

Solidarity beyond the grave

Yielding organs in a Nordic welfare state

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Abstract

According to a survey carried out in 2009, Finnish citizens are exceptionally willing to donate their organs after death, an attitude that paved the way for a 2010 amendment to the Tissue Law that introduced an ‘opt-out’ consent policy. Reactions to the legislative change ranged from taking a highly utilitarian stance on the issue to expressing indignation over the welfare state meddling with citizens’ right to self-determination and ownership of the body. In this article I consider how willingness to donate is linked to the notion that donation is a civic obligation, as well as a means to distribute the valuable national resource that organs are deemed to be. I explore how the welfare state relates to national attitudes towards donation, and I discuss culturally specific terms for donation as a way of understanding the emotions that surround it. By examining the rhetorical moves that turn the body into a community resource, I analyse the specifics of bodily citizenship in Finland, and particularly how the notion of solidarity can be used to explain citizens’ motivation to donate their bodies after death. A key finding is that solidarity is not only needed in order to bring about donation but also produced as a result of donation.

Keywords

donation, transplant, Finland, solidarity, welfare state

Introduction

In a survey carried out in 2009, commissioned by the National Federation of Kidney and Liver Diseases in Finland, 89 percent of respondents were positively inclined to organ donation (Munuais- ja maksaliitto 2009). The survey took place in 2009 prior to the passing of an amendment to the Law on the Medical Use of Organs, Tissues, and Cells (Finlex 2001, henceforth the ‘Tissue Law’), introducing an enforced presumed consent policy in Finland, which means that a person must ‘opt out’ of donation. In practice, the will of the donor now takes precedence, and it is no longer necessary to obtain the consent of donor kin regarding postmortem donation. The survey results paved the way for the transformation of the law, which was also in line with requirements set out in the European Council Directive of 2010 to increase the safe supply of donated organs in member states (European Council 2010).

Just prior to the passing of the 2010 amendment to the Tissue Law a lively discussion took place on the internet forum of the main national daily newspaper *Helsingin Sanomat*. Opinions were divided into two camps: those who took a highly utilitarian stance toward the body and supported the ‘recycling’ of body parts, and those who felt the legislation was an affront to their right to self-determination and ownership of the body. Between 31 October and 8 November 2009 a discussion chain titled ‘*elinsiirrot pakolliseksi?*’ (donation made compulsory) received 185 posts from a number of different participants. The distribution of those discussants in favour and those against the amendment was fairly even, eighteen to fifteen. For many respondents it was matter of principle that they should be allowed to decide the fate of their body, rather than the state making this decision for them. One discussant going by the handle ‘alkuasukas’ put it like this: ‘[I] am disturbed by the fact that the state with a unilateral contract decides that after death the body is its property. It would have been much more sensible to start a campaign in favour of organ donation. Finland is the promised land of must-dos, prohibitions and commands’. Individuals who adopted a pragmatic stance to the issue challenged such statements. JM-K’s post illustrates the perspective of those who favour compulsory donation:

As a practical man I have donated my body to medicine with the principle of ‘do what you like’. Everything that is of use should be recycled, the remains to medical students as material to practice on and the rest into the oven and the ashes [spread] anywhere. EDIT: I forgot the essential thing that, yes, organ donation should be compulsory. You won’t be doing anything with them [your organs] once you are dead.

When the legislation was passed, but also prior to it, there was a notable lack of public debate about what these changes entailed for individual citizens, questions about what the proposed legislative amendment would mean in the context of their lives, or discussion of the ethical

issues tied to the expropriation of body parts. Finland lacks a strong tradition of national consensus; when policy decisions are taken, they are based on statements made by experts that are then communicated to decision makers and state bureaucrats. Most of the material published on this question in the national daily papers, the *Finnish Medical Journal* (*Suomen Lääkärilehti*), and the journal of the Finnish Medical Society *Duodecim* around the time of the amendment presented organ transplantation as an accepted and recommended form of care for certain types of terminal illnesses. The commentaries underscored the necessity of transplant surgery, and, by extension, the need for transplantable tissue. They also highlighted the fact that a lack of transplantable tissue resulted in patients dying while waiting for these valuable resources. Building their arguments, the authors kept a positive tone: they noted the economic advantages of providing patients with a transplant compared to keeping them alive while they wait to receive an organ, reassured the public of the worthiness of transplantation, said that organs are handled with the utmost care and that they are in the hands of skilled professionals, pointed out the good results achieved in life expectancy among transplant recipients, and reminded readers of the increase in quality of life that patients experience after receiving a transplant (see, for example, Isoniemi 2011; Salmela 2010a; Höckerstedt and Hermanson 2010; Kulonen 2010; Vierula 2009; Toikkanen 2009).

A guest editorial written by Kaija Salmela (2010a), a transplant surgeon at the Helsinki University Central Hospital (HUCH), neatly summarises the above points, but also presents donation as a moral imperative. She refers to balancing the supply and demand of organs as a social responsibility, drawing a parallel between autopsy and organ donation:

Medical or forensic autopsy is accepted as a necessary measure following death. One should in a similar manner accept post-mortem organ donation through which it is possible to rescue 5–6 terminally ill patients to a new life. You can never know when you or your family member desperately needs a transplant organ.

Salmela is basically telling the public to regard the use and manipulation of the deceased body as a routine procedure. She also reminds the public of how donation of organs entails solidarity both with other citizens as well as one's own family. For medical professionals who work within transplantation it is a moral imperative to extend the lives of terminally ill patients and to enable them to live as normal a life as possible. Organ transplantation is also something that medical technology has made possible and within the welfare state context all Finnish citizens are given equal access to this technology. The role of the welfare state as an institution in charge of moving along transplant tissue within a complex system of exchanges is central. It is a trajectory that extends beyond the boundaries of the nation to other Nordic countries in the form of the regional organ exchange system Scandiatransplant.

However, the comments posted in the newspaper's discussion forum illustrate that need is not always a primary concern of citizens. Given the lack of critical debate, and agreement among public commentators, we might ask whether ethical issues surrounding organ transplantation were sufficiently discussed before initiating preparation of the legislative amendment. Understanding why the Finnish population is, on a conceptual level, inclined towards donation is difficult because no qualitative data have been collected and there is very little social science research on the topic. Nonetheless, a variety of perspectives on donation have been examined by researchers elsewhere, which inform my analysis here. The majority of qualitative studies within medical anthropology, sociology, and psychology have focused on the reception side of donation, the metaphor of the gift, and perceptions of death that enable the practice of deceased donation (see for example Sanner 2001, 2006, 2007; Sharp 2006, 2007; Lock 1997, 2002; Simmons, Marine and Klein 2002; Siminoff and Chillag 1999; Fox and Swazey 1974, 1992). Within ethics research the issue of willingness to donate organs has been explored to some extent (see for example Schweda and Schicktanz 2009, 2012; Childress 2001; Fentiman 1994; Zeiler 2009; Zeiler, Guntram, and Lennerling. 2010; Steiner 2003, 2010), but there remains a lack of broader qualitative studies that explain what motivates or hinders donation in specific settings, and how citizens have reacted to legislative changes concerning organ and tissue donation.

In this article I consider willingness to donate in Finland, and how it relates to the notion that donation is both a citizen's obligation and a means to distribute the valuable national resource that organs are deemed to be. I focus on two central aspects of the organ transfer process: the cultural valuations linked to the notion of donation in Finland and the view of the transplant organ and tissue in public discourse. Choosing these two aspects allows for an analysis of the culturally specific terms *luovuttaminen* (donation) and *siirrännäinen/elinsiirto* (transplant/transplant organ), which in turn may explain the sentiments of citizens who express discomfort and annoyance at having their organs taken from them at death, and those who conversely adopt a pragmatic stance supporting the 'recycling' of organs. Solidarity, or the idea of organ donation being a citizen's responsibility, is referred to in research on organ donation and transplantation, but the notion of solidarity itself is seldom thoroughly explored or explained (see Prainsack and Buyx 2011, 2012 for a review on solidarity in bioethics research). What understanding of solidarity are we to use to explain what values act as a force that drives citizens to give of their bodies at the time of death?

Methods

This article is based on data collected during a postdoctoral research project I conducted between January 2010 and December 2012 on the social and cultural context of organ transfer in Finland, focusing particularly on understanding subjective experiences of the

transplantation process and the meanings organ recipients construct of this experience. It was the first study of its kind to be conducted in Finland. The respondents in this study, eighteen kidney transplant recipients, were recruited through a national-level patient organisation and its regional partner organisation. The research process included in-depth interviews with transplant recipients, and participant observation of activities organised for them as well as at events aimed at increasing the general public's knowledge of organ transplantation, such as discussion clubs, leisure activities, lectures, rehabilitation courses, sporting events, theme days, and campaign events. In addition, secondary data in the form of newspaper and journal articles as well as patient manuals were used to gauge how transplantation is described to the general public as well as how it is discussed within the research and recipient community. I conducted one formal interview as well as several informal discussions with transplant surgeons. For the purposes of this article I also searched through national databases using the phrase 'organ and tissue transplantation' for journal and newspaper articles produced in Finland covering the time period 2000–2015. As no qualitative research has previously been conducted in Finland on motivations to donate organs, I chose to use newspaper articles dealing with the question in order to piece together a picture of how the issue is presented to the public and how it is spoken of among medical experts and media representatives. My research suggests that this material has had an impact on how the general public views organ donation and potentially also on their willingness to donate.

The interviews provided insight into how recipients view the transplanted organ and the obligations and methods of reciprocity they use to repay the welfare-state-run health care system, and also, by extension, the donor families. The issue of reciprocity is a central theme because when something is given by one party (the donor/donor kin) it is also received by another party (the transplant recipient). Though it has been explored at length by other scholars, I integrate analyses of reciprocity into this analysis alongside interview excerpts to illustrate the ambiguities inherent in giving of the body after death and in receiving someone else's body in order to extend one's own life.

Transplantation in Finland

The ratio of organs procured from deceased donors compared with those from live donors is a figure that sets Finland apart from other countries. The majority of Finnish transplant organs come from deceased donors – only 3–5 percent of donated kidneys are obtained through premortem donation, although at present live kin donation is also actively encouraged (Salmela 2010b, 2556; Isoniemi 2011). In an interview I conducted with transplant surgeon Lauri Kyllönen at the HUCH in November 2009, he explained that, as Finland passed legislation on brain death much earlier than in the other Nordic countries, the practice of live donation never needed to expand as the kidney supply was replaced by organs from deceased donors early on

(see also Inomaa 2011). This has contributed to low donor (and donor family) visibility in the media and other public forums. In Denmark and Norway, around half of all transplants used to be elicited through live kin donation, but the gap between live and deceased donors has been narrowing over the past ten years (Scandiatransplant 2016). Since Finland passed the amendment to the Tissue Law in 2010, the number of organ transplantations carried out has increased from an annual total of 265 to 391 in 2015 and 245 of these were kidney transplants (Munuais- ja maksaliitto 2016). In addition to the legislative changes, transplant specialists have been pushing for logistical improvements (appointing donation coordinators in procurement hospitals), budgetary changes (shifting payment for care of brain-dead patients who are potential donors from a municipal level to a national level), and social changes (more actively encouraging live kin donation) in order to increase the supply of organs.

Organs are procured and surgically removed by transplant surgeons at twenty-two regional hospitals and transported to the surgical units at HUCH, where all transplantation surgery is carried out. A number of medical institutions are mobilised to move a transplant organ from the deceased donor's body to the body of the recipient. It requires trauma units in regional hospitals to identify and prepare potential donors for future organ procurement and to inform close kin of the removal of organs for transplantation and the significance of this procedure, which is also a legislative requirement as per the 2010 amendment made to the Tissue Law. Once a potential donor is identified and selected, the transplant surgeons from HUCH are called in to remove the organ. The organ is transported to Helsinki where the tissue is tested and recorded in the tissue bank records maintained by the Finnish Red Cross Society. When a suitable match is found it is offered to the next candidate on the organ waiting list, or it may be transferred to Scandiatransplant, the Nordic organ exchange system. Finding the best possible match increases the probability of the transplant being successful, which diminishes the number of retransplants (Satuli 2009; Salmela et al. 2004). During the preparatory stages before transplant surgery and in the post-transplant period, patients are cared for and monitored by internal medicine units such as nephrology, cardiology, hepatology, and pulmonology. Nonclinical institutions are also involved in ensuring that transplant recipients and live donors receive the necessary support they are entitled to, such as sick-leave benefits through the National Social Insurance Institute. All costs related to transplantation are highly subsidised, including dialysis, transplant surgery, and post-transplantation maintenance of the organ through the use of immunosuppressive medication (Saha et al. 2010). This is a very different system than in the United States, where costs are covered by private health insurance and organ procurement activities are run by corporate organisations (Sharp 2006).

All activities relating to organ procurement are closely documented so as to ensure the safety of organs and to make them traceable (Sosiaali ja terveystieteiden ministeriö [Ministry of Social Affairs and Health] 2004). These are practices that consolidate the population's trust in the expertise

of medical specialists. The high degree of trust and faith placed in the expert knowledge of medical professionals in Finland is linked to a general trust in the functionality of democracy, the educational system, and health care in Finnish society, all rooted in active membership in voluntary associations (Tupasela 2007, 2008; Tupasela et al. 2010; Jallinoja et al. 2008; Sihvo et al. 2007; Kankainen 2009). A high value placed on education and particularly higher education increases respect for the skills of medical professionals and the power of science and its progress. Transplant professionals are known to follow very strict standards when cross-matching tissue, so as to ensure over 94 percent graft survival rate one year after surgery (Salmela et al. 1994). Keeping these statistics at a high level is also related to Nordic cooperation and exchange of information on organ transplantation practices, and the maintenance of Scandiatransplant. The exchange of organs between the Nordic countries is dependent on the member countries of Scandiatransplant (Denmark, Finland, Iceland, Norway, and Sweden) following the same quality and safety standards, and it also positively impacts on the potential to find the best possible match (Satuli 2009; Salmela et al. 2004). The success of the inter-Nordic exchange is dependent on trust that organs removed are treated with care and that organs received are 'repaid' in equal measure (Idvall 2012, 207). In most Nordic countries, during the past decades, a view has developed of transplants and tissues being national resources; the programmes that handle and further transplantation and regulate these activities have developed through national legislation, directives, and infrastructure. At the same time, these national systems are dependent on international collaboration through research contacts, legislation, and meetings between transplant professionals, as well as a global market of organs and tissues that are sold illegally (*ibid.*).

The welfare state context

The welfare state model in Finland stipulates that all citizens have a constitutional and equal right to access public health services. Both health care and social services are highly subsidised (Anttonen 2002). The model is one of an all-encompassing solidarity (Hiilamo 2014) and is based on a contractual relationship between citizen and state and built around a sense of rights and obligations (Sulkunen 2007). It is firmly grounded in an ethos of Nordic universalism (Anttonen 2002). These ideals have, nonetheless, been crumbling since the introduction in the early 1990s of a market-based ideology in Finnish health care, with resulting processes of privatisation, auditing, and individualisation of service delivery (Helén and Jauho 2003; Wrede and Henriksson 2005; Helén 2008; Ollila and Koivusalo 2009). There is also a clear increase in health-based inequalities in the population (Vaarama et al. 2014; Palosuo et al. 2007) and a gradual move away from the principle of universality. Long-term austerity measures designed to bring the country out of two eras of recession have led to cuts in welfare spending, social services, and social benefits (Kalela et al. 2001). A recent OECD report shows that Finland is lagging behind other European nations in GDP and that spending per capita on health care is

lower than in other nations in the region. If the economic situation does not rapidly improve, it will in coming years result in the erosion of the quality and availability of health care services under a government-run system (Punnonen 2015).

The ideology of sharing and of participating in the social project of the welfare state is deeply engrained in Finns; as subjects of the welfare state, a strong sense of duty, obligation, and solidarity has been bred in people. Participating in this project of shared national resources is based on state-propagated altruism (see Titmuss 1970). People want to take part in the public project of the welfare state and do their share by giving back to a system that has provided benefits to them from ‘cradle to grave’, in a parental embrace of caring and control. There is also a long historical development of the concept of health citizenship (Helén and Jauho 2003). In the contemporary context, the link between health care and citizenship is presented through the notion of rights. According to Helen and Jauho, up until the 1800s the discussion surrounding citizenship and society in Finland was focused on viewing the nation and the state as a totality. Citizenship was defined through the notion of belonging to a nation and a people. There were two dimensions to health citizenship at this time; individuals were made into citizens through civilising efforts, such as health education, and they were controlled and categorised by the state in the name of promoting public health (ibid., 14).

Pivotal agents in the construction of the welfare state were the voluntary and civic associations, and most importantly the workers’ movement that was preceded by voluntary associations focused on cultural, educational, religious, sports, and temperance issues, reflecting a history and background similar to that of voluntary associations in Sweden (Süsiäinen 1991; see Hoyer 2003). The dominant ethics of these movements was to breed responsible, self-disciplined citizens endowed with a sense of solidarity. Voluntary associations have long cultural roots stretching back to the mid- to late 1800s when labour-intensive tasks used to be carried out through *talkoo* work, performed by voluntary work parties and building on the principles of reciprocity and helping one’s neighbour (Vilkuna and Mäkinen 1943; Korhonen 1999). The principle of *talkoo* work was used in the postwar reconstruction period when citizens were called upon to contribute to the common struggle of paying back Finland’s war debt to the Soviet Union. Also in contemporary quotidian discourse, the term ‘*kansalaistalkoo*’ (citizens’ *talkoo* work) is used in a variety of contexts to mobilise individuals or groups to engage in a certain issue.

Relinquishing the body

The cultural discourse of ‘gifting’ body parts has strongly influenced organ donation and transplantation practices and attitudes towards these practices all over the world. In most countries that are involved in organ transplantation there are vigorous donor-procurement

campaigns. The strategy employed to increase organ donation in Finland is similar to that used by other nations: donation is presented as a social good and organs are viewed as a national resource (Sharp 2007, 17–18). According to Sharp, in the United States the phrase ‘gift of life’ originated from the blood donation industry and has also been applied in relation to gestational surrogacy (Sharp 2007, 17). In 1995 the ‘gift of life’ slogan (*lahja elämälle*) was officially used in Finland for the first time as the name of a communications project aimed at increasing organ donation.¹ Those involved in the project organise events during international organ transplantation day and other theme days to inform the public about the importance of increasing donation rates. They are also involved in getting citizens to fill out and carry an organ donor card as a civic obligation (Munuais- ja maksaliitto 2010, 72–73). Newspaper articles featuring human interest stories of organ recipients or articles describing the donation and transplantation process also serve to encourage people both to fill out and carry a donor card and to inform their family members about their stance towards donation.

Organ donation campaigns used to appeal primarily to the emotions with the phrase ‘give a gift of life’ and reference to this metaphor is still visible on the website and Facebook page of the present national donation campaign. The use of this phrase has been discussed within the National Kidney and Liver Federation due to the discomfort felt by organ recipients in using it and because the organisations that are members of the *lahja elämälle* communications project perceived there to be a cultural mismatch between the phrase and Finnish values tied to giving.² As of 2010 a new donation campaign was designed by an advertising agency, which now appeals to citizens’ agency and their ability to act in the common good. The campaign slogan is imperatively formulated – ‘Say yes to organ donation’ (*kyllä elinluovutukselle*) – and the campaign posters include these additional phrases: ‘Hundreds of individuals die in Finland while waiting for a new organ. On a yearly basis tens of people die while on the waiting list. Say yes with a donation card. Tell your intentions to your next of kin. Forward this information’. Citizens are no longer encouraged to engage in donation through the use of the gift metaphor because it may communicate the need for reciprocation and being in debt does not fit well into Finnish notions of exchange, as it means the scales are unbalanced, which creates dependence and social discomfort as long as the debt is not reciprocated.

¹ The project was set up by five organisations actively working on issues linked to organ donation: The National Kidney and Liver Federation, The Lung Association, The Finnish Federation of the Visually Impaired, the Finnish Diabetes Association, and the Finnish Heart Association. At a later stage a sixth organisation joined, the Finnish Heart and Lung Transplant Association.

² This information was provided to me during informal discussions with the director and information officer of The National Kidney and Liver Federation in 2010.

A historical precedent that has positively influenced the public's attitude toward organ donation – visible today in the idea of goodwill and of helping a fellow citizen in need – is the life-saving quantities of blood collected by the Finnish blood donation services in the pre- and postwar years (the Winter War of 1939–40 and the Continuation War of 1941–44). These early drives, run by voluntary associations, to get citizens to become donors were part of a national effort. A highly centralised activity administered first by the Scout Movement, followed by the Army during the war years and later by the Red Cross Association (Leikola 2004; Nevanlinna 1968), blood donation mobilised citizens to extend support to soldiers wounded on the frontlines. Giving blood was seen as a civic duty and a positive form of nationalism, explicitly performed. In Finland, donating blood has never involved any remuneration for donors and it has been run largely through voluntary efforts, leading to the country being self-sufficient in blood products. Berner (2013) who has compared the history of blood donation activities in Sweden and Finland, outlines the differences between the countries, arguing that in Finland the social embeddedness of the activity, and the solidarity that was central to its success, was what created an intensive and organic relationship between donors and the organisations running the donation activities. In contrast, the situation in Sweden was decentralised, donors were paid to give blood, and there was a lack of a broad base of donors. The moral sense of obligation and civic spirit tied to blood donation typical of countries that had been involved in the big wars of the 1900s was thus absent in the Swedish context.

Two values central to Finnish society are hard work and autonomy. The ethos of managing on one's own is grounded in rural society where life was hard and one was forced to work to survive (Kortteinen 1992, 50; Siltala 1994a, 1994b; Roberts 1989; Abrahams 1991; Ådahl 2007). The centrality of being a hard-working individual is also related to the harshness of early industrial society where securing one's livelihood also required a substantial input of labour (Heinonen 2006, 55). In a society where these values are a central driving force in everyday life, it is appropriate to encourage citizens to fulfil their obligations as citizens. But encouraging donation by appealing to citizens' sense of obligation is separate from how citizens react to these messages and how they actually respond to the opportunity to donate. Although willingness to donate organs is high in Finland at a hypothetical level, it does not mean it automatically translates into individuals acting to make donation happen (Prainsack and Buyx 2011, 47). Research conducted on the degree of willingness among Finns to donate tissue samples to a national biobank indicates that obligation is not necessarily the primary reason for one's willingness to donate; only 9 percent of respondents listed obligation as a motivational factor. The motivations that topped the list were: to contribute to advancing medical research (91 percent), to benefit future generations (82 percent), to ascertain one's own health-related risks (52 percent), and to increase the competitive edge of Finnish researchers internationally (30 percent) (Snell and Tupasela 2012, 1687). Similar results were reported from a study of DNA databases in the United Kingdom that found that donors were

more concerned about contributing to the common good than what they could personally gain (Haddow et al. 2007).

Why has live donation not been encouraged in Finland prior to the amendment of the Tissue Law? There is a belief among medical professionals working in the transplant sector that Finns are so well informed about transplantation practices that they will automatically discuss the possibility of live kin donation if a family member is in need of a transplant. In an article featured in the magazine for members of the local chapter of the National Federation of Kidney and Liver Diseases, Inomaa (2007, 7, 11) outlines the benefits and disadvantages of live kin donation. He states that kin donation is an ideal option for the recipient, and that the organ can be transplanted into the patient directly after procurement surgery, which improves the quality of the organ and usually allows it to function immediately in the recipient's body. He points out that there are both advantages and disadvantages with live kin donation: 'There are many good experiences of donations between kin but they have also caused problems between relatives. The issue of donation may be brought up even at the time when inheritance claims are made. The donor may later experience that donation has caused problems for him or her. The recipient may experience that he or she is constantly indebted to the donor'. In spite of these reservations, live kin donation is encouraged more actively today than in previous years.

In Finnish the word to denote donation is '*luovuttaminen*', which means to give in, consent, yield, or acquiesce. Donation, on the other hand, traces its roots to the Latin word '*donare*' that comes from the word '*donum*', which means 'gift'. Another context in which the act of *luovuttaminen* took place was the Winter War, when Finland had to yield parts of its territory to Russia. These areas are now referred to as '*luovutet alueet*', the yielded areas, and are seen as a lost national resource in the form of strategically important territory. The term thus carries with it historical and cultural baggage that colours the nature of the act of yielding a valuable national resource, but also tells us something vital about what the giving of one's body entails. If one yields a resource that one has possessed, it does not necessarily mean that it is given up voluntarily; it, rather, entails obeying a demand and in this sense it is an act of subservience. Here a parallel can perhaps be drawn to the analogy of the use of the phrase 'a gift of life' that, according to Shildrick (2015), originates in the notion of the sacred heart of Christ that represents both the actual physical heart of Christ and a spiritual offering, conceived of as a gift to humanity. Research conducted in the United Kingdom shows that grieving relatives may view organ donation as a sacrifice, rather than a gift of life, and that to them the wish to protect the integrity of the deceased's body may override the will to do good (Sque et al. 2008; see also Shaw 2010). Donor kin may not necessarily express an objection to donation, but instead be concerned with not meddling with the integrity of the human body.

In addition, consent is an important issue in the Finnish context. The indignation expressed by Finns in the discussion forum ‘donation made compulsory’, described at the beginning of this article, related to not being asked. Since the law was amended and transformed into a presumed consent model, individual citizens now have to register their refusal to participate. The change was seen as an assault on individual autonomy. Similar concerns have been expressed in relation to tissue samples procured for biobanking purposes; respondents in that study felt that participation in research should be based on being asked whether one consents to one’s tissue being used (Snell and Tupasela 2012). A new piece of legislation on biobanking was passed in Finland in the autumn of 2013 and in 2015 a suggestion was put forth for the development of a national genome strategy, as well as preparations to amend the legislation to put in place a presumed consent opt-out model (Snell 2016). The welfare state is once again exercising its authority to force donation, framing citizens as a national resource in the name of the good of the nation. However, the problem is that the benefits of tissue sample use cannot be contained within the borders of a single nation. As tissue sample donors pointed out with concern, the handling of tissue samples and research conducted on them is linked to the international arena through collaboration and commercial interests (Snell and Tupasela 2012).

Sharp (2007) contends, in relation to the question of reciprocation in the context of the United States, that another form of giving thanks for the gift of the deceased is to memorialise them. In Finland there is, as yet, no mechanism through which recipients can convey gratitude to the kin of deceased donors, nor any form of recognition or memorialisation of donors. Perhaps one reason why no channels to express gratitude have been provided has to do with the belief that if these channels were made available it might make recipients feel obligated to reciprocate. However, since 2010 intensive care professionals at donor hospitals and the National Federation of Kidney and Liver Diseases have started discussing the need to provide donor families with some basic information on how the organs procured from their family member have been used and to support them in their grieving. In addition, those recipients who have been trained as ‘experts-by-experience’ are invited to tell their personal stories of the transplantation experience in various public events and can in these contexts convey a general sense of gratitude.

Movable tissues and organs

Medical professionals view transplantation surgery as a medical necessity and a means of prolonging a terminally ill patient’s life. Their objective stance toward the transplant organ is linked to the employment of a strict anonymity protocol. The Tissue Law clearly stipulates that giving out information about donors and recipients is prohibited, which makes it impossible for organ recipients and donors to get even the most basic information about their

counterparts (Finlex, 2001). This differs quite markedly from some parts of the United States, where there are channels through which recipients can send letters to donor families and have some form of contact with them (Sharp 2006). During an informal discussion on 13 January 2011 with Kaija Salmela, a transplant surgeon at HUCH, she explained that in the initial years of kidney transplantation, recipients could be provided with some basic information on the origin of the kidney. When the Kidney and Liver Transplant Unit was established at the Surgical Hospital of HUCH, the practice was abandoned. What this principle of anonymity is based on and how it came into the medical discourse in Finland has been difficult to trace, as the history of this process has not been officially recorded. Procurement hospitals do record key information – the donor’s age, height, weight, blood type, previous illnesses, injury leading to brain death, and medical treatment prior to organ removal – and communicate it to the transplant unit at HUCH, but this information remains protected.

Medical professionals working with transplantation believe that if the transplant is stripped of any references to a donor it will facilitate the reception process for the recipient, by removing a sense of guilt or indebtedness that the recipient may feel if the giver were personalised (Inomaa 2007, 11; Sharp 1995). Their objective stance toward the organ as a biological object is communicated to patients. The transplant is referred to in biological and instrumental terms, communicating that the organ no longer holds a connection to the character traits or personality of its previous host. Only a few of the recipients interviewed in my study pondered the origin of their organ, or admitted to having thoughts about any personal traits of the donor being transferred to them following transplantation. Most accepted and adopted an instrumental view of the transplant, although some had a lingering sense that it represented something more than tissue and did seek to subjectify it by, for example, naming it or celebrating the anniversary of the transplant as a ‘birthday’ of the organ (Ådahl 2013, 141–43). The ambiguity inherent in the status of the transplant organ as an in-between entity has been noted by several other researchers who discuss how this indeterminacy complicates the question of whether the organ is ‘mine’ or ‘other’ (Shildrick 2008, 2012, 2015; Strathern 2012; Sharp 2006, 2007). Objectification is a necessity for both transplantation professionals and donor families, as recent research by Bornø Jensen (2016) in Denmark illustrates. She points to how the whole system or community involved in the transplantation endeavour expresses a need to objectify the products that are being channelled through the system, but she also observes an inherent ambiguity that characterises the system. Although donor kin in Denmark use the strategy of objectification at some stages of the process of relinquishing their deceased loved one to the Danish welfare state’s medical system, they also have ambivalent feelings about letting go. Bornø Jensen (2016) notes that not only donor kin feel this ambivalence: professionals also switch between using objectifying and subjectifying terms when handling the donor and donor body.

On a symbolic level, transplants are objects or idioms of transformation that have the capacity to move between realms, to bring life in a situation where death is impending. They are thus saturated with a strong enabling force, pointing to the malleability of the human body. Preparation for procurement is initiated prior to the death of the donor; the donor body is transformed and the organs are manipulated medically to ensure survival and rebirth in another body. Already in life the organs are equipped with boundary-crossing capacities in the form of medical technology. The efficacy of these preparatory actions has been well researched in biomedicine: they improve the quality of the organs, facilitate the process of them being restarted in someone else, and prolong the longevity of the organ in the recipient. This movability is dependent on citizens' trust, both in the manner that tissues and organs are handled and used and in the authorities and medical professionals who are responsible for doing so. Yet another important aspect is citizens' trust that the benefits of medical research are channelled back into society so as to benefit the welfare state system and those who invest in the system by relinquishing tissues and organs for transplantation. As noted earlier, this has been a particularly central issue in relation to biobanking in Finland (Snell and Tupasela 2012; Tupasela and Snell 2012).

The term commonly used in Finland when referring to transplant organs is '*siirrännäinen*', derived from the root word '*siirtää*', which means 'to move'. A look at the etymology of the word reveals its connection to the meaning of 'something that is outside of oneself'. The word '*siirtää*' is derived from '*siiri*', which means border, edge, or margin (Suomen kirjallisuuden seura 2001). Another word for border in Finnish is '*vieri*', which also is the root word for '*vieras*', which means odd, unknown, or someone that is not kin (Häkkinen 2004). Viewing the transplant organ or tissue as something that is outside of the self is thought to facilitate its movability because it is just an organic object, something that can be moved aside, shifted from centre to margin. Although the background of the term is hardly something that transplant professionals or recipients ponder, it is nonetheless interesting to consider its etymology and how it signals the alien quality of transplant organs; they are not quite of the self and this may be the reason why they cannot be wholly incorporated (Ådahl 2013).

Giving something back

Donating body parts postmortem is linked to wanting to be of use and fulfilling an obligation as a citizen, to 'do one's share' (Hoyer 2003). As a citizen of a welfare state, one wants to contribute, not only to saving a fellow citizen's life, but also to advancing biomedical research and interventions that will serve the common good, including oneself (Snell and Tupasela 2012). Although half of the respondents participating in this research (nine out of eighteen) felt no need to give something back to the welfare state institutions that had enabled transplantation, the remaining half who expressed a desire to reciprocate constructed specific

ways of doing so. To understand this desire, we need to first see how patients who have suffered from chronic kidney dysfunction over an extended time period have been gradually socialized into a process of care and medicalised communion (see also Sharp 2007); this socialization has shaped them into compliant, 'good' patient-citizens. Throughout their illness they received regular information on how to live well during the various stages of the illness trajectory. They are advised to change certain eating habits to support their kidneys and prescribed various medications, for example to lower blood pressure prior to the dialysis stage of illness. An attitude of compliance, of following the doctor's orders, continues to be adopted by recipients after they have received a transplant. To many interviewees, this form of medical compliance is a way of giving back to the welfare state, as this statement by one recipient shows:

Since I have received this kidney I should take care of myself and care for the kidney so that it works. So I do not through my own doing wilfully destroy it. Like smoking cigarettes – although I have never smoked – but smoking or many other things. Now I have been careful. I take my medication at the specified times. Of course, you have to do it. And when I was out skiing I was careful, for the time being, and these types of things. It's my obligation in this matter. You cannot [reciprocate] in another way.

Patients know that they have been given a medical asset, a valuable one, because kidneys are scarce. They are also acutely aware of the need to take their medications and to strictly adhere to the medical regime their physician has prescribed.

A forty-year-old warehouse worker has a clear perspective on how he in his daily life concretely pays back his debt to the various people he sees as involved: society in general, the donor's kin, and the medical professionals who cared for him at the surgical hospital. As he says:

I try to care for my kidneys in such a way that I do not purposefully drink [alcohol] or drink it to death or do something bad to it on purpose. I try to care for myself better than one normally would and take my medication. And then I try to repay my debt to society by working. Every time I pay my taxes I am paying back my debt to society. That's how I think of it. . . . Yes, I pay my debt back in that way and I have some obligations towards this Rose [his kidney]. Because someone has out of the goodness of their heart donated the kidney when they died, or the relatives. I have obligations to fulfil towards those individuals. I have some obligations to fulfil towards the surgical hospital because they have worked so hard to make it happen. And then towards society in general because it has paid for my surgery, which I would not have been able to do if I would have had to pay for it myself.

Someone else's sense of obligation to donate has given this recipient a new kidney and he, in return, feels obliged to treat the kidney well; it is as if the kidney is a representation of the welfare state system that enabled the transplantation surgery to take place. Receiving a transplant helps this recipient fulfil that important Finnish cultural value: being a hard-working individual. In his account, through salaried work he pays taxes that flow back into the health care system as a concrete form of repayment. Doing so also takes an edge off the dependency relationship that all kidney recipients inevitably have with the Finnish health care system for the rest of their lives through the necessity of medical check-ups and the use of immunosuppressive medication.

Interestingly, respondents who were no longer part of the workforce sought to fulfil their civic obligation through voluntary work. A retired secretary extended solidarity to fellow citizens by supporting and helping others who face the same predicament she experienced:

Peer support or attending the meetings [of the patient organisation] and you can talk to the others about something, if needed. If one can in this way be of help, because I know that I talk so much [laughs]. But one cannot – as the person is already dead, one cannot do anything. One cannot go and thank that person. Then one just has to on a general level try to be somehow [helpful]. And those that have somehow helped me, if I, in my turn, can somehow help them.

Interestingly, the recipient above is directing their reciprocity in the form of solidarity with other recipients.

A sixty-year-old woman living in a small town in southern Finland felt strongly about giving back by helping others, and devised mundane ways of reciprocating the new chance at life that she was given:

I have done like this, when I have been given this new chance, then I want to give back through this patient organisation. And then there are women who phone me, this peer support that I have been involved in . . . I have been active in the retired people's associations, helping out with elderly people who cannot manage on their own. I have taken them to the hospital; I have gotten them home care services and helped them with getting someone to do the repairs. I have helped them get all sorts of things.

Perhaps it is not wise to reduce the question of donation and transplantation to organs as biological resources or to the idiom of the 'gift of life'. A donated organ is so much more than life-extending tissue. In this setting, donating and receiving transplant organs is a social practice that creates and upholds a string of vital social relationships between organ recipients

and the institutions of the welfare state, between organ recipients and their family members, between donor kin and the welfare state, and, between the welfare state and its citizens. Organ transplantation is a form of high-tech medicine, but also an intervention into a social reality. More than general exchange relations within a welfare state context, it is a manner of practicing citizenship.

Donation as an expression of solidarity

May (1996) defines solidarity as the establishment of bonds of sentiment that connect individuals to each other, which also involves conscious group identification, interest in the group's well-being, shared values and beliefs, and readiness to show moral support. Opening this article, I asked how the notion of solidarity could be used to explain the values that drive citizens to give of their bodies at the time of death. Solidarity as a socially significant principle has long been a force to reckon with in Finnish society and it is closely linked to notions of altruism. In the radical left-wing ideology of the 1970s, 'solidarity' was used as a collective call to oppose bourgeois values and to show alliance with the Soviet Union (Sihvola 2011). It is also aptly illustrated in the films of Aki Kaurismäki, in which political solidarity is often pitched against civic solidarity (Laitinen and Pessi 2011). Solidarity is visible in social practices and is strengthened through them. Finns are exceptionally willing to help individuals they feel are closely part of their shared community, those they can identify with. A survey carried out in 2006 indicated that 70 percent of respondents found that it is important to help others and 86 percent reported having helped strangers in the past year (Laitinen and Pessi 2010, 361). The organ transfer process ties people to each other, and people to institutions. In this manner, the practice of organ transplantation displays one of the central features of solidarity: unification, tying people to each other in mutual bonds of obligation (Honkasalo 2011). The creation of bonds is a process that involves people acting together (Arendt [1958] 1998); in organ donation, this means acting toward and receiving the acts of imagined others. Solidarity is directed towards individuals one empathises with and who are recognized as similar to oneself, but is also extended to unknown others to whom one has an imagined relationship.

This research shows that solidarity is not only needed in order to bring about donation but also produced as a result of donation. The Finnish public is encouraged to donate through the use of a rhetorical language in public media that communicates an idiom of need and shortage, as well as assuring the public that organs procured are circulated and handled in the national and Nordic exchange system in a socially responsible manner. The rhetoric surrounding organ transplantation and the information communicated about these practices in the public sphere serve to construct the imagined community of potential organ recipients (Anderson 1983). In the Finnish context the role of the state, as represented by medical experts, social workers, legislators, and other individuals involved in transplantation, is to encourage citizens to

consider and include this imagined community of individuals in need of organs as part of a communal 'we'. This 'we' wants to help others (total strangers) because of a sense of community that springs out of recognition. Organ donors can identify with individuals who are in need of a new organ. Donating one's organs to total strangers is an act of communal sharing, where the donor gives out of an awareness of another individual's need. The empathy involved in this act is based on having common interests and concerns.

Transplantation practices are aptly referred to as a 'social community' (Sharp 2007). Aafke Komter (2005) posits, in line with Durkheim ([1893] 1931) and Mauss ([1923] 1990), that social solidarity is the bond between all individuals within a society, and gift giving (donation) is a manner of confirming those social ties. In organ transfer it is the human body, both the body from which organs are procured and the body to which organs are transplanted, that comes to act as a site and sign of solidarity; organs themselves act as 'bonds of sentiment' (May 1996), connecting individuals to each other. What complicates matters is that it is not a direct exchange between donor and recipient and there are no mechanisms of direct reciprocation.³ It is an exchange that takes place between individuals and institutions governed by the welfare state. By agreeing to become a donor, an individual agrees to allow the state, as represented by the medical community, to extract organs from one's body, and in doing so the donor lacks the right to decide who the recipient of this exchange will be.

Conclusion

At the centre of the social and economic system of organ donation transactions in Finland, there is a relation of mutual dependence between citizen and welfare state. Like other accounts of the Nordic region, my analysis attends not only to the cultural specifics of a state-centred system of donation but also to how the ideal of 'giving something back' is expressed. Organ donation can be understood in relation to national histories of blood donation and their rhetoric; a similar message about the shortage of transplant organs is used today to persuade citizens to donate their bodies and organs for postmortem use by other citizens.

A 'needs' perspective drives the public image of transplantation practices and it underscores the mutuality of the dependence that is at stake. In Finland, every citizen may potentially need to receive a transplant organ, therefore citizens also need to invest their organ resources into the system. But a donated organ is so much more than life-extending tissue. In the process of transplanting organs, a string of vital social relationships is created between organ recipients

³ Strathern (2012) has discussed the issue of indirect counter-gifts; some donors may expect that the altruism they have shown will encourage future altruism in others.

and state welfare institutions, between organ recipients and their family members, between donor kin and the welfare state, and between the welfare state and citizens at large. Organ transplantation may signify high-tech medicine, and be grounded in general exchange relations within a welfare state context, but it is also a manner of practicing citizenship and fulfilling civic obligations, of creating and upholding social solidarity.

Organ donation and transplantation represent an embodied form of social 'body work'; organs act as bonds of sentiment, an indication of the relationship between individuals giving and receiving donated organs. This solidarity is needed in order to bring about donation, but is also produced as a result of donation. The recognition of the 'other in me' is a socially based recognition that is sentimentally informed. The purpose of campaigning on organ donation and otherwise informing the public of the need to increase the supply of organs is to move the sentiments of the Finnish public from being 'me' oriented to becoming 'we' oriented. A person's organs become a means of connecting to a larger imaginary community of other fellow citizens through the voluntary act of donation.

The view of the body as a resource is dominant in this linkage between organ donation and state welfare, but such a view is made possible both by the centrality of the state in practices of donation and by the trust engendered in these systems. To date, the justification for making this resource part of the 'commons' has been dependent on an ideology of participation in the social project of the welfare state. This is a strongly felt duty for most Finns. However, as I noted, with the erosion of health provision by the state, it may be that Finland is moving away from the Nordic model that both justified and made use of the principle of solidarity in donation. If an increasing number of services previously provided by government institutions are now run by private health care companies (Tiusanen 2015), it may generate ambiguity and ambivalence towards the solidarities involved in voluntary donation. How does the donation of one's organs constitute a national resource if profits generated within the system flow into a corporation and not into a welfare system that benefits all citizens?

According to social historian Tony Judt (2010), the economic and political crisis of our contemporary times has propelled us into an era of uncertainty where fear leads to a narrowing of trust, which in turn decreases mutual dependence among citizens. It is particularly generalised trust, defined as trust in the fact that unfamiliar citizens will not wilfully hurt us, that is at risk of waning (Delhey and Newton 2005). How will willingness to donate be impacted? In Finland, donation is encouraged by appealing to citizens' sense of civic obligation. However, in tissue sample donation surveys, 'obligation' is not a dominant response on the list of motivational factors. This seems to indicate that talking about obligation is perhaps misguided, particularly in a climate of economic austerity and ever-increasing privatisation of the health sector where corporate interests may override human interests. If obligation is also waning as a discourse and motivator of donation, what will replace it?

Finally, I want to consider the culturally specific meanings of the central terms for donation and transplant in Finnish: *luovuttaminen* (to give in, consent, yield, or acquiesce) and *siirrännäinen* (something residing on the border, edge, or margin). I suggest they point to what is at stake in the conceptualisation of Finnish organ transplants. The transplant is a moveable object that is foreign to the person who receives it; it is a product taken from the margins. It is also something one is asked to yield as a citizen, to relinquish; it is an object that may be difficult or impossible to give away, particularly for the surviving kin. In a society in which autonomy is a valued cultural trait, being asked to yield parts of one's self represents a loss of autonomy, but it stands side by side with the injunction to express goodwill. Here we have a tension particular to the Finnish donation context. Although citizens are taught to manage on their own, they are also taught to participate in the common project of the welfare state, a project that now insists that one donate to the common good.

Following Strathern (2012), perhaps the best path is to part with the market-oriented thinking that has coloured anthropological debates and understandings of gifts and reciprocity. Her comments are apt for the Finnish context: it is not an issue of 'repayment', with its financial and market connotations, but of 'giving back'. It is about common needs and the common good, constructing particular forms of giving back, and thereby engaging in social relationships that are believed to strengthen social cohesion. Organ donation in Finland enacts solidarity, making donation an act of citizenship, and, crucially, an act that allows others to continue on as hard-working and autonomous citizens. In this way, Finnish citizenship holds over into death, as the bodies of the dead continue to express solidarity beyond the grave.

About the author

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