

学位論文

「Tracing six Japanese donor families'  
attitudes, 2002-2016

(日本のドナー家族6例の追跡調査:2002-  
2016)」

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## 著者の宣言

本学位論文は、著者の責任において調査を遂行し、得られた真実の結果に基づいて正確に作成したものに相違ないことをここに宣言する。

# Tracing Six Japanese Donor Families' Attitudes, 2002–2016

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## 論文要旨

### 背景：

臓器移植法改正から6年、約7倍に臓器提供数は増加したが、その総数は384例に留まり(2016/06/21)、依然として深刻な臓器不足に直面している。また、国内外からも、脳死からの臓器提供において日本人の心性や日本の文化的背景が臓器提供を阻む原因になっていると捉えられている。しかしながら、実際に身内の臓器提供の決断をしたドナーの遺族に着目した研究は殆ど無く、臓器提供後のドナーの遺族の実態はベールに覆われたままである。本調査の目的は実際に臓器提供の体験したドナー家族のインタビュー調査を基にした実態調査から、彼らが体験した「臓器提供」にはどのような問題を包含しているか人類学的手法を用いて問題の所在を明らかにすることである。

### 方法：

2002年から移植医療の当事者（移植医・レシピエント・ドナーの遺族）のインタビュー調査を始め、特にドナーの遺族6例に焦点を当てた(調査時の脳死臓器提供数19件)。調査対象の選定は日本移植者協議会主催の移植者スポーツ大会で、ドナーの遺族と海外レシピエントの通訳を務めることでファースト・コンタクトを試みた。また、調査対象者の選定基準は、身内の死後に臓器を提供した遺族と限定した（生体移植を除く）。臓器提供の経緯は、脳死（交通事故4例・病死1例）と心臓死（病死1例）であった。現在に至るまで追跡調査を継続し、14年間（2002~2016年）の遺族のナラティブデータから、悲嘆のプロセスの結果を纏め、臓器提供直後のドナーの遺族の悲嘆と10年以上経過した彼らの悲嘆の意味内容の変容の比較考察を行った。

## 結果：

調査対象者6例のドナーの遺族のインタビュー調査から、ドナーの「臓器提供の意思表示」の有無と遺族の悲嘆のプロセスに想定外の変化が5例(83%)に生じていた。臓器提供直後(2002年)、ドナーの「臓器提供の意思表示」が有った遺族3例(50%)は臓器提供を受容し、臓器提供をしたことが遺族の悲嘆軽減要因となっていた。一方、ドナーの「臓器提供の意思表示」が無かった遺族3例(50%)は臓器提供を後悔し、家族の忖度で臓器提供をしたことが遺族の悲嘆増幅要因となっていた。約10年後(2014~2016年)の追跡調査では、①ドナーの「臓器提供の意思表示」が有り、臓器提供は「Gift of Life」と評価する遺族が1例(17%)、②ドナーの「臓器提供の意思表示」は有ったが、臓器提供を後悔している遺族が2例(33%)。③ドナーの「臓器提供の意思表示」が無く、臓器提供を後悔していた遺族3例(50%)全てが、10年以上に及ぶ様々な悲嘆のプロセスを経て、臓器提供を「結果としてのGift of Life」と受容していた。

## 結論：

本研究の結果、ドナーの「臓器提供の意思表示」の有無が遺族に臓器提供の決断を促し、臓器提供直後の悲嘆を軽減するが、長期的効力は認められなかった。ドナーの「臓器提供の意思表示」以上に、10年という時間を共有した遺族たちが帰属するコミュニティの「移植医療への関心・正しい知識と理解」が長期的には遺族の悲嘆を和らげる要因となっていた。

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## **1. Background**

Six years have passed since the Japanese organ transplantation law was revised in 2010. Between the original law's creation in 1997 and the 2010 revision, donations increased about sevenfold, and total donations to date (06/07/2016) stand at 382. Nevertheless, the organ shortage is still seriously severe because donation numbers have only increased from about 6 cases per year to 49. As a result, most Japanese organ recipients depend on living donors within blood family circles or overseas transplants from both developed Western countries and developing South Asian countries. This is strongly connected with the Japanese medical refugee phenomenon, worldwide organ trafficking problems and human rights issues among developing countries. Although severe chronic organ shortages are not just a Japanese but a worldwide problem, the organ donation numbers in Japan are by far the lowest among medically advanced countries (Figure 1). Japan has world-class high-quality medical technologies, but despite both this and the many organ recipient candidates and donor card holders in the country nowadays, organ donations have not increased to meet demand.

Organ transplantation from brain-dead donors is an emerging medical technology that has produced a number of social, legal, philosophical, ethical and cultural issues throughout the world. Many specialists have pointed out that cultural issues in Japan are the main reason that barriers have been created, stalling the progress of brain-dead organ transplantation in the country (Abe, 1994). These cultural issues surrounding the medical practice remain unresolved; this point is especially brought into focus by research into donor families.

### **1-1. The History of Organ Transplantation in Japan**

The history of Japanese organ transplantation is unique and scandalous. The first Japanese heart transplant was performed soon after the procedure was first created (it was the world's 30th such operation and took place in August 1968) but the second was not conducted until February



1999. This 31-year intermission occurred as a result of the “Wada case”. According to a medical anthropologist in North America, organ donation numbers from brain-dead donors are still at very low level in Japan because of the fallout from the Wada case, which caused serious side-effects for Japanese people, including the creation of a great deal of mistrust (Lock, 2002). My data, expanding on Dr Lock’s findings, revealed that two kinds of mistrust are present among the population: mistrust of brain-dead organ transplant medical care itself and mistrust in general of doctors, especially transplant surgeons (Yasuoka, 2015).

## **1-2. The Current Situation**

Japanese organ donation numbers have increased dramatically since the transplantation law was revised in 2010. The original law of 1997, established very late compared to most other countries, was the strictest in the world, requiring organ donation wills from both the donor and donor family and prohibiting organ donation by children under the age of 15 years. Total donation numbers from brain-dead donors stand at 382 at the time of writing (06/07/2016) – this includes 86 cases before (October 1997 to July 2010) and 296 cases after the revision (July 2010 to June 2016). These figures show that Japanese organ donations rose from 6.7 cases per year to 49.3 (about a sevenfold increase). The most significant reason behind this increase is the change to accepting donor families’ “presumed consent”: this means that while agreement to donate an organ is required from a donor family, the donor’s own donation will is no longer always necessary. Despite this, however, Japan has the most severe organ shortages among medically advanced countries.

Since 2010, organ donations from brain-dead donors have increased and the revised law also permits organ donations from children of less than 15 years of age. However, organ donation among children is rare (only six cases among children aged 6–15 years and five among those aged under 6 years, as of 06/07/2016), and to make matters worse, numbers of cadaveric donations have decreased since the law was revised. In addition, the revised law includes a rule that is unique to

Japan – the “family-first organ donor rule” – through which donor family members can receive organ priority (Figure 2). Thus, while living donor numbers have increased, they can only donate organs to their family members and not outside the family circle.

### **1-3. Innovative and Challenging Research**

Many researchers have studied organ transplantation issues, focusing on various areas such as medicine, law, philosophy and ethics, but only a few have approached these issues from an anthropological stance in Japan. In the United States many medical anthropologists are researching the cultural issues surrounding medical topics and contributing to overcoming medical problems from anthropological points of view with their work. Organ transplantation is a completely unknown medical therapy in terms of the agency of the donor and donated organ, not only for concerned parties such as transplant surgeons, recipients and donor families but also for currently unconcerned parties such as potential donors in communities. Because of this lack of knowledge, I decided to start my innovative research into organ transplantation in Japan, considering it as a cultural issue, in 2002.

When I began my research, I learned that organ transplantation is a unique medical treatment, in that it depends on a completely new agent – the “donor” – an unknown dead person who forms a crucial part of the process. In fact, both the donors and their bereaved families (donor family) were new agents, created as a result of this cutting-edge medical treatment. The aim of my research was to understand the donor family’s grief for the donor’s death and their assessment of organ transplant medicine, as well as the gaps in understanding between transplant surgeons, recipients and donor families. My challenging research question has been: “How is organ replacement understood among concerned parties?” I focused on the direct narratives of all these concerned parties to learn about their experiences and to reveal their dilemmas and ambivalent assessments through their experiences of organ replacement, transplantation and donation, and their transformed concepts of life and death in Japan, during 2002–2016 (Figure 3, Figure 4). In

this research, I focus on donor families and compare their assessments of organ donation (satisfaction or regret) between the original data from 2002–2003 and follow-ups in 2014–2016 through their narratives.

## **2. Methodology**

In my research, I chose 23 concerned parties as informants (ten Japanese transplant medical staff, seven Japanese organ recipients and six Japanese donor families), who were in the US, Australia or Japan when they transplanted/received/donated organs and were in Japan during 2002–2003 (original research). I also compared six donor families' assessments of organ donation between the original data (2002–2003) and follow-up research data (2014–2016). For the details of the families interviewed, see Table 1 and Table 2.

- Of the transplant medical staff informants, seven transplant surgeons worked in both the US and Japan, two recipient coordinators worked in both Australia and Japan and one donor coordinator (a position created with the transplantation law in 1997) was a Japanese nurse who retrained in Japan. Japanese organ transplant medical care is performed only from living donors and cadaveric donors.
- The recipient informants received organs only from unknown dead donors (both brain-dead and heart-dead, not within the family circle). They included two liver recipients from brain-dead donors in Australia; one simultaneous pancreas/kidney recipient from a brain-dead donor in Japan; and four kidney recipients from two brain-dead donors in the US, one brain-dead donor in Japan and one cadaveric donor in Japan.
- The donor family informants had donated their family members' organs in both Australia and Japan. They included the families of one daughter (who became a cadaveric donor), one husband (who became a cadaveric donor) and three sons (two became brain-dead donors in Australia and one became brain-dead donor in Japan); one became a cadaveric donor in Japan). Note: the parents of one donor had separated so were interviewed individually.

## **2-1. Fieldwork 1: Participant Observation**

My anthropological research was conducted as participant observation for the first contact (preparation), in order to create the research design and to build rapport with the informants. At this first stage I attended many organ transplant events, such as recognition ceremonies, lectures for recipients and mutual understanding events for recipients and donor families. I then worked with concerned parties as an English interpreter for overseas recipients and donor families during 2002–2003 at the annual meeting of the Transplant Games (Figure 5, Figure 6) in Japan.

I started follow-up research in 2006 to understand matters that concerned parties felt were changing. I kept in contact with them to continue casual interviews and met with them regularly, thus also creating opportunities to be introduced to new informants. I attended both domestic and international organ transplant conferences in both North America (the US and Canada) and Japan to keep in contact with transplant surgeons and undertake formal interviews. In this way I learned about specific organ transplant medical questions and the changing situation, because transplantation care continues to develop and change as an emerging medical technology.

In 2014 and 2015 I acted as master of ceremonies (MC) at the Transplant Games in Japan, and will do so again in 2016. As MC I act as overall host of the event and work with recipients, medical staff and donor families, which has helped me to continue my follow-up research during 2014–2016.

## **2-2. Fieldwork 2: Interview Research**

I started formal interview research to identify narrative data for my PhD dissertation (2006) and created definitions of the informants for my research. These included Japanese transplant medical staff who had worked in Australia, the US and Japan; Japanese organ recipients who received organs in Australia, the US and Japan from dead donors (both brain-dead and cadaveric (heart-dead)); and Japanese donor families who had donated organs from both brain-dead and heart-dead family members to unknown recipients in Australia and Japan.

When I started fieldwork in 2002, only 19 donations had been made from brain-dead donors in Japan, so it was difficult to set up many interviews with informants (transplant medical staff, recipients and donor families). Furthermore, Japanese organ transplantation law prohibits recipients and donor families from making contact to avoid possible trouble and to protect donor families' privacy; researchers also cannot make direct contact with any donor families under the law.

I flew to the US, where I learned some research methodology (grounded theory approach and qualitative research approach) used in North America by medical anthropologists. The US holds "recognition ceremonies" and protection of donor families' privacy, while of course strict, is more flexible than under Japanese law. I heard about the World Transplant Games, at which many recipients gather from all over the world, and to which donor families are also invited. This was held in Kobe, Japan, in 2001; many recipients from both Japan and overseas and some Japanese donor families were invited.

I made contact with the Japan Transplant Recipients Organization (JTR) when I came back to Japan, and started work as a volunteer interpreter at their events. The law prohibits recipients making contact with donor families, but the Japanese recipients in the JTR want to communicate with donor families, to try to construct good relationships and mutual understanding. Japanese organ transplant surgeons and coordinators, who are also members of the JTR, support the recipients in wishing to show their appreciation for donor families, so they hold events at which they try to organize meetings between recipients and donor families, since they can only meet in the presence of the medical staff. Some staff of the JTR introduced me to transplant surgeons, recipients and donor families, and I had a chance to meet them directly; finally I succeeded in setting up formal interviews with donor families.

I used snowball sampling: having been introduced to a donor family for an initial interview, I was then introduced to their friends – another donor family. Eventually I undertook

formal recorded interviews with a total of six Japanese donor families. I asked the introducers to explain the formal recorded interview process first before asking their friends for permission to interview them; only once my offer was accepted did I email to ask for a recorded interview directly. Following the acceptance we met at a place designated by the donor family, such as their home or a coffee shop, and I reconfirmed the information about the recorded interview by semi-structured interview method to deeply understand donor families' narratives. The participants agreed to my offer, and I interviewed with an interview guide for donor families of my own design. For details of the interview guides and actual questions for donor families in 2003, see Table 3, Table 4 and Table 5. Thereafter, I have been trying to keep in touch with the six donor families, but every donor family has a different and unpredictable course for their grieving. Thus, as for my follow-up interview research, I have had no choice in some cases but to depend on informal interviews in 2014–2016.

### **2-3. Data Analysis**

The data were word-for-word transcripts and all the words were picked up, including even sighs and other non-verbal sounds, to recreate the narration and atmosphere clearly and correctly. I also combined the grounded theory approach and qualitative research methods to analyse my narrative data (Glaser, 1967; 1997). I used the coding method from the grounded theory approach to objectively clarify the narratives and to generate the data (Kayama, 2002). I also utilized qualitative research methods to deeply understand the narratives and emphasize the uniqueness of the narratives (Table 6, Table 7, Table 8) (Flick, 1999; Oda 2002).

Narrative data themselves are very subjective and emotional, so I tried to code and categorize them to create objective data, as far as possible. I also tried to find the narratives' realities and the informants' own rationalities: since the donor family is a new agent, their feelings and speech about organ donation were impossible to predict. However, such interview research, using bottom-up data directly from concerned parties, made the grounded theory approach very useful

and strong.

The total number of informants is very low at only six people. In this case, the quantitative research method is impossible, but even with few informants and subjective characterized data, the findings are significant, and the qualitative research method is powerful when only a few informants are available. I chose and created the combined methodologies to cover the low number of informants.

#### **2-4. Statement on Ethics: Principles of Professional Responsibility**

I had full access to and take full responsibility for the integrity of the raw interview data. All study informants agreed that I could use their narratives for my academic papers.

### **3. Results**

#### **3-1. The Correlation Between Organ Donation Wills and Donor Family Reactions, 2003**

When I undertook interview research with six Japanese donor families in 2003, the data showed that three donor families were satisfied with their choice of organ donation from their family members (two sons with organ donation wills and one husband with an organ donation will). The other three donor families regretted their choice to donate their family member's organs (two sons without organ donation wills and one daughter without an organ donation will).

The motivations behind the organ donations among the satisfied group were based on the presence of the donors' wills. Their resulting satisfaction after the procedure was also based on the wills: one family volunteered the organ donation and two were requested by emergency medical doctors, but all felt that they had made the right choice.

Family agreement to donate was achieved among five donor families (three with donor's donation wills and two without); one donor family (without a donation will) was forced by the doctor to agree to the donation.

### **3-2. The Correlation Between Organ Donation Wills and Donor Family Reactions, 2014–2016**

When I conducted follow-up research via casual interviews with the six donor families in 2014–2016, the data showed that four donor families were now satisfied with the organ donations (two sons without organ donation wills, one daughter without an organ donation will and one husband with an organ donation will). The other two donor families now regretted the donations (two sons with organ donation wills).

Family assessments of the organ donations had changed among five donor families between 2003 and 2014–2016 (four sons – two with organ donation wills and two without – and one daughter without an organ donation will). Only one donor family's assessment had not changed (one husband with an organ donation will).

Among the satisfied group now, only one donation had been motivated by the donor's organ donation will (one husband). The reasons for the family's continuing satisfaction were that the donation was based on the donor's will, that time had helped the family to heal as part of the grieving process and that the family had made positive assessments internally and experienced the admiration of friends and acquaintances. This donor family (D) had retained both its own satisfaction and the receptive attitude of others.

Inter-family consensus was achieved among four donor families, either at the time of donation or by the follow-up interviews in 2014–2016 (one with a donor's donation will and three without, including one donor family that was forced into organ donation by medical staff). For example, one mother offered her son's organs for donation to keep him alive inside the recipients' bodies, but did not ask permission of her husband or her younger son. Soon afterwards, she and her husband separated and in the 2003 interview she stated that she regretted her choice to donate, but by the time of the follow-up she, her son and their extended family were proud of the decision and of the difference the donation had made. This donor family had no donor's organ donation will but the fact of the donor's kidneys (two functioning organs) living in two unknown recipients'



bodies and her supportive family members' attitude changed the donor mother's assessment about organ donation from regret to satisfaction.

Figure 7 and Table 9 detail the changes in donors' assessments of the organ donations. Two donor families in the satisfied group had changed to the regretful group; three donor families in the regretful group had changed to the satisfied group and one donor family had remained in the satisfied group.

In the acute stage of grief, three satisfied groups had a donor's donation will and this motivated the positive behaviour of organ donation for each donor family. The three regretful groups had no donor's donation will and this led only to grief for each donor family. Thus, it is possible to draw a conclusion on the basis of these research findings from donor families' narratives that the organ donation will was the most important factor for donor family in 2003. In the chronic stage of grief, only one donor family with a donation will retained the satisfied assessment of organ donation, while the other two families changed from satisfaction to regret for organ donation even with donor's organ donation will. On the other hand, the three regretful donor families changed to satisfaction in 2014–2016. The findings suggest that the organ donation will may no longer be an important factor for donor families some years after the donation (Table 9).

The relationships between donor families and donors are also significant, potentially influencing the outcome of the assessments of organ donation by donor families themselves. The six donor families include two donor fathers, three donor mothers and one donor wife. Both donor fathers changed their assessments of organ donation of their son/daughter. All the donor mothers also changed their assessments of organ donation of their sons. The one donor wife retained satisfaction for organ donation of her husband. The data suggest that the relationships between parents and children are very emotional and donor father/mothers' assessments are changeable and unstable. The husband and wife donor relationship is very logical, and the donor wife keeps a stable assessment for her late husband, respecting his organ donation will (Table 10).

Follow-up research data imply a change in importance in the donor's organ donation will

over time. Having been perceived as the most important factor in initial narrative data (Yasuoka, 2006), during follow-up research it appears that immediate and wider environments (such as family and friends; colleagues, neighbours and the community) have become a more important factor in the donor family's grieving processes.

## **4. Discussion**

### **4-1. The Role of the Donor's Organ Donation Will in the Acute Grief of the Donor Family**

Donor families' narrative data in 2003 showed that a donor's organ donation will is the most important factor in the family's response to the donation: every satisfied donor family had an organ donation will belonging to the donor, while no regretful family did. This led me to conclude at the time of my PhD dissertation in 2006 that the donation will was the most important factor in healing a family's grief over the donor's death and in reducing a family's sadness over the loss of their family member.

### **4-2. The Role of the Donor's Organ Donation Will in the Chronic Grief of the Donor Family**

According to my follow-up research, five donor families' assessments had undergone a large and unpredictable change; only one donor family kept the same assessment in 2014–2016. Two originally satisfied donor families changed to regret over the donation of the organs of their sons, who had organ donation wills. The three originally regretful donor families had become satisfied with the decision to donate the organs of their sons and daughter with no organ donation wills. Only one donor family kept the satisfied assessment about the organ donation of the husband, who had held an organ donation will for 14 years. The data show that an organ donation will is not as important a factor in donor families' chronic grief around a decade after the event as it is in their acute grief. Since only one donor family who had a donation will remained satisfied, this demonstrates the possibility that the role of a donor's donation will, even if signed by a family

member (one option of the Japanese donor card), can transform over time for the family. We also have to pay attention to the difference between the donor's organ donation will and the donor family's organ donation will in the chronic grief stage (Table 11).

#### **4-3. A Comparison of the Roles of the Organ Donation Will**

The organ donation will is always an important factor in organ transplantation treatment, but the data show clear differences in the role it plays between acute and chronic grief. In acute grief the donation will obviously reduced donor families' grief and supported their positive assessments of the organ donation, even though their lost family members became simply "donors". Although all the donor families in the satisfied group in 2003 had donation wills, the role of the donation will in chronic grief is harder to assess: the link with supporting donor families' chronic grief care is not as clear. In the 2014–2016 data, of the four donor families in the satisfied group, three had no donation wills; thus, the donor's donation will was no longer the strongest reason for satisfaction. In addition, two donor families in the regretful group had had a donor's organ donation will and had been satisfied with the organ donation in 2003. This shows that other new elements had been added, transforming the grieving processes of the donor families and changing their minds from regret to satisfaction at the donation. Only one donor family remained in the satisfied group during 2003–2016. Thus, the organ donation will is still an important factor in the response to organ donation, but its role varies for different donor families, especially in the chronic stage of grief.

Nevertheless, although the role of the donor's organ donation will changes over time, there is a constant significant effect in its importance when a bereaved family has to decide whether or not to donate organs from a lost family member. The presence of a donation will makes it easier for the donor family to decide on organ donation because it is the only accessible evidence of a donor's opinion about organ donation.

#### **4-4. Meanings of the Donation Will in the Chronic Grief of the Donor Family**

A donor's organ donation will is very valuable for donor families as it helps them to understand whether or not their family member wished to donate organs. Some families perceive it almost as a sacred link that holds a conversation with the soul of the lost person. As research into this cutting-edge medical care continues, we are learning more and more about the power and control of the donor as a new agent. The donation will has various roles and meanings for donor family members – in particular, it is a communication tool for the donor family to understand whether the donor wanted to donate his/her organs. The new arena in which families are asked to decide whether or not to donate their loved ones' organs is a pivotal moment for all concerned parties, including recipients and transplant surgeons: making the decision to donate organs is the starting point for recipients to receive transplanted life from a donor. Simultaneously, it is the moment that a dead family member becomes a donor. Thus, the donation will is necessary for the donor family in the acute grief stage to make a decision about organ donation; in the chronic grief stage the family continues to turn to the donation will for inspiration but their interpretations may transform over time (Table 12).

#### **4-5. Shifting the Donor's Organ Donation Will to Environmental Factors of Donor Family**

In 2014–2016, the chronic grief stage, donors' organ donation wills were present among both the regretful and the satisfied groups of donor families. However, the meanings and roles of the donation wills were now absolutely different for them. The regretful group now felt that the donation will had an incomprehensible meaning and a powerless role for the donor family; they had mostly forgotten its precious meaning and felt that it did not work well in their daily life. Contrastingly, the satisfied group had come to believe that their family member donor would have been pleased with their decision to donate, creating a positive feeling and a fitting environment for their life circumstances. However, the organ donation will was a less significant factor in the chronic grief stage and its role appeared to have changed in various ways. Research into these new

findings is continuing and more is needed to create a deeper understanding of these grieving processes.

#### **4-6. Research Limitations**

Further research is necessary to reveal donor families' grieving processes with much richer data. First, the number of donor families providing narrative data is too low to make generalizations. Second, these narratives are only from donor fathers, mothers and a wife: in the future it will be necessary to gain evidence from donor husbands as well as other relationships such as brothers, sisters, sons, daughters and so on. In addition, this research obtained data from donor families' narratives only during 2003–2016: it is necessary to continue follow-up research over a longer duration in the future.

However, such a long-term follow-up study faces difficulties because it is impossible to conduct interview research with the same situation over a long duration. It was impossible to perform semi-structured interviews in both 2003 and 2014–2016 because every donor family lives in a world which is changing. One donor family member had a stroke and suffered memory loss; one suffered from dementia and entered full-time care, no longer attending transplant events; one left the donor family activities; one continues to exchange messages with me (both snail mail and email) and I have the chance to meet two every year.

Some informants (medical staff, recipients and donor family members) have passed away and some cannot join my research due to increasing age; on the other hand, some have had a chance to meet every year during 2002–2016. It is predictable to gain variability in the quality and situation of research findings because everything (everyone) changes. So we have to grasp a complementary way of conducting research, and adjust and respond to changing situations flexibly.

### **5. Conclusion**

I conclude that a donor's organ donation will is very important factor for concerned

parties to organ transplantation from brain-dead and heart-dead donors. It is especially significant for donor families, although it appears that its role changes over time. A donation will is very helpful for all donor families when deciding whether to donate organs from a family member after heart or brain death. In addition, after donation, all family members face the sadness of having lost a loved one and can feel confused that as a newly bereaved family they are now called a donor family. All donor families with a donation will felt that the acute grief stage was reduced, but the power of the donation will appeared to fade over time, changing how the donor families perceived it. All donor families create new lives for themselves in the world they face having made the decision to donate. If their circumstances lead to a negative attitude towards organ donation, they regret the donation and their grief becomes deeper, whether or not they had a donation will. If their circumstances lead to a positive attitude towards organ donation, their assessments turn to satisfaction with their decision and their sadness is reduced at the chronic grief stage.

### **5-1. Future Problems**

This research shows the changeable assessment of organ donation by donor families over time. Some donor families move from satisfaction to regret, and some from regret to satisfaction; only one donor family remained satisfied during the 14 years of my research (2002–2016). More research is necessary to reveal negative or encouraging environmental factors in society by following up on concerned parties' narrative data over the course of two or three decades and longer. Also we should pay increasing attention not only to recipients but also to donor families' issues, because a recipient lives with a donor's organ and this partial body is thus functioning (alive) inside the recipient, according to the concerned parties' narrative data.

## **6. Acknowledgements**

I am grateful to all my informants: the transplant surgeons, organ recipients and donor families in both Japan and the US. In particular I greatly appreciate the six donor families, who

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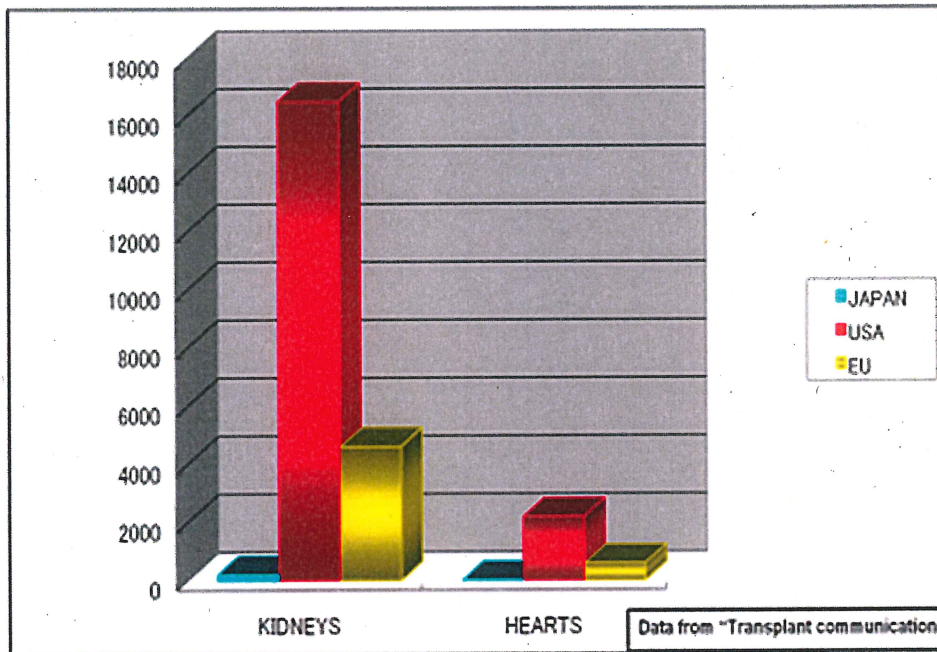
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## 8. Figures

Figure 1. Heart and Kidney Donation Numbers in the US (Red), EU (Yellow) and Japan (Blue) in 2008.



Source: Medical Information Network Society (Transplant Communication), 2016.

Figure 2. The Latest Japanese Donor Card

**< Please circle (○) either 1, 2, or 3 below. >**

- 1. In the event that competent medical authority declares me either brain dead or cardiac dead, I hereby agree to donate my organ(s) for transplantation purposes.**
- 2. In the event that competent medical authority declares me cardiac dead, I hereby agree to donate my organ(s) for transplantation purposes.**
- 3. I will not donate any organs.**


*<For those who circled either 1 or 2, please check (X) the name of following organ(s) you do not wish to donate, if any.>*  
 Heart, Lung, Liver, Kidney, Pancreas, Small Intestines, Eyes

**(Special comment column: \_\_\_\_\_)**

**Date of Signature :** \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
(Month) (Day) (Year)

**Cardholder Signature :** \_\_\_\_\_

**Family Member Signature :** \_\_\_\_\_



*Note on designating family members as priority recipients for organ donations:* since 17 January 2010 it has become possible to designate family members as priority organ recipients. If you wish to designate family members as priority donor recipients, write “Prioritise family” in the special comment column. To donate organs to family members it is necessary to meet all three of the following requirements:

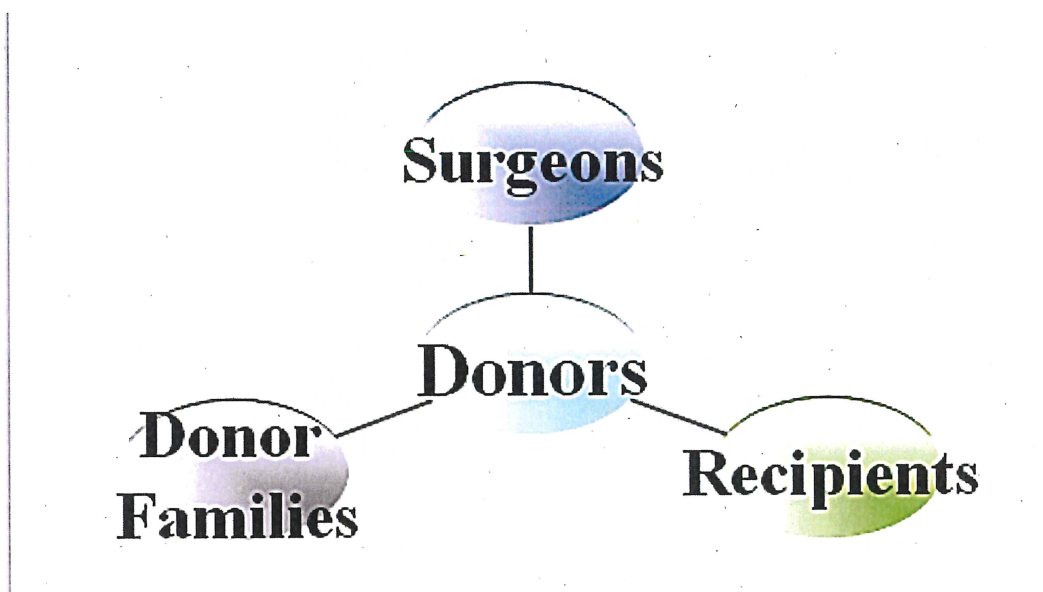
1. In addition to declaring their intention to donate organs, the individual (aged over 15) should put in writing their wish to prioritise family members as organ recipients.
2. Any designated family member(s) (spouse\*, children\*\* or parents\*\*) will need to be currently registered in order to be eligible.
3. Medical requirements (e.g. compatibility) need to be met.

\* This refers to legally recognised spouses who have submitted their marriage notifications, but does not include those in de facto relationships.

\*\* In addition to biological parents and children, this extends to foster/adopted children and parents in special adoptive relationships recognised by law.

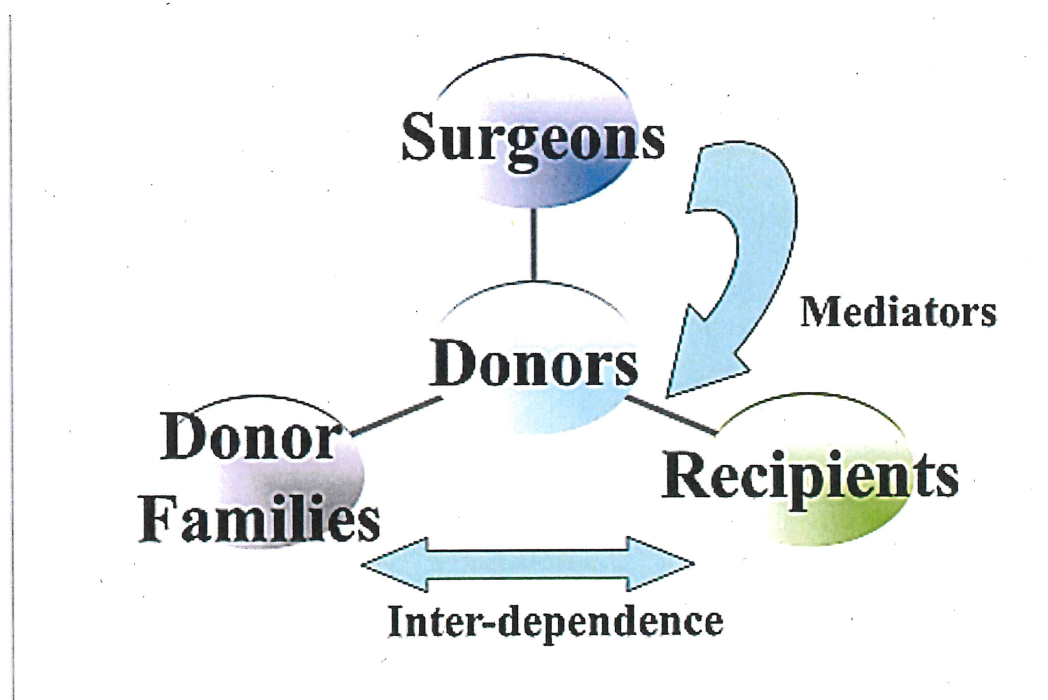
Source: JOTN (The Gift of Life), 2016.

**Figure 3. Expected Relationships between Concerned Parties to Organ Transplantation**



*Note:* existing medical treatments provide medical care between doctors and patients or recipients (medical paternalism). But organ transplantation is a special treatment that depends on donors (and donor families): donors are seen as the central agent in this.

**Figure 4. Actual Relationships between Concerned Parties to Organ Transplantation, According to Narrative Data**



*Note:* according to the narrative data collected through my research, donors are seen as the central agent and can “control” concerned parties as follows.

- Donor families feel that organ transplantation is giving donors’ love to recipients.
- Recipients feel that organ transplantation is receiving donors’ love.
- Surgeons feel like mediators, connecting donors and recipients by harvesting donors’ love and transplanting it into recipients’ bodies.
- Recipients and donor families create inter-dependent relationships, meaning that recipients can survive with donors’ organs and donors can stay alive inside recipients’ bodies (via the donated organ).
- Donor families in regret group have poor interpersonal relation with recipients but have too strong relationship with donor who passed away.
- Donor family in satisfied group have well-balanced interdependent relationship with recipients and have moderate relationship with dead-donor.

*Source:* Yasuoka, 2015.

**Figure 5. A Japanese Donor Father awards an Australian Victor Recipient a Medal at the World Transplant Games**



**Figure 6. New Life Circle at the World Transplant Games**



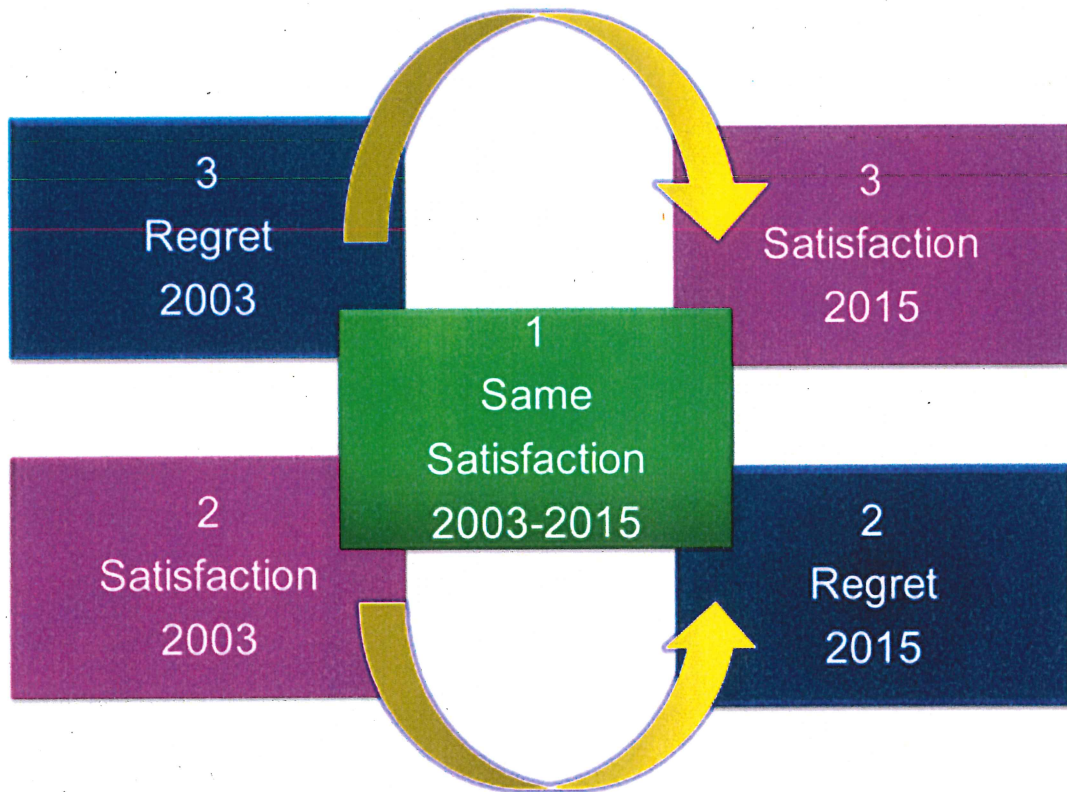
*Note:* At the end of each Transplant Games, all the participants – transplant surgeons, recipients

and donor families – form a big circle (called the “new life circle”) and unite their hearts, thinking of the donors and sharing their feelings across the different positionalities, nationalities, genders and age groups.

*Source:* JTR (Photographs of the 11th Organ Transplant Games), 2016.



**Figure 7. Donor Families' Ambivalent Views**



*Note:* three donor families (50%) were satisfied and another three (50%) regretted their choice to donate in 2003; four donor families (67%) were satisfied and two (33%) were regretful in 2015. However, their views changed unpredictably: and three originally regretful donor families (50%) changed to satisfaction and two originally satisfied families (33%) changed to regret. Only one donor family (17%) remained satisfied.

## 9. Tables

**Table 1. Donors' Status of Death, Organ Donation Country and Recording Place**

Donor Family	Relationships of donor	Status of death	Organ donation country	Recording place	Remarks column
A (Father)	Daughter	Cadaveric death <sup>1</sup>	Japan	Donor's house Okayama	Donor's mother refused interview
B (Mother)	Son	Cadaveric death <sup>1</sup>	Japan	Hokkaido Univ. Sapporo	
C (Mother)	Son	Brain death <sup>2</sup>	Japan	Donor's house Tokyo	
D (Wife)	Husband	Cadaveric death <sup>1</sup>	Japan	Coffee shop Tokyo	
E (Father)	Son	Brain death	Australia <sup>3</sup>	Donor's house Tokyo	Donor's mother refused interview
F (Mother)	Son	Brain death	Australia <sup>3</sup>	Donor's house Tokyo	Donor's father refused interview

*Notes:* <sup>1</sup> Donor family donated their family members' organs on heart death before the organ transplantation law was established in Japan in 1997 allowing brain-dead donations – these donor families decided on organ donation and had to wait for the donor's heart death.

<sup>2</sup> Donor family donated their family members' organs on brain death after the organ transplantation law was established.

<sup>3</sup> Donated in Australia.

These six families gave full permission to allow me to record their narrative data for my research.

Many other families refused to allow an interview to be recorded at one of the following stages.

- Donor family rejected my request when a member of JTR staff asked for a recorded interview.
- Donor family initially accepted but later rejected my request when an interviewer confirmed by email.
- Donor family initially agreed to an interview but refused to allow recording just before the interview.

**Table 2. Personal Data**

<b>Donor family</b>	<b>Age</b>	<b>Occupation</b>	<b>Family structure</b>	<b>Donated organs</b>	<b>Duration (year)*</b>	<b>Duration (year)* *</b>
<b>A (Father)</b>	53	Salaried worker	Wife Son <b>Daughter</b> Daughter	A Kidney	5	13 and 14
<b>B (Mother)</b>	53	Office worker	Husband (divorced)  <b>Son</b>  Son	Kidneys	7	8 – 20 (every year)
<b>C (Mother)</b>	77	Unemployed	Husband (died)  <b>Son</b>	Kidneys, Heart valves, Eyes (cornea), Skin, Bones, Cells	6	9
<b>D (Wife)</b>	43	Ballet instructor	<b>Husband</b> Daughter	Kidneys, Heart valves, Eyes (cornea), Skin, Blood vessel, Throat	4	16
<b>E (Father)</b>	62	self-employed business	Wife  <b>Son</b> Daughter	Kidneys Liver	12	23
<b>F (Mother)</b>	61	House wife	Husband  <b>Son</b> Daughter	Kidneys Liver	12	23

Note: Red-coloured family members (husband, son and daughter) are the donor in each family

structure box.

\* Duration (year) means the time after organ donation that the first interview was recorded.

\*\* Duration (year) means the time after the first interview that the next interview was recorded.

**Table 3. Interview Guide (for Donor Family): Face Sheet and the Actual Example**

<b>Face Sheet for Donor Family</b>	<b>Feb 1<sup>st</sup>, 2003</b>
<b>① Personal Data</b>	
Name	Donor Family A
Sexes	Male
Marital Status	Married
Age	53
Occupation	Salaried man
Education	High school
Family structure	4 (Wife, first son, second daughter)
<b>② Medical Data</b>	
Donated Organs	One kidney
Duration of organ donation	5 Years (Sept 1997), First daughter (21)

**Table 4. Interview Guide (for Donor Family)**

<b>Interview Guide (implementation)</b>	<b>Agreement</b>
① Explanation about the purpose of interview	All (donor families)
② Obtaining permission to use by anonymous narrative data from the donor family	All
② Explanation of the progress of the interview	All
③ Obtaining the consent of the tape recording	All
④ Confirmation of interviewee's (donor family's) questions	All
<b>Interview guide (main questions)</b>	<b>Remarks</b>
① Narrative interview (constraining and generating narratives)	All donor families were talkative and talked for about 1~4 hours.
② Follow-up questions	
③ Overview and summary questions	
④ Gleaning questions	

*Note:* Although I had heard that donor family interviews were very difficult because they didn't talk about organ donation, they talked a lot and looked forward to having the chance to talk about their experiences and their current feelings for others.

**Table 5. Interview Guide (for Donor Family)**

**Interview Guide (implementation) for Donor Family\***

- ① まず私の意図を説明します。私の関心は、ドナーのご家族の臓器移植に関する個人的なご経験とご意見です。実際に、臓器提供をされたドナーのご家族の方から、臓器移植について学ぶことができると思います。それが私の研究のきっかけです。
- ② ドナーのご家族・レシピエント・医療者のお話に基づいて、私は博士論文を書く予定です。その際、皆さんのお名前を匿名にいたします。
- ③ これからの話を次のように進めていきたいと思います。まず移植医療について導入質問を2つします。その後で補足質問を7つします。
- ④ 1つお願いしたいのは、今日のお話をテープに録音させていただくことです。と申しますのは、ドナーのご家族のお話を理解し分析するには、正確な記録が必要だからです。もちろんその録音テープやあなたのご発言を内密に扱うことを約束いたします。ご承諾いただけますでしょうか。
- ⑤ このインタビューについて、ご不明な点がありましたら、今おっしゃってください。

**Questions\***

- ① あなたは、どのような経緯で臓器提供に同意されましたか？
- ② ご自身の臓器移植観を教えてくださいませんか？
- ③ 臓器移植はどのような“命の贈りもの”とお考えですか。
- ④ 臓器提供をなさって、移植医療のために何が重要だとお感じですか。
- ⑤ あなたがご家族の臓器提供を決断された時、御自身の状況は心理的・肉体的にどのようなものでしたか。
- ⑥ ご家族の臓器提供をされる前と、現在と比べて何か変わった点はありますか。
- ⑦ ご自身の臓器提供の経験から何を学ばれましたか。
- ⑧ レシピエントや医療者にアドバイスなさいたいことはありますか。
- ⑨ ご自分の“いのちの贈りもの”観を教えてくださいませんか。
- ⑩ 総括：整理すると、どうしてあなたは臓器提供を選択なさったとお考えですか。
- ⑪ 何か言い忘れたこと、思い浮かんだこと等、どうぞお話しください。

\*Interview guide for donor family and questions are placed here as they were asked, in Japanese.



### **Interview Guide (implementation) for Donor Family**

- ① First of all, I will explain my intentions in today's interview. I'm interested in donor families' personal experiences and opinions about organ transplantation. I believe that I will be able to learn about organ transplantation issues from donor families who had donated a family member's organ. That's my motivation of my research.
- ② I plan to write a doctoral dissertation based on donor families, recipients and medical staff. I will anonymize your names in my dissertation.
- ③ I would like to ask you some questions now. First, I will ask you two main questions about organ donation, and then seven supplementary questions.
- ④ I would like to record your talk on tape today because I need accurate records to understand and analyse donor families' speech. I promise to regard the recorded tape and your talk as strictly confidential. Could you give your consent?
- ⑤ If you have any questions about today's interview, please let me know now.

### **Questions**

- ① Would you tell me whether you agree with organ donation?
- ② Could you tell me your own philosophy about organ transplantation?
- ③ What are your thoughts about organ donation as a "gift of life"?
- ④ What do you feel is important for transplant medical care through your own family member's organ donation?
- ⑤ How were your psychological and physical states when you made the decision of organ donation of your family member?
- ⑥ Has anything changed, comparing before and after the organ donation of your family member?
- ⑦ What did you learn from your own experience of organ donation?
- ⑧ Do you have any advice for recipients and transplant medical staff?
- ⑨ Could you tell me your own philosophy about the "gift of life"?
- ⑩ General overview and summary: Why do you think that you chose organ donation, to put it briefly?
- ⑪ Please tell me if there is anything you forgot to say, or any questions that come to mind.

**Table 6. Coding Process – an Example**

<b>Coding Processes; Donor Families' Narratives</b>
<p><b>“Wish”</b></p> <p>① Wish of Father</p> <p>“I want my daughter to live even if it is only her organ! Although she is a missing child, she lives inside a recipient’s body somewhere. I want to see the...”</p> <p>② Wish of Mother</p> <p>“I’d like to make my son alive in someone else’s body to avoid his death. I had a feeling that I didn’t lose everything from me. I’m always with my son!”</p> <p><b>“Life”</b></p> <p>① Gift of life →as a result, “gift of life”</p> <p>--Organ donation is a ritual to make donors be reborn as one of the members of donor families</p> <p>② Life with a Donor</p> <p>--Donors can be reborn in donor families’ minds with various narratives</p> <p>③ <u>Rebirthable Life (donor)</u></p> <p>--A donor can be reborn in donor family’s minds through organ donation but invisible and limitless life</p> <p>⇔Renewable Life (recipients)</p> <p>--A recipient can renew his/her life with a new donor’s organ(s) but biological and limited life</p> <p>④ Donor’s Life</p> <p>What is a Donor’s Life?</p> <p>--Donor’s life is narrated and reproductive life</p> <p>--Donor’s life can control concerned parties’ concepts of life flexibly</p> <p><b>“Experience”</b></p> <p>① Vicarious experience</p> <p>--Parents will experience vicariously of their child as parents’ duty</p>

## **“Relationship”**

### ① Interdependent Relationship

--Recipients need Donors' organs

--Donor families need recipients' bodies

--Concerned parties are sharing donors' lives

*Note:* When each donor family use the same words (terms) such as “wish”, “life”, “experience” and “relationship”, they have choices of key words, but every meaning is different, reflecting their own positionalities.

**Table 7. Coding Process from Field Notes – an Example**

<b>Coding Processes; Donor Families' Narratives (Motivation)</b>	
<b>Donor Family</b>	<b>Raw data</b>
A	I hope that my daughter will live somewhere, but I have no permission from my daughter
B	I just make my son stay alive, not make him a "gift of life"
C	My son had no donor card but I was forced to donate by his doctor: I feel that my son pities me
D	He kept an organ donation will and only I could follow that through for him
E	I'm proud of my son because his organ donation will was clear and saved recipients!
F	I'm proud of my son because his organ donation will was clear and saved recipients!
<b>Donor Family</b>	<b>Meaning</b>
A	Father expects daughter is alive in recipient but he blame himself for not having her permission
B	Mother never accept her son's death and seeks another way to keep her son alive
C	Mother couldn't refuse organ donation and she blame herself to her son
D	Wife feels she is making her husband's wish comes true, reducing her sadness
E	Father has strong pride for his son who had a donation will and saved some recipients
F	Mother has pride for her son who had a donation will
<b>Donor Family</b>	<b>Sub-category</b>
A	Regret: (Parent's ego)
B	Regret: (Mother's ego)
C	Regret (dreadfully sorry for her son as Mother)
D	Satisfaction (Mission as a wife)
E	Satisfaction (Father's pride)
F	Satisfaction (Mother's pride)

*Note:* Each donor family's motivation of organ donation varies, according to the raw data; the meanings of their narratives were unexpected and it was difficult to understand them easily. Further, their narration was sometimes too unique, eccentric and fantastical for their expressions to be easily categorized.

**Table 8. Coding Process from Field Notes – an Example**

<b>Coding Processes; Donor Families' Narratives (Donor Family A: Regret → Satisfaction)</b>	
Organ donation (2003)	
①	I want my daughter live inside someone's body somewhere, even partially
②	Motivation of organ donation was to avoid perfect death of daughter
③	Organ donation is a way to save my daughter's complete death
④	There was family consensus for organ donation of family member
Temporary satisfaction	
①	"We have peace of mind that we did a good thing for a while"
②	We had a good assessment of organ donation
③	Temporary satisfied organ donation
Mental Abuse	
①	We had mental abuse by verbal violence: the worst words were "How much did you receive donate your daughter's organ?"
②	Our satisfaction feeling of the organ donation weakened
Donor's organ donation will	
①	"There was no organ donation will of my daughter's at all."
②	"After verbal violence and mental abuse, we noticed that my daughter didn't expect organ donation ..."
③	We had strong sadness and regret organ donation
First meeting with recipients	
①	"When I met recipients first at the Transplant Games, I thought, 'Why are you so lively? Can you look like more sick people?'"
②	I felt strong resentment toward recipient (although I know that it is a great pleasure that the recipient's life is saved)

③	Logically I feel that pleasure of saving a recipient's life came out of the sadness of my daughter's death, but illogically I feel jealous at the unfairness that the recipient was saved but that my daughter was not.
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*Note:* The coding processes revealed a mix of rational and irrational feelings within informants' narratives; I have tried to seek and analyse rational responses from their data.

**Table 9. Donor Families' Satisfaction/Regret at Donation and Presence of a Donation Will**

Donor Family	2003 Assessment (A03)	2014-16 Assessment (A14/16)	Donation will
A	Regret (R)	Satisfaction (S)	Without (-)
B	Regret	Satisfaction	Without
C	Regret	Satisfaction	Without
D	Satisfaction	Satisfaction	With (+)
E	Satisfaction	Regret	With
F	Satisfaction	Regret	With

*Note:* Each assessment and expression of donation will is abbreviated in parentheses; these abbreviations are used in later figures.



**Table 10. Relationships among Donor Families and Donors, Cause of Death,**

**Donor's Donation Will, Donor Family's Donation Will and Satisfaction/Regret**

Donor Family	Donor	Donor's Cause of Death	Cause of Death	Donor's Donation Will	Family's Donation Will	A03	A14/16
A Father	Daughter	Car accident	sudden death	-	-	R	S
B Mother	Son	Car accident	sudden death	-	-	R	S
C Mother	Son	Subarachnoid hemorrhage	sudden death	-	-	R	S
D Wife	Husband	Brain tumours	death from chronic disease	+	+	S	S
E Father	Son	Car accident	sudden death	+	-	S	R
F Mother	Son	Car accident	sudden death	+	-	S	R

*Notes:* The relationships between donors and donor families may be an important factor:

1) parents – children: donor families' assessments are changeable and sensitive to others' assessments – donor families are very emotional; 2) husband –wife: donor family's assessment is stable and respects spouse's wish – donor family keeps a sense of composure (more than parent donor families).

The cause of death, whether sudden or from chronic disease, does not appear to have a different impact on the donor family. Donation after a car accident with a donation will may cause satisfaction initially but this may not last; donation after a car accident without a donation will cause regret in the early stage but the donor family may feel satisfaction a decade later. The family

of a donor dying of a chronic disease with a donation will may feel satisfaction without changes.

The relationships between donors' donation wills and donor family's donation wills are an important factor to satisfy organ donation; 1) Donor Family A, Donor Family B and Donor Family C didn't have donation wills when they donated organs from their family members, but they have donation wills now;

- Donor Family A ⇒ "I will donate my own organ, because my daughter did. I can't say that I won't donate"
- Donor Family B ⇒ "If my second son gives me permission, I want to donate my organs and I will have the same experience as my son (donor). But my second son will donate my organs, which means I rely on his decision."
- Donor Family C ⇒ "My son got a rebirthable life (*mouichido no inochi*) and he is saving someone and his organs are living inside someone. It's wonderful! I hope to do so. But I wonder if I'm too old to donate. But I want to. However, I can't recommend organ donation for others though."
- Donor Family E and Donor Family F didn't have donation wills when they donated organs from their family members and they still don't.
- Donor Family D had a donation will when they donated; the wife still has one and her grown-up daughter also has a donation will at present.

**Table 11. Transforming the Effectiveness of the Donor's Donation Will for the**

**Donor Family**

Donor Family	Donor's donation will (2003)	A03	Donor's donation will (2014–2016)	A14/16
A	Weak	Regret	Stronger	Satisfaction
B	Weak	Regret	Stronger	Satisfaction
C	Weak	Regret	Stronger	Satisfaction
D	Strong	Satisfaction	Strong	Satisfaction
E	Strong	Satisfaction	Weaker	Regret
F	Strong	Satisfaction	Weaker	Regret

*Note:* A donor's organ donation will is always effective for the donor family, but its power is very changeable and transformed during 2003–2016;

(1) Donor Family A, Donor Family B and Donor Family C didn't have a donor's donation will when they donated organs from their family members, and so did not know their family members' preference.

- Donor Family A ➔ “When our doctor whispered to me ‘There is a way to organ donation to keep your daughter's kidney alive’, I thought that it was a good idea and I donated my daughter's kidney without her own donation will, so I think that my daughter is angry because the doctor cut her body and harvested her kidney. I made her experience pain. And I begged for her forgiveness ... I received a thank you letter from the recipient and she thanked me a lot; this means that my daughter has now forgiven me...”
- Donor Family B ➔ “When I received a certificate of gratitude letter from the Ministry of Health and Welfare I gave it back because I didn't do anything to be thanked for at all ... just keeping my son alive.... When I saw many recipients in the Transplant Games and both recipients and donor families gave more than a passing thought to donors together, I thought

we can share feelings (we are the same – organ donors and organ receivers). I donated my son's organs to keep him alive and saved recipients' lives... As a result, this is the 'gift of life'!"

- Donor Family C ➔ "His doctor offered organ donation... I felt I could not say no. I was full of sorrow for harvesting my son's organs as his parent without his donation will, when he was given back to me and I looked at his lifeless form! It was an unbearable feeling as a mother to see my son's body with its organs harvested.... However, time is the best medicine and time heals everything. And I thought that I could imagine my son's organs living and existing somewhere in this universe..."

(2) Donor Family E and Donor Family F had donor's donation wills when they donated organs. However, both of them were overwhelmed with grief for the donors (losing their children) and can't accept the donor's death yet.

(3) Donor Family D had a donation will and keeps it still; she has more objectivity that her husband's death (the donor) and organ donation are completely different things, but obeying his donor's will heals her sadness at losing her husband.

**Table 12. Meaning of Donor's Organ Donation Wills and Reasons for Regret**

Donor Family	Communication tool between donor and donor family 2003	A03	Reason for regret 2003	Communication tool between donor and donor family 2014–2016	A14/16	Reason for regret 2014–2016
A	None	R	Thoughtless question	Thanks letter	S	
B	None	R	Mental abuse	Meeting and talking with recipients	S	
C	None	R	Forced decision making by doctors	Attending recipients' events	S	
D	Donor's will	S		Memory of donor	S	
E	Donation will	S		None	R	unacceptable donor's death
F	Donation will	S		None	R	unacceptable donor's death

*Notes:* A donor's organ donation may play the role of a communication tool. In particular, at the moment of reaching the decision of organ donation, most donor families respect the organ donation wills of donors. Thus, the donor families that did not have organ donation will hesitated over organ

donation and regretted it afterwards. However, those that had the communication tool with their donors overcame their sadness at losing family member and tried to communicate with recipients directly or indirectly.

1) Donor Family A, Donor Family B and Donor Family C didn't have a donation will when they donated the organs of their family members so they made the decision on behalf of the organ donors. However, each donor family has now found and is communicating with a living recipient instead of his/her donor.

- Donor Family A ➔ "I decided on organ donation because of my daughter's doctor, but I did not know whether she had a positive opinion of transplantation and donation beforehand. But I do not care now whether she was pro or con organ donation, because meeting and talking with recipients, I felt sure that my decision was not wrong. That's why I can meet them and feel happiness... I think that my daughter's "Yes" provides me such a wonderful time with recipients..."
- Donor Family B ➔ "Although I voluntarily offered my son's organ, I just wanted to avoid a topic on my son's death. Now I can always feel and see my son within recipients: I hope that they have long lives and keep my son alive. Both the recipients receiving his organs and me (donor family) donating his organs are equal in the sense that the donor is very precious for both of us!"
- Donor Family C ➔ "I was forced to donate my son's organ by medical doctors and coordinators and I couldn't say no... but when he was back home with his hollow-eyed, organ-harvested body, it made me so sad and I apologized to him... Time is the best medicine... Whenever I meet recipients, when I come back home, I will tell my story with recipients to my son in a family Buddhist altar. And I tell him 'You did a good thing!'"

2) Donor Family E and Donor Family F had a donor's donation will and they respected it with a satisfied feeling.

- Donor Family E ➔ However, his sadness over the donor's death has become more and

more serious. He avoids topics on organ donation and finds no need for the communication tool of the donor's will (he still believes that the donor was alive before organ donation).

- Donor Family F ⇒ Her son had a donation will and she respected it and donated with satisfaction. However, she regrets it now: "I always think why I donated against my will even though there was my son's donation will and family consensus. Just me, I should be against my son's organ donation... After donation he will never come back to me anymore. Why wasn't I against it?" She thinks that organ donation is accepting her son's death so she never touches on this topic with her family after the donation.

The reasons for regret for organ donation are varied.

- 1) Donor Family A, Donor Family B and Donor Family C had a kind of social abuse (environmental factors).
- Donor Family A ⇒ "Organ donation itself, my family had no problem actually, although we didn't have our daughter's organ donation will: we accepted her doctor's donation offer and things went well. But at the funeral of my daughter, I was asked by my relatives, 'How much did you receive? How much? How much you could earn money with donating your daughter's organ? How much?'... My wife and I had a great shock and we regretted the decision deeply and we feel guilty for my daughter...." (he cried)
  - Donor Family B ⇒ "I told my husband about my son's organ donation after my decision was made; my younger son was still too young but we had no problem at that time. But after the donation, the rumour spread through the entire neighbourhood and we were attacked by people throwing rocks at our house's windows and harassing us with notes through our letterbox that asked, 'Are you really parents to sell your son's organs?' etc. Finally we divorced and I moved to Hokkaido with my younger son." (They had lived in Kobe previously.)
  - Donor Family C ⇒ "I was forced into donating my son's organ by doctors; my son had no donor card and my husband was in the hospital. So I was forced to say yes... When my son's

harvested organ body came back home I felt strongly guilty toward my son and husband and after harvesting organs, I didn't hear a word from them..."

- 2) Donor Family E and Donor Family F had a donor's donation will, but neither of them can accept their donor's death, even now.
- 3) Donor Family D had and still has a donation will and her relatives do too. In addition, not only her relatives but also husband's colleagues admired his organ donation. She said, "My organ donation is a case in which everything went well, but I have heard that there are many sad and tragic cases... I'm so sad..."