

an assemblage of body parts, such as organs. Yet they also believe that these body parts play a role in differentiating one individual from another. Transplant surgery causes problems because it creates an ambiguous border between one person (the donor) and another person (the recipient). Therefore, the self of the individual is disrupted by the surgery.

### **6.2.5 Narratives of body with a transplanted heart**

In this section, I will explore how recipients narrate their bodies, based on their experiences of a heart transplant. As we have explored in the previous chapter, soon after having a heart transplant, the recipients experience different body conditions from before, mainly because the transplanted heart is in a healthy condition and beats strongly in the body. This condition makes the recipients perceive the transplanted heart as something new. As a result, in the very early period after the transplant, the recipients pay special attention to the heart. They then gradually come to establish their identity as a heart transplant recipient through communication with other people. In this process, how do the recipients come to think about their new hearts?

Recipients tend to perceive the transplanted heart as a new body part which makes the body live. Not only the medical integration by the transplant surgery and the immune system control, but also an understanding of the heart by the individual recipients, is important for the recipients. In relation to the integration of the transplanted heart, Ms. Kato describes the following:

(Ms. Kato) ‘I feel that the transplanted heart is almost unified with my body. I guess, compared to other heart transplant recipients in Japan, the extent of my unification of the heart to the body is quite high. ... Whenever I have a medical check-up by catheter to take cells from inside the heart, I have begun to feel pain. I heard that this pain usually does not happen to other recipients, because the nerves of the transplanted heart should not connect to the nervous system of the recipient’s body. If this assumption is true, I should not feel such pain. By experiencing such pain, I have come to think that the transplanted heart has been unified with my body even at the nervous system level. This is my hypothesis from an amateur’s perspective.’

This recipient experiences a condition that medical explanations do not support. It seems that, through the pain, the recipient feels that the heart is more unified with the body than before. The pain makes the recipient feel the unification of the transplanted heart and the body. The experience of ‘pain’ is important; because there is a view that

withstanding pain is a virtue (Hoka, 2004; Long, 2002). In other words, not having pain means not having a chance to have this virtue. Therefore, it can be considered that, as Ms. Kato has gradually experienced pain, she has experienced virtue with the transplanted heart. This symptom makes her feel that the transplanted heart is unified to her body. Another recipient, Mr. Noguchi, describes such pain experiences in more detail:

(Mr. Noguchi) ‘There is a health professional who researches how the neurological system of the transplanted heart is unified to the body. .. In the early period after the transplant, we can’t recognise it even though the heart pounds. ... A heart transplant recipient, Mr. Hamada is in his fifth year after having the transplant. I heard that a health professional saw a neuro signal in the transplanted heart when Mr. Hamada had a medical check-up in his fourth year after the operation. Although the sign of the neuro signal is still small, the signal gradually appears. ... It seems that the neuro system is integrated between the body and the transplanted heart.’

Ms. Kato narrates her individual experience, and Mr. Noguchi not only explains his individual experiences, but also refers to other recipients’ experiences and medical data by a health professional who presumably visualised these responses on some kind of monitor. Both narratives show how important it is that the neurological system of the heart is integrated, because the unification between the body and the transplanted heart can be experienced by having ‘pain’. This experience is important for the recipients to perceive that their whole body belongs to them. In other words, the recipient can perceive that his or her identity is established by the body, including the transplanted heart. In addition, as Mr. Noguchi’s narrative shows, the visualisation of the pulse of the transplanted heart, which is medically read, and the data shown to other people, explains the individual experience of pain; although the medical community does not have good evidence for the symptoms. This visualisation may assist the recipients’ idea of the relationship between the transplanted heart and the body. Furthermore, this visualisation makes it possible to promote other people’s understanding of each recipient’s experience and their narrative; therefore the visualisation may help to establish the recipients’ identities in relation to other people.

In these narratives, the transplanted heart seems to be both medically and mentally unified with the body. However, the unification is not a simple process like water flowing from high to low. Mr. Toda talks about how he automatically thinks about the relationship of his body’s condition to the transplanted heart even though more than ten years have passed since the transplant.

(Mr. Toda) ‘More than ten years have passed since I had a heart transplant. Nevertheless, when I feel an uncomfortable condition somewhere in my body, I think that the transplanted heart causes the discomfort. ... Even though I may feel pain in my legs, I think the transplanted heart has caused the pain in my legs.’

This narrative shows how strongly recipients perceive the influence of the transplanted heart. The heart seems to insist on its existence in the body. In other words, the recipient always thinks about and looks at his or her body in relation to the transplanted heart. In this regard, the transplanted heart strongly impacts upon recipients’ perspectives on their bodies. It is rather like Goffman’s idea of a ‘master status’ – it governs how people perceive an individual and explain a person’s behaviour. In this case, the presence of the heart in one’s own body is thought to ‘explain’ all kinds of bodily experiences that might have otherwise been explained by some other factor.

In summary, the exploration of the narratives written by heart recipients in this section demonstrates how heart transplant recipients perceive the body. Recipients have a view that considers body parts, such as organs, individually. Based on this idea, they have both a medical understanding of an organ’s function and a cultural meaning for each organ. They think that the body is constructed according to these functions and meanings. In relation to having a heart transplant, the meaning that a heart holds becomes important for transplant recipients. A heart organ has a history by belonging to another person, and the individual history establishes a person’s identity. Thus, organ recipients differentiate their own hearts from those of others.

Moving from this exploration of the recipients’ ideas of a heart, to an exploration of their actual experiences with the transplanted heart, recipients show how they integrate the transplanted heart into their body. The ‘neurological system’ is an important factor. In the early period after the transplant operation, recipients recognise how different his or her body condition is from the time he or she had his or her diseased heart. Although the transplanted heart is medically unified within the body, recipients do not feel that the transplanted heart is fully integrated with their body. After several years have passed, the patient’s neurological system is in some cases felt to be connected with the transplanted heart and the recipient’s body. A health professional may even record this neurological system adjustment. As a result of this greater integration, recipients begin to experience pains, for example, when they have medical check-ups for their hearts. By seeing the visual display on a monitor and experiencing these pains, recipients come to



feel that the transplanted heart is unified with their body. Even as the unification increases, the recipients constantly think about how the transplanted heart fits into their body. In this regard, the transplanted heart, medically and mentally, has a strong impact on the body, and is related to the establishment of the recipient's identity after the operation.

These narratives of heart transplant recipients are not normally expressed openly to other people, such as health professionals and family members. This is probably because they do not expect to be taken seriously. In the next section, I will explore how surgeons and family members view transplanted hearts and will compare these views with recipients' ideas.

### 6.3 Narratives of a heart by surgeons

In this section, I will explore surgeons' narratives about heart transplantation. I have interviewed four surgeons for this: Dr. Sono, Dr. Fukushima, Dr. Minami, and Dr. Kyo. They have all been involved in heart transplantation in various ways.

Dr. Sono was one of the foremost surgeons in the history of heart transplantation in Japan. He established a connection between Harefield Hospital in the U.K and Kobe City Hospital in Japan. This was the first time that it was possible for Japanese patients to have heart transplants in the U.K. It was also a first in terms of establishing international relations for heart transplantation between a hospital in Japan and a hospital in another country.<sup>26</sup> Additionally, Dr. Sono established a further connection between a hospital in the U.S in 1996 and a hospital in Japan after the U.K stopped giving heart transplants to Japanese patients. He did not have any opportunities to perform heart transplant surgeries in Japan; however, he played an important role in improving the situation for patients in Japan who needed heart transplants, in particular before the creation of the Organ Transplant Law in 1997 (New Heart Club, 1993).

Dr. Fukushima is a heart transplant surgeon and was one of the medical team members for the first heart transplant operation to be conducted in Japan. He also had a key role in persuading members of parliament to pass the Organ Transplant Law in 1997 and then to amend it in 2009 (Aranami, 2008).

Dr. Minami used to work at Bad Oeynhausen, University of Bochum, Germany, and has worked at hospitals in Japan since 2000. He has played an important role in providing heart transplant surgeries for Japanese patients in Germany (Minami, 2008).

Dr. Kyo was one of the members of the team which performed a transplant using the Ventricular Assist System (VAS) in 1980, the first such surgery in Japan. Since then, he has been a leading figure in this field. By performing these operations, he assists the lives of the patients who wait for heart transplants (Aranami, 2008).

Unlike health professional who are opposed to heart transplantation, these professionals clearly claim the validity of heart transplant as a medical procedure. In addition, they have close communication with heart transplant recipients and potential heart transplant recipients. In the following section, I will examine how these surgeons

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<sup>26</sup> Mr. Makino was the first Japanese heart transplant recipient to go abroad. He had a heart transplant operation in 1984 at Stanford Hospital & Clinics in the U.S. However, the connection to send Japanese patients to hospitals in the U.S from hospitals in Japan did not immediately develop.

developed their ideas about heart transplantation and their related medical skills. Then, I will explore how they negotiated the cultural concerns related to heart transplantation. Finally, I will consider how these attitudes among surgeons influence the recipients of heart transplants.

### **6.3.1 Establishing attitudes towards heart transplantation as a heart surgeon**

Heart transplant surgeons were the first individuals to develop the knowledge and skills for heart transplant operations. As described in the literature review chapter, the discussion of issues surrounding heart transplantation in Japan has not always been positive towards heart transplantation in terms of cultural perspectives (Lock and Honda, 1990; Namihira, 1990; Ohnuki-Tierney, 1994; Umehara, 1992; Deguchi, 2001). There was a more sceptical attitude towards heart transplantation in the early period (Nakajima, 1985; Watanabe and Abe, 1994). Under these conditions, some health professional became pioneers in this field. Socially and culturally, they were members of Japanese society, so had to contend with typical Japanese attitudes towards transplantation in order to attain their pioneer status. It is therefore worth exploring the ways in which these heart transplant surgeons developed their ideas and skills in the early part of their medical careers.

The first heart transplant in Japan was conducted in 1968 by Dr. Wada, also known as the ‘Wada heart transplant’, which brought him considerable notoriety (Corson, 2000; Nakajima, 1985). Following this there was a long interval until a heart transplant became considered a realistic medical treatment. Health professionals in other countries started heart transplant operations again in the 1980s (Brannigan, 1992). Japanese health professionals and patients began to use this opportunity for heart transplants abroad (New Heart Club, 1993; The Japan Society for Transplantation Publicity Committee, 2009). So heart transplants for Japanese health professionals and patients started in other countries prior to domestically establishing a system in Japan. Among the health professionals who learned to perform heart transplant surgery abroad in the early period was Dr. Sono, who also took on a pioneering role.

Meeting with a U.K.-based heart transplant surgeon, Dr. Madgi Yacoub, changed Sono’s life. Listening to a lecture about heart transplantation by Dr. Yacoub in 1983 in Japan, Dr. Sono made a decision to go to the U.K to learn about the operation and to be supervised by Dr. Yacoub (New Heart Club, 1993). He describes his feelings in the early period when he first went to the U.K as follows:

(Dr. Sono) ‘I could have a chance to study at Harefield Hospital for one year from 1986. Before going, I half doubted the value of heart transplantation. On seeing heart transplant recipients in the U.K, the doubt disappeared. I was amazed by the truth of how heart transplantation improves the patients’ quality of lives. I saw people who really recovered from heart disease. They could have lives which were almost same as other (healthy) people, except for that they need to take medicine every day and regularly go to a hospital for medical check-up. Therefore, I recognised that a heart transplant is really amazing medicine.’

Even though Dr. Sono was a surgeon and already had certain knowledge about, and interest in, heart transplantation, he had a somewhat sceptical attitude towards that value of heart transplantation until he saw the actual recipients. To see was then to believe. Acquiring more knowledge and experience of heart transplantation from the recipients, he developed his speciality as a heart transplant surgeon.

Dr. Minami, who is younger than Dr. Sono, has performed many heart transplant operations. He developed his career as a heart surgeon mainly in Germany. His experience at a conference abroad initiated his move to Germany. When he was in his second year of traineeship at a university hospital after graduating from medical school, he had the opportunity to travel to Scotland to attend a conference regarding heart disease with an associate professor and other colleagues from the same university. After the conference, they travelled to Germany to visit Düsseldorf University Hospital. Dr. Minami knew that each surgeon performed about tow hundreds to three hundreds operations at the hospital. This number was about ten times bigger than in Japan. Dr. Minami describes how he felt at that time as follows:

(Dr. Minami) ‘When knowing this fact and also considering the death rate after heart operations in Japan, I thought that it would be more practical to come here to receive training to be a surgeon rather than studying in Japan. Initially, I was planning to continue my training programme in Japan after travelling; however, I recognised that it would take ten years to perform the same number of heart operations as in Germany.’

From this experience he made the decision to move to Germany. Soon after returning to Japan, he began to study German and started preparing to go there to be a heart surgeon. He initially planned to study there for one year; nevertheless in the end he finally worked there for about thirty years. Minami describes heart transplants in his career as follows:

(Dr. Minami) ‘Heart transplants made me diversify my medical treatment skills. In other words, I as a heart surgeon acquired more skills to treat the patients.’

This extract shows that he considers heart transplant operations as just one part of his skills as a heart surgeon, not thinking of heart transplants as privileged medical treatments, which is a different attitude from the majority of people in Japan. It can be assumed that he acquired the idea because he has performed many heart transplants. The extract below gives details regarding his experience performing heart transplants and his ideas about this experience.

(Dr. Minami) ‘Regardless of the geographical location – either Germany or Japan – and regardless of the type of heart surgery, all surgeries have a common aim which is to help patients. Even if the operation is for heart valves or for the pericardium, they have a common aim – to help patients. As this is my fundamental attitude, I do not feel any resistance to transplanting an organ from a dead person to another patient.... I have performed heart transplants for 17 Japanese patients in Germany and about 1,500 German patients. As far as listening to their opinions towards heart transplants, I did not see any significant differences between German patients and Japanese patients. ... I assume that there are moral issues surrounding heart transplants. I also imagine that the patients may have sentimental emotions about their donors’ families.’

This extract shows that Dr. Minami focuses on heart disease and heart surgery as a treatment for this. However, as he describes in the last part of this extract, he does not neglect the fact that there are some other aspects to heart transplants: cultural, moral and emotional perspectives. He differentiates the medical perspectives from the rest of them. This attitude seems to be important in the communication with the patient, As observed in Section 6.2.2, a surgeon sometimes demonstrates to his or her patient how he or she understands the non-medical aspects surrounding heart transplants. By knowing the surgeon’s view, patients have chances to talk about heart transplantation from a non-medical standpoint.

Younger surgeons knew about heart transplants through the mass media before becoming surgeons. Dr. Fukushima, who is younger than Dr. Sono and Dr. Minami, was a student in a primary school when the first heart transplant was performed in Japan in 1968. He came to be interested in medicine during his childhood and was initially curious about organ regeneration. Dr. Fukushima describes his experience.

(Dr. Fukushima) ‘When hearing about the first heart transplant in Japan, I knew that the death of the donor was a problem. I was wondering whether it would be possible to develop medicine which did not require the donor’s death. This was the first time when I became to be interested in regenerative medicine. ... I thought that organ transplants would not be needed by anyone if a new organ itself is made. I came to think about making organs, and lives. I came to think about something like that.’

Dr. Fukushima ultimately moved from regenerative medicine to transplant surgery.

(Dr. Fukushima) ‘I attempted some research into regenerative medicine after entering a university. Then, I recognised that regenerative medicine would take a long time to be used in actual medical treatment. Therefore, I made a decision to be a transplant surgeon.’

These surgeons established their attitudes towards heart transplants and developed the necessary skills through clinical experiences with heart disease patients who had successful heart transplants, and with heart transplant operations in clinical settings. These were common ways in which attitudes and experiences among these surgeons were established. In relation to the establishment of an attitude towards heart transplantation, Dr. Kyo interprets the process as follows:

(Dr. Kyo) ‘Many physicians in Japan do not study heart transplants extensively. They do not think that a heart transplant is a valid medical treatment.’

In other words, this extract conveys the message that having knowledge about heart transplants distinguishes or, at least, decreases doubts about heart transplantation. Dr. Kyo points that out surgeons’ attitudes towards heart transplants are shaped by how much they study heart transplantation. The more they study it, have more information from the patients in a hospital setting and experience heart transplants, the more they understand heart transplants. As far as a surgeon constantly updates his or her knowledge regarding the latest medicine, understands it, digests it and develops the medical treatment skills, he or she can offer that particular medical treatment to patients. This can be described as a surgeon’s experience in acquiring new medical skills. What does this experience make possible for the doctor? The key answer to this question may be the development of the surgeon’s ability to explain heart transplant medicine to patients. The skill to explain it needs to be considered from both medical and cultural perspectives. In the next section, I will explore the cultural perspective in relation to this

‘accountability’. More precisely, I will explore how surgeons understand cultural and emotional resistance to heart transplants. I will also investigate patients’ concerns surrounding heart transplants and how they explain such concerns.

### **6.3.2 Surgeons’ views of heart organs**

Cultural influences on surgeons’ views about heart transplants can be examined from three points of view: their understanding of the heart as an organ, ideas about death, and ideas about brain death. These three perspectives appear as central concerns for heart transplant recipients when the recipients integrate the transplanted heart into the body. These concerns are also shared by surgeons. First, I should investigate surgeons’ ideas about heart organs.

Medical perspectives offer an understanding of how surgeons view the body, focusing on the functional aspects. This function-based perspective has led to the development of heart transplants. Dr. Fukushima’s explanation of the heart organ directly reflects this idea.

(Dr. Fukushima) ‘A patient waited for a chance to receive a heart transplant for two years. During the two years, this patient’s heart was stopped; the patient lived with the assistance of an artificial heart. Despite the fact that the heart was no longer beating, no one thought that the patient had died. The patient communicated with other people. ... The heart is merely a pump. Therefore, the heart is a replaceable organ.’

Based on this notion of the heart as a pump, when medicine has developed the ability to transplant it from one person’s body to another’s, the surgeons think that it is a pity to waste the organ after the first person’s death. Dr. Sono directly expresses this attitude.

(Dr. Sono) ‘After my death, regardless of whether my brain dies or my heart stops beating, I want my organs to be used on someone. My body will just be cremated.’

These extracts from the interviews of Dr. Fukushima and Dr. Sono show that transplant medicine looks at body parts and organs as replaceable resources; therefore, these resources should be put to good use to help someone who needs them. Dr. Kyo clearly insists upon this perspective.

(Dr. Kyo) ‘We must stop wasting resources. We should not waste organs.’

Dr. Minami explains that many Japanese people tend to consider receiving an organ transplant and donating organs as very special events. He thinks that it is important to change these attitudes in order to improve the situation surrounding organ transplants (Minami, 2008). As seen in the previous section, heart transplant recipients tend to consider the heart as a special organ, which has special meaning, rather than as a resource. This is the main difference between surgeons and recipients.

### **6.3.3 Surgeons' view of the notion of death and Japanese culture**

Next, I will explore how surgeons view the notion of death within a Japanese cultural context. The perspective of the heart organ as a medical resource is fundamental to heart transplant progress. When the heart organ is used as a resource for medical treatment, both surgeons and recipients face the issue of someone's death when extracting the heart. Surgeons experience patients' deaths at the end of medical treatment. At the same time, they see many patients' families' responses. Explaining and understanding a patient's death involves both medical knowledge and cultural responses. How, then, do health professionals – and in particular here, surgeons – express their attitudes towards death?

The surgeons I interviewed observed that the Japanese attitude towards death is an obstacle in thinking about heart transplants. Dr. Sono referred to one of his experiences with a patient who was brought to a hospital due to a cardiac infarction. This patient was already in a serious condition. Finally, the patient moved into the most severe condition and was not expected to survive more than one evening. When the patient's heart stopped beating, Dr. Sono attempted to give electric shock therapy to revive the patient's heart. After several attempts, it was obvious that the heart would not beat without electric shock therapy. As long as the therapy was continued, the heart would keep beating. Otherwise, the heart would stop. Dr. Sono refers to a conversation involving how he explained this to the patient's family.

(Dr. Sono) 'If there was a hopeful sign of her recovery, I would continue this therapy. I will continue it tonight. As your surgeon in charge has already explained, she will not recover from this condition. Could you let me stop repeating the electric shock therapy? If you ask me to continue this therapy, I will. However, electric shock therapy burns your mother's skin. This therapy will just damage her body.'

Despite his explanation, the patient's family asked Dr. Sono to continue the therapy. Dr.



Sono, in the extract that follows shows that he possessed empathy towards this family. At the same time, he differed from the family in his attitude towards death.

(Dr. Sono) ‘He [this patient’s son] was the president of a famous IT company and was a very smart person. ... I understand that it was very difficult to accept it [his mother’s death]. Although I understand his feelings, it is important to recognise that people will die someday. It seems that many Japanese do not truly believe that people die. If a person refers to death in everyday life, people ask them not to mention the topic of death, because the topic of death is ‘ominous’ or talking about death is inauspicious.’

By introducing this experience, Dr. Sono points out that death tends to be strongly and carefully hidden in everyday life among the Japanese. Dr. Fukushima also notes that death is a taboo in Japanese culture.

(Dr. Fukushima) ‘Japanese people don’t want to hear about the topic of death. Death is a taboo for the Japanese. Japanese people don’t want to think about death while they are alive. ... When a person gets an illness or any physical problem, he or she begins to think about death. In a similar way, Japanese people don’t want to think about organ transplants. People don’t want to assume that they may become organ donors or they may need organ transplant operations.’

Both surgeons state why people tend to avoid thinking and talking about death as follows.

(Dr. Sono) ‘I think that Japanese people aren’t educated to understand that a person dies, which is the fundamental truth.’

(Dr. Fukushima) ‘Japanese people don’t have any chances to learn about death in school.’

They point out that Japanese society carefully controls the lack of focus on death in everyday life. In other words, this means that education about death is neglected, despite being possible to provide people with an education on death. In reality, surgeons learn about death as part of their medical education. These surgeons do not simply criticise the Japanese people’s attitude towards death. Rather, they discuss the fact that there is a problem in Japanese society that does not provide people with an education regarding death. In current Japanese society, medical education may be the only way to learn about death, as it is not a taboo in this context. Taking a close look at what these surgeons said and the current ethos in Japan, I believe that it is possible that death will

not always be a social taboo. This may become possible by establishing a subject that educates people about death. After receiving this education, some people may still have a strong resistance to talking about death. Although this is unavoidable, at least death will not be a social taboo as it is now.

From these considerations, it is evident that one of the key factors that divide surgeons from other people may be the frequency with which they care for people who die, and the fact that they do so in hospital settings. Despite the fact that surgeons received education about death, there are various discussions about the diagnosis of death in the medical field. The argument has become prominent in discussions on the issue of brain death. Due to this, the method of diagnosing brain death is being continually developed.

#### **6.3.4 Surgeons' interpretation of the issue surrounding brain death**

Finally, in the end of this section I will explore what has been discussed in terms of the issue of brain death in the medical field. Health professionals point out two main perspectives for considering the issue of brain death: knowledge of brain death and the diagnosis, and the medical system. Dr. Minami indicates a lack of knowledge regarding brain death among health professionals.

(Dr. Minami) 'There are still many health professionals who do not have an in-depth understanding of the differences between brain death and a vegetative condition, much less journalists.'

Dr. Fukushima also refers to the same point.

(Dr. Fukushima) 'Some newspapers convey news of a patient who is in a similar condition to brain death. In the newspapers, the condition is written as a brain-death "condition" [Noshi-joutai]. This patient has not experienced a brain death, but a brain dead "condition". This kind of story easily attracts public attention. A newspaper article that conveys the story of the patient who returned from unconsciousness to consciousness can collect more public attention. In this kind of article, it does not matter whether brain death is diagnosed or not. Such information is conveyed to society; as a result, the truth is overshadowed by sensationalised stories.'

In relation to the issue of the mass media's dissemination of incorrect information regarding brain death, Dr. Fukushima points out that the information leads to a different understanding of brain death among the public from that of medical experts.

(Dr. Fukushima) ‘Actual brain death is different from what the public assumes to be the condition of brain death. These two different conditions should not be confused. A condition that is close to brain death is not brain death. A patient is alive under a brain dead condition, and a patient is dead with actual brain death.’

These explanations indicate that there is a gap in the information on brain death. The gap exists not only between medical experts and the public, but also among health professionals. The gap is a reason for public anxiety towards the diagnosis of brain death. Besides, as health professionals’ understanding of brain death is not consistent, some health professionals’ explanations may enforce the public’s anxieties.

One question is raised here: Why is there a gap among health professionals? Looking at the situation in the U.S, which, in terms of the number, has been the world’s leading country for heart transplants, the broad consensus on the definition and diagnosis of brain death has weakened in recent years, whereas a strong consensus was held in the 1980s (Aita, 2008a; Kodama, 2008). Health professionals in the U.S. have faced cases in which patients after the diagnosis of brain death showed several symptoms which caused them to reconsider the validity of the diagnosis of brain death. Having accumulated these experiences, many health professionals in the U.S have come to reconsider the validity of brain death in recent years. Nevertheless, these discussions in terms of a sceptical perspective towards brain death are not reported to the public (Aita, 2008a; Kodama, 2008). In particular, Aita (2008a), through interviews with health professionals in the U.S, found that they did not want to disseminate the discussion among health professionals to the public so as not to decrease organ donation. She also points out that health professionals in the U.S consider brain death not as biological death, but as a socially constructed death for organ transplants. The discussion about brain death had once calmed down, but then it came to the fore again following the accumulation of medical experiences. By contrast, in Japan, fewer cases of brain death have been diagnosed than in the U.S. Health professionals in Japan have had less experience of seeing patients who were diagnosed with brain death than in the U.S. Thus, the discussion has continued without a large amount of medical experience of brain death; unlike in the U.S. Transplant surgeons in Japan insist upon the validity of brain death at a biological level, while some other health professionals show a sceptical attitude towards the biological definition and diagnosis of brain death. The gap among health professionals also causes conflicts in the public's attitude towards brain

death.

In addition to the knowledge-based perspective of brain death, the medical system, and in particular, the system of emergency medicine is identified as a problem.

(Dr. Minami) 'Emergency medicine does not operate enough in Japan yet. Due to a lack of medical staff of health professionals and nurses, patients often are sent from one hospital to another, this occurs quite frequently. Under this situation surrounding emergency medicine, if a patient who seems to be brain dead or likely to experience brain death was brought to a hospital, many health professionals would not want to accept the patient. They are typically not eager to go through a brain death diagnosis process, because it will cost money for the diagnosis and the health professional must get up even at midnight. As it were, health professionals and hospitals are lazy. ... In addition to this situation, some health professionals have already simply given up on developing and promoting transplant medicine in Japan. ... After the establishment of emergency medicine, organ transplantation becomes possible. ... 99.9% of patients are diagnosed with brain death in emergency hospitals after receiving full medical treatment. In the end, the attitude of health professionals and nurses who work in emergency hospitals is very important to increase organ transplant. Their attitude is the key to communicate with the patients' families, which will make the family consider organ donation.'

This explanation regarding brain death shows that the medical system influences the diagnosis of brain death in a hospital setting.

To summarise, transplant surgeons do not necessarily believe in heart transplantation from the beginning. Rather, they establish their attitude towards heart transplantation through their experiences in the medical field. This process can be described as a process of developing their professionalism. What is the 'professionalism' of surgeons in the context of heart transplantation? On the one hand, surgeons provide medical treatment based on scientific data. On the other hand, they show sympathy for their patients' concerns. Surgeons are obliged to provide medical reasons for treatments, and also to satisfy the patients' needs by providing emotional support.

## 6.4 Conclusion

This chapter has explored how the notion of the body in Japan influences heart transplant recipients' identities, focusing on recipients' and surgeons' narratives of heart transplants, respectively. As described, recipients tend to consider body parts individually rather than in terms of the body as a whole. This attitude is established through the experience of having a heart transplant. They also tend to consider the heart as a special organ. At the same time, each recipient differentiates his or her heart from the hearts of others. This attitude can be considered to reflect the fact that it takes time to regard the transplanted organ as a part of their own body (Castelnuovo-Tedesco, 1973). These attitudes mean that a person is differentiated from another by their physical bodies, and the body establishes the self of each individual. Thus, I analysed how heart transplantation disrupts the self, and how this may cause fear. Heart transplant recipients come to hold two different ideas about the heart, considering it as a machine or material object, and as a symbolic object through their experiences. The recipients' bodily experiences strongly influence their way of thinking about the heart and the self.

Similarly, 'experiences' play an important role in the process of establishing surgeons' ideas about the heart organ and the transplant. Transplant surgeons come to establish their attitudes towards heart transplants through their experiences in the medical field. In this process, they find that the Japanese medical system rather than cultural resistance causes many obstacles related to heart transplants in.

At the end of this chapter, I examine the way in which surgeons' thoughts and attitudes towards heart transplants impact upon the recipients' identities. In order to examine this impact, I attempt to explore three perspectives that appeared in the surgeons' narratives: (1) Surgeons tend to look at the heart as a medical resource, in which a diseased heart can be replaced by a healthy heart. (2) Surgeons point out that talking about death is a social taboo in everyday life. They also highlight that the lack of death education in Japan is a social problem, while surgeons have the opportunity to learn about death through medical education and hospital experiences. (3) Related to this lack of education regarding death, surgeons also discuss issues regarding brain death. The majority of brain deaths are diagnosed in emergency medicine. Nevertheless, surgeons insist that there are problems with the fundamental emergency medical system

and health professionals who work there. In addition to these medical system problems, they also insist that inaccurate information relating to brain death is often disseminated to the public through the mass media. In sum, surgeons describe these issues as being issues with the medical and social systems.

Regarding the first perspective of the heart as a medical resource, as described in the previous sections, it became clear that both the surgeons and recipients have a common conceptualisation, viewing the body in terms of its specific parts, rather than having a holistic perspective that perceives the body as a whole. Under the same umbrella of the Japanese cultural context concerning the body, the public, transplant surgeons and recipients can be considered in general to share similar attitudes towards body. Commenting on people's ideas about the body, Ozawa-de Sylva (2002) points out that the public in both Japan and Western countries perceive their own bodies as in need of control. Enthusiasm for dieting and exercising is popular in both regions. This researcher argues that the Japanese public attitude towards diet and exercise is highly influenced by consumerism, while that of people in the Western countries is based on a contemporary non-religious ascetic. People in both these regions share the idea that an individual can control his/her own body. However, there is a different underlying reason behind people's urge to control their bodies through diet and exercise in the different cultural contexts. In a Japanese context, surgeons have come to formulate the perspective regarding the body through the receipt of medical education and providing medical treatment to their patients.

The recipients acquire their perspective through the experience of having a heart transplant; since surgeons provide medical treatment to the patients, and the patients receive it. Attempting to interpret the attitude towards the body among transplant surgeons and organ transplant recipients from a different perspective, it shows that the majority of the Japanese public hold holistic views concerning body. Therefore, the attitudes amongst transplant surgeons and recipients seem to be different from the major Japanese cultural views.

In a heart transplant procedure, a healthy heart organ is the main resource involved in treating the disease. In this situation, it is obvious that both the surgeons and patients consider the heart a replaceable body part, although recipients sometimes perceive the heart as more than just this.

Now, moving to the second perspective involving death, the recipients tend to discuss their feelings towards the donors' death. Based on this emotional experience, many recipients attempt to find a way to accept the transplanted heart. During this process,

some recipients initiate new habits for the transplanted heart. As discussed in the previous chapter, for example, one recipient goes to church out of respect for the donor who might be Christian, even though the recipient is not Christian. In contrast, surgeons tend to talk about the issue of death in a broader social context, as a matter of education about death. Thus, recipients tend to focus on the donors' death, while surgeons consider the issue of death as something that requires education. There is a gap regarding the focus point of death between recipients and surgeons, i.e. recipients and surgeons pay attention to different aspects of death.

Here, further questions are raised about the underlying reason for recipients' tendency to focus on the donor's death, and what a 'good death' is for each of them. As Haddow (2005) argues, a powerful representation of the self is attached to a newly dead body. This attitude seems to be shared in many cultural contexts. Looking at Japan, Klass argues that Japanese people hold an idea by which the person's soul lives for 50 years after the individual's death. This length is more or less equal to the length of lifetime of those who people knew the deceased person. In the attempt to maintain the relationship between living and dead family members, Buddhist rituals such as O Bon take on an important role in Japan (Klass, 1996). Thus, 'ancestor worship is an expression of the human community that cannot be separated by death' (Klass, 1996: 70). This attitude is shared by the majority of Japanese people. As a result, some new habits developed by a recipient after receiving a transplant operation can be considered a reflection of respect for the dead individual.

In addition to recipients' attitudes, I examine surgeons' perspectives towards death, where they regard death as something that requires education for a proper understanding to develop. I argue that Japanese transplant surgeons should adopt similar attitudes to transplant recipients, and gradually develop another perspective on death in terms of the medical viewpoint. This is because the Japanese ritual in terms of death is not easy to harmonise with the medical view of death.

Orpett Long (2004) researched cultural scripts for a 'good death' in terms of comparative perspectives between Japan and the United States. The researcher found that people in both countries have a sense of spirituality when it comes to death. In the U.S., more people tend to demand explanations about death from a scientific perspective than Japanese people do. For Japanese people, as Orpett Long (2004) points out that family members engage in the process of medical care until the family member's death. In addition, the researcher illustrates the importance of social status and age as elements in the acquisition of a good death at the end of the individual's life.

It appears that the spiritual aspect of death is more important for Japanese people compared to Western people, and Japanese surgeons need to fulfil the role of helping the transplant recipient and the public to understand death in terms of medicine. Thus, I argue that surgeons consider the issue of death as something that requires education.

Finally, the third perspective to be considered related to how surgeons explore issues of emergency medicine in Japan primarily by addressing brain death and its diagnosis. On the contrary, recipients often experience social pressure after having a heart transplant. In relation to brain death, they focus on different aspects of the issue surrounding brain death respectively. Information on brain death and vegetative conditions is sometimes confused in the mass media, which may result in the general public misunderstanding what brain death actually means. As a result, this information may cause confusion among the public regarding whether a person diagnosed with brain death may actually recover. As the recipients know that such information and public discussion exists, they sometimes suffer from others' negative attitudes towards heart transplantation. In sum, surgeons explain the issue of brain death in a medical context, while the recipients tend to experience social pressure as a result of the information that is disseminated by the mass media.

It is clear that there are gaps between the heart transplant experiences of the surgeons and the recipients. As such, it is important to notice what happens between them. When surgeons see the patients and the recipients and provide medical treatment, surgeons automatically and unconsciously label them as 'patients' and 'recipients'. This label lasts forever in their relationship. Both parties recognise these labels, and behave as either a patient or a recipient when communicating with their surgeons. This label is always present in their relations, even though they have opportunities to communicate outside of the hospital setting. Thus, the doctor-patient relationship is fixed by this labelling. What does this fixed relation bring to the recipients? As I have indicated, the recipients do not openly talk to the surgeons about their identity-related concerns that may result from the heart transplants. This hesitation among the recipients means that they do not share such issues with the surgeons. The obstacle that causes such hesitation is the surgeons' labelling of the recipients' role. In other words, in the relationship between surgeons and recipients, the surgeons' identity is stable while the recipients' identities are fluid. Nevertheless, labelling by surgeons has the ability to make the recipients' fluid identities stable.



## **Chapter 7 The notion of gift-exchange in Japanese culture and heart transplants**

### **7.1 Introduction**

This chapter explores how gift giving customs in Japan affect heart transplant recipients' experiences. The notion of gift-exchange developed by Mauss (1954) provides a framework to explore issues of organ transplantation (Gill and Lowes, 2008; Lamanna, 1997; Lock, 2002; Saher et al., 2003). As Titmuss (1970) argues, in the case of blood donations, a system based on altruistic donations can maintain a better balance between the supply and demand of blood than one relying on market-oriented donations. In Japan, selling blood used to be popular, but it ultimately failed to keep the blood quality high (Kouzai, 2007). The studies by Titmuss (1970) and Kouzai (2007) are insightful in explaining both how medical use of body parts and the organ transplant experience elicit an altruistic attitude. In addition, Shaw (2008) explores the way in which altruism is established by organisations and institutions in terms of gift-relationships. However, these studies lack a perspective that examines the relationship between altruistic gift-exchange and organ transplantations that occur within a consumer culture in a capitalist economy.

Gift-exchange customs have been increasingly involved in economic transactions. In Japan, consumerism has encouraged gift-exchange to occur more than before (Daniels, 2009). In light of this economic change, it is important to examine how people perceive a gift that is initiated from a market. Therefore, based on the framework introduced by Mauss (1954), I will explore how heart transplant recipients view (1) donating a heart, (2) receiving a heart and (3) repaying this donation. Finally, I will examine how the altruistic act of donating a heart is interpreted from a consumerist perspective by the recipient.

### **7.2 Donating a heart**

In Fox and Swazey's (1992) assessment of organ transplantation in the U.S, they describe how organ transplants in that society are conducted under the assumption of both a patient's and a donor's freedom of choice and voluntary participation. Considering that in Japan organ donation is done based on an altruistic attitude of a

donor and the family, it can be said that heart transplants are performed in the same social situation as in the U.S. However, the issue of altruism needs further consideration, in terms of the degree to which altruism is forced upon people in a society where altruistic behaviour is a strong social obligation. Fox and Swazey (1992), for example, observe in the U.S that a family may experience pressure to donate their dead family member's organs through a communication from an organ donation coordinator. These authors also point out that a family member may agree to the donation because it allows them to attach a special meaning to their family member's death (ibid), another feature which suggests that acts of altruism may in fact be motivated by a degree of self interest. In this section, I will therefore explore the narratives of altruistic organ donation among those involved in heart transplants in Japan.

### **7.2.1 Altruism**

An act of organ donation is described by many as a 'gift of life'. The Japan Transplant Recipient Organisation (2011) defines the 'gift of life' as the ultimate form of altruism:

'Donors and donor families neither have any channels to receive repayment for the organ donation, nor know who the recipients would be. Both the donors and their families understand this. In this regard, they are extremely generous. Imagining the difficult situations families experience in making a decision to agree to donate the organ; we cannot express our appreciation enough' (The Japan Transplant Recipient Organisation, 2011).

This extract emphasises how wonderfully altruistic organ donations are. At the same time, it refers to the organ recipients' appreciation of donors and donor families. Similar perspectives are found in the narratives of surgeons, the recipients, and their families.

(Mrs. Sano) 'Organ donation is an act of love. Different from other gifts, organs are donated for nothing.'

A heart transplant recipient, Mrs. Sano refers to the altruistic aspect of organ donation, while also differentiating it from other types of gift giving. This extract emphasises the uniqueness of heart organ donation as a gift. A heart transplant recipient, Mr. Toda, describes the situation for donor families in Japan.

(Mr. Toda) 'I heard that donor families are heroes in the U.S. By contrast, it seems that Japanese people become easily suspicious that some negative

things might have happened.’

He describes the differences in relation to the attitude towards the donor families between the U.S and Japan. His description shows that it seems to be difficult for Japanese people to believe in altruistic organ donation; therefore Japanese may tend to be sceptical of the donation. Some of the surgeons I interviewed were able to explain this in more detail. They both described the altruism that donation is supposed to reflect and suggested that, in Japanese society, such altruism is perhaps not as pure as it might be. For example, Dr. Sono said:

(Dr. Sono) ‘I think that an act of organ donation is the ultimate volunteerism.’

But then Dr. Sono proceeded as follows.

(Dr. Sono) ‘I think that organ transplant represents the development not only of medicine, but also of the ultimate voluntary attitude. In this regard, the organ transplant is a unique treatment. ... *It really is a pity that such transplants are not ingrained in Japan.*’ [Author’s emphasis]

Dr. Minami explains further why it is that it is so difficult to, as Dr. Sono puts it, ‘ingrain’ the concept of organ transplantation in Japan.

(Dr. Minami) ‘On the one hand, as shown in the film *Departures (Okuribito)*,<sup>27</sup> generally speaking, Japanese people tend to try not doing anything to damage the dead body. ... On the other hand, while families who do donate their family member’s organs may hold the feeling that they want to send the family member through a funeral ritual process without damaging the body, nevertheless they triumph over their sentimental feelings. ... I think that it is still difficult for many Japanese to develop such sentiment. The idea of [organ donation being] a voluntary action which arises purely out of a desire to help has not developed well among Japanese. This is my impression. Voluntary actions, for the Japanese, are not thought to be possible without an eventual repayment. ... I think that many Japanese people do not have an idea of a gift without repayment. Even though people do not express this idea, they may hold the idea in their minds.’

Dr. Minami states that organ donation is an act in which a person overcomes

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<sup>27</sup> This movie depicts a person who works on dead bodies prior to funerals. The dead bodies were carefully cleaned and makeup was applied in order to make the dead person look good. This process is aimed at sending the dead body to its life after death without any damage appearing on the body. Asai et al. (2010) argue that this movie depicts that the Japanese traditional view of the dead as impure still exists in contemporary Japan. They also argue that Japanese people in current society have complicated and ambivalent attitudes toward the dead body.

sentimental feelings they may possess in relation to his or her family member's death. When experiencing such sentiments, the person focuses on his or her own feelings, leaving little space in his or her mind to consider others. He makes another interesting point about the character of Japanese people, who he suggests tend to expect to receive repayment for 'voluntary actions'. This attitude is clearly evident in Japanese gift-exchange culture (Rupp, 2003), as confirmed by one of the recipients I interviewed.

(Mrs. Okamoto) 'I think that it's difficult to give selfless love [altruism] to another. There are still few people in Japan who have this [ability]. ... In everyday life, for example, even when communicating with neighbours, gift-exchange has an important role. ... As I am a heart transplant recipient, I shouldn't say that the character of the Japanese might influence the negative attitude towards organ donation. However, I think that this might be an obstacle to disseminating the idea of heart transplantation.'

However, these opinions need to be approached carefully, as Dr. Sono points out.

(Dr. Sono) 'Are Japanese people very cruel? Of course Japanese people aren't cruel at all. For example, if a patient needs support with raising funds from the public, hundreds of millions are donated to the patient by the public.'

Why do people donate money to an anonymous person, while many have difficulty in donating their organs to an anonymous person? These questions seem to reflect a contradictory attitude in terms of the volunteering attitude and behaviours among Japanese people. Here, reviewing the discussion of volunteer work among Japanese, there are discussions that suggest that a volunteering attitude and behaviour developed, in particular, after the major earthquake related disaster in 1995 in western Japan, designated as the Great Hanshin Awaji earthquake (Yatsuduka, 2008). The discussions describe a very different set of behaviours than is the case for people's attitudes regarding organ donations. Why does this difference occur? To answer this, I compare the case whereby a person is expected to do volunteer work to the case of organ donation. In a case such as that which follows a major earthquake, people provide money, material goods for daily life and the power of their own labour. Money and goods for life are generally circulated in a market, with labour also exchangeable in a market. Under these conditions, different people can provide the same things. In contrast, someone's organ is unique and is not exchangeable in a market. Thus, the volunteering attitude and behaviour among Japanese has developed in settings in which a person is able to provide *exchangeable* goods and labour *in a market*.

Public opinion surveys have shown that the number of people who agree with organ donation has increased (The Japan Society for Transplantation Publicity Committee, 2010). Nevertheless, the actual number of heart transplants in Japan did not increase substantially in the period up to the amendment to the Organ Transplant Law in 2009 (ibid). During this time, more patients have travelled abroad to have a heart transplant (ibid). Considering this trend, in particular between 1997 and 2009, which was the era between the passing of the Organ Transplant Law in 1997 and the amendment in 2009, two provisional explanations can be referenced. First, people may have a strong resistance to damaging the body after death. Second, people may also have a strong impulse to help other people as long as they are not directly involved in organ donation. A recipient, Mr. Sano, provides the following perspective:

(Mr. Sano) ‘Regarding organ donation, I guess that Japanese people use different expressions than Americans to describe it. I imagine that Americans use an expression referring to donating a family member’s *organs*, while Japanese use an expression which refers to giving a family member’s *life*.’ (Author’s emphasis)

As Mr. Sano says, it can be considered that in Japan organ donation symbolises the giving of life rather than just an organ. If this is the case, giving such a gift makes much higher demands on the altruism of the donor, and this could explain the reluctance of many Japanese to become donors.

### **7.2.2 Complicated feelings after organ donation**

As we have seen, behind the altruism of organ donations, there can be an immense emotional struggle within each donor family. How do the recipients view the donor families’ bereavement? Due to the anonymity between the donor and the recipient, there are limited opportunities for recipients to hear donor families’ experiences of bereavement. Also, donor families have historically tended not to be looked after well. The situation which used to surround donor families in Japan is well represented in a document describing the aims of the Japan Donor Family Club:

‘...A donor and the donor’s family get a lot of attention from health professionals, recipients, recipients’ families and the public only when donating organs. After the donation, the donor and the donors’ families tend to be put into a social shadow. It is no exaggeration to say that donors’ families begin to experience great mental anguish after the donation. We have

established the Japan Donor Family Club in order to look after donor families, to encourage them and to enable them to share their bereavement with each other' (Mazawa, et al., 2000).

Mr. and Mrs. Mazawa, who established the Japan Donor Family Club, experienced what organ donation involved when they donated their deceased daughter's organs in the U.S. (Mazawa, 1999). They were looked after by caregivers in the U.S. The caregivers spared their time to listen to the family's feeling of bereavement. Through the communication with these caregivers, they had opportunities to express grief. This mentally helped Mr. and Mrs. Mazawa (ibid). By contrast, these caregivers did not exist in Japan. After the donation, Mr. and Mrs. Mazawa were contacted by other donor families in Japan who had donated the organs of their family members. They knew that Japanese donor families had no support and no caregivers, seeing the differences between the situation surrounding donor families in Japan and the U.S. They recognised that donor families needed a way of sharing their bereavement; therefore, they established the organisation The Japan Donor Family Club in 2000. As Mr. and Mrs. Mazawa's experiences show, other donor families in Japan have tended not to get the chance to share their emotional struggles.

In a personal communication with a donor family in Japan, Mr. Yamaguchi told me how his wife had been after their daughter's donation.<sup>28</sup> According to his account, his wife had been terribly shocked by the process of organ donation. The most striking thing for her was that the organ donor coordinator brought a list of organs and tissues. It was about three pages long. Using the list, they had to confirm which organs and tissues would be donated, and which ones would not be. This experience made her feel as though her daughter had passed away again (Yamaguchi, 2009). Here, it is important to understand that some donor families cannot express their bereavement even to the Mazawas' organisation due to their sense of deep depression. Such families may completely stop expressing their bereavement to outsiders.

Although not every donor family attempts to share its bereavement, donor families have had more opportunity to describe their experiences since the passing of the 1997 Organ Transplant Law. Ms. Kondo is one such recipient:

(Ms. Kondo) 'I had a chance to listen to the experiences of donor families. In the meeting, I listened to the talks by three people. The three of them spoke of how they were attacked with terrible opinions by the public: 'How much did

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<sup>28</sup> When attending the Transplant Game in 2009 in Japan, I had a chance to talk to some donor families during the events.

you sell the organ for?’ ‘How dare you do something as terrible as donate organs?’ ‘If I were you, I could not do a terrible thing to hurt a dead body.’ They said that they were not confident about their decision to donate the organs of their family members. It was the first time I heard the donor families talking of their experiences. Before I went to the meeting, I could not have envisaged what they would talk about. I had not imagined that they would talk about such extremely negative opinions. I was really shocked. I had gone to the meeting with my mother that day. On our way back home in the train, both of us were lost for words. After that, I began blaming myself more: even though the donor families regret their decisions, I am alive. I was completely lost.’

The donors’ bereavement had involved greater suffering than she had imagined. Due to the experience, Ms. Kondo began to blame herself. The person who receives the gift of another person’s heart may be mentally depressed after learning how emotionally attached to that person’s body the donor’s family still is. In addition, Ms. Kondo had already received this gift – one that could never be returned to the giver. This truth may bring about further emotional turmoil for the recipient.

Recipients do not always choose to listen to the experiences of donor families. Many recipients feel they need some time before deciding whether to communicate with donor families. Mr. Oda, a recipient, describes the self-conflict that accompanied his decision.

(Mr. Oda) ‘I heard that donor families experience much suffering after the donation. They have only their bereavement from losing a family member, while I have been made happy by receiving a transplant. ... I am thinking of going to a meeting to listen to donor families’ experiences. However, in all honesty, I am afraid to listen to their experiences directly.’

These extracts provide another interesting insight. Neither of the recipients quoted here refer to listening to their own donor’s families. This clearly implies how these recipients categorise the relationships between themselves, the donors and the donor families. The gift-giving of a heart is seen not as a direct exchange between recipient and donor. It is as if these recipients think of the entire group of donor families as giving them this gift, rather than considering the gift as coming from an individual.

### **7.2.3 Sharing responsibilities**

While it seems conventional to consider organ donation as an altruistic act, Dr. Kyo insists that it is a citizen’s duty to be an organ donor.

(Dr. Kyo) ‘We all have to discharge our duties and responsibilities in a society. This is fundamental to living well in a society. ... We must stop wasting resources. We should not waste organs.’

Dr. Kyo went on to explain how he came to think about the validity of organ transplant as a medical treatment. He said that people who do not understand this validity lack sufficient education on the subject. Even health professionals, he suggested, might not understand the validity of heart transplant as a medical treatment, should they stop endeavouring to obtain up-to-date knowledge. Another claim made by Dr. Kyo is that the post-war education system in Japan was flawed, as it failed to recognise how important it was that each individual perceives and fulfils his or her duties and responsibilities. Dr. Kyo has a very critical attitude towards the Japanese educational system after the Second World War. He thinks that this educational system destroyed the idea that people should share their responsibilities and duties as citizens. This educational system also created the negative associations with organ donation, because it did not encourage people to share duties and responsibilities. In other words, Dr. Kyo does not think that Japanese cultural attitudes towards the body are the key reason why people hesitate to donate their organs. Moreover, he asserts that the failure to discharge one’s duties and responsibilities influences society in many other ways. The issues relating to heart transplant are part of wider social problems in Japan. As have seen so far, this is a perspective not expressed by recipients and donor families.

To summarise, altruistic organ donation seems to be considered by people who are involved in transplants as a positive, ethical act. However, people, including the recipients, do not recognise how difficult it is for the donor families to overcome the bereavement created by the experience of organ donation. In addition, due to the anonymity which exists between the donor families and the recipients, no channel exists to clarify with whom the gift of a heart has been exchanged. As a result, recipients tend to think of the donor and their families as a group of people. There are two central features of Japanese gift-exchange customs. The first is that it is a one-to-one exchange. The second is that a gift is expected to be returned. Heart donation has neither of these features. Firstly, it is not one-to-one, because the recipient and the donor never discover each other’s identity. Secondly, it is very difficult to determine how to give an exchange-gift. People who are considering and want to get involved in heart donation cannot think about it in a way that fits normal gift giving customs, because the heart is



not a normal gift. In particular, it is perceived as strange to give a heart, because one person cannot get anything back from the other person.

## **7.3 Receiving a heart organ**

Existing studies have shown that organ transplant recipients tend to express similar emotions in relation to receiving an organ (Fox and Swazey, 1992; Sharp, 1995). These emotions often appear animistic. This animistic attitude may be caused due to the emotional and social meanings attached to an organ, which are considered to be transplanted into a body with the organ (Fox and Swazey, 1992). As discussed in the previous chapter, Japanese recipients regard the heart as a special organ: more than merely a device to assist life, animistic attitudes seem to be common, regardless of cultural background. In this section, I will examine the recipients and their families' narratives regarding receiving a heart organ. Specifically, I will explore how the Japanese recipients express their feelings regarding receiving a heart organ. Then, I will explore what it means for the recipient to receive a heart, attempting to answer questions of what meaning the heart organ has as a gift, and the differences between receiving a heart organ and other kinds of gifts.

### **7.3.1 Nervousness about receiving a heart: the days of waiting**

As explored in Chapter 4, until patients are registered on the transplant waiting list the patients and their families spend a significant amount of time suffering from serious symptoms as a result of both their condition and the administrative procedures relating to the registration. When patients and their families need fundraising support from the public to have a heart transplant abroad, they experience financial pressure as well. The registration is completed once; then they need just to wait until the opportunities arise. They are released from the stressful period through the registration. During this period, they contemplate their decision and weigh-up the pros and cons of the operation. Regardless of age and gender, most recipients seem to spend some time in such contemplation. Ms. Sakata, for example, said she had reservations about receiving a heart transplant.

(Ms. Sakata) 'During my hospitalisation in Germany while waiting for a chance to have a heart transplant, I often talked to other Japanese patients about how I felt about the heart transplant. I often said that waiting for the chance caused mixed emotions in me, because heart transplants are only possible because of someone's death. ... This Japanese patient told me one

thing. ... In Germany, it is said that organ transplants do not simply mean the donor's end of life. The donor's life is transferred to another person, which is a 'relay of life'. The transplanted organ lives in the recipient's body. ... Hearing this message, I was then able to feel positive about waiting for a chance of heart transplant.'

Recipients tend to consider receiving a heart transplant as taking the other person's life. They may have difficulty in viewing the heart as a replaceable organ. Narratives which refer to receiving a heart show that the idea of the heart as replaceable is not embraced without hesitation by recipients. They confront the truth of the procedure: that someone's death saves their lives; in other words, transplantation is a matter of the donor's death and the recipient's continued life. This truth makes them feel conflicted about receiving a heart organ. Kasai's narrative portrays this complicated feeling quite well.

(Ms. Kasai) 'I came to Germany to recover from heart disease. Nevertheless, when the chance came to me, I strongly wished that nobody would have to die.'

Hesitation and complicated feelings seem to be common among patients during the waiting period, as well as among recipients. They spend time thinking about the meaning of the organ they will have implanted and the significance of receiving it. Through communication with other recipients, they recognise that they all share similar feelings. In addition, they attempt to find ways of convincing one another that receiving a heart is not a problem, either medically or emotionally. It seems, therefore, that the recipients can understand one another's complex feelings. This communication is considered a passive way of expressing their knowledge and understanding of these complicated feelings. As such, some recipients may expect other recipients to experience similar emotions to their own. Noguchi refers to other recipients' attitudes towards one particular heart transplant recipient.

(Mr. Noguchi) 'Receiving a heart transplant means to get a new opportunity at life (from a donor). I have seen some patients as if they believe they should be given what they wish. I feel that they think about a heart transplant too simplistically. ... For example, some patients give me the impression that they think they will be able to have the heart transplant sooner if they pay money. ... It seems to me that they take it too lightly.'

Heart transplant recipients not only share ideas about receiving the heart organ, but they

also observe each other's ideas. Such observations form part of their evaluations of one another's attitudes.

For heart transplant recipients, receiving a heart transplant has a special meaning (Fox and Swazey, 1992; Sharp, 2006; Sylvia and Novak, 1997). It is more than merely receiving an organ from a dead body, which does not have the function of continuing a person's life (ibid). Recipients consider the act as a matter of inheriting the donor's life. Another important point here is to note a comment made by Mr. Noguchi. He makes the point that patients are not always able to receive heart transplants, regardless of how much they want them and that therefore they should not assume that having a heart transplant will be possible or easy. This suggests a different perspective from simply viewing the heart as a replaceable organ.

Moreover, Mr. Noguchi describes his view of what attitudes heart transplant recipients should have in relation to receiving a heart. He emphasises how important it is that heart transplant recipients should remember that many patients pass away before having the chance to get a heart transplant.

(Mr. Noguchi) 'There are many patients who have passed away waiting for the chance to have a heart transplant. I have visited these patients many times. I have even gone to their funerals. Nobody goes, even hospital staff do not go. After these patients die, medical staffs do not look after the patients' families. Who will treat them? ... Looking at this reality, there is a hidden side to conducting heart transplants.'

He describes the significance of taking care to recognise that many patients and their families are not given the same high degree of attention paid to recipients who successfully receive heart transplants. The point of his account is that the recipients' attitudes and behaviours are influenced by their perception of reality surrounding heart transplant. Whether Mr. Noguchi is correct about this or not, his main aim is to emphasise that recipients should behave in a sensitive way, particularly with other patients waiting for transplants.

As this extract from Mr. Noguchi's interview shows, recipients tend to be sensitive to other recipients' attitudes and behaviours. They first look at one another's attitudes and behaviours, then evaluate whether other recipients have reasonable attitudes and behaviours as recipients. Such observation permits each recipient to reflect upon his or her own attitudes, and if he or she believes that it is necessary to change any behaviours, recipients may then improve them. This process of self-reflection may influence the recipients' identities. In addition, when recipients think that it is necessary for them to

try to change the behaviour of other recipients, they may attempt to do so. In this regard, the attitudes and behaviours amongst recipients are influenced by one another. Having a heart transplant means receiving a heart with accompanied by both a new attitude and behaviours which are regulated by other recipients.

These narratives show that recipients pay a great deal of attention to their relationship with their donors. They also show that the recipients think about the relationship between themselves and their donors as a relationship between two individuals rather than as a relationship between themselves and an anonymous mass of donors. This looks, at a glance, to be a contrary attitude to that discussed in Section 7.2.2. Thus, in my analysis of the recipient's thoughts towards their donors and the donor families, I propose that the recipients hold two main views. First, the recipients initially perceive donors and donor families as a group of people rather than imagining an individual with a name. This may be due to the anonymity between the recipient and the donor as the recipient does not know the identity of his or her donor. Secondly, and by contrast, when the recipient reviews his or her everyday behaviour, they imagine that their donor and donor family make an evaluative assessment of their behaviour as a heart transplant recipient. In this process, the recipient tends to imagine an individual donor and the donor family rather than anonymous group of people.

Why, though, do recipients focus on the relationship with the donor? It may be useful in this respect to reference Mauss's (1954) explanation of the 'gift'. As reviewed in Chapter 2, Mauss (1954) points out that a gift has physical, emotional and symbolic attributes. These three aspects are attached to a gift, with the gift seen as holding the spirit of the gift giver, which can be considered a part of the giver; a part of the giver's self is therefore given to the recipient (Mauss, 1954). Applying his ideas to the case of heart transplantation, the physical attribute of the gift is the heart organ. The emotional attribute is the donor's wish for his or her organ donation to save someone's life. The symbolic attribute is that the heart is an organ that holds a special meaning. The recipients receive not only an object (the heart), but also the character of the donor which is attached to it. In this regard, the recipients receive a part of the donor's self. On the surface, then, although many transplant recipients consider a transplanted heart to be an organ, recognising it as an important key to life, beneath this they view the transplanted heart as a part of the donor as an individual. However, there is one difference between a gift as discussed by Mauss and the heart organ as a gift for a transplant. In Mauss's (1954) study, the giver and the recipient know each other. In contrast, the donor is unknown to the heart transplant recipient. This issue of anonymity

between the two parties will be discussed in a later section (Section 7.4.3).

### **7.3.2 A gift from God**

One recipient and his family held different perspectives towards receiving a heart transplant: this is the case of Mr. and Mrs. Sano. This case raises two issues. First, they do not think that having a heart transplant means that they receive a donor's life. Second, instead, they think that God has guided them to the chance of having a heart transplant.

(Mrs. Sano) 'I believe that brain death is a person's death [although I know that some people still have resistance to this idea, like I used to]. Therefore, I don't think that receiving a heart transplant means receiving someone's life. ... From our [I and my husband's] perspective, we received a heart from God, rather than from an individual. Thus, having a heart transplant was not because of our efforts. I think that this was God's doing. Our religion [Christianity] may affect the way we think about having a heart transplant.'

The attitude described by Mrs. Sano sees heart transplantation according to a wider network of factors, rather than just focusing on the recipient and the donor. Here, similar to Mauss's discussion of a gift, it is obvious that they share a common idea with other recipients and families an understanding of the meaning of receiving the physical object of the heart. However, with regards to the emotional aspect, they seem to have a different perspective. They consider receiving a heart as the will of God. In addition, in terms of the symbolic aspect, they seem to dismiss the idea of a special meaning being attached to the heart. Rather, they seem to look at the transplanted heart as an object from a dead person. Although I cannot insist that they have such a view of the transplanted heart, I assume that their way of looking at the transplanted heart as an object is stronger than others. Considering these attitudes, it can be argued that, unlike many other recipients, they do not understand heart transplantation as representing an interpersonal gift, as discussed by Mauss (1954). This was common among the other recipients. Mr. and Mrs. Sano themselves said that they understood that this perspective is not a popular way of thinking if the issue amongst Japanese recipients and the families. This therefore means that the common way of viewing a heart transplant in Japan is to look at it as a gift. In this regard, their case, though a counterexample, serves to reinforce the view that most Japanese recipients perceive the donated heart as being a gift given by the donor.

### 7.3.3 The choice to receive a heart transplant

In relation to receiving a heart transplant, one recipient raises the question of whether receiving a heart transplant is really a matter of choice for patients. Mr. Watari describes the emotional conflict that surrounded receiving a heart transplant.

(Mr. Watari) ‘I was told by a surgeon that transplant surgery was the only way to survive, otherwise I would have no chance of living. Therefore, I decided to take the chance to have a transplant. At the same time, I wondered whether this was my own choice. ... I didn’t have any other options for ensuring my survival, and a transplant operation was the only way to survive. I really struggled with this fact. ... Now, I think this is a matter of a choice in relation to a medical treatment, because a patient can choose not to have a transplant operation.’

When a surgeon diagnosed Mr. Watari as needing a heart transplant, he recognised that he did not have other options if he wanted to ensure his survival. Whatever a patient’s preferences, certain conditions do not always provide patients with alternative treatment possibilities. As Mr. Watari indicates, choosing against a heart transplant is a matter of choosing between ‘to be’ and ‘not to be’. Health professionals attempt to do their best to save their patients, therefore when a health professional suggests a possible treatment as the only option, the patient seems to have no other choice. The patient has no choice but to place themselves under the control of the health professional. In this situation, in the process of deciding to undergo a heart transplant, health professionals seem to have the decision-making power.

In addition to this, Dr. Kyo observes that there are a certain number of health professionals who do not provide patients with information about heart transplantation as an option for treatment:

(Dr. Kyo) ‘Considering the number of Japanese heart transplant recipients, which is about 20 to 30 patients including domestic and international cases, the patients who get the chance are quite lucky. The major reason that a small number of heart transplant operations are performed in Japan is that it is assumed that many health professionals do not provide information about heart transplants to the patient even if the patient needs it.’

This extract reveals a situation in which health professionals sometimes have more power than patients in providing the opportunity to get a transplant. However, Dr. Kyo also points out the significance of patients’ attitudes towards the treatment.

(Dr. Kyo) ‘It is only from the 1980s onwards that heart transplants have become globally perceived as an appropriate medical treatment. Therefore, patients who know about heart transplants will consider taking the chance. Even when a patient did not know about transplants, if the patient knows someone [else] who knows about them, and this person suggested it, the patient may then study heart transplants and consider it as a possible medical treatment. Whether the patient has the opportunity to attempt to have a heart transplant depends on a situation surrounding the patient.’

He refers to situations where not only health professionals, but also patients have the power to make a decision to have the transplant. Watari reflects upon his experience prior to making his own decision, and on the power relationship between him and his surgeon.

(Mr. Watari) ‘Soon after the first heart transplant in Japan in 1999, I was introduced on a TV programme as a person who needed a heart transplant. At that time, I was still in a condition which did not urgently need a heart transplant. ... A few days after, I had a medical examination with Dr. Fukushima. On the day, I told him I would not to come to see him for a while. Fukushima empathised, saying “you still have many things which you want to do”. I assume that he interpreted this as an indicator that it was too early for me to seriously consider a heart transplant, considering my physical and mental condition.’

Surgeons carefully observe whether or not their patients are ready to register on a heart transplant waiting list. It is important to note that surgeons observe not only the physical condition, but also the mental condition of their patients. This means that the behaviour and attitude a patient demonstrates to the surgeon impacts upon the decision making process that accompanies medical treatments, heart transplants in particular. On the one hand, patients express their own feelings about having a heart transplant; on the other hand, surgeons keep their eyes open and observe how patients are responding. In this communication process, the power to make a decision for a heart transplant moves between the surgeon and the patient.

Having several choices regarding medical treatment may cause that the patients to experience complex a range of emotions. Mr. Watari describes his emotional struggle prior to his decision.

(Mr. Watari) ‘I thought that it was cruel to know there was hope. ... I was not sure when my wish would come true. The operation might result in my recovery from disease. However, I wasn’t sure when I would get the chance.



The hope was far away. I thought this was a rather cruel situation. ... If I had not been given the option to have a transplant, I would not have struggled [with the hope]. I came to have this kind of feeling.'

His explanation reflects the situation surrounding patients who need heart transplants. Most patients do not get the chance to have a transplant, even though they are told that having a heart transplant is the only thing that can save them. In such situations, being introduced to the heart transplant as a possible treatment causes additional stress to the patient. Dr. Kyo summarises this situation as follows:

(Dr. Kyo) 'The patients who have heart transplants are extremely lucky.'

Receiving a heart transplant is one of the medical treatments potentially available for patients; however, it is not always a realistic choice.

To summarise, it seems that there are two main perspectives. One perspective is that the recipients understand receiving a heart transplant as a matter of a relationship between the donor and the recipient. Another perspective is that they view it as a gift from God, and understand it in relation to a wider social context rather than as an individual experience with the specified donor. The latter seems to be a minority attitude among the Japanese recipients.

In both cases, it is obvious that recipients confer symbolic meanings on the transplant experience. This causes complicated feelings among the recipients, and they cannot simply feel happy about receiving a heart transplant in order to survive. They also observe and evaluate one another's attitudes towards receiving a heart.

Here, it is also important to note that donors are always anonymous and therefore unknown to the recipients. Receiving a heart is a gift which has special meaning, given by someone whom the recipient does not know and with whom they cannot establish a relationship. This is different from other types of gifts, which can generate further relationships between the giver and the receiver. Therefore, it may become complicated for the recipients to complete a gift-exchange process in the case of a heart transplant. In the next section, I will explore the way in which recipients deal with this difficulty.

## **7.4 Repaying a special gift**

A gift encourages growth in the relationship between a donor and a recipient (Mauss, 1954). This idea assumes that the giver of the gift and the recipient know each other. Therefore, the giver expects certain behaviour from the recipient, and the recipient attempts to respond to this expectation. Considering gift-exchange in relation to heart transplants, the specific gift of a heart does not allow a relationship to be established under the Organ Transplant Law in Japan. In this section, I will explore the recipients and their families' attempts to repay donors. I will also explore whether or not there are any differences in strategies of repayment from heart transplant recipients to donors in Japan, compared to those used by recipients who have their transplants abroad from foreign donors, both those who are self-funded and those supported by donations.

### **7.4.1 Narratives of appreciation expressed by the recipients**

A special gift of a heart organ gives recipients a strong appreciation for this (Fox and Swazey, 1992). Recipients express their appreciation to their donors, the donor families, their own families, friends, medical staff and everyone involved in the heart transplant process by writing a thank you letter. Some such letters have been published by the Japan Organ Transplant Network (Fujita, 2006). In this section, I will explore the way in which they express their appreciation. Only a limited numbers of thank you letters have been published in public, and the content of the letters may represent only part of the recipients' feelings. Therefore, using interviews makes it possible to examine how the recipients recognise a heart organ as both a gift and as demanding a form of repayment that involves a series of gift-exchange processes in everyday life. In the interview, Hoshino's mother simply and directly expresses her feeling towards the donor.

(Hoshino's mother) 'We are really grateful to the donor.' [in Japan]

Mrs. Sano, on the other hand, refers to the donor's family.

(Mrs. Sano) 'I don't think that he [my husband] received a life from a donor [because the donor had already passed away when the heart was extracted].

What I really appreciate about the donor families is that they made a decision to donate their family member's heart when the body was still warm, soon after the person had passed away.' [abroad by self-funded]

The form of expression and words chosen to express their feelings of gratitude depend on the recipient. Ultimately, it may be that their appreciation cannot be fully expressed, because there are no gifts as comparably precious as a donated heart (Fox and Swazey, 1992). This internal conflict can be seen in Mr. Watari's narrative.

(Mr. Watari) 'Ultimately, I cannot fully express my appreciation. ... I find that it is difficult to precisely express my feelings of gratitude. I also feel that I don't want to talk about it, as I think it's impossible to talk about my whole appreciation. If I say something, this will only be a part of my feelings. Therefore, I would be irritated with myself if I tried to convey my feelings since it would be impossible to perfectly describe my feelings. The more I talk, the more I feel stressed because of the imperfect expression of my feeling.' [in Japan]

Due to the extremely strong feeling of appreciation, a recipient may have a problem expressing the feeling precisely. Mr. Oda describes the similar experience which he faced a difficulty of the expression.

(Mr. Oda) 'I don't always openly express how much I appreciate having had a heart transplant and my gratitude to the donor. ... [When I was interviewed by a journalist after returning to Japan,] the journalist asked me what kind of message I wanted to send to my donor. He also asked me whether I felt appreciation towards my donor. I responded to him that I wasn't sure. ... Then, this journalist continued asking me whether I didn't feel appreciation. I said, "Don't you realise that I can't say thank you to the donor, because the donor had already passed away?" He asked me, "If you were able to do so, what would you tell your donor?" My response was, "I think that my donor gave me the time to find the appropriate words to express my appreciation to him. The only thing that I know about my donor is that the donor was a man. I think that there probably should be appropriate words for him. They would be neither to say thank you nor am I sorry, which don't seem to be enough for him." How could I respond? Should I pray that his soul may rest in peace? No, I didn't. I don't think that he donated his heart wishing for such prayers. If I were in his position, I wouldn't expect a prayer from the recipient.' [abroad by fund-raising]

The quote shows that Mr. Oda has a full and complex appreciation of his donor in mind. It is not so difficult for the public to imagine that the recipients have such a strong appreciation towards donors. In fact, the public may take it for granted that the recipients always express their appreciation. This expectation often forces a person to

behave as others expect (Goffman, 1969). The journalist who interviewed Mr. Oda imposed his expectation on Mr. Oda. The journalist attempted to draw out a simple expression that described Mr. Oda's appreciation for his donor, but such straightforward appreciation expressed only a part of what Mr. Oda felt. His feelings were more complicated than the journalist imagined. This appears to be a shared problem for recipients. So far, it is obvious that regardless of whether the patient received a heart transplant either in Japan or abroad, either self-funded or through donations, all recipients expressed their appreciation to their donor and the donor's family. It is therefore appropriate next to explore the ways in which the recipients attempt to express their appreciation.

#### **7.4.2 Wishes to establish contact with an anonymous donor and the family**

In seeking ways to express their appreciation some recipients and their families describe their wish to establish contact with their donor families, although they understand that this is not possible. It is as if through this, they are seeking a way of repaying the anonymous donor. The following extract represents some of the complicated feelings among recipients.

(Mr. Sano) 'It [the relationship between me and my donor] is a one-sided relationship, isn't it? I cannot repay anything to the donor, because I don't know who my donor is. I only received their heart. Therefore, I have done my best to live with a feeling of appreciation. This is my way of expressing my appreciation to the donor. I cannot repay anything by sending something. The only way for the repayment seems to be expressing my appreciation, as I cannot repay him/her by sending a gift.' [abroad by self-funding]

In order to repay donors and their families, 'feeling' suddenly takes on an important role. This is an expression that does not have an exact shape and is fluid, being constantly influenced by a person's emotions, and social and cultural factors. Some express this by publicising their identity as heart transplant recipients. In this respect, this point, Hoshino's mother provides the following opinion:

(Hoshino's mother) 'He still can't do many things by himself [due to his speech disability]<sup>29</sup>. The only thing that he can do now may be to show how

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<sup>29</sup> Prior to having a heart transplant operation, this patient had a ventricular assist device (VAD) transplant. By using a VAD, he experienced cerebral thrombosis, and this caused a speech disability. He can still hardly speak.

well he is after having a heart transplant. Therefore, we have tried to come to this hospital frequently to show how he is fine. ... Apart from this, we aren't sure how we could possibly repay the donor. I wish we had the opportunity to contact the donor's family like in other countries.' [in Japan]

Similarly, Ms. Hamada refers to how important it is to her to show how well she is.

(Ms. Hamada) 'I think donors' families would be happy to see the recipient, because they know how their families' organs are fine inside recipients' bodies. ... We wish we had a chance to express this appreciation, saying "We cherish life by looking after the heart".' [abroad by fund-raising]

Mr. Noguchi describes his complexity of his feelings:

(Mr. Noguchi) 'I wish I could be able to see my donor's family. ... I do understand that contacting them is prohibited in Japan. Therefore, I wouldn't even ask a surgeon to let me know about them. I wish I could have the chance to express my appreciation. The only thing I can do [to be closer to the donor's family] is to visit the hospital [where I received a heart transplant]. I sometimes come to this hospital to see hospitalised patients and show them some photos to tell how I had been in the hospital.' [in Japan]

These recipients come to see other patients who need a heart transplant. As they do not have a way of directly repaying their donor and the families, they do this as an alternative. In addition to communication among the recipients, communication between recipients and potential recipients has been popular. As discussed in the previous chapter, in particular in the decision making process leading up to a heart transplant, being part of a network helps the recipient in making their decision. This network has another important role, as the recipient can use it to find an alternative way to repay the donor. In so far as this occurs within this network, the process of repaying the gift of a heart is experienced only among people who have been involved in a heart transplant. The public is omitted from it.

### **7.4.3 Break the anonymity of a donor**

The anonymity of both brain dead donors and transplant recipients has been carefully maintained in Japan. The first brain dead donor under the Organ Transplant Law in 1997 became a big target for the mass media. The donor's family experienced upheaval at the hands of the mass media, including the TV, the press and magazines (Brain Death and Organ Transplant News Team, Kouchi Newspaper, 2000). This furore brought a

considerable amount of stress to the family, because the commotion caused by the press negatively impacted upon the family's reputation (ibid). After this experience, the hospital requested that, in future, the media maintain the anonymity of donors and recipients (ibid). But, as Dr. Fukushima pointed out in the interview in 2008, with the increasing the number of the transplants from brain dead donors, the media's interests gradually decreased. One heart transplant recipient, named Ono, who had the operation in Japan, was nonetheless introduced to the general public through the press. Ono is the 10th heart transplant recipient in Japan since the passage of the Organ Transplant Law. The media involvement was at his surgeon's request. He agreed to respond to the press with some hesitation.

(Mr. Ono) 'The press requested that I provide an interview in order to show how well I was. ... The reason I agreed to this request was that I thought the coverage with my photo would help future patients in some way. I also thought that I might show my appreciation to my donor's family.' [in Japan]

He thus describes two reasons why he agreed to respond to the press interview. By publicising himself with the label of a heart transplant recipient he could help potential patients and also thank the donor family. As the first heart transplant in Japan under the law in 1997 showed, the relationship with the press is not always comfortable for the patient and the family (Brain Death and Organ Transplant News Team, Kouchi Newspaper, 2000). Nevertheless, Ono and his family agreed to it after consideration. His wife describes the process of reaching this decision.

(Mrs. Ono) 'I do understand that donors' families have a very difficult decision, as they offer the only thing [which belongs to the donor's body]. I thought that, if a patient gets a chance to receive it [a heart], the best way to show respect to the donor would be to do the best in the rest of our life after receiving it. I thought that this way of thinking and decision would be better, because this would not be impolite. Fortunately, we shared this idea with others around us.' [in Japan]

As they did not have a way to express their appreciation to the donor, Mrs. Ono says, they decided to do so via a press interview. As the donor and the donor families are anonymous, they are in a same position as the public in relation to the recipient and the family. Ono and his wife attempted to establish an emotional connection with the donor families by using the press.

#### 7.4.4 “Thank you” letters to donor families

Due to the anonymous nature of the relationship between the recipient and the donor family, for some the only channel for direct contact following the transplant operation is to send a "thank you" letter. Some of these letters have been published by the Japan Organ Transplant Network, which aims to increase the understanding of organ transplantation among the public (Japan Organ Transplant Network, 2011a). In these letters, the recipients tend to describe how they experienced improved health and quality of life as a result of receiving heart transplants, and express how much the recipients appreciate the donors and their families. At the end of such letters, they also describe how they will live.

Mr. Uchida received a letter from his donor family. As he had the operation in the U.S and the letter was written in English, he asked his surgeon to reply to his donor's family. He describes how he replied to them as follows:

(Mr. Uchida) ‘I received a letter from my donor's family after the operation. I told my surgeon to reply and write that I was doing quite well, and was full of appreciation to them. Although the surgeon told me that I did not need to reply to them, I wanted to express my appreciation.’[abroad by self-funding]

Mr. Uchida simply and frankly expresses how he showed his appreciation to his donor and the donor's family. This kind of appreciation is one that can be easily accepted by public. As previously described by Mr. Oda, who was forced to express his appreciation through an interview with a journalist (section 7.4.1), transplant recipients tend to be expected to express their gratitude to their donors using terms of appreciation.

However, when the recipient expresses their appreciation to their donor and donors' families, they are very careful for choosing words to avoid being misunderstood by their donors' families. When Mr. Watari wrote a first draft of a thank you letter to his donor family, Watari asked another organ transplant recipient – the first double-lung transplant recipient in Japan – to read it. Watari noted how his expressions reflected transplant recipients' attitudes in general.

(Mr. Watari) ‘He [the first double-lung transplant recipient] told me that I should be glad to have had a transplant; however, [also that] your donor family lost a family member. Therefore, he advised me not to use expressions such as “glad” and “happy”. He suggested using different expressions that did not focus on my emotions. In the letter, I used an expression, “my second birthday”. In relation to this expression, he told me that the day of my

operation may have been my second birthday, but for the donor family, it was the day they lost their family member. ... Based on his advice, I rephrased feeling “glad” and “happy” to having “gratitude” and “appreciation”. By changing the way I described my feelings through the communication with him, I attempted to express my actual feelings in order to be understood by the donor family.’ [in Japan]

As Mr. Watari’s experience shows, attempts to express the recipient’s feelings remind the recipient of the meaning of his or her heart transplant experience in different ways. His experience shows how difficult it is for the recipients attempt to show their gratitude to the anonymous donor and his or her family. In the next section, I will explore what the recipients attempt to do in order to express their appreciation to the donors and the donor families in their everyday lives.

#### **7.4.5 Living in a way that expresses an appreciation of the donor and their family**

For a recipient, the experience of having a heart transplant means that they cannot forget the anonymous donor. The imagined relation between the two may affect the recipients’ decisions in everyday life.

(Ms. Hamada) ‘I want to help other people through my work [after finishing at university]. As I have been helped by many people through the process of having a heart transplant, I have come to think quite a bit about the repayment. ... I assume that many other recipients think about the repayment and they want to repay other people [including the donor’s family]. ... One answer I’ve come up with is to cherish every single day with all of my might. I think that I should not ruin my life.’[abroad by fund-raising]

Although she wanted to repay the donor, she knew she would not to be able to do it. Therefore, she tried to find an alternative way and she reached an answer: cherishing every single day. In other words, her exploration of ways to repay to the donor affected her behaviour in her everyday life. Similar attitudes are found among other recipients.

(Ms. Kato) ‘I always try to live my life in the best way possible. By doing my best, I think that I will live my life without disrespecting my donor. I will also show my respect to the donor.’[abroad by fund-raising]

(Mr. Noguchi) ‘I highly appreciate the donor who gave me another life. I would be upset with myself if I became lazy in doing my rehabilitation. I started rehabilitation myself.’[in Japan]



As their experiences show, the recipients tend to establish new behaviours in the process of exploring ways to repay their donors. In this process, during which the recipients keep thinking about their donors, these new behaviours may increase their self-consciousness as heart transplant recipients. In this regard, the recipients seem to be unconsciously regulated by their donors' existence, and their selves as recipients are established through the accumulation of attempts to change behaviours. A recipient's family describes the dilemma caused by her not being allowed to have any relation with his donor.

(Mrs. Hoshino) 'If permitted, I'd like to visit the donor's grave and offer incense sticks. As my son had a heart transplant operation on the 16<sup>th</sup> of February, I only join my hands in prayer on that day.<sup>30</sup> Therefore, I wish I could have more ways to express my feelings. Every recipient may not agree with this thought. Nevertheless, I wish I could be closer to the donor and the donor's family.' [in Japan]

As an active behaviour, she prays for her son's donor. By including the prayer as part of her everyday ritual, she may feel that, as a substitute for a face-to-face relationship, the recipient can share her everyday life with the donor. This ritual also reflects the fact that recipients' lives are kept separate from the donors' lives. As I have discussed in a previous section, many donor families are isolated from society because they have limited chances to express their grief. This ritual carried out by this recipient's mother symbolically tries to remedy this problem.

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<sup>30</sup> In a Japanese cultural context, the behaviour of joining hands in prayer often brings an image in which a person prays at someone's grave, in a temple or a shrine, and in front of a Buddhist altar at home.

## 7.5 Conclusion

In sum, in terms of the anonymous relationship between the donors and the recipients, recipients and their families explore alternative ways to repay the donors and their families. There are four main ways they express their appreciation.

One way is to attempt to provide emotional support for other patients by showing them how their transplant improved their health condition. The recipients want to show the donor families that the transplanted heart is fine. Instead of direct contact, which is not possible due to the regulations forbidding this, the recipients attempt to use their body as a resource of information for other patients.

Second, some recipients respond in the media through interviews, and others publish thank you letters in public.

Third, while maintaining anonymity, letters are sometimes exchanged between the recipient and the donor's family. Writing a thank-you letter also makes the recipient recognise that a heart transplant has a two-sided meaning. In other words, for the recipient, improving his or her health is a positive result of the heart transplant; however, the same thing has the opposite meaning for the donor and his or her family.

Eventually, the recipients face the dilemma of how to express their appreciation. Finally, as a form of repayment for the donor and the family, the recipients tend to change their behaviour and attitude in their everyday lives. This eventually regulates the recipients' lives, and reinforces their self-consciousness as a heart transplant recipient. The recipient has a strong appreciation of this special gift that came from an anonymous person. Due to a situation in which the recipients do not have a way to repay to the donor, the recipients thus tend to attach their expressions of appreciation to their own identities.

Regarding repayment to donors by heart transplant recipients in Japan, there are differences with those receiving transplants abroad, both those who are self-funded and those funded by donations. All recipients described their immense appreciation for their donors and the donors' families. However, when the recipients attempted to find a way to anonymously repay the donor's family, in particular, the recipients abroad who were funded by donations tended to more actively express their appreciation compared to the other two groups of recipients.

Finally, I consider how the altruistic act of heart organ donation is interpreted from a consumerist perspective by the recipient. Considering heart transplants from the

perspective of gift-exchange customs in Japanese culture, a gift of a heart is sent from an anonymous donor to a recipient, who is also anonymous. In this regard, a heart transplant is a gift-exchange between anonymous individuals. As such, both the recipient and the donor can only imagine each other. Imagining the other person is a process to assign a label of a recipient and a donor respectively on each other. In gift-exchange customs in Japanese consumer culture, this labelling has an important role. The label represents a relationship between people. At the same time, due to the label, a person can choose another gift in a market for purposes of repayment. The market provides the information that people need in order to make a choice in a certain situation. People in Japan are used to this market-oriented gift-exchange situation. However, in relation to a heart transplant, people cannot find any appropriate gift in the market. Therefore, both the donor families and the recipients have to find a way to appropriately handle the stress caused by a situation in which they cannot rely upon their familiar method of completing gift relations. Furthermore, the majority of the public do not have the opportunity to see the actual situation that exists between donor families and recipients. Therefore, the public may tend to imagine their relationship conforms to that of the familiar market-oriented gift-exchange, fulfilled by the exchange of goods. This may cause a negative reputation to develop with regard to donation and heart transplantation. Thus, on the one hand, the recipients see the difficulty of repaying the altruistic gift of donors; while on the other hand, they face the difficulties of perhaps being misunderstood by a public accustomed to market-oriented gift-exchange customs.

## **Chapter 8 Conclusions**

This thesis aims to facilitate an understanding the experiences of Japanese heart transplant recipients from a sociological perspective. In order to achieve this aim, their experiences were analysed as an issue of transforming identities through the process of a heart transplant. Three key factors influence the shaping of the heart transplant recipients' identities. One factor is the experience of the surgical procedure; this is based on an individual's experience with the surgery. The second factor is the way in which the Japanese government labels the recipients. The label is socially constructed and attached to them. Third, this study demonstrates how Japanese cultural factors are important, as they are not officially written down and are not always orally expressed in individual communications. This study has explored those influences by examining the relationship between the surgical procedure of heart transplantation, experiences of the body, and Japanese identity in both a local and global context. In the concluding chapter, a summary of the results are discussed. Finally, the theoretical contributions of this study are posited and recommendations are put forward for the future planning of heart transplantation in Japan.

### **8.1 Summary of findings**

Heart transplant surgery is a clinical procedure that is recognised as being suitable for patients with certain forms of heart disease. As existing studies show, this type of surgery brings about a number of changes on the recipient: physical, physiological, psychological and social-psychological (Bialystok, 2006; Kaba et al., 2005; Sanner, 2001; Sharp, 1995, 2006). These studies do a certain amount to show how medical science is able to alter and control the body through transplanting the heart.

However, two aspects have not been examined by existing in any depth. One is the experiences of patients who travel abroad to receive heart transplants. Another is the influence on the experiences of patients who receive heart transplants on the fact that they live in a society where the discussion of heart transplantation over many years has taken a particular form. My study has shown that we need to consider the relationship between local and global contexts in order to understand the meaning of medical technologies and treatments. Heart transplantation has been developed in many

countries and information and experience in carrying it out has been globally disseminated. This means that patients can access information about the procedure and can come to realise that they too have a chance to receive the treatment. By contrast, the regulations and health care systems governing who can receive such treatment are variable in each country (Eurotransplant International Foundation, 2011d; Japan Organ Transplant Network, 2011a; L'Agence de la biomedicine, 2008; Organ Donation, 2011; United Network for Organ Sharing, 2011a). As a result, the chances for patients to receive heart transplantation depend upon the country in which the patient lives and their social position within it. Considering the situation in which both information and people can travel globally, while each country has its own medical care system and regulations, it is important to consider the relationship between global context and local context in relation to one's opportunity to receive medical treatment.

My research has sought to explore the consequences of this for patients by examining the relationship between the surgical procedure of a heart transplant, experiences of the body and Japanese identity both in global and local contexts.

Heart transplantation is different from conventional medical treatment. While the main actors in conventional medicine are health professionals and patients, heart transplants require another entity, which is an organ from a dead person who has been diagnosed as brain-dead. The use of this third entity causes many concerns for the people involved reflected, in the last four decades, in a number of discussions about heart transplantation in Japan (Crowley-Matoka and Lock, 2006; Kimura, 1998; Lock, 2002; Namihira, 1990; Ohnuki-Tierney et al., 1994). Five meetings were officially organised by the Japanese government in relation to the passing of the Organ Transplant Law (1997) and its amendment (2009). The key actors in the discussion have been transplant surgeons, the Japanese government, legal and life ethics experts, social scientists and the mass media.

By contrast, the patients have not taken part in government commissions that directly impacted upon the Organ Transplant Law. Some of them had several chances to describe their opinions and experiences in study groups which were organised by the committee members. However, the opportunities were limited, so they have mostly been passive entities in the discussion. When they are reported by the mass media, they are still passive entities. Opinion poll surveys offer significant insights into the public's attitude towards heart transplants. These surveys have been conducted by the Japanese government (Cabinet Office, Government of Japan, 2008) and several broadsheet newspapers (Yomiuri Newspaper, 1987, 1991), showing that the public seems to have a

positive attitude towards donating their own organs. However, the actual number of people who donate their organs and register with the Japan Organ Transplant Network to show their interest in donating has not increased in line with the rising support for transplantation that is evident from opinion poll survey results (Japan Organ Transplant Network, 2011d). The gap seems to indicate that the majority of Japanese people have a strong interest in donating organs or that they do not perceive the necessity of organ donation. Overall, the majority do not think of issues of organ transplantation as a personal matter.

In this circumstance, the actual number of heart transplant recipients is very small (Japan Organ Transplant Network, 2011b). These few recipients are labelled as 'disabled' by the government, due to their health condition which requires considerable medical attention (Bureau of Social Welfare and Public Health Tokyo Metropolitan Government, 2009). However, their status as heart transplant patients is not immediately visible in public, so this is a relatively 'hidden' status.

Heart transplantation has been controversial in Japan for the last four decades. The majority of the public has not been outwardly supportive of organ donation, and the physical changes of a heart transplant are invisible for the public. Due to the issues associated with heart transplantation, I propose that there are three main issues surrounding heart transplant recipients. Firstly, due to the small number of heart transplant recipients in Japan, they tend to receive a lot of public attention, even though (as stated earlier) they have not taken part in policy discussions. Secondly, the public's attention reinforces the stigma regarding the master status (discussed in section 5.4) of heart transplant recipients; because when the public knows the individual as the recipient, the public tends to recognise the person not as an 'anonymous person', but as a 'heart transplant recipient', i.e. the public may not imagine other possible labels which can be attached to the recipient. Thirdly, a certain stereotyped image tends to be associated with the recipients, as their actual situation is not always well understood by the public.

Based on these three assumptions, my research questions were:

- (1) How does the recipient experience and perceive the process of heart transplantation?
- (2) What is needed to plan for the future of heart transplantation in Japan?

I reviewed the literature on chronic illness, body image and gift exchange theories. As transplant recipients need to maintain immune health control for the rest of their lives, they are in a chronic condition supported by lifelong continuation of medication. Based

on the review of chronic illness studies, I argue that the experiences of heart transplant recipients conform to the definition of a chronic condition both before and after receiving the transplant surgery. Their experiences consist of both unpredictable and predictable elements. Thus, the review showed that it becomes important to consider the impact of contingent events in the recipient's life at different times and in different situational settings.

In order to explore the situational factors, I have pointed out three key concepts: shame, body image and gift-exchange. In terms of the notion of shame, in particular, it is important to recognize how the others' gaze is given to individuals. The studies concerning body image provided an understanding of how an individual's body image is reconstructed reflecting to reflect the image of the ideal body. The discussion of gift exchange elucidates the relationship between a recipient and a donor. I discuss the summary of findings, along with these three concepts, in this section.

In the first findings chapter (Chapter 4), I argued that developing heart disease disrupts one's life due to the chronic condition of pain and distress. Patients finally only make a decision to have a heart transplant if they have been informed that having a heart transplant is the only way to recover. However, as heart transplantation is not a popular treatment, and the majority of patients do not have the opportunity to receive a heart transplant, patients feel a significant amount of anxiety. In addition, they begin to apprehend the cultural meaning of a heart organ, which they would normally not consciously think about. In addition to the physical disruption caused by heart disease, when facing these social, practical and cultural factors, patients begin to experience an identity crisis. In this regard, I argued that a heart transplant can be thought of as a transformation of the self into a new person.

The data analysis of the patients' experiences during the pre-operative period in Chapter 4 showed that there were two levels of disruption: physical disruption and emotional disruption. The analysis of the post-operation experiences in Chapter 5 demonstrated how these disruptions changed by having a heart transplant.

### **8.1.1 Physical disruption and emotional disruption**

Heart disease such as Dilated CardioMyopathy (DCM), highly restricts a person's life. Being in a condition for which a heart transplant is the only medical treatment, patients cannot continue with their familiar everyday lives. For example, due to their weakened physical condition, the patients are often forced to leave workplaces and schools. In

particular, as Chapter 4.6 shows, the effect on patients' lives becomes apparent in cases involving the implantation of a Ventricular Assist Device (VAD). As a result of this disease, patients' spaces of everyday lives are relegated to hospitals.

After the procedure, the physical disruption that the patients previously experienced is substantially reduced. The ability to function is dramatically improved; the recipients are released from their hospitalisation and can go back to their everyday lives which are not heavily dependent on medical treatments. Patients can return to work, school or community activities in society. In accordance with this improving process, the recipients' physical disruptions are decreased.

While coping with their physical conditions that distance them from their everyday lives, patients also have to understand their heart disease. As Section 4.2 illustrates, patients experience intense anxiety about their lives, particularly concerning death, as they become aware that a heart transplant is the only way to overcome their condition. This anxiety is exacerbated by a lack of information regarding the transplant procedure and the reality that the majority of patients cannot receive a heart transplant operation. Despite experiencing such anxieties, patients tend to avoid expressing their feelings to people who are close to them, such as family members, friends and health professionals. This attitude creates a distance between the patients and people around them at an emotional level, i.e. the patients put themselves in an emotionally isolated condition.

The anxiety that the recipients experience during their waiting periods disappears after their surgeries. As Section 5.2 demonstrates, the recipients perceive how their physical condition is improved by heart transplant surgery. Although their perception of their bodies may be 'new', they gradually become familiar with the transplanted heart and the subsequent changing of their bodies. This shift of awareness in the context of recovery makes recipients release their pre-operative anxieties.

As time progresses, emotions of anxiety are replaced by a sensitivity to the 'gaze' of others, i.e. perceptions of others. Being sensitive to the gaze of others is related to feelings of 'shame'. I argued in Section 5.1 that the key factor that causes emotional disruption is this shift from 'anxiety' to 'shame'. I therefore conclude that stigma is an important part of the experience and exploration of the distribution of shame and its consequences for personal identity are further elaborated upon below.



### **8.1.2 Information control in terms of the relationship with others**

Emotional disruption on the part of patients during the decision-making process is compounded by their close relationships. Patients imagine how the people around them will worry about their condition. In order to minimise their concerns, patients often behave as if they do not worry about their condition, or about the fact that they need a heart transplant and the potential problems associated with the operation. This imagined process first happens in patients' minds and then they decide how they should behave in front of people. I argue that patients assume a certain persona as 'patients' in relation to the outside world, and that this role creates a 'new self' in their minds. This is a reflexive process, in that a person perceives the gaze of others, and tries to adjust his or her behaviour according to their expectations. This adjusting process is continuously going on between the person and other people (Giddens, 1991).

This reflexive identity process defined by face-to-face communication seems to extend to communication between a recipient and the public after the heart transplant. After the operation, recipients think that they are recovered from their disease. Conversely, both people who are close to the recipient and the public view the individual as a diseased person. In other words, recipients maintain their own perceptions of self – who they are and how they want to be perceived by other people – not as 'patients'. For them, this is a struggle with 'master status', which is determined by others at an emotional level (as shown in Section 5.4). Therefore, they tend to want to manage how they disclose their personal information, because they know that they may be stigmatised. From their experiences during the pre-operative period and the post-operative period, the recipients recognise how much they care about their reputation and the evaluations others make of them. They understand more acutely than is normal that their own identities are highly dependent on their relationships with others, i.e. the whole issue of identities is embedded in a social context.

### **8.1.3 Situational factors: variations in experience by gender, location, age and wealth**

In this process of transformation of the self, gender, geographical location and wealth influence whether you have a heart transplant and whether you have to raise funds.

### *a. Gender*

As reviewed in Section 4.2, statistical data concerning Japanese heart transplant recipients shows that there have been more male heart transplant recipients than female. In Section 4.2, I showed that the gender balance in recipients parallels the gender balance in patients who are registered as being on the waiting list for a heart transplant. The gender imbalance therefore arises at the point at which registration occurs. There are two possible reasons behind this gender difference.

- (1) Of the Japanese patients who need heart transplants in the Japanese population, many have congenital disease such as Dilated CardioMyopathy (DCM), rather than acquired disease. More males have this sort of disease than females.
- (2) Female patients may be more likely than males to perceive disease symptoms at an early stage and go to hospital, i.e. female patients may be more likely to receive medical treatment before reaching the condition where a heart transplant is needed. As a result, more male patients may then need heart transplant surgery. Why does this happen? Generally speaking, in Japan, men work longer hours than women. Therefore, if a man feels any symptoms, he tends to postpone going to hospital to check them out. By contrast, a woman has more chances to rest when she perceives any symptoms. In addition, male patients tend to seek less help for medical care than women as existing studies show (Addis and Mahalik, 2003). O'Brien et al. (2005) found that physical and visible symptoms in men are less likely to be triggers to seek help from health professionals. Due to this character, male patients tend to be late in seeking help, and the disease condition deteriorates to a point where a heart transplant operation is required.

Looking at these possible reasons, while reason (1) provides a medical explanation, the explanations of (2) reflect the role played by cultural expectations of men and women.

### *b. Geographical location*

Looking at locations of hospitals for heart transplants which are all in big cities, patients in big cities may have more opportunity to receive heart transplants simply because they live near the facilities that carry out the procedure. However, there are no existing studies on the relationship between geographical location and heart transplant accessibility.

### *c. Age*

Age is another important variable in the transformation process of identities from a patient to a heart transplant recipient. When patients need fund-raising support from the public, younger patients have more access to resources than elderly patients do (as shown in Section 4.5). In addition to this, younger patients experience greater difficulties in establishing their post-transplant identities, because they are growing up anyway, and identity has not yet become securely established when heart disease and transplantation intervenes. Younger patients need not only to consider the body's growth with the biomedical management of the transplanted heart, but also seek a way to accept the identity of a heart transplant recipient (Section 4.2 and Section 5.2).

### *d. Family wealth*

Family wealth is an important factor that influences a patients' experience of stigma. Patients need to disclose their decision to have a heart transplant to other people such as co-workers and friends in addition to families and clinicians. To what extent and to whom they disclose their decision depends on their social and economic background. Patients can be categorised into three groups: (1) patients who have heart transplants in Japan, (2) those who have transplants abroad by self-funding, and (3) those who have transplants abroad by fund-raising. Clearly, patients in category 2 tend to be wealthier individuals who can keep their personal affairs to themselves if they so choose. However, patients who seek fund-raising support from the public to go abroad (category 3) are forced to disclose personal information, which is ultimately made public, not only during the time they seek fund-raising support prior to their transplants, but also when they deal with the public's attention after their operations.

As Section 5.4 highlights, heart transplant recipients know that there is a gap between their own self-image and the image that others have of them. For instance, Ms. Okamoto knew that the public viewed a heart transplant recipient as a physically vulnerable person, even after the surgery.

(Ms. Okamoto) 'I go sometime grocery shopping. This doesn't cause any harm for me. Nevertheless, some people who saw me tell to my husband, "I saw your wife in a supermarket. She can walk by herself, can't she?" There seem to be many people who assume that I need a wheelchair.'

After having a heart transplant operation, the recipient thinks that they are recovered from heart disease. By contrast, the public considers the recipient as a diseased person.

In other words, the perceptions of recipients as to who they are and who they want to be can be very different from the master status conferred on them by others. This involves experiencing a division between an inner perception and external perceptions, and also between personal and social identity. Therefore, recipients tend to want to manage how they disclose their personal information, because they know that otherwise they may be stigmatised.<sup>31</sup> Through their experiences during the pre-operation period, patients recognise how much they care about their reputation and the evaluations others make of them, so that they understand more acutely than normal that their own identities are highly dependent on their relationships with other people. This finding leads to another question: why people are so highly sensitive to other people's gaze. I will consider the reason behind it in the next section.

#### **8.1.4 People's gaze**

Paying significant attention to one's reputation and evaluation by other is also a significant characteristic of Japanese culture (Naito and Gielen, 1992). This characteristic has been reinforced after the Second World War. In the post war period, many people share a similar idea of family size, quality and length of education, and type of job. The majority of the population share the idea of similar life course. By the mid 1960s, more than 80% of the population came to consider that they were middle class and from the 1970s onwards this increased to more than 90% of the population (Honda, 2005). Many people attempted to have such a similar lifestyle. This then meant that people increasingly came to view deviation from this as negative or as being behind other people. As heart transplants have not been a common medical treatment, this places the heart transplant patient in the position of one who is not pursuing a similar idea of life according to Japanese norms. In sum, patients' experiences of stigma are caused by a gap between recipients' perception of themselves and others' perception towards heart transplant recipients as mentioned in the previous section. People's perception towards the recipients is highly influenced by the attitude among the majority of Japanese people which tend to share idea of similar life course in Japanese

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<sup>31</sup> For example, an interviewee lung transplant recipient in this study reported a situation that occurred when she was diagnosed as needing a lung transplant. Because the chances of receiving an organ transplant from a brain dead person were very limited, she expected that her family would help her to start a public fund-raising campaign so that she could go abroad to have the transplant. However, her father told her that he would not be able to help her. He said that because he had two more sons, he could not spend all of his money only on her, and he also said that he could not ask for charity from the public because of the effects on life after seeking this type of help.

culture, i.e. the idea of similar life course reinforces the recipients' stigma experiences.

### **8.1.5 Relationship with health professionals**

Patients, who have faced an identity crisis before having a heart transplant, begin to re-establish their self-identity as they regain consciousness after surgery. The initial establishment of the self is conducted in his or her subconscious. The patients perceive a change in the condition of their body as they regain consciousness soon after surgery. They think about how the transplanted heart is working in their body. This initial experience involves just the patient's mind and body, and the transplanted heart. In this regard, this is very personal, and the patient's communication at this level is unknown to others and closed to any other people, so that it is not a fully social experience. At this early stage patients do not seem to be influenced by such things as a culturally similar life course, which may have loomed so large in the pre-operative period.

Once they start talking to people after regaining consciousness, they begin to reformulate their identities in a fuller sense. In terms of this communication, the relationship with health professionals in particular affects patients' identities. Considering that this is a chronic condition for which patients need life-long medical treatment, the doctor-patient relationship can be categorised as an example of the 'mutual participation model' as described by Freidson (1970). Moreover, this research shows that the mutual participation model as it is experienced by Japanese heart transplant patients needs to be considered in its wider social context. The transplant surgeons and patients not only experience and treat a chronic condition, but they are also involved in enhancing the public's understanding of heart transplant medicine in Japan. Therefore, I argue that a new type of medical treatment such as heart transplantation requires health professionals and patients to establish a mutual relationship not only for the sake of medical benefit, but also to improve the social standing of transplantation. Patients' social identities are now fixed as heart transplant recipients, so that they must behave as recipients not only in front of the health professional during treatment, but also in front of the public outside the hospital setting.

### **8.1.6 Private intention and public intention**

In the post-operative period, the experience of stigma becomes a more serious matter for patients than in the pre-operative period, because the patients cannot change the fact that

they have had a heart transplant. As I have discussed previously, when deciding to have a heart transplant, patients worried about the potential for stigma, because they knew the Japanese public's perception of heart transplant recipients could sometimes be negative. In the pre-operative period, patients who have heart transplants abroad through fund-raising support from the public seem to experience more stigma than patients who either have the procedure in Japan or abroad using self-funding. However, these differences between fund-raisers and others regarding the degree of stigma seem to decrease in the post-operative period. This study explored the patients' stigma experiences, categorising them into 'enacted stigma' and 'felt stigma' (Scambler and Hopkins, 1986), showing that although patients experienced enacted discrimination, they experience felt stigma more frequently; whereby patients assume possible discrimination if people get to know the person as a heart transplant recipient. This phenomenon, in which felt stigma is powerful for the patient, exacerbates the tendency already present in Japanese people to hide their feelings on the surface. This tendency in Japanese norms about demeanour is referred to as the idea of 'private intention' and 'public intention' ('Honne' to 'Tatema'e') in Japanese culture (Naito and Gielen, 1992). Private intention means what people really think, while public intention means what people convey. Heart transplant patients' stigma experiences show that there are four aspects in relation to 'private intention' and 'public intention' (Honne to Tatema'e):

- (1) the patients' private intention
- (2) the patients' public intention
- (3) the public's private intention
- (4) the public's public intention.

Patients tend to be quite sensitive to both what the public really think about (private intention) and what they convey to heart transplant patients (public intention) in order to avoid stigma experiences. If patients rely on what the public tells them, the patient may easily experience enacted stigma, because the public does not necessarily tell patients what the public really think about the patients. Patients attempt to explore what the public truly think about them using their own knowledge about Japanese cultural norms governing how people generally express their feelings and behave, particularly when they may not wish to show their true feelings. Therefore, the patient's public identity is highly influenced by their speculation about the public's perception of heart transplantation.

### **8.1.7 Influence of Japanese cultural norms concerning the dead body**

This study also explored the relationship between heart transplants, the body and Japanese identity, demonstrating how this can sometimes fuel a sense of shame about having had a heart transplant. Firstly, this study showed that recipients tend to perceive the body as an assemblage of functions and meanings attached to organs. A heart has a history because it has belonged to another individual, and the history establishes an individual's identity. In relation to a heart transplant, patients differentiate their own diseased hearts from the hearts of others. I argue that this attitude among the recipients demonstrates that the patients recognise that their identities are established by organs which have histories, through the experience of having a heart transplant. This recognition tends to become stronger after the operation. In particular, patients perceive that it takes time to integrate the transplanted heart into the body. The heart's integration therefore occurs at both the physiological and emotional levels. For example, from the physiological standpoint, the recipient can perceive to what extent the transplanted heart is integrated into the body by looking at how nerves are connected between the transplanted heart and the body, which is monitored on the screen. Similarly, at the emotional level, the recipient comes to perceive the transplanted heart as his or her heart, instead of someone else's heart. This experience is highly influential on patients' efforts to re-establish their identities as recipients.

However, although this demonstrates that body organs are more than just physical phenomena, this is hardly characteristically Japanese: similar feelings about body parts can be found in other cultures. More particularly associated with Japanese culture are traditional views about the dead body, which lead some people to resist transplantation of the heart and suggest that such a procedure may be something to feel shame about. In Japan, it is important that the dead body is properly looked after in a ritual process, including a funeral; in addition, it is important that the dead body is eventually satisfactorily buried. The body has special meaning after death, and the notions of brain death and organ procurement from a brain dead person break this ritual process. This gap between the medical perspective regarding transplants and the traditional Japanese attitude towards the dead body characterises the Japanese attitude towards the body. Heart transplant recipients perceive both aspects, giving them a different perspective from medical specialists, in particular transplant surgeons, and the perspective of the public. Surgeons are familiar with brain death and the use of organ transplantation as a resource for medical treatment on a practical level. The public is familiar with the ritual

processes for the dead body, and organ recipients are sensitive to the way in which the public views heart transplant recipients in their everyday lives. The recipients' sensitivity to the public's attitude towards the dead body influences his or her behaviour in front of other people. In this regard, the Japanese traditional attitude towards the dead body is one of the factors which influence recipients' identities.

### **8.1.8 Gift-giving in Japan: impact upon heart transplant experience**

In relation to another explanation for the shame and stigma that can sometimes be felt by heart transplant recipients, this study also explored the way in which the Japanese implementation of the custom of gift-exchange affects the experiences of heart transplant recipients. Existing studies (Gill and Lowes, 2008; Lamanna, 1997; Sahar et al, 2003) provide insights regarding the impact of an altruistic attitude on patients' experiences, as well as the role of altruism in the organisational processes of organ donation (Shaw, 2008). These are highly influenced by the notion of gift-exchange, on which Mauss (1954) has written. Gift-exchange in consumer culture is not the focus of Mauss's study and current research does not appear to examine the impact of consumer culture on gift-exchange customs. Considering the economic changes of the 20<sup>th</sup> century in advanced industrialised countries like Japan, it is important to understand gift-exchange customs in a context of a modern consumer market. This study has therefore analysed how the recipient interprets the altruistic act of a heart donation from a consumerist perspective in a country where gift-exchange is particularly strongly embedded in everyday life.

Pursuing this, I argue that the following points are important. On the one hand, recipients are familiar with gift-exchange customs in the everyday life of Japanese consumer culture, in which gifts are exchanged between people who know each other. On the other hand, due to the regulation of transplantation in Japan (Japan Organ Transplant Network, 2011a), anonymity between the recipient and the donor is fundamental. Therefore, the gift of a heart organ is anonymous. This anonymity causes stress since both the recipient and the donor families cannot complete the process of gift-exchange that is usual in Japan, as it requires knowing who the giver has been so that something can be given back. Both parties in heart transplantation – donor and recipient – therefore attempt to find ways to decrease this stress. Both parties to the 'exchange' imagine each other. In their imaginations, they think about the other party as a representative of a group (e.g. 'donors' or 'recipients') instead of thinking about



particular individuals who may have donated or received the gift of a heart. This attitude is considered as a process during which they define one another, placing labels on the other of a 'recipient' and a 'donor' respectively. In particular, my study has shown that recipients often try to show their respect and appreciation of their donors by the manner in which he or she lives after the transplant. For example, as shown in Section 7.3.5, a recipient said, 'I always try to live my life in the best way possible. By doing my best, I think that I will live my life without disrespecting my donor. I will also show my respect to the donor.'

The actual attempts by recipients to 'repay' donors and the situation of donor families are not well understood by the majority of the Japanese public. The public is familiar with gift-exchanges in which markets promote the traditional habit of gift-exchange; people may imagine that the relationship between recipient and donor families is similar to an exchange of goods. It is difficult for the Japanese public to understand altruistic organ donation given the overwhelming predominance of a market oriented gift-exchange culture in which donors and recipients are known to each other and can directly exchange gifts. Moreover, in Japan, it is evident that both recipients and donor families are highly sensitive to the public's potentially negative evaluation of heart transplantation. As a result, these sensitivities influence the identities of heart transplant recipients.

## **8.2 Theoretical contribution to medical sociology**

A patient's opportunity to have a heart transplant is influenced by both the local and global contexts of heart transplantation. Focusing on the medical development of heart transplants and information dissemination among the public, heart transplantation is a global issue. In order for patients to locally receive the operation and for health professionals to conduct the operation, regulations similar to the Japanese Organ Transplant Law (1997) are fundamental in each country. As this study showed, heart recipients and heart disease patients in need of a heart transplant experience tensions between the global and local contexts. The number of patients who have the opportunity to receive a transplant is very limited. Even after having the operation, recipients continuously control their identity as heart transplant recipients. This experience involves a continuous reconstruction of the self. In this process, the recipient experiences social stigma. In particular, situational factors influence the self as a heart transplant recipient. Notions of 'shame', 'body' and 'gift' hold strong resonance for the identity reconstructing process. In particular, this study provides additional perspective in terms of gift theory to explore how heart transplant recipients attempt to repay their donors. Since the pioneering study by Fox and Swazey (1978), many studies have discussed the issue of the immense gift which an organ transplant recipient received, and the fact that they cannot fully repay this to the donor even though the recipient strongly wishes to do so. This means that recipients remain in need of such a strategy.

This study examined the experiences of three different categories of heart transplant recipients. Through the categorisation, I pointed out both common experiences and the different aspect of those experiences. All heart transplant recipients in this study showed that they commonly have strong feelings of appreciation toward their donors. This finding overlaps with existing studies as well. Focusing on strategies of repayment, many recipients in this study seemed to have been familiar with models of repayment under market-oriented societies, which are not applicable to heart transplantation.

The question raised here is why differences exist among heart transplant recipients. Regarding this question, this study provides a viewpoint from which situational factors and social settings may influence the repayment strategies employed among recipients. Recipients in Japan know that their donors are Japanese; however, they cannot know

more than this. These recipients can only imagine that the donor was Japanese and the donor's family is also Japanese. Geographically, it is not very difficult to visit the donors' families, if they choose to do so. Due to the fact that both the recipient and the donor are the same nationality, the recipient may reinforce his/her self-identity as a 'Japanese' heart transplant recipient.

Recipients abroad often receive not only clinical support, but also more non-clinical support than recipients in Japan. For example, recipients abroad need special treatment for transportation from a hospital in Japan to a hospital abroad. Furthermore, recipients abroad who are funded by donations receive support through fund-raising. By having these experiences, the recipients abroad tend to think that they have more people to repay. At the same time, these recipients geographically maintain distance with their donors. They imagine their donors, and they tend to find a way to express their appreciation in their minds and in their everyday lives. Then, they physically tend to repay people in Japan who helped them as heart transplant recipients, as if implementing an alternative repayment strategy. Considering these phenomena, anonymous relationships between heart transplant recipients and donors are not uniform; rather they are varied in terms of gift-relationship. In summary, this study provides an important perspective on repayment strategies among Japanese heart transplant recipients, depending on whether the recipient receives the transplant in a global context or in a local context.

### **8.3 Suggestions for future planning of heart transplantation in Japan**

This study is based on interviews with nineteen Japanese heart transplant recipients and thirty-four other people who have been involved in heart transplants. Considering the limited number of interviews in this research, it is difficult to generalise issues surrounding heart transplantation in Japan. Nevertheless, I believe that this research has succeeded in achieving a deeper understanding of the experience of heart transplantation, both by recipients and others involved. Their voices have not been heard in the past. In this regard, this study provides valuable insights for the future planning for heart transplantation in Japan.

The findings of this study show that there are two perspectives in considering the future planning of heart transplantation in Japan. Cultural lack of acceptance of heart transplantation causes a lot of pain among heart transplant recipients; they feel stigmatised. Their stigma experiences were categorised as ‘felt stigma,’ which is imagined possible social discrimination, and ‘enacted stigma,’ which is actual discrimination. Culturally, there tends to be inhibition among the Japanese public when it comes to the verbal expression of actual feelings. I argued this as an issue of preferring ‘Honne’ to ‘Tatema.’ In other words, many emotions are not typically expressed to the public, even though someone may feel strongly about an issue. The resulting of this cultural aspect are that the recipients consider how important it is to be appropriately aware of people’s expectations of their behaviour. Heart transplantation is not just a physical experience; it is also an emotional and, to some extent, spiritual experience. This is not fully recognised in the Japanese medical system. I argue that a system should be established to support recipients in a much broader way than current medical support provides. It is clear that many recipients experience health professionals’ attempts to provide them with social support as transplant survivors is associated with a pressure to ‘act happy’ and agree that the experience of transplantation is almost entirely positive. Recipients need to be allowed to reflect more freely on the negative aspects of heart transplantation, as well as to acknowledge the benefits it brings. For this reason it is particularly important to establish a support organisation outside hospitals and without, or at least complementary to the care provided by health professionals and hospitals.

Considering that repayment strategies are different among heart transplant recipients, support organisations need to develop methods to decrease the stress caused

by issues of repayment. Also, individual support organisations need to specialise according to each category of heart transplant recipient and the particular needs associated with each type of recipient. Based on these differences local organisations can provide detailed support. Then, several organisations will be able to establish wider networks to support more complicated issues in relation to heart transplantation.

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**Yomiuri Newspaper** 2001c 'America de shinzou isyoku no Chiba no 13sai, 1nen 1kagetsuburi kitaku, raigetsunimo fukugaku e [A 13 year-old boy had a heart transplant in America, he returned to home after 1 year and 1 month, he will return to school next month]' *Yomiuri Newspaper*, 23 March 2001: 32.

**Yomiuri Newspaper** 2001d 'Shinzou isyoku de tobei, Takuma chan syujutsu seikou, youtai antei, okaasan no kao nimo hannou [Takuma chan successfully had a heart transplant in America, his condition is stable, he responds to his mother]' *Yomiuri Newspaper*, 11 April 2001: 31.

**Yomiuri Newspaper** 2001e 'America de shinzou isyoku Fujuta Maho chan, genki ni hai, Koushiba Shimoda syou de okaeri syuukai [Maho Fujita who had a heart transplant in America cheerfully responds 'Yes' to a homecoming party at Shimoda school]' *Yomiuri Newspaper*, 8 September 2001: 31.

**Yomiuri Newspaper** 2001f 'Shinzou isyoku syujutu no 2sai joji ga America kara kikoku [2 year-old girl who had a heart transplant in America returned to Japan]' *Yomiuri Newspaper*, 27 September 2001: 38.

**Yomiuri Newspaper** 2001g 'America de shinzou isyoku syujutsu ni seikou shita Aida san, yorokobi no kikoku, hayaku shokuba ni fukki shitai [Mr. Aida who successfully had heart transplant in America returned to Japan with pleasure, He would like to return to his place of work as soon as possible]' *Yomiuri Newspaper*, 10 October 2001: 30.

**Yomiuri Newspaper** 2001h 'Shinzou isyoku de tobei, syujutsu, Shimada meidai kyouju ga kikoku "Hayaku kenkyuushitsu ni fukki shitai [A professor Shimada at Nagoya University who had had a heart transplant in the US returned to Japan "I would like to return to my research as soon as possible"]' *Yomiuri Newspaper*, 31 October 2001: 38.

**Yomiuri Newspaper** 2001i 'Bokin "Henkyaku" Kansya kome, America de shinzou isyoku no Nakasaki san, hatachi no tanjoubi ki ni [Mr. Nakasaki who had had a heart transplant in America with fund-raising support from the public "returned" some money on his 20th birthday]' *Yomiuri Newspaper*, 15 December 2001: 32.

**Yomiuri Newspaper** 2001j '21 seiki - Nihonjin no ishiki, iryou jouhou motomeru kanja

[21 century, Japanese people's thoughts, people seek more information of medical treatment]' *Yomiuri Newspaper*, 29 December 2001: 26.

**Yomiuri Newspaper** 2002a 'America de shinzou isyoku no Niisaki Shingo san kikoku "yume no you" to egao [Shingo Niisaki who had a heart transplant in America returned to Japan, he smiled saying "feel like dreaming"]' *Yomiuri Newspaper*, 9 January 2002: 30.

**Yomiuri Newspaper** 2002b "'Donor no bun mo ikitai" America de shinzou isyoku no Sugita san, genki ni kikoku kaiken ["I would like to live for a donor, too" Ms. Sugita who had a heart transplant in America returned to Japan and responded to a press interview]' *Yomiuri Newspaper*, 8 October 2002: 32.

**Yomiuri Newspaper** 2002c 'Bokin ni sasaerare America de shinzou isyoku Hikaru chan raigetsu kikoku he [Hikaru chan who had a heart transplant in America supported by fund-raising, she will return to Japan next month]' *Yomiuri Newspaper*, 11 October 2002: 32.

**Yomiuri Newspaper** 2002d 'America de shinzou isyoku no Moe chan, genki ni kikoku "donor no katara ni kansya" [Moe chan who had a heart transplant in America returned to Japan with energy "I appreciate my donor"]' *Yomiuri Newspaper*, 6 November 2002: 27.

**Yomiuri Newspaper** 2003a 'Karen chan, 20ka ni kikoku America de shinzou isyoku, jutsugo junchou [Karen chan who had a heart transplant in America will return to Japan on the 20th, She is in a good condition after the operation]' *Yomiuri Newspaper*, 11 February 2003: 33.

**Yomiuri Newspaper** 2003b 'Shinzou isyoku syujutsu no Kazuki chan, ryoushin orei no chirasshi kubari JR Kusatsu ekimae de [Kazuki chan who had a heart transplant, his parents hand out message cards to express appreciation to the public, in front of JR Kusatsu station]' *Yomiuri Newspaper*, 2 June 2003: 28.

**Yomiuri Newspaper** 2003c 'Boku no new heart ha totemo tsuyoi, America de shinzou isyoku seikou, Takei Toshitaka kun ga kikoku ["My new heart is very strong", Toshitaka Takei who had successfully had a heart transplant in America returned to Japan]' *Yomiuri Newspaper*, 11 June 2003: 31.

**Yomiuri Newspaper** 2003d 'Nanbyou no Nishitani kun ga shinzou isyoku Canada de 1nen taiki teikyousya arawareru [Nishitani who had a serious disease have waited for a chance for a heart transplant in Canada for 1 year, a donor appeared]' *Yomiuri Newspaper*, 9 October 2003: 26.

**Yomiuri Newspaper** 2003e '2nenburi genki na egao, Doitsu de shinzou isyoku seikou Ishida san Nobeoka ni kikyou [Ms. Ishida who had a heart transplant in Germany returned to Nobeoka with energy after 2 years]' *Yomiuri Newspaper*, 5 December 2003: 32.

**Yomiuri Newspaper** 2004a 'Shinzou isyoku no Murakami kun, America no syouni byouin wo buji taiin [Murakami who had a heart transplant was discharged from a pediatric hospital in America without any problems]' *Yomiuri Newspaper*, 21 June 2004: 34.

**Yomiuri Newspaper** 2004b 'Doitsu de shinzou isyoku Nagahama no Fujita san tain [Fujita who is from Nagahama had a heart transplant in Germany, he was discharged from a hospital]' *Yomiuri Newspaper*, 21 July 2004: 31.

**Yomiuri Newspaper** 2004c 'Naze nihon de isyoku dekinai? [Why can't a patient receive a heart transplant in Japan?]' *Yomiuri Newspaper*, 3 September 2004: 31.

**Yomiuri Newspaper** 2005a 'America de shinzou isyoku, Kawauchi Nagano no Hira san kikoku, "Ooku no hito no okage" to egao, Keika ha ryoukou [Hira who is from Kawauchi Nagano had a heart transplant in America returned to Japan, She smiled saying "I was helped by many people", she is in a good condition]' *Yomiuri Newspaper*, 6 January 2005: 33.

**Yomiuri Newspaper** 2005b 'Nobeoka shi no Kikuchi san, shinzou isyoku syujutsu seikou, Doitsu kara haha Itoe san renraku [Mr. Kikuchi who is from Nobeoka city had a heart transplant in Germany, his mother made contact with the people who had supported fund-raising]' *Yomiuri Newspaper*, 5 March 2005: 34.

**Yomiuri Newspaper** 2005c 'America de shinzou isyoku syujutsu, Komochi mura no Misaki san tain, kongo ha tuuin chiryou e [Misaki, who is from Komochi village had a heart transplant in America, is discharged from a hospital, she will continue to have medical treatment at outpatient]' *Yomiuri Newspaper*, 11 April 2005: 31.

**Yomiuri Newspaper** 2005d 'Doitsu de shinzou isyoku noIshihara kun, rihabiri junchou raigetsucyuu no kikoku mo [Ishihara who had a heart transplant in Germany is in a good condition continuing rehabilitation, he may be able to return to Japan next month]' *Yomiuri Newspaper*, 19 April 2005: 32.

**Yomiuri Newspaper** 2005e 'Syujutsu ga seikou shinzou isyoku de tobei no Manami chan, keika mo ryoukou aki niha kikoku mo [Manami successfully had a heart transplant in America, her health condition remains in good condition, she may be able to return to Japan in autumn]' *Yomiuri Newspaper*, 21 May 2005: 26.

**Yomiuri Newspaper** 2005f 'America de shinzou isyoku, Kaita no Mizote san modotte rihabiri junchou [Mizote who is from Kaita had a heart transplant in America, he is in good condition, continuing rehabilitation after returning to Japan]' *Yomiuri Newspaper*, 8 June 2005: 29.

**Yomiuri Newspaper** 2005g 'Noushi ishoku no younin hirogaru "kazoku syoudaku nomi" sansei 50% [The number of people who agree to perform organ transplant from brain dead donors, 50% of population think that the deceased's family should make the decision to consent to organ donation from their brain dead relative]' *Yomiuri Newspaper*, 2 July 2005: 13.

**Yomiuri Newspaper** 2005h 'Murayama Shizuka san no shinzou isyoku seikou, America, jutsugo no keika mo antei [A heart transplant operation for Shizuka Murayama was successful in America, her post operation condition is stable]' *Yomiuri Newspaper*, 6 August 2005: 30.

**Yomiuri Newspaper** 2005i 'America de shinzou isyoku Aume no chu 1, Sato kun ga kikoku [Sato who is from Oume and in his first year at a secondary school returned to Japan after receiving a heart transplant in America]' *Yomiuri Newspaper*, 14 September 2005: 35.



**Yomiuri Newspaper** 2005j 'Doitsu de shinzou isyoku seikou no joji, genki ni kikoku [A girl who successfully had a heart transplant in Germany returned to Japan with invigorated]' *Yomiuri Newspaper*, 3 October 2005: 31.

**Yomiuri Newspaper** 2005k 'Shinzou isyoku de tobei Sennmoto san kikoku [Mr. Sennmoto who had a heart transplant in America will return to Japan]' *Yomiuri Newspaper*, 3 November 2005: 31.

**Yomiuri Newspaper** 2005l 'Tobei shi shinzou isyoku no Hiromi san buji kikoku fukugaku mezasu [Hiromi who had a heart transplant in America safely returned to Japan, she will start to prepare to return to a school]' *Yomiuri Newspaper*, 16 November 2005: 33.

**Yomiuri Newspaper** 2005m 'America de shinzou isyoku no Kawakami Rina chan, takusan no kata no shien ni kansya, chichioya ga houkoku [Rina Kawakami received a heart transplant in America, her father expressed his appreciation for all those who gave their support]' *Yomiuri Newspaper*, 16 December 2005: 31.

**Yomiuri Newspaper** 2006a 'Tomoki chan 22nichi ni kikoku, shinzou isyoku syujutsu de tobei [Tomoki who had a heart transplant in America is returning to Japan on the 22nd]' *Yomiuri Newspaper*, 17 January 2006: 35.

**Yomiuri Newspaper** 2006b 'America de shinzou isyoku no Hibari kun, syujutsu ga buji syuuryou [Hibari had a heart transplant, the operation went well]' *Yomiuri Newspaper*, 16 February 2006: 34.

**Yomiuri Newspaper** 2006c 'America de shinzou isyoku no Yamachika san, 6ka ni kikoku [Mr. Yamachika who had a heart transplant in America is returning to Japan on the 6th]' *Yomiuri Newspaper*, 2 March: 30.

**Yomiuri Newspaper** 2006d 'Shinzoubyou no Hazumi san iku, America de isyoku syujutsugo ni youtai kyuuhen [Hazumi passed away shortly after having a heart transplant operation in America]' *Yomiuri Newspaper*, 4 April 2006: 29.

**Yomiuri Newspaper** 2006e 'Reina san shinzou isyoku seikou, chichioya ga shien ni kansya, bokin tsunori sakunen 6gatsu tobei [Reina successfully had a heart transplant, her father expresses appreciation to people who helped raise funds to travel to America last June]' *Yomiuri Newspaper*, 26 May 2006: 31.

**Yomiuri Newspaper** 2006f 'America de shinzou isyoku, Ohtsuki no Amino san, keika junchou, raigetsu 8ka ni kikoku [Ms. Amino who is from Ohtsuki had a heart transplant in America is in a good condition, she is returning to Japan on the 8th next month]' *Yomiuri Newspaper*, 8 September 2006: 33.

**Yomiuri Newspaper** 2006g 'Shinzou isyoku ge seikou, Atsugi no Shiraishi san, tobei chokugo ni teikyou ukeru [Mr. Shiraishi who is from Atsugi city had a heart transplant shortly after arriving America]' *Yomiuri Newspaper*, 9 November 2006: 35.

**Yomiuri Newspaper** 2006h 'America de shinzou isyoku no Keita kun, syujutsu seikou [Keita had a heart transplant in America, the operation was successful]' *Yomiuri Newspaper*, 27 November 2006: 35.

**Yomiuri Newspaper** 2007a 'Mitaka no Sakura chan, America de shinzou isyoku buji

syuuryou, sudeni hokou kunrenchuu [Sakura who is from Mitaka city had a heart transplant, the operation went well, she has started walking practice]' *Yomiuri Newspaper*, 11 January 2007: 30.

**Yomiuri Newspaper** 2007b 'Kakuchougata shinkinsyou, tobei no Tezuka san, shinzou isyoku syujutsu ga seikou [Mr. Tezuka who was diagnosed with dilated cardiomyopathy successfully underwent a heart transplant in America]' *Yomiuri Newspaper*, 21 May 2007: 35.

**Yomiuri Newspaper** 2007c 'Syuri chan 5kagetsuburi kikoku "Oneechan to asobitai", Doitsu de shinzou isyoku shujutsu [Syuri chan returned to Japan after 5 months, "I want to play with my sisters", she had a heart transplant in Germany]' *Yomiuri Newspaper*, 25 June 2007: 35.

**Yomiuri Newspaper** 2007d 'America de shinzou isyoku Takkun, 4kagetsu buri ni kikoku [Takkun who had a heart transplant in America returned to Japan after 4 months]' *Yomiuri Newspaper*, 18 July 2007: 31.

**Yomiuri Newspaper** 2007e 'America de shinzou isyoku, Hiro kun egao "Tadaima!" ryoushin "sekai ichi shiawase" [Hiro kun had a heart transplant in America, Hiro kun smiles saying "I'm home!", his parents say "We are the happiest family in the world"]' *Yomiuri Newspaper*, 5 September 2007: 34.

**Yomiuri Newspaper** 2008a 'Shinzou isyoku syujutsu de tobei 7kagetsu, Haruka chan genki ni kikoku [Haruka who had gone to America to have a heart transplant 7 months ago returned to Japan]' *Yomiuri Newspaper*, 16 January 2008: 31.

**Yomiuri Newspaper** 2008b 'Nanbyou no Segawa san, Doitsu deno syujutsu seikou [Ms. Segawa who had severe heart disease had a transplant in Germany, which was successful]' *Yomiuri Newspaper*, 26 April 2008: 33.

**Yomiuri Newspaper** 2008c "'Issyou kenmei ikiru" America de shinzou isyoku no Kaneko kun, egao no kikoku ["I'll do my best for the rest of my life" Mr. Kaneko who had a heart transplant returned to Japan with invigorated]' *Yomiuri Newspaper*, 4 June 2008: 31.

**Yomiuri Newspaper** 2008d 'America de isyoku syujutsu no Uno san kikoku "Minasan no sasae ni kansha" [Mr. Uno who had had a heart transplant in America returned to Japan "I appreciate people's support"]' *Yomiuri Newspaper*. 28 August 2008: 27.

**Yomiuri Newspaper** 2008e 'America de shinzou isyoku syujutsu Kyouusuke kun, 28nichi kikoku [Kyouusuke who had a heart transplant will return to Japan on the 28th]' *Yomiuri Newspaper*, 19 September 2008: 28.

**Yomiuri Newspaper** 2008f '15 sau miman no noushi zouki isyoku, tobei syuzjutsu, haha ga kurou kataru, kyou cyuouku de taikai [Organ transplant from a brain dead donor, a mother whose child had a transplant in America talks about her arduous experience]' *Yomiuri Newspaper*, 28 October 2008: 31.

**Yomiuri Newspaper** 2009 'Noushi ha Hito no Shi' Seiritsu, Kaisei Zoki Isyokuhou, Nenrei Seigen Teppai / Sanin ('Death is defined by brain death', Amended the Organ Transplant Law, age restraints regarding brain death is abolished / The House of Councillors)' *Yomiuri Newspaper*, 13 July 2009: 1.

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## Appendix 1 The number of worldwide heart transplants

	1980	1981	1982	1983	1984	1985	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995
Japan	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
US	-	62	103	185	363	749	1,413	1,487	1,750	1,772	2,159	2,178	2,218	2,357	2,411	2,432
Eurotransplant *1	-	3	7	29	65	121	260	393	438	538	706	832	785	801	741	774
France	10	18	20	38	77	147	302	493	601	700	722	703	618	571	466	430
UK	1	2	3	9	37	156	225	290	342	357	374	317	348	323	338	348
Scandia Transplant *2	-	0	0	1	8	17	29	22	64	79	79	102	103	122	119	106
U.A.E	-	-	-	-	-	-	-	-	-	0	0	0	0	0	0	0
India	-	-	-	-	-	-	-	-	-	0	0	0	0	0	0	4
Indonesia	-	-	-	-	-	-	-	-	-	-	-	0	0	0	0	0
Oman	-	-	-	-	-	-	-	-	-	0	0	0	0	0	0	0
Korea	-	-	-	-	-	-	-	-	-	0	0	0	1	1	26	21
Saudi Arabia	-	-	-	-	-	-	-	-	-	-	-	5	6	-	-	-
Singapore	-	-	-	-	-	-	-	-	-	0	1	5	1	2	3	-
Thailand	-	-	-	-	-	-	-	-	-	14	15	6	12	-	-	13
Taiwan	-	-	-	-	-	-	-	-	-	0	0	0	2	37	31	24
China	-	-	-	-	-	-	-	-	-	0	0	0	0	2	2	2
Pakistan	-	-	-	-	-	-	-	-	-	0	0	0	0	0	0	0
Bangladesh	-	-	-	-	-	-	-	-	-	0	0	0	0	0	0	0
The Philippines	-	-	-	-	-	-	-	-	-	0	0	0	1	0	0	0
Hong Kong	-	-	-	-	-	-	-	-	-	0	0	0	1	0	1	4
Malaysia	-	-	-	-	-	-	-	-	-	0	0	0	0	0	0	0
Bahrain	-	-	-	-	-	-	-	-	-	-	-	0	0	0	0	0
Qatar	-	-	-	-	-	-	-	-	-	-	-	0	0	0	0	0
Total	11	85	133	262	550	1190	2229	2685	3195	3460	4056	4148	4096	4216	4138	4158

(Sources: Transplant Communication, 2009a; 2009b; The Japan Society for Transplantation Publicity Committee, 2010; United Network for Organ Sharing, 2011b; Organ Donation and Transplantation, 2011b; Eurotransplant, 2011a; 2011b; 2011c; Scandinavian Transplant, 2011)

\*1 Austria, Belgium, Luxembourg, Netherlands, Germany. Including Slovenia since 2000

\*2 Denmark, Finland, Iceland, Norway, Sweden

	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Japan	0	0	0	3	3	6	5	0	5	7	10	10	11	7	23
US	2,382	2,355	2,395	2,239	2,247	2,229	2,188	2,086	2,055	2,160	2,224	2,240	2,190	2,241	2374
Eurotransplant *1	794	825	779	737	644	598	604	593	572	564	587	598	579	572	630
France	424	391	397	349	353	342	339	299	339	360	380	386	379	-	-
UK	305	288	312	276	237	198	174	163	180	148	162	137	133	-	-
Scandia Transplant *2	155	109	118	110	94	102	95	134	110	88	117	83	123	123	-
U.A.E	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-
India	7	2	22	14	1	2	0	-	-	-	-	-	-	-	-
Indonesia	0	0	0	0	0	0	-	-	0	0	-	-	-	-	-
Oman	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-
Korea	20	29	30	28	14	21	10	15	23	26	-	-	-	-	-
Saudi Arabia	5	5	4	6	3	3	2	5	4	8	-	-	-	-	-
Singapore	0	1	1	5	1	2	2	0	-	-	-	-	-	-	-
Thailand	7	14	5	3	3	5	5	5	-	-	-	-	-	-	-
Taiwan	41	66	54	41	43	52	28	68	-	-	-	-	-	-	-
China	1	7	12	15	26	-	-	-	-	-	-	-	-	-	-
Pakistan	0	0	0	0	0	0	0	0	0	0	-	-	-	-	-
Bangladesh	0	0	0	0	0	0	0	0	0	0	-	-	-	-	-
The Philippines	0	0	0	0	0	0	0	0	-	-	-	-	-	-	-
Hong Kong	3	7	2	6	6	10	11	5	7	8	-	-	-	-	-
Malaysia	0	1	3	2	3	4	0	2	-	-	-	-	-	-	-
Bahrain	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Qatar	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Total	4144	4100	4134	3834	3678	3574	3463	3375	3295	3369	3480	3454	3415	2943	3027

(Sources: Transplant Communication, 2009a; 2009b; The Japan Society for Transplantation Publicity Committee, 2010; United Network for Organ Sharing, 2011b; Organ Donation and Transplantation, 2011b; Eurotransplant, 2011a; 2011b; 2011c; Scandinavian Transplant, 2011)

\*1 Austria, Belgium, Luxembourg, Netherlands, Germany. Including Slovenia since 2000

\*2 Denmark, Finland, Iceland, Norway, Sweden

The data in the table includes heart-lung transplant operations. Japanese patients who went abroad are recorded in respect country where they received the operation. Regarding the data of the UK, year of 2005 is from April 2005 to March 2006, 2006 is from April 2006 to March 2007 and 2007 is from April 2007 to March 2008. Blank space means either 'no answer' or 'unknown'.

Transplant Communication (2009a; 2009b) collected the data of the number of heart(-lung) transplant recipients from JOT, UNOS, Eurotransplant, Agence de la biomedicine, UK transplant, Scandia Transplant. Regarding the data of other Asian countries, Medical Information Network Society referenced the data released by Novartis Pharma K.K (1989 and 1990; from 1993 to 1995), the 16<sup>th</sup> International Congress of The Transplantation Society (from 1991 to 1995), the 17<sup>th</sup> International Congress of The Transplantation Society (1993 and 1994), the 18<sup>th</sup> International Congress of The Transplant Society (from 1995 to 1999), and the 7<sup>th</sup> Congress of the Asian Society of Transplantation (from 1996 to 2000).

## Appendix 2 List of Japanese heart transplant recipients abroad between 1984 and 2008

No	Initial	Gender	Age of transplant	Hospital to have a heart transplant	Country	Date of Surgery	Payment	Reference
1	T. M	M	41	Stanford University	US	1984.05.05	Fund-raising	Data from Dr. Sono <sup>32</sup>
2	S. I	F	6	Harefield Hospital	UK	1988.10.04	Self-funded	
3	K. N	F	43	Harefield Hospital	UK	1989.10.31	Fund-raising	
4	Y. M	M	40	Harefield Hospital	UK	1990.05.31	Self-funded	
5	T. H	M	11	Harefield Hospital	UK	1990.07.20	Self-funded	
6	R. A	M	17	Harefield Hospital	UK	1990.08.13	Self-funded	
7	S. K	F	39	Harefield Hospital	UK	1990.11.11	Fund-raising	
8	K. M	M	13	Harefield Hospital	UK	1991.01.15	Self-funded	
9	M. K	F	7	University of Utah	US	1991.07.25	Fund-raising	
10	K. H	M	1	University of Utah	US	1992.07.24	Fund-raising	
11	M. O	M	18	Texas Heart Institute	US	1992.10.22	Fund-raising	
12	Y. Y	M	48	UCLA	US	1993.03.03	Self-funded	
13	H. K	M	23	UCLA	US	1993.07.23	Fund-raising	
14	N. M	M	32	University of Utah	US	1993.08.01	Self-funded	
15	A. K	F	8	German Heart Center	Germany	1994.03.19	Fund raising	
16	Y. S	F	10	University of Utah	US	1994.06.05	Fund raising	
17	D. S	M	1	UCLA	US	1994.08.08	Self-funded	
18	M. S	M	36	University of Utah	US	1994.08.15	Self-funded	
19	M. A	M	43	Sharp Anniversary Hospital	US	1994.11.10	Fund raising	
20	A. W	F	17	UCLA	US	1995.02.24	Fund raising	
21	A. M	M	23	UCLA	US	1995.05.05	Fund raising	
22	Y. N	M	19	Pittsburgh University Hospital	US	1995.05.13	Fund raising	
23	K. T	M	11	University of Utah	US	1995.05.29	Self-funded	
24	T. T	M	39	St Vincent Hospital	France	1995.06.01	Self-funded	
25	A. K	M	46	German Heart Center	Germany	1995.07.15	Fund-raising	
26	K. H	M	20	UCLA	US	1995.09.07	Fund-raising	
27	K. M	M	46	Texas Heart Institute	US	1995.11.03	Self-funded	
28	K. A	F	9	University of Utah	US	1995.12.06	Self-funded	
29	K. T	M	56	Sharp Anniversary Hospital	US	1996.02.15	Self-funded	
30	H. H	M	36	UCLA	US	1996.03.15	Fund raising	
31	Y. H	M	29	UCLA	US	1996.10.17	-	
32	M. S	M	6	UCLA	US	1996.11.05 1996.12 (Second transplant)	Fund raising	
33	K. N	M	30	UCLA	US	1997.03.02	Fund raising	
34	T. S	M	47	University of Utah	US	1997.06.06	-	
35	Y. M	M	44	UCLA	US	1997.10.07	-	
36	-	F	1	-	US	1997.10	-	
37	-	M	30	University of Utah	US	1997.11	Fund-raising	
38	R. H	F	1	UCLA	US	1997.12	Fund-raising	
39	T. S	M	3	Children's Hospital of Denver	US	1998.03	Fund-raising	
40	S. O	M	20	NRW Herz und Diabetes zentrum	Germany	1998.06.28	Fund-raising	
41	H. Y	F	5	Loma Linda University Children's Hospital	US	1998.07	Fund-raising	
42	T. F	M	48	Pittsburgh University Hospital	US	1998.08.27	Fund-raising	

<sup>32</sup> I received the data from Dr Sono on the 2<sup>nd</sup> of December when I interviewed him.

43	I. N	M	16	Cleveland Clinic	US	1998. 10	Fund-raising	Yomiuri (2001.12.15, p.32)
44	R. E	F	1	UCLA	US	1998. 10. 22	Fund-raising	Yomiuri (1998.10.23 p.38)
45	-	M	3	-	US	1999. 02	-	An experience of Batista operation (2004)
46	K.S	F	5	University of Utah	US	1999. 08. 18	Fund-raising	An experience of Batista operation (2004)
47	H.T	M	1	UCLA	US	1999. 08. 21	Fund-raising	Yomiuri (2000.1.19 p.30)
48	R.S	M	14	Texas Heart Institute	US	1999. 09. 03	Fund-raising	Yomiuri (1999.10.5 p.15) Ryoukun wo sukuu kai (1999)
49	T.M	M	46	UCLA	US	2000. 01. 08	Fund-raising	Yomiuri (2000.1.18 p.29)
50	S.S	F	18	UCLA	US	2000. 05. 31	Fund-raising	Yomiuri (2000.7.4 p.32)
51	A.T	M	4	Loma Linda University Children's Hospital	US	2000. 06. 21	Fund-raising	Yomiuri (2000.7.11 p.37)
52	T.Y	M	12	UCLA	US	2000. 06. 24	Fund-raising	An experience of Batista operation (2004)
53	H.T	F	8	NRW Herz und Diabetes zentrum	Germany	2000. 07. 15	Fund-raising	An experience of Batista operation (2004)
54	A.M	F	4	Children's Hospital of Denver	US	2000. 08. 10	Fund-raising	Yomiuri (2001.2.15 p.31)
55	-	F	3	-	US	2000	-	An experience of Batista operation (2004)
56	T.Y	M	12	UCLA	US	2000	Fund-raising	Yomiuri (2001.3.23 p.32)
57	M.F	F	9	UCLA	US	2000. 09. 14	Fund-raising	Yomiuri (2001.9.8 p.31)
58	T.H	M	1	Columbia University Hospital	US	2001.03. 31	Fund-raising	Yomiuri (2001.10.4 p.34)
59	T.M	M	2	UCLA	US	2001. 04. 10	Fund-raising	Yomiuri (2001.4.11 p.31)
60	Y.H	F	1	Children's Hospital Los Angels	US	2001. 05. 01	Fund-raising	Yomiuri (2001.9.27 p.38)
61	T.S	M	56	UCLA	US	2001. 08. 24	Fund-raising	Yomiuri ( 2001.10.31 p.38)
62	Y.A	M	52	UCLA	US	2001. 06. 11	Fund-raising	Yomiuri (2001.10.10 p.30)
63	S.N	M	19	UCLA	US	2001. 10. 11	Fund-raising	Yomiuri (2002.1.9 p.30)

64	-	M	46	-	-	2001	-	An experience of Batista operation (2004)
65	T.I	-	28	-	-	2001	-	An experience of Batista operation (2004)
66	M.S	F	16	Children's Hospital of Denver	US	2002. 03	Fund-raising	Yomiuri (2002.10.8 p.32)
67	K.T	F	4	Loma Linda University Children's Hospital	US	2002. 06. 23	Fund-raising	Yomiuri (2003.2.11 p.33)
68	H.Y	M	1	UCLA	US	2002. 07. 11	Fund-raising	Yomiuri (2002.10.11 p.32)
69	T.T	M	19	UCLA	US	2002. 10. 04	Fund-raising	Yomiuri (2003.6.11 p.31)
70	K.K	M	1	Loma Linda University Children's Hospital	US	2002. 10. 31	Fund-raising	Yomiuri (2003.6.2. p.28)
71	M.F	F	2	Southern California University Children's Hospital	US	2002. 07. 18	Fund-raising	Yomiuri (2002.11.6 p.27)
72	-	F	-	-	US	2002	Fund-raising	Yomiuri (2008.10.28 p.31)
73	-	M	43	UCLA	US	2003. 01. 11	-	An experience of Batista operation (2004)
74	E.I	F	18	NRW Herz und Diabetes zentrum	Germany	2003. 08. 13	Fund-raising	Yomiuri (2003.12.05 p.32)
75	N.N	M	15	The Hospital for Sick Children	Canada	2003. 10. 08	Fund-raising	Yomiuri (2003.10.9 p. 26)
76	S.A	-	49	-	US	2003. 10. 13	-	An experience of Batista operation (2004)
77	S.T	F	24	Stanford University Hospital	US	2003. 11. 22	Fund-raising	An experience of Batista operation (2004)
78	-	-	-	-	-	-	-	The Japan Society for Transplantation Publicity Committee (2010)
79	-	-	-	-	-	-	-	The Japan Society for Transplantation Publicity Committee (2010)
80	M.M	F	1	Loma Linda University Children's Hospital	US	2004. 02. 24	Fund-raising	An experience of Batista operation (2004)
81	Y.O	F	17	UCLA	US	2004. 05. 23	Fund-raising	An experience of Batista operation (2004)



82	T.M	M	13	Children's Hospital of Denver	US	2004. 05. 15	Fund-raising	An experience of Batista operation (2004)
83	S.F	M	34	NRW Herz und Diabetes zentrum	Germany	2004. 06. 05	Fund-raising	Yomiuri (2004.7.21 p.31)
84	-	M	13	Children's Hospital of Denver	US	2004. 06	Fund-raising	Yomiuri (2004.6.21 p.34)
85	H.F	F	4	Columbia University Hospital	US	2004. 06. 24	-	An experience of Batista operation (2004)
86	M.H	F	37	UCLA	US	2004. 07. 31	Fund-raising	Yomiuri (2005.1.6 p.33)
87	S.Y	-	-	-	US	2004. 08	-	An experience of Batista operation (2004)
88	K.Y	M	37	-	US	2004	-	An experience of Batista operation (2004)
89	Y.M	M	32	-	US	2005. 02. 16	Fund-raising	Yomiuri (2005.6.8 p.29)
90	S.K	M	37	NRW Herz und Diabetes zentrum	Germany	2005. 03. 03	Fund-raising	Yomiuri (2005.3.5 p.34)
91		M	12	Children's Hospital of Denver	US	2005. 03. 17	Fund-raising	Yomiuri (2005.9.14 p.35)
92	M.C	F	14	Oregon Health and Science University	US	2005. 03. 22	Fund-raising	Yomiuri (2005.4.11 p. 31)
93	H.I	M	13	NRW Herz und Diabetes zentrum	Germany	2005. 04. 10	Fund-raising	Yomiuri (2005.4.19 p.32)
94	M.T	F	7	UCLA	US	2005. 05. 19	Fund-raising	Yomiuri (2005.5.21 p.26)
95	-	M	-	-	US	2005	-	The Japan Society for Transplantation Publicity Committee (2010)
96	M.S	M	53	University of Utah	US	2005. 05. 10	Fund-raising	Yomiuri (2005.11.3 p.31)
97	M.I	F	8	-	Germany	2005. 06. 25	Fund-raising	Yomiuri (2005.10.3 p.38)
98	R.K	F	3	UCLA	US	2005. 06. 29	Fund-raising	Yomiuri (2005.12.16 p.31)
99	A.T	F	18	Arkansas Children's Hospital	US	2005	-	Yomiuri (2005.11.16 p.33)
100	H.H	F	17	UCLA	US	2005. 08. 04	Fund-raising	Interviewed / Yomiuri (2005.11.16 p.33)
101	S.M	F	15	Columbia University Hospital	US	2005. 08. 05	Fund-raising	Yomiuri (2005.8.6 p.30)
102	N.Y	M	26	UCLA	US	2005, 09, 22	Fund-raising	Yomiuri (2006.3.2 p.30)

103	T. I	M	6	Arkansas Children's Hospital	US	2005. 12. 22	Fund-raising	Yomiuri (2006.1.17 p.35)
104	H.U	M	14	-	US	2006. 02.14	Fund-raising	Yomiuri (2006.2.16 p.34)
105	H.I	M	20	Washington University Hospital	US	2006. 04. 02	Fund-raising	Yomiuri (2006.4.4 p.29)
106	T. A	F	45	University of Utah	US	2006. 04	Fund-raising	Yomiuri (2006.9.8 p.33)
107	R.S	F	10	Harper University Hospital	US	2006. 05. 22	Fund-raising	Yomiuri (2006.5.26 p.31)
108	-	-	-	-	-	-	-	The Japan Society for Transplantation Publicity Committee (2010)
109	E.S	M	22	Oregon State University Hospital	US	2006. 11. 06	Fund-raising	Yomiuri (2006.11.9 p.35)
110	K. M	M	1	Columbus Children's Hospital	US	2006. 11. 21	Fund-raising	Yomiuri (2006.11.27 p.35)
111	S.U	F	4	Loma Linda University Children's Hospital	US	2007. 01. 05	Fund-raising	Yomiuri (2007.1.11 p.30)
112	H.A	M	3	Columbia University Hospital	US	2007. 02. 24	Fund-raising	Yomiuri (2007.9.5 p. 34)
113	S.A	F	3	Heart Center North Rhine-Westphalia	Germany	2007. 03. 20	Fund-raising	Interviewed the recipient's mother / Yomiuri (2007.6.25 p.35)
114	T.M	M	13	Chicago University Hospital	US	2007. 04. 19	Fund-raising	Yomiuri (2007.7.18 p. 31)
115	Y. T	M	43	UCLA	US	2007. 05. 19	Fund-raising	Yomiuri (2007.5.21 p.35)
116	H.I	F	4	Loma Linda University Children's Hospital	US	2007. 06. 14	Fund-raising	Yomiuri (2008.1.6 p.31)
117	M.H	F	21	Pittsburgh University Hospital	US	2007. 08. 01	-	Yomiuri (2008. 9.19 p.28)
118	K.O	M	25	NRW Herz und Diabetes zentrum	Germany	2007. 08. 10	Fund-raising	Interviewed
119	T.Y	-	50	UCLA	US	2007. 12. 03	-	Yomiuri (2008. 9.19 p.28)
120	S.S	M	38	UCLA	US	2008. 01. 09	Self-funded	Interviewed
121	K.K	F	17	NRW Herz und Diabetes zentrum	Germany	2008. 01. 18	Fund-raising	Interviewed
122	-	M	5	-	US	2008. 02	Fund-raising	Yomiuri (2008. 9.19 p.28)
123	R.K	M	10	UCLA	US	2008. 03. 04	Fund-raising	Yomiuri (2008.6.4 p.31)
124	M.S	F	46	NRW Herz und Diabetes zentrum	Germany	2008. 04. 24	Fund-raising	Interviewed / Yomiuri (2008.4.26 p.33)
125	M.I	F	6	Arkansas Children's Hospital	US	2008. 07. 03	Fund-raising	Yomiuri (2008.8.28 p.27)
126	J.U	M	22	Pittsburgh University Hospital	US	2008. 07. 07	Fund-raising	Interviewed

127	M.O	F	30	NRW Herz und Diabetes zentrum	Germany	2008. 10. 13	Fund-raising	Interviewed / Yomiuri (2008.8.28 p.27)
128	-	-	-	-	-	2008	-	The Japan Society for Transplantatio n Publicity Committee (2010)

## **Appendix 3 Interview guide and questions for heart transplant recipients**

### **Questions for the interview (heart transplant recipients):**

#### **(1) Could you describe the circumstances surrounding your need to undergo heart transplantation?**

- Can you tell me what heart transplantation is and what the procedure involves?
- Can you tell me, during the period immediately afterwards when recovering from the operation...
  - ...who was with you?
  - ...who did you meet?
  - ...what were these people like?
  - ...what did they do?
  - ...what did they say?
  - ...how did they make you feel about yourself?
- Did you have any worries or fears regarding the procedure for heart transplantation?
- What kind of expectations did you have for this procedure?
- Did you have opportunities to share these concerns and expectations with someone, like your doctor, your family, or anyone else? What were their responses? What did they say? What did you think about their response?
- How did you gather information about heart transplantation? Did anybody help you to gather the information? Who helped you?

#### **(2) Could you talk about how your life has changed after heart transplantation?**

- What were the challenges such as worries, fears and difficulties you faced in resuming your routine after the procedure?
- How has the operation influenced your life?
- How often do you undergo medical check-ups after the operation?
- I assume that you regularly go to the check-ups. Have you got to know other recipients, and have you made friends with other recipients and doctors?
- Have you discussed these issues with your doctor, family members, or anyone else?
- How have other people responded to the fact that you have had a heart transplant? Is it something that everyone knows about, or just some people?
- Do you know anyone else who has had a heart transplant? How does your experience compare with their experiences?
- What are your views about the way the Japanese media, politicians, and doctors treat the topic of transplantation?

#### **(3) Could you tell me your opinion on heart transplantation?**

- Have your impressions about the heart transplantation procedure changed?
- What do you think needs to be done for heart transplantation to become more socially accepted as a treatment?
- Do you think that reciprocal gift-exchange influences the idea of organ transplantation?
- What sort of impressions do you have about an idea that an organ transmits the donor's memory to the recipient?
- How has your attitude towards heart transplantation changed since undergoing the

procedure?

- How do you perceive the heart? Some say that the heart is merely a mechanism that pumps blood, while others say that the mind inhabits in the heart. What, according to you, does the heart mean in Japanese culture?

**(4) Is there anything else you would like to say that has not been covered in today's interview?**

**Questions for the interview (liver and lung transplant recipients):**

**(1) Could you describe the circumstances surrounding your need to undergo organ transplantation?**

- Can you tell me what organ transplantation is and what the procedure involves?
- Can you tell me, during the period immediately afterwards when recovering from the operation ...

...who was with you?

...who did you meet?

...what were these people like?

...what did they do?

...what did they say?

...how did you feel with them?

- Did you have any worries or fears regarding the procedure for organ transplantation?
- What kind of expectations did you have for this procedure?
- Did you have opportunities to share these concerns and expectations with someone, like your doctor, your family, or anyone else? What were their responses? What did they say? What did you think about their response?
- How did you gather information about organ transplantation? Did anybody help you to gather the information? Who helped you?

**(2) Could you talk about how your life has changed after organ transplantation?**

- What were the challenges such as worries, fears and difficulties you faced in resuming your routine after the procedure?
- How has the operation influenced your life?
- How often do you undergo medical check-ups after the operation?
- I assume that you regularly go to the check-ups. Have you got to know other recipients, and have you made friends with other recipients and doctors?
- Have you discussed these issues with your doctor, family members, or anyone else?
- How have other people responded to the fact that you have had an organ transplant? Is it something that everyone knows about or just some people?
- Do you know anyone else who has had an organ transplant? How does your experience compare with their experiences?
- What are your views about the way the Japanese media, politicians, and doctors treat the topic of transplantation?

**(3) Could you tell me your opinion on organ transplantation?**

- Have your impressions about the organ transplantation procedure changed?
- What do you think needs to be done for organ transplantation to become more socially accepted as a treatment?
- Do you think that the reciprocal gift-exchange influences the idea of organ transplantation?
- What sort of impressions do you have about an idea that an organ transmits the donor's memory to the recipient?

- How has your attitude towards organ transplantation changed since undergoing the procedure?
- How do you perceive the transplanted organ?

**(4) Is there anything else you would like to say that has not been covered in today's interview?**

**Questions for the interview (doctors):**

- (1) Could you let me know how did you choose to be a transplant doctor?**
- (2) Could you tell me your opinion on a situation surrounding Japanese organ transplant recipients from a brain dead donor?**
- (3) What do you think about the discussion of heart transplantation in Japan?**
- (4) Is there anything else you would like to say that has not been covered in today's interview?**

## **Appendix 4 Information sheet (Original was written in Japanese)**



**Barts and The London**  
School of Medicine and Dentistry

### **Heart transplantation: its risks, the expectations, and cultural negotiation in Japan**

**Queen Mary, Ethical Committee Ref: QMREC2009/65**

Thank you for agreeing to respond to interview. Prior to the interview, please confirm the following points.

- (1) I intend to write a thesis for my PhD project. The interview is for the project.
- (2) My research aims to uncover the influence of Japanese culture on patients who have undergone heart transplantation. This is important to understand the actual recipients' experiences to consider the future planning of heart transplantation.
- (3) I am going to record the interview using IC recorder.
- (4) Records of the interview will remain confidential, in my custody, and be used only for the purposes of my study.
- (5) All information identifying an individual was taken from interview transcripts.
- (6) The interview data will be translated from Japanese to English by a research in the thesis.

If you have any questions, please feel free to ask now. Whenever you would like to stop the interview, you can always leave the interview.

Interviewer: Ikuko Tomomatsu  
PhD student  
Centre for Health Sciences  
Institute of Health Sciences Education  
Barts and The London  
Queen Mary's School of Medicine and Dentistry  
University of London  
Abernethy Building  
2 Newark Street

## Appendix 5 Profile of participants

### A list of interviewees of heart transplant recipients

	Name of initial	Gender	Marital status	Current age	Age of transplant	Date of surgery	Hospital /	Country	Funding	Residence
1	M. K	F	Single	25	7	91, 07, 26 (LOCAL:25)	University of Utah	US	Fund-raising	Yamanashi
2	M. O	M	Single	35	18	92, 10, 23 (LOCAL:22)	Texas Heart Institute	US	Fund-raising	Osaka
3	K. H	M	Single	34	20	95, 09, 07 (LOCAL:6)	UCLA	US	Fund-raising	Chiba
4	T. K	M	Single	26	11	95, 05, 28	University of Utah	US	Self-funding	Chiba
5	K. M	M	Married	60	46	95, 11, 03	Texas Heart Institute	US	Self-funding	Hiroshima
6	A. K	F	Single	23	8	95, 12, 06	University of Utah	US	Self-funding	Chiba
7	K. T	M	Married	69	56	96, 02, 15	Sharp Anniversary Hospital	US	Self-funding	Hyogo
8	K. K	F	Single	20	17	08, 01, 18	NRW Herz und Diabetes zentrum	Germany	Fund-raising	Fukuoka
9	T. O	M	Married	58	50	01, 02, 26	Osaka University Hospital	Japan	Self-funding	Osaka
10	A. H	M	Single	30	25	05, 02, 16	Kyushu University Hospital	Japan	Self-funding	Fukuoka
11	H. H	F	Single	22	17	05, 08, 04	UCLA	US	Fund-raising	Tokyo
12	H. N	M	Married	54	50	06, 03, 25	Kyushu University Hospital	Japan	Self-funding	Fukuoka
13	K. O	M	Single	28	25	07, 08, 10	NRW Herz und Diabetes zentrum	Germany	Fund-raising	Osaka
14	S. S	F	Married	40	38	08, 01, 09	UCLA	US	Self-funding	Saitama
15	M. S	F	Married	48	46	08, 04, 24	NRW Herz und Diabetes zentrum	Germany	Fund-raising	Chiba
16	T. H	M	Married	59	57	08, 05, 14	Kyushu University Hospital	Japan	Self-funding	Oita
17	J. U	M	Single	24	22	08, 07, 07	University of Pittsburgh Medical Center	US	Fund-raising	Fukuoka
18	M. O	F	Married	32	30	08, 10, 13	NRW Herz und Diabetes zentrum	Germany	Fund-raising	Akita
19*	M. W	M	Single	35	35	09, 01	Osaka University Hospital	Japan	Self-funding	Osaka

\* Heart-lung transplant recipient



## A list of interviewees of family member of heart transplant recipients

	Name of initial	Gender	Relationship with a heart recipient	Hospital	/	Country	Funding	Living place
1*	M. K	M	Father	University of Utah		US	Self-funding	Saitama
2	M. T	F	Wife	Sharp Anniversary Hospital		US	Self-funding	Hyogo
3	M.M	F	Wife	Texas Heart Institute		US	Self-funding	Hiroshima
4	M. K	F	Mother	University of Utah		US	Fund-raising	Yamanashi
5	K. H	F	Mother	University of Utah		US	Fund-raising	Kanagawa
6	M. O	F	Wife	Osaka University Hospital		Japan	Self-funding	Osaka
7	N. F	F	Fiancé	Osaka University Hospital		Japan	Self-funding	Osaka
8	I. S	F	Wife	UCLA		US	Self-funding	Saitama
9	T.O	F	Husband	NRW Herz und Diabetes zentrum		Germany	Fund-raising	Akita
10	N. N	F	Mother	Loma Linda University Medical Center		US	Fund-raising	Kanagawa
11	M. K	M	Father	UCLA		US	Self-funding	Chiba
12	C. A	F	Mother	NRW Herz und Diabetes zentrum		Germany	Fund-raising	Saitama
13	H. K	F	Mother	NRW Herz und Diabetes zentrum		Germany	Fund-raising	Fukuoka
14	S. H	F	Mother	Kyusyu University Hospital		Japan	Self-funding	Fukuoka

\* This person is a member of a patient support organisation.

## A list of interviewees of doctors

	Name	Gender	Hospital
1	Sono, J.	M	Kobe City Hospital *
2	Fukushima, N.	M	Osaka University Hospital
3	Minami, K.	M	Japan University
4	Kyo, S.	M	University of Tokyo

\* This doctor is retired as a surgeon, and currently a director of Nishinomiya City Health Center

## A list of interviewees of people from patient support group

	Name	Gender	Organisation	Additional information
1	Okubo, M.	M	The Japan Transplant Recipient Organisation	Kidney transplant recipient
2	Kenmoku, M.	M	New Heart Club	His two children had heart transplants in the US
3	Aranami, Y.	M	TRIO Japan	His daughter did not take the chance of liver transplant abroad for his daughter

## A list of interviewees of journalists

	Name	Gender	Organisation
1	Asai, M.	M	Asashi Newspaper
2	Onishi, M.	M	Yomiuri Newspaper
3	Maemura, S.	M	Nikkei Newspaper

### A list of interviewees of other organ transplant recipients

	Name of initial	Gender	Marital status	Current age	Age of transplant	Date of surgery/ Organ	Hospital /	Country	Funding	Residence
1	R. W	F	Married	38	30	02, 08, 30/ Lung	University of Kyoto Jackson Memorial Hospital, University of Miami	Japan	Self-funding	Aichi
2	K. I	M	Married	66	64	08, 04, 09/ Liver	Jackson Memorial Hospital, University of Miami	US	Self-funding	Osaka

### A list of interviewees of family member of other organ transplant recipients

	Name of initial	Gender	Relationship with a heart recipient	Hospital /	Country	Funding	Living place
1	Y. I	F	Daughter	Jackson Memorial Hospital, University of Miami	US	Self-funding	Tokyo
2	K. I	F	Wife	Jackson Memorial Hospital, University of Miami	US	Self-funding	Osaka

### A list of other interviewees

	Name of initial	Gender	Status
1	M.A	M	Working at a pharmaceutical company
2	Y. M	F	Donor family

## Appendix 6 Coding Sample

### Pre-operational experiences

Main code	Sub code	Sample
Master status	-	Some worried about my situation with a hose. However, my close friends didn't refer to my heart disease. They talked to me same as before. I was very glad with their attitudes. I didn't want to be treated as a diseased person. For example, one said "pass the cup to me." This means that this friend treated me as if I was not a diseased person. I felt that I was still with them same as before. (Mr. Uchida)
Information control	Information disclosure	At that time, we did not understand well about a heart transplant, and my parents did not, either. Once we (I and my husband) made the decision to receive a heart transplant and told the decision to both parents, they began to support us. (Mrs. Makabe)
	Dissemination of recipients' feelings	If I have a negative feeling, usually I can't hide the feeling. My family members, in particular my mother and my husband, easily read the negative feeling from my face. I tried not to express the negative feeling to them. However, I think that I sometimes took out my frustration on my husband. (Mrs. Okamoto)
	Gathering and sharing information about medical treatment	In my life, I haven't thought about my condition of having a heart transplant as unique or extraordinary, because I have had this heart disease since childhood. Taking medicine, having a machine inside of my body, experiencing surgeries... all of them are ordinary matters for me. Therefore, I have talked about these experiences to my friends without hesitation. (Ms. Kasai)
Communication	The Own	<p>Mr. Ozaki [another heart transplant recipient who had the transplant in the US before Mr. Makabe] visited me when I was hospitalised. He told me how his health condition improved after having a heart transplant. ... By seeing him and talking to him, I understood how I could recover from the heart disease by having a heart transplant. ... At that time, I hardly moved on the bed in a hospital, had problems even breathing and was connected to many tubes. It was about 2 weeks before flying to the US. Seeing him encouraged me a lot. (Mr. Makabe)</p> <p>I had an opportunity to meet a heart transplant recipient when I was hospitalised in Japan. He told me that I would be able to lead a normal life after heart transplant surgery, although I would need to keep taking medicine for the rest of my life. Even though he explained to me how a heart transplant would improve my life, I could not easily be positive about receiving a heart transplant. However, through the conversation with him, I gradually began to feel positive about receiving a heart transplant. Finally, I felt that I wanted to recover from my illness for my children. (Mrs. Seki)</p>
	The Wise	Prior to leaving for Germany, two of my friends came to see me and told me, 'other friends are doing everything they can to help you. We have decided not to do anything for you. We're really sorry about this. However, you might have some complains that you cannot express easily to other people. You can express such feelings to us whenever you need to. We want to be your friends; therefore, we won't give you any funds.' When they told me so, I didn't understand why they told me like that. However, I appreciate that they didn't help the fund-raising for me. (Mr. Oda)
	The Public	I began to receive letters and e-mails from people who watched me on TV. For example, a person wrote to me "knowing about you, I felt my concern seemed very small, therefore, I'll do my best in life." I received many other similar messages a lot. I was surprised that I was told "thank you" by someone else, because I was hospitalised. (Mr. Uchida)

		<p>I knew that there were many Japanese patients who needed heart transplants. If I received a heart transplant abroad, I would recover from my heart disease. However, I also knew that, in Japan, the situation regarding Japanese patients with heart disease must change. Therefore, I decided not to go abroad, but to stay in Japan waiting for a chance at a heart transplant, and to do anything I could to improve the circumstances surrounding heart transplants in Japan. I explained my feelings to my mother and neighbours. They helped me to share this idea with the public. (Ms Kasai)</p>
	Social pressure	<p>Imagining that people are in the street to ask the public people for fundraising to have a heart transplant abroad for me, I felt ashamed and miserable at the thought of fund-raisers in the street asking the public for money so I could have a heart transplant abroad for me. I saw them on the TV news and felt even more miserable. I took my frustration out on my parents, and I told them, “I don’t need help like that.” (Mr. Oda)</p> <p>My diagnosis was that the only way I could survive was with a heart transplant. Since I was only fourteen years old, I could not get a heart transplant in Japan. Therefore, people around me urged me to go abroad for a heart transplant. However, I wanted to work for a future in which I could receive a heart transplant in Japan by changing the legal system. (Ms Kasai)</p>
Stigma	Felt stigma	<p>I felt that I had to return people’s support. This is a common feeling among patients who have raised funds for their transplant. I felt this way, too. During two years, I rehearsed in my mind simulations of how I would repay people. Although they had helped me financially to get a heart transplant abroad, I began to fear that I would be under their constant surveillance. (Mr. Oda)</p> <p>In Japan, some patients have gone abroad for heart transplants with the support of fund raising. The cost is very high, and the public is made aware of this huge cost because they see the fund-raising activities. I think that these actions have created the perception that Japanese patients are buying organs. I worried that, if I went abroad for a heart transplant, this negative image might be attached to me. (Mrs. Sano)</p>
	Enacted stigma	-
Personal experiences	The moment of being notified of the need for a heart transplant	<p>One day, my parents told me that I had the same heart disease as my brother; therefore, I needed a heart transplant surgery. I think that my parents were sure that I would have a chance of having a heart transplant. Without any hopes, I think, they couldn’t tell me about it. Generally speaking, I am very sensitive to how others feel under certain conditions, and I try not to put any extra pressure on them. At that time, worrying about my parents, I behaved as if I had already predicted this situation of a heart transplant. (Ms. Kato)</p> <p>I immediately rejected the option of receiving a heart transplant. My parents were very disappointed with my response. I told them that I was hospitalised in one the best hospitals in Japan and was receiving the best possible medical treatment, so if I died under these conditions, then that would be my destiny. (Mr. Higashi)</p>
	Describing health condition	<p>My previous heart worked very slowly. My previous heart sometimes stopped working, and I would know the moment just before it stopped. (Mrs. Okamoto)</p>
	Internal self conflict	<p>If I have a heart transplant, I may die or I may survive. I have one of these possible outcomes. I began to feel anxiety related to the possibility that I might not be helped by the surgery... Although I couldn’t tell this anxiety to anyone, I felt so. (Ms. Hamada)</p> <p>Health professionals told me that my life expectancy was one to two years. However, I did not tell this to anyone except for a monk who belonged to a temple that takes care of my family’s dead, burying them and performing ceremonies in their souls’ favour, generation after generation. I did not think about the possibility of a heart transplant, and chose instead to keep my limited</p>

		life expectancy in mind. (Mrs Okamoto)
Organ donation	Thoughts about the donor	Thinking about that someone had passed away, I felt terribly sad, and cried. A nurse was with me and she told me, "You don't need to cry, nobody died for you." (Ms. Kasai)
	Thoughts about donor family	The donor's family suddenly lost their family member. Thinking about how they made a decision so quickly to agree to donate their family member's organ, I was amazed by their having made the decision in their deep sadness. Thinking about this donor family, I could become positive about having a heart transplant, as if mist had disappeared. (Ms. Kasai)  When an organ donor is diagnosed with brain death, the family is faced with a very difficult situation. The family surely suffers as it struggles to accept the family member's death, and yet they must still decide to approve organ donation in this difficult situation. I think that it is very important to treat these families in a way that decreases their suffering and stress as much as possible. (Ms. Katoh)
Medicine	Thoughts about doctors	I heard that some patients had big arguments with doctors to transfer from a hospital to another.... If we depended on doctors in Japan with a passive attitude, we may have involved in such politics among the doctors, and so we did not have any chance to go to the US to have a heart transplant. (Mrs. Sano)
	Thoughts about medical system	I experienced a kind of 'culture shock', because the medical system in Germany was different from the one in Japan. ... In the end, the pain I had experienced in Japan disappeared. (Mrs. Sakuta)
Media	Description of media's enthusiasm	It sometimes happens. I was surprised that the hospital allowed the press to enter the hospital with the patient... In my case, I didn't have such a problem. However, I received a considerable amount of media attention. My mother had promised interviews to the press. (Ms. Kondo)
	Thoughts about the mass media	The news article in which I was introduced may have been useful for the potential heart recipients and their families. However, except for people who urgently need a heart transplant, I think, such news articles did not gather the attention of the public. (Mr. Higashi)
Finance	Experience of fund-raising	When we were told that I could most likely be accepted by a hospital in the US, we needed to prepare the money to pay for the deposit to the hospital. Without money, this chance to go to the US couldn't proceed. Therefore, I appeared on TV as many times as possible to ask for fundraising. When appearing in TV programmes, I attempted to introduce my disease and how it was. I thought that the public's understanding of my disease was fundamental prior to asking for fundraising. (Mr. Uchida)
	Self payment	A nurse told me, "You're very optimistic, aren't you? Do you understand how much it will cost to have a heart transplant?" (Mrs. Makabe)  We paid for the cost of receiving a heart transplant in the U.S. by using private health insurance which my husband had paid for, by selling the land on which we had planned to build a house, and by exhausting our savings. My husband and I agreed that, if we were unable to pay the cost, we would give up on receiving a heart transplant abroad. (Ms Sano)

### Post-operational experiences

Main code	Sub code	Sample
Master status	-	I gradually took it upon myself to ensure that I always looked fine, and had a smile for everyone to prove it. I began to play this role with the earnestness of doing a duty. (Ms. Kondo)
Information control	Information disclosure	I used to often respond to TV interviews in order to encourage future heart transplant recipients by showing how I was able to recover by having a heart transplant. (Mr. Higashi)

	Dissemination of recipients' feelings	Even now, I need to undergo medical check-ups regularly. I need to go to a hospital for the check-up every month. In addition, I need to be hospitalised for an annual medical check-up. When I was a junior high school student, I was sometimes late for school or had to leave school early in order to be present for my hospital appointments and my never-ending schedule of check-ups. While I might have been justified in feeling stressed as a result of the regular medical check-ups, in reality, I was much more troubled by the role that I was expected to play—a girl who had come back from the brink of death owing to a heart transplant done abroad. I had to express this in my interviews with the mass media because there were only a limited number of Japanese heart transplant patients. (Ms. Kondo)
	Passing	Before I had the heart transplant, I sometimes frankly told my friends how exhausted I was because of heart disease. However, I can't tell them that now as before. If I told my friends something like before, they might respond to me, 'This is a small matter', or 'You'll be fine'. Some issues are very important for me, whereas friends might not understand them. I can't explain to you very well about these issues in relation to my friends. One thing that I can tell you is that I have come not to express my worry and feeling to friends. I feel that I can't do it, or I shouldn't do it. (Mrs. Okamoto)
	Covering	I sometimes meet a person who tells me, 'I didn't know that you had a heart transplant. That was you, wasn't it?' I am very glad if someone told me about a heart transplant very frankly like her. Then, I can respond to her, 'I did it, however, I'm fine now.' (Mrs. Okamoto)
	Gathering and sharing information about medical treatment	Before my discharge from the hospital, a nurse explained to me what I had to be careful of in everyday life. She also explained to me about meals, what I should and should not eat and drink. (Mr. Hamada)  After the heart transplant operation, I felt that the donor heartbeat did not match my breathing. I worried about the transplanted heart working properly. Even though I felt sleepy, I perceived that the heartbeat was very strong. I explained this to a surgeon. He explained to me that I would gradually get used to the heart's beating. (Mr Uchida)
Communication	People's responses: The Own	It was a very enjoyable time. I took many photos of other recipients. Many photos were taken of me by other attendances.... I was impressed that there were many people who had had transplants.... In total, I think, there were about 100 attendees including recipients, their families, and medical staff. (Mr. Higashi)
	People's responses: The Wise	My son's heart transplant surgery was the first case at this university hospital. As this transplant surgery was successful, everybody was happy with the outcome. The doctors seemed to be excited by this success; therefore, they enjoyed taking photos of both him and us, even in the ICU on the second day after the transplant surgery. (Mr. Hoshino's mother)  My friends and neighbours expressed how glad they were that I successfully received a heart transplant. (Mr Higashi)
	People's responses: The Public	My hometown is in the countryside, and the people in the town knew me very well; many had donated money for my transplant surgery. They would sometimes tell me 'I'm so glad to see you back, recovered from your illnesses'. They used to send me warm messages, saying, for instance, 'I donated money for you', or 'You experienced a very severe situation, and we're glad you came through it'. (Ms. Kondo)  After my family and friends started asking for fund-raising support on the street, I sometimes received letters from the public. My family and friends also told me how they were encouraged by the public during their fund-raising activities. These messages began to encourage me about receiving a heart transplant. Before listening to these messages, I was very pessimistic about many things, and I felt that my life wasn't valuable enough to be supported by so many people. So, through the process, I learned to feel positive about living. (Mrs. Kasai)
	Social pressure	I gradually took it upon myself to ensure that I always looked fine, and had a smile for everyone to prove it. I began to play this role with the earnestness of

		<p>doing a duty. (Ms. Kondo)</p> <p>I recognized the significance of living everyday life by always trying to do my best. (Ms Hamada)</p>
Stigma	Felt stigma	<p>I wanted to behave as a “normal person” like other friends as much as possible. Therefore, one day, I tried to sprint, although I understood that I didn’t have enough stamina to fully attend the gymnastics class, and I should not try it.... In reality, I developed anaemia after the gymnastics class. (Ms. Kato)</p>
	Enacted stigma	<p>When sending my CV, I didn’t include the fact that I’m a heart transplant recipient. However, during the job interviews, I always needed to explain it, and I never got those jobs. Therefore, I began to write in my CV that I was a heart transplant recipient. After that I often failed to get jobs for medical reasons. (Mr. Oda)</p>
Personal experiences	Describing health condition	<p>After the transplant surgery, I recognised how the rhythm of my pulse was regular. (Mr. Makabe)</p>
	Internal self conflict	<p>I had a chance to listen to the experiences of donor families. In the meeting, I listened to the talks by three people. The three of them spoke of how the public attacked them with their terrible opinions: ‘How much did you sell the organ for?’ ‘How dare you do something as terrible as donate organs?’ ‘If I were you, I could not do a terrible thing to hurt a dead body.’ They said that they were not confident about their decision to donate the organs of their family members. It was the first time I heard the donor families talking of their experiences. Before I went to the meeting, I could not envisage what they would talk about. I had not imagined that they would talk about extremely negative opinions. I was really shocked. I had gone to the meeting with my mother that day. On our way back home in the train, both of us were lost for words. After that, I began blaming myself more: Even as the donor families regret their decisions, I am alive. I was complete lost. (Ms. Kondo)</p>
	Thoughts towards the life plan	<p>I am always scared that I may be rejected by a person because I’m a heart transplant recipient. Therefore, I can’t be so positive about going out with someone. (Ms. Kato)</p> <p>Thinking about marriage and a partner I will meet in the future is not a simple issue for me. I feel that it may not easy for someone to marry the recipient of a heart transplant. Therefore, I cannot simply progress to being a partner to someone. (Mr Kato)</p>
Organ donation	Thoughts about the donor	<p>I think most discussions around organ transplant have been taking place around an emotional perspective. ‘A person wants to save the life of another person who is in front of him/her.’ This is the emotion of a person. Needless to say, nobody can deny the same emotions in the other person. Therefore, there is a personal emotional connection on both sides: the donor’s family wishes to prevent the donor’s death, while the recipient’s family is anxious to receive the donor’s organ for transplant. In other words, it gets complicated if someone insists emotionally that they want to save the life of both the recipient and the donor. (Ms. Kondo)</p>
	Thoughts about organ	<p>I think that less people think that organs from a dead person will live in someone else’s body, and these organs will acquire new lives. (Mrs. Okamoto)</p> <p>I do not think that the life is no longer attached to a transplanted organ simply because the donor has passed away. (Mrs Sano)</p>
	Thoughts about donor family	<p>In my opinion, nobody is interested in resolving the issues of terminal care and donor families. While transplant doctors are interested in them, no one has actually attempted to tackle these issues. Neither the Organ Transplant Network, nor the Japan Society for Transplantation has tried to address these issues. There are not many organisations that can address these issues. As a result, the people concerned, that is, the patient groups, have to tackle these issues. (Ms. Kondo)</p>

Medicine	Thoughts about doctors	I came to the conclusion that doctors in Japan considerably focus on the biological aspect. Their attitude may have led to people's distrust of medicine or to feel somewhat uncomfortable about medicine. (Ms. Kondo)
	Thoughts about medical system	When a patient needs to move from the usual hospital to another hospital to receive a different type of medical treatment, the transfer is a problem for the hospital because it implies an affront to the honour of the hospital. (Mr. Higashi)
Media	Description of media's enthusiasm	As soon as we got back to Japan, the press organised a press conference at the airport. (Ms. Kondo)  Shortly after Japan passed the Transplant Law in 1997, the mass media again requested interviews with me. However, they did not understand what I wanted to convey. Instead, they used some expressions from the interview and interpreted them in their own way. They wanted to use interviews with me to support their own perspectives. (Mr Higashi)
	Thoughts about the mass media	I was advised by other people to understand the main aim of the interview by the mass media, because interview contents were often edited by the media. (Mr. Higashi)
Finance	Experience of fund-raising	I seldom go shopping around here. I only do grocery shopping and small shopping for my daughter. ... I don't buy my clothes here, and don't go even window-shopping. For example, I earned a negative reputation even for window-shopping at a watch shop. Therefore, I don't buy anything for me and my husband. (Mrs. Okamoto)  The company where I work now financially supported me when I went to the U.S. to receive a heart transplant. Therefore, the company's employees know that I am a heart transplant recipient. As I did not have the opportunity to tell them how I had been before coming to this company, I explain to them now how I was and how I am whenever they ask me. (Mr Uchida)
	Self payment	A recipient who had asked for fund-raising support needed to inform the people who had helped the fund-raising how they spent the money. I received a report from a recipient, and he had recorded everything, even a bottle of Coke. We did not need it. (Mrs. Toda)

### Notion of body

Main code	Sub code	Sample
Body and soul	Thoughts about discussion regarding body and soul	When I talked to nurses, they expressed how they experienced an uncomfortable feeling about extracting organs, because they were not completely sure about the validity of the diagnosis of brain death. I was considering becoming an organ coordinator; however, I concluded that it would be very difficult to work with these nurses, because their idea was different from mine. (Mrs. Sano)
	Thoughts about body and soul	I believe that the soul exists apart from the body.... I know that the majority of Japanese people traditionally hold an idea that the body parts cannot be separate from the soul. (Ms. Sakata)
Heart	Thoughts about discussion regarding a heart organ	When Dr Minami explained about a heart transplant he told me, "some people say that donor's memory is also transplanted with the donor's heart. However, it's not true. The heart is merely a pump, and it just works to circulate blood in the body. The heart is different from the brain, and the heart organ itself cannot think. Therefore, you don't need to worry about those rumours." ... As he is a doctor, he told me that this story is ridiculous. I also thought so'. (Ms. Okamoto)  Unlike in Japan, here I feel that a heart transplant is just an ordinary form of medical treatment. Therefore, I have had opportunities to talk about the transplanted heart with other recipients in a hospital in the U.S. The conversations are simply usual conversations with no hesitation to talk. In Japan, I still do not have such opportunities. (Mr Sano)



	Thoughts about a heart organ	<p>The heart is a special organ, because I understand that one can't live without a heart. ... I don't think it [mind] lives in a heart. (Ms. Hamada)</p> <p>I know that some people say that an evil spirit is transplanted along with a transplanted heart. I did not disagree with this idea. I thought that I would be a friend of evil if my husband received a heart transplant. (Mrs Ono)</p>
Religion	Thoughts about the influence of religion to the people's attitude towards heart transplant	<p>I think that western people have different national identities from us. We Japanese hold Samurai's soul. (Mrs. Okamoto)</p> <p>Although religion may influence people's attitudes towards heart transplants, I do not simply accept that influence. Considering the fact that heart transplants are less popular in Japan than in the U.S., even though both nations have Christians, I think that religion and in particular Christianity is not the main factor influencing people's attitudes. (Ms Hamada)</p>
	Thoughts about his or her own religion	<p>I believe that brain death is a person's death (although I know that some people still have resistance to this idea, like I used to be). Therefore, I don't think that receiving a heart transplant means receiving someone's life. ... In our (I and my husband's) idea, we received a heart organ from God, rather than from an individual. Thus, having a heart transplant was not due to our efforts. I think that this was God's doing. Our religion (Christian) may establish our way of thinking about having a heart transplant. (Mrs. Sano)</p> <p>I have not thought about religion so much. I am not sure to what extent any religion impacts Japanese people's everyday lives. (Ms Kono)</p>
Death	Thoughts about death	<p>I believe that brain death is a person's death. (Mrs. Sano)</p> <p>The idea of brain death is still relatively new, so I suspect that many people cannot easily accept the new idea. Furthermore, people have been revived or awakened from the brain dead condition. This probably confused many people about how precisely death can be diagnosed. (Ms Kato)</p>
	Thoughts on the other people's attitude towards death	<p>Generally speaking, I think death is a taboo, and thus, death should be unseen by the Japanese people. This attitude towards death may be a problem when considering organ transplant. (Ms. Kondo)</p>

## Gift-exchange

Main code	Sub code	Sample
Appreciation of the gift of a heart	Thoughts	<p>Eventually, I cannot fully express my appreciation. ... I find that it is difficult to precisely express my feelings of gratitude. I also feel that I don't want to talk about it, as I think it's impossible to talk about my whole appreciation. If I say something, this will only be a part of my feelings. Therefore, I would be irritated with myself if I tried to convey my feelings since it would be impossible to perfectly describe my feelings. The more I talk, the more I feel stress because of the imperfect expression of my feeling. (Mr. Watari)</p> <p>I really appreciate everyone who helped me to receive a heart transplant, although I do not continually think about them every day. (Ms Kato)</p>
	Actions	<p>I received a letter from my donor's family after the operation. I told my doctor to reply and write that I was doing quite well, and was full of appreciation to them. Although the doctor told me that I did not need to reply to them, I wanted to express my appreciation. (Mr. Uchida)</p>
Repayment of the gift	-	<p>It (the relationship between my donor and I) is a one-sided relationship, isn't it? I cannot repay anything to the donor, because I don't know who my donor is. I only received a heart organ. Therefore, I have done my best to live with a feeling of appreciation. This is my way of expressing my appreciation to the donor. I cannot repay anything by sending something. The only way for the repayment seems to be expressing my appreciation, as I cannot repay him/her by sending a gift. (Mr. Sano)</p> <p>I thought that I didn't need to repay them. I really thought that I could repay people by showing them that I was always fine. (Mr Oda)</p>

## Appendix 7 Copy of consent form



コンセント・フォーム

Heart transplantation: its risks, the expectations, and cultural negotiation in Japan

心臓移植：日本におけるリスク、期待、そして文化の影響  
Queen Mary リサーチ倫理委員会 Ref: QMREC2009/65

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署名: 佐藤靖一 日時: 2010.2.20

調査者:

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署名: 友松郁子 日時: 2010.2.20

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署名: 岡部 美里

日時: 2010. 2. 22

調査者:

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署名: 友松 郁子

日時: 2010. 2. 22

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私 本田 裕美は、この調査について十分な説明を受け、理解しました。よって、調査に協力することに同意いたします。

署名: 本田 裕美 日時: 2月25日

調査者:

私 友松 郁子は、本調査について、被調査者に対して、十分な説明を行いました。

署名: 友松 郁子 日時: 2010. 2. 25

Heart transplantation: its risks, the expectations, and cultural negotiation in Japan

心臓移植：日本におけるリスク、期待、そして文化の影響  
Queen Mary リサーチ倫理委員会 Ref: QMREC2009/65

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- ・ 調査への協力を決める前に、被調査者は不明な点について本調査者に質問をし、その点について説明を受けました。
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被調査者:

私 瀬川 美由起 は、この調査について十分な説明を受け、理解しました。よって、調査に協力することに同意いたします。

署名: 瀬川 美由起 日時: 2010. 2. 26

調査者:

私 友松 郁子 は、本調査について、被調査者に対して、十分な説明を行いました。

署名: 友松 郁子 日時: 2010. 2. 26



コンセント・フォーム

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被調査者:

私 小笠原 憲一は、この調査について十分な説明を受け、理解しました。よって、調査に協力することに同意いたします。

署名: 小笠原 憲一

日時: 2010/3/2

調査者:

私 友松 郁子は、本調査について、被調査者に対して、十分な説明を行いました。

署名: 友松 郁子

日時: 2010/3/2

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被調査者:

私 江田 果瑠奈 は、この調査について十分な説明を受け、理解しました。よって、調査に協力することに同意いたします。

署名: 江田 果瑠奈 日時: 2010年 3月3日

調査者:

私 反松 郁子 は、本調査について、被調査者に対して、十分な説明を行いました。

署名: 反松 郁子 日時: 2010年 3月3日

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被調査者:

私 野中 又雄 は、この調査について十分な説明を受け、理解しました。よって、調査に協力することに同意いたします。

署名: 野中 又雄 日時: 平成22年3月4日

調査者:

私 反松 郁子 は、本調査について、被調査者に対して、十分な説明を行いました。

署名: 反松 郁子 日時: 平成22年3月4日

コンセント・フォーム

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被調査者:

私 宇野 純平 は、この調査について十分な説明を受け、理解しました。よって、調査に協力することに同意いたします。

署名: 宇野 純平 日時: 3/4

調査者:

私 友松 郁子 は、本調査について、被調査者に対して、十分な説明を行いました。

署名: 友松 郁子 日時: 2010. 3. 4



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被調査者:

私 松友久 は、この調査について十分な説明を受け、理解しました。よって、調査に協力することに同意いたします。

署名: 松友久 日時: 2010.8.7

調査者:

私 友松郁子 は、本調査について、被調査者に対して、十分な説明を行いました。

署名: 友松郁子 日時: 2010.3.4

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被調査者: 濱崎 晃洋  
私 濱崎 晃洋 は、この調査について十分な説明を受け、理解しました。よって、調査に協力することに同意いたします。

署名: 濱崎 晃洋 日時: H 22. 3. 4 14 05

調査者: 友松 郁子  
私 友松 郁子 は、本調査について、被調査者に対して、十分な説明を行いました。

署名: 友松 郁子 日時: H 22. 3. 4

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- ・ インタビューを中止したい場合は、いつでも、その旨を調査者に伝え、中心することを、理解しました。
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被調査者:

私 左藤 いずみ は、この調査について十分な説明を受け、理解しました。よって、調査に協力することに同意いたします。

署名: 左藤 いずみ 日時: 2010.2.20

調査者:

私 友松 那子 は、本調査について、被調査者に対して、十分な説明を行いました。

署名: 友松 那子 日時: 2010.2.20

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被調査者: 岡部 武  
私 岡部 武 は、この調査について十分な説明を受け、理解しました。よって、調査に協力することに同意いたします。

署名: 岡部 武 日時: 平成 22 年 2 月 22 日

調査者: 友松 郁子  
私 友松 郁子 は、本調査について、被調査者に対して、十分な説明を行いました。

署名: 友松 郁子 日時: H22. 2. 22



コンセント・フォーム

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被調査者:

私 中澤 奈美枝は、この調査について十分な説明を受け、理解しました。よって、調査に協力することに同意いたします。

署名: 中澤 奈美枝 日時: 2010. 2. 24

調査者:

私 友松 郁子 は、本調査について、被調査者に対して、十分な説明を行いました。

署名: 友松 郁子 日時: 2010. 2. 24

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被調査者:

私 見目 政隆 は、この調査について十分な説明を受け、理解しました。よって、調査に協力することに同意いたします。

署名: 見目 政隆 日時: 2010.2.25

調査者:

私 友松 郁子 は、本調査について、被調査者に対して、十分な説明を行いました。

署名: 友松 郁子 日時: 2010.2.25

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被調査者:

私 赤石千秋 は、この調査について十分な説明を受け、理解しました。よって、調査に協力することに同意いたします。

署名: 赤石千秋

日時: 平成22年2月25日

調査者:

私 友松 郁子 は、本調査について、被調査者に対して、十分な説明を行いました。

署名: 友松 郁子

日時: 2010. 2. 25



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被調査者:

私 江田 博子 は、この調査について十分な説明を受け、理解しました。よって、調査に協力することに同意いたします。

署名: 江田 博子 日時: 2010年3月3日

調査者:

私 友松 郁子 は、本調査について、被調査者に対して、十分な説明を行いました。

署名: 友松 郁子 日時: 2010年3月3日



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被調査者:

私 濱崎 さえ子 は、この調査について十分な説明を受け、理解しました。よって、調査に協力することに同意いたします。

署名: 濱崎 さえ子 日時: H22. 3. 4. PM 2:05

調査者:

私 友松 郁子 は、本調査について、被調査者に対して、十分な説明を行いました。

署名: 友松 郁子 日時: H22. 3. 4

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署名: 白平 繁功 日時: 22年2月28日

調査者:

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署名: 反松 郁子 日時: 22年2月28日

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署名: 反松 郁子 日時: 22年2月28日

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署名: 和田 るみ

日時: 2010/3/1

調査者:

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署名: 友松 郁子

日時: 2010, 3, 1



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