

# 1. Making Sense of Donation

## Altruism, Duty, and Incentives

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### 1. Introduction

One of the major questions in the field of postmortem organ donation revolves around reasons for donation: What motivates potential organ donors and donor families to donate organs? If it were possible first to identify a set of factors associated with willingness to donate, and then to influence these factors, answering this question might help promote donation frequency and alleviate the global lack of organs often highlighted in public debates and academic literature. In this chapter, we take another route. Instead of identifying factors, we explore how people make sense of death and donation – how they reason when confronted with the option to donate. We believe that if we understand these meaning-making practices, we might better ensure the long-term sustainability of postmortem donation as well as create positive donation experiences. This, we believe, is a fundamental precondition for the practice of organ donation, and more feasible than controlling factors that lead to donation.

Based on ethnographic studies in Denmark, we provide examples of how donor families and registered donors make sense of the act of donation. We suggest that reasons for donation reflect the way organ donation facilitates new ways for future donors to deal with the prospect of death, as well as new ways for donor families to make sense of a tragic loss. Reasons for donation are embedded in meaning-making practices that build upon wider sets of ideas and life values, hopes and ideals. This means that policymakers must stay attentive to the meanings of organ donation if they wish to align political frameworks and practical organizational arrangements with the expectations and wishes of potential donor families.

As many studies debating donor motivation have argued, donation reasoning can be explored through conceptual frameworks and principles that have their roots in philosophy and various branches of the social sciences. While acknowledging these important contributions, our chapter emphasizes the importance of understanding the social practices of donation decisions. Organ donation produces meaning for people in different ways and engage them in relationships with ambiguous effects. These meanings vary over time and across cultural contexts. Sociologist Kieran Healy has argued that donation policies have worked to establish values such as altruism as a particular form of social force. From his perspective, altruism should be seen more

as a product of organ donation practices than as a pre-existing motivational cause (Healy 2006). Inspired by his work, we see reasons to donate as not necessarily the cause of donations, but rather as decisions that gradually emerge as people make sense of organ donation practices and death. As we will show, reasons for postmortem donations emerge as families attempt to align the donation decision with the values and personality of the deceased, and with their perception of 'the good death'. By constructing a post-donation narrative that transform a tragic sudden death into something meaningful because of organ donation, families orchestrate death (Jensen 2011a) and gradually articulate reasons for donation.

When discussing reasons to donate, it is important to recognize the difference between reasons based on actual donation experience (the families of potential donors) and donation wishes (registered donors). Registered donors articulate the reasons behind their donation wishes in their daily life settings and are detached from the actual turmoil of a sudden donation decision. Many are not aware that in reality, only one in 1.000 deaths occur in a manner that makes postmortem donation an option (Hoeyer/Olejaz 2020). Donor families, conversely, make decisions in the hospital in the immediate aftermath of a sudden tragedy, while they are still deeply emotionally affected. The death they encounter is no longer a potential death, but a very real one. For such families, sudden death raises many questions other than those relating to organ donation. A donation request comes in a stream of other emotionally charged questions that families have to tackle. Studies have underlined that families base donation decisions on what they consider meaningful in light of their individual situation (Berntzen/Björk 2014; Forsberg et al. 2014; Jensen 2011a, 2016; Sque/Payne 1996). Our point is that although altruism, duty, or incentives might all factor into 'reasons for organ donation', in practice, the concrete experiences and meanings attached to those reasons can be very different.

The chapter begins by outlining how reasons for donating interconnect with how meaning-making reflects the cultural and political context. Then we describe how three reasons for donating have featured prominently in the international literature (and in policymaking): altruism, duty, and financial incentives. Thereafter, we use more detailed examples from studies we have conducted in Denmark to discuss how Danish donor families and registered donors experience their donation decisions, and how these practices relate to attempts to make sense of death. Finally, based on these findings, we suggest that policymaking must take into account empirical insights into donors' and donor families' reasons and interests in order to balance the wish for increased donor rates with family care and public legitimacy.

## 2. Donation Decisions Reflect Cultural and Political Contexts

Many studies highlight the influence of national, ethnic, social, political and religious contexts on reasons for donating and donation policies across the world (Bruzzone 2008; Joralemon 1995; Sharp/Randhawa 2016; Shaw 2015; Schicktanz et al. 2010; Schweda/Schicktanz 2009; Wakefield et al. 2011). Some studies, for example, suggest that African-Americans, based on particular experiences and historical injustices, are more suspicious towards brain death and express less trust in American organ donation agencies than the white majority population (Sharp 2006; Siminoff et al. 2006).

Many countries and big cities with diverse populations have launched campaigns targeted at specific ethnic groups and developed partnerships with religious leaders and cultural groups in order to foster cultural acceptance of donation practices (Jensen 2007; Randhawa/Neuberger 2016). Conversely, recent studies suggest that even if ethnicity plays a significant role in donation processes in clinical practice, donation reluctance cannot be directly associated with culture, religion or heritage (Cooper/Kierans 2016; Kierans/Cooper 2013). The point is not to see, for example, ethnicity as having a particular impact on donation willingness, but instead to explore the experiences that make particular positions meaningful to people in given situations – and thereby to avoid prejudice.

When people reflect on why they donate, their reasons are typically related to how death becomes meaningful, and how they envision a 'good death'. What constitutes a good death differs among individuals as well as across contexts, not only because of cultural values and traditions, but also because of the different affordances of medical organizational systems for donation and follow-up care. The use of dead bodies in medicine is and has been practiced with significant variation over time and in different locales. Anthropologist Margaret Lock (2002) has illustrated how postmortem donation was received differently in the USA and in Japan, and how policies and practices took particular forms that reflected differing ideas about dead bodies and kinship rights and obligations. Important work has illustrated similar variations in other parts of the world (Hamdy 2012; Hogle 1999; Sanal 2011), pointing to the need to engage local perceptions, values and institutions when working to ensure the acceptability and social sustainability of new initiatives.

Donations reflect the values and beliefs of the individuals of a given country; people are affected by the norms and values of the society in which they live. In Israel, some people believe that a 'heroic death' involves giving one's life for one's country, and that when soldiers die in battle, their individual bodies become symbolically a part of the collective body of the nation. Suicides or traffic accidents do not have the same social significance. Still, if the family consents to organ donation, these 'ordinary' ways of dying can be transformed into heroic deaths worthy of national attention and recognition (Ben-David 2005). Families adopting this view might find comfort in the donation and deal with the tragedy of sudden death. Likewise, in the US, organ donors are honored in a manner not dissimilar to the celebration of war heroes, and especially in the New York region, donors are compared to the heroic firefighters of 9/11. It is quite common to hold public recognition ceremonies for organ donors where their images and life stories are on display. In some instances, families are presented with 'gift of life' medals, and donor family stories are publicly celebrated (Sharp 2000, 2001, 2006; Jensen 2007, 2010, 2011a, 2011b). Such practices of recognition cannot be uncritically adapted to other cultural contexts because social dynamics differ (Hogle 1999). The importance of context for the reasoning through which support for donation emerges points to the need to study the social values of local settings before adopting policy tools developed elsewhere.

### 3. Known Reasons for Donating Organs: Altruism, Duty and Financial Incentives

People can have many different reasons for deciding to donate or for declining to become an organ donor. Providing an overview of the entire philosophical and social science literature on the full spectrum of articulated reasons is thus beyond the scope of this chapter. We have chosen instead to focus on three of the most common and most debated reasons: altruism, duty, and financial incentives. In practice, different reasons – including these three – often intersect. As argued above, they are articulated in different ways depending on political, social and cultural context – and they do not necessarily precede and cause a decision; they are sometimes retrospectively constructed as people try to make sense of an overwhelming donation situation. The three reasons chosen here have been discussed in the literature as being both descriptive (explaining why people donate) and prescriptive (as a normative guidance to how organ donation should work and why people ought to donate). We do not want to assume that one can move from ‘is’ to ‘ought’ – and thereby commit what Moore defined as a naturalistic fallacy (Moore 1903). Nor do we take sides in the debates about whether a descriptive argument can overrule a normative or vice versa. Our point is simply to introduce key elements of the literature and provide a sense of the existing scholarship on reasons for supporting post-mortem organ donation. In relation to policymaking, however, we take a clear stance. We believe that an empirical understanding of donation reasoning in local settings is imperative if policymakers are to achieve the effects they desire.

#### 3.1 Altruism

*Altruism* has been defined as “behaviour intended to benefit another, even when this action risks possible sacrifice to the welfare of the actor” (Monroe 1996: 6). Concern for others has been an enduring topic in philosophy, but the modern notion of altruism is typically attributed the French philosopher August Comte, who in the beginning of the 19<sup>th</sup> Century identified an unselfish desire to “live for others”. Comte wrote at a time when he feared egoism or individualism would ruin solidarity in modern urban society (Piliavin 2001). Altruism in this sense need not be directed towards specific individuals (see also chapter 10 in this book). Recently, the complexities of the concept of altruism have been central to studies of both deceased and living organ donation that discuss how altruism intersects with public policies and information, and with solidarity and self-interest in donor reasoning (cf. Hansen et al. 2018; Healy 2006; Moorlock et al. 2014; Saunders 2012; Thornton 2019).

This ideal of an unselfish act devoid of expectations of something in return has been challenged empirically by mostly anthropological scholarship drawing on gift exchange theory. Marcel Mauss (1990) famously argued that all gifting is engrained in a threefold obligation to give, receive and reciprocate. He thereby claimed that there is no such thing as pure altruism. This position has shaped a great deal of anthropological work on organ donation, which has unfolded the relational character of obligations between giver and recipient (Alnæs 2001; Fox/Swazey 1992; Jensen 2007; Sharp 1995, 2000, 2001; Sque/Payne 1994). The anthropological claim has been that gifting helps to maintain social order exactly by exerting demands for reciprocity (Mauss 1990, see

also chapter 10 in this book). The articulation of the altruistic ideal might nevertheless provide the act of gifting with a particular social texture that sustains relationships between people, institutions, and the communities in which they live. The social articulation of ideals can influence practices, even if ideals do not determine practice.

The notion of altruism has shaped a rhetoric of ‘gifts’ often used in campaigns for organ donation (Hansen et al. 2018; Siminoff/Chillag 1999). Here, gifting relates to the idealized and normative sense of donation, not the anthropological theory. Normative discourses can thereby influence the meanings that are attributed to donation. In public campaigns, popular media and in many scientific studies, post-mortem exchange of organs is often framed through the concept ‘the gift of life’ (Alnæs 2001; Lock 2002). Lesley Sharp (1995: 365) suggests that a rhetoric of altruism is designed to encourage the involved parties to regard organ transplants as an unselfish and generous action that does not require any kind of reciprocal action: it is prescriptive rather than descriptive. Ideas about altruism also influence policies that aim to promote organ donation based on an assumption that provision of information about the needs of recipient will make people donate (Hoeyer et al. 2015, Nuffield 2011; Tontus 2019; Sharp/Randhawa 2014). However, other studies have shown how donor families, transplant patients, and organ procurement organizations continue to reflect on obligations of reciprocity (Jensen 2007, 2011, 2017; Sharp 2006; Siminoff/Chillag 1999).

Many donor families and members of the public embrace (or are deliberately encouraged to adopt) the organizational language of organ donation as a ‘gift’ (Jensen 2010; Sharp 2006). However, the social relations that are closely associated with the gift can also cause problems. Sociologists Fox and Swazey have argued that in transplantation, the psychological and moral burden is especially onerous because the gift is so extraordinary that it is inherently un-reciprocal: “It has no physical or symbolic equivalent” (1992: 40). People usually give gifts in return. Hence, the giver and the receiver are “locked in a creditor-debtor vice that binds them one to another in a mutually fettering way” (ibid). This is what they call the ‘tyranny of the gift’. Their work primarily focuses on living donation between family members, but the idea that reciprocity is more or less impossible or problematic has also had tremendous impact on the field of post-mortem donation (Alnæs 2001; Lock 2002; Sharp 1995, 2006; Siminoff/Chillag 1999). While this work seeks to empirically challenge the notion of altruism as the primary reason for donation, it does not address the normative argument as such. Furthermore, the normative reasoning can be seen to have empirical effects as it is used in campaigns and shapes organizational logics, which makes altruistic reasoning an empirical phenomenon.

### 3.2 Duty

Another and related reason commonly discussed in the literature is *duty* (Altman 2011; Brecher 1994, Gerrand 1999; Merle 2000). In modern ethics, the normative concept of duty is mainly associated with the deontological ethics of Immanuel Kant. Kant’s famous categorical imperative suggests that one should ‘act only according to the maxim whereby you can at the same time will that it should become a universal law’. It can be discussed whether a universal duty to donate (or to help others) in any way follows from the imperative. However, in a narrow sense, many assume that helping those in existential need is a duty of humanity. When people articulate a duty to

donate, they typically refer to this type of inclination. It is thereby not derived from a particular (Kantian) philosophical position: the word is used in ways resembling some more akin to a *social obligation*. It is an obligation that can be argued in various ways and be based on multiple values. The word ‘duty’ nevertheless permeates donation debates, perhaps because of (rather than despite) its ambiguous meanings.

Today, *duty* is mobilized in its more general sense to encourage donations, and often by relating it to altruism, which thereby loses its meaning as unconditioned gifting (see also chapter 14 in this book). As with altruism, the donation literature often refers to duty in a prescriptive manner. In turn, this use has empirical effects as it enters campaigns and organizational policies. When related to altruism in political campaigns, the duty principle of organ donation becomes regarded and articulated as a social obligation towards society: in public debates, statements such as ‘if you want to receive, you have to be willing to give,’ aim to classify organ donation as an ideally fair and socially acceptable exchange, and thus the social obligation to donate as something natural (Jensen/Larsen 2020). The work of John Rawls (1999) on ‘free riders’ that seek to benefit without contribution has substantiated this further. The social obligation to donate is aligned with fairness (it is not fair to benefit without contributing). Sometimes reluctance to accept this logic is even considered irrational (Almassi 2014; Eaton 1998; Hester 2004; Jarvis 1995; Steinberg 2004). Social obligation also features in some arguments favoring presumed consent legislation. In presumed consent systems, citizens are automatically regarded as organ donors unless they opt out (see also chapter 2 in this book). Such systems have been legitimized with reference to a social obligation (termed duty) to donate. Other policies articulate instead an obligation to make up one’s mind about donation (Gill 2004; Hoeyer/Olejaz 2020). Recent studies have debated whether presumed consent actually promotes donation rates as intended, how it may challenge clinical end of life care, and how its inherent sense of obligation creates ethical dilemmas and high public ambivalence across Europe (Jensen/Larsen 2020; Molina-Perez et al. 2019; Prabhu 2019; Sheperd et al. 2014).

### 3.3 Incentives

As a third reason, we will mention how some studies discuss whether *incentives*, such as financial remuneration, can or should influence the propensity to donate. Scholarship supporting incentives adopts a view of human agency that emphasizes self-interest rather than duty or altruism, and offers a number of suggestions in terms of practical policy. Literature in this vein can be both prescriptive and descriptive. Discussions about incentivized action tend to stimulate reflections on body ownership and rest on a view of human organs as spare parts in strong demand (Brecher 1994; Burrows 2004; DeCastro 2003; Murray 1996). Some scholars even suggest financial compensation in the form of a so-called ‘market model’, where monetary exchange delivers the mechanism for allocation of organs (Satel 2008). Incentives are typically defended on the grounds that donation policies based on altruism and duty have failed, but incentives have also evoked ethical dilemmas and public debates (Becker 2009; Cherry 2005; Goodwin 2006; Hippen et al. 2009; Schweda and Schicktanz 2008; Taylor 2005). Some support ‘softer’ models of financial compensation, which can include remuneration of health care costs, or special health benefits to the family of the donor. An example of this is the priority rule allocation (Li et al. 2013). While only few states use incentive

strategies to promote organ donation, priority rule allocation has been implemented in Israel since 2010 (Levy 2018; Stoler et al. 2016). It entails moving registered donors, or relatives of deceased donors, to the front of organ waiting lists. To the extent that it builds on the idea that ‘if you have been willing to give, you should be allowed to receive,’ it can be said to link the reasoning involved in social obligations (as discussed above) with that of incentives.

A critique of the use of financial incentives can be found in studies on the organ trade (see also chapter 11 in this book). American anthropologist Nancy Scheper-Hughes (1996, 2004), for example, has argued that the organ trade symbolizes global power structures, and the divide between rich people in high-income countries on the waiting list and poor people in low-income countries, who may, for example, sell their kidney for a minor sum, risking their health in the process. This critique is directed at a globally free market solution where organs are bought and sold, not regulated incentives via state policies. Based on studies from the US, anthropologist Lesley Sharp has argued that financial incentives involve a ‘commodification’ of the body, which can harm public attitudes towards organ donation because it indicates that a person only consists of valuable parts, and it “dehumanize[s] individuals in the name of profit” (2000: 293). In interesting ways, this is similar to a Kantian position. Even if organ transplantation was not a medical possibility at his time, Kant also spoke against commercializing bodily donations, fearing they would reduce bodies to means for other people and thereby undermine their inherent dignity. Commenting on the selling of teeth for transplants (a common practice during his time), Kant argued:

Man cannot dispose over himself, because he is not a thing. He is not his own property – that would be a contradiction; for so far as he is a person, he is a subject, who can have ownership of other things... for it is impossible, of course, to be at once a thing and a person, a proprietor and a property at the same time. [...] He is not entitled to sell a tooth, or any of his members. (Kant 1997: 157)

How do contemporary citizens view incentives in this area? A review from 2013 on public attitudes towards financial incentives for organ donation identified a considerable preference for non-commercial forms of organ procurement, but also a need to consider alternative perceptions of financial means. These incentives could include remuneration of expenses in ways that could be experienced as signs of respect and reciprocity, such as payment of funeral expenses (Hoeyer et al. 2013). It is, however, important to keep in mind that what might seem like similar policies on financial incentives can have different implications in different contexts depending on, for example, available options for social security and health care and cultural perceptions of the body (Schweda/Schicktanz 2009).

#### 4. Denmark as Case Study: Methods and Context

In the following, we will substantiate our central claim that reasons for donations relate to how people make sense of death, dying and donation, and that this process of sense-making reflects the social context in which people contemplate these issues. We base our argument on anthropological studies of Danish donor family experiences and



the attitudes of registered donors in Denmark (Hoeyer et al. 2015; Jensen 2011a, 2011b, 2016; Olejaz/Hoeyer 2016). We draw on data from twelve years of anthropological studies across several research projects, and some quotes have been published in the publications we reference. Anja Jensen has conducted field studies at neuro-intensive care units, including participant observation during organ donation cases, and she has conducted interviews with donor and non-donor families (N=102). Together and independently, we have interviewed hospital staff (N=78) and registered donors (N=48). Along with colleagues, we have also administered a national survey of public attitudes to donation in Denmark with questions based on our qualitative work (Nordfalk et al. 2016), from which we will include data on reasons for donation.

Denmark, it is worth pointing out, is a rather special context for organ donation. Denmark has low donation rates compared to other European countries, and also struggles to encourage individuals to sign up to the donor registry. In 2018, three out of four organ donors in intensive care units had not registered a prior decision in the register. Donations therefore had to be decided by their families (Jensen/Larsen 2020). Denmark was once known among the medical community internationally for its skepticism towards brain death and organ donation (Lock 2002; Rix 1999). Brain death did not become a criterion of death until 1990, after an intense public debate. More recently, in contrast to most other European countries, Denmark has rejected adopting presumed consent legislation in organ donation (Jensen/Larsen 2020). There is evidence, however, that the Danes' stance towards organ donation has changed. In 1995, just 30 per cent of the population stated that they were 'positive towards organ donation'. In 2016, that number had risen to 92 per cent (Nordfalk et al. 2016). In 2021, Denmark will follow the majority of European countries and implement donation after circulatory death.

In the following, we make three claims about the reasons for donations. We substantiate these claims with material from our fieldwork in each section. Our hope is that the three general claims might be valid in contexts other than Denmark, though we believe the particular values enacted in practice will remain local.

#### 4.1 Organ Donation Helps Relatives Making Sense of Tragedy and Creates a Legacy for the Deceased

Danish families often articulate their donation decision as a way to ascribe some meaning to a tragic death. For them, the most important issue is not primarily saving other patients; it is about making a decision that is in accordance with the legacy of the deceased and thereby creating a meaningful aftermath (Jensen 2010, 2011a, 2011b, 2016a). Often this kind of reasoning reflects stories about the kind of person the donor used to be. Leo, a man in his thirties who lost his father, Erling, had always been in favor of organ donation and had had no doubts when deciding whether his father should become a post-mortem donor. His sister and his mother, however, found the decision very difficult and were not sure they could allow Erling's body to be submitted to surgery. Leo explained that he and his brother then talked to their sister and mother about it, using these words:

I thought we should see it in relation to how my father lived his life and my father's values. And that can be very hard to apply to such a situation, and it is not something



you can redo. But my father was always helping others. He supported us no matter what and always thought of others first. He was the kind of man who helped all of us adult children renovate our bathrooms. He always worked hard so we had the freedom to educate ourselves. So in relation to how he lived his life, we had no doubts that he should donate his organs. (Jensen 2011a: 110)

After he shared his thoughts with them, Leo explained, his sister and mother agreed. They could also see that helping others to survive was in accordance with the way Erling had lived his life. In this way, by looking at the social history, the values and the previous actions of the individual, the family members could construct organ donation as a respectful and sense-making way of ending life. Here, we also see the connection between the normative arguments about altruism and the social practice of deciding: Erling's family relied on values associated with altruism to make sense of his life and death. For Leo, and also many other families in Jensen's studies, acknowledging the deceased and his life values, which included helping others, becoming a donor is a meaningful way of orchestrating death during and after a tragic loss (Jensen 2011a).

One time, Jensen sat at the kitchen table of Betty, a woman in her late 40s who had lost her brother John. John and his ex-wife had divorced ten years before his death, and after this his already serious drinking habit turned into alcohol abuse, isolating him physically and socially from his family and friends. After several attempts to treat his alcohol abuse, he ended up in a treatment center, but his drinking nevertheless persisted. Betty gave several examples of her efforts to support her brother. She blamed herself: "Why was I not able to help my brother?" she said. "I felt like a failure." Some months after entering the center, John was rushed to hospital with a brain hemorrhage. Betty and her father were told that John was brain-dead and asked if they would consider donating his organs. "We said yes right away," Betty told me. "John was that kind of person, and it made perfect sense if somebody could benefit from this." Just like Leo's relatives, she characterized her deceased brother as an altruistic person, and it helped her remember him in a positive manner, despite his difficulties with fulfilling these ideals in the course of his lived life.

Betty revealed that despite the tragic situation, she thought the time following the decision to donate was exciting. Doctors were running in and out for tests and blood samples. She was intrigued about which organs could be used, who was going to receive them, and how the transplants would turn out in the end. She told Jensen that she had even considered sneaking into the hallways of the hospital in Copenhagen to see the recipients of her brother's kidneys. "I can only imagine the newspaper headlines," Betty said, laughing: "Mysterious woman caught sneaking around in the kidney department at the Copenhagen University Hospital." Betty was not able to help John, but by donating his organs, she was able both to help others and to find meaningful closure to his life. Associating organ donation with John's personality was so much better than remembering the severe alcohol abuse, the loneliness and the many failures that characterized his last decade. "It is a good aftermath," she said (Jensen 2011a: 228–229). When discussing the fact that families in other parts of Denmark receive a 'thank you'-letter, Betty said: "I would have liked such a letter. I could have put such a letter in the folder I have with all his papers with pride. I would have placed it in the front of the folder as a way to wrap up the life of my younger brother." (Ibid: 229)

While the story of organ donation cannot change John's issues with alcohol abuse – his *life history* – it can somehow change the *story* of his life. By way of organ donation, John's death becomes a 'good death,' and, ironically, a contrast to his tragic life. Betty likes the idea of recognition of reciprocity, almost as if it can mend the failure to connect reciprocally during the period of alcohol abuse. In these ways, themes of altruism, duty and the social obligations of reciprocity become resources for sense-making when people are confronted with death and organ donation.

## 4.2 The Thought of Usability can be Comforting

A persistent theme in the literature on post-mortem organ donation has been the proposition that technology manipulates death in order to align it with what Lock has coined "the utilitarian interests of the transplant world" (Lock 1996: 596). The critique of utilitarian reasoning has suggested that it promotes the type of 'spare parts' view of the human body discussed above (Fox/Swazey 1992). Many studies suggest a potential conflict between dignity and utility – a conflict that resonates with famous divides in philosophy. While we do not dismiss the relevance of the normative debate about this conflict, our empirical studies among Danish donors and donor families suggest that, for some, utility can support the sense of dignity. Furthermore, it is not only the 'transplant world' (i.e. the medical staff) who objectify body parts; donors and donor families can experience objectification and utilitarian discourses as meaningful and dignified. We have encountered families and registered donors who use objectification and the image of utility when coping with despair and when trying to make sense of death and donation. Bente and Carsten, for instance, are the parents of a teenage boy, Adam, who was shot in the head. Thinking about the donation process, Carsten explained:

Before we got the message that the left part of the brain was ruined, the hope we had that he would survive had turned around to a hope that the doctors would give us that message. As I was quoted in one of the newspapers, it was a question of vegetable or funeral. So it turned into a hope that it went fast – and a hope that his heart would last the pressure. If his heart stopped, he could not be used for organ transplantation and that would be bad! I was very cynical and said of course we are going to do that; we cannot use him for anything else. So we hoped that he would last. (Jensen 2016: 386)

For this family, hope for survival changed into a hope that death would finally come and that his body could be used for something. For Bente and Carsten, organ donation was a better alternative than a life 'as a vegetable'. Of the scenarios they could imagine, organ donation became the best outcome they could hope for. Such narratives often figured in the stories of donor families, sometimes with strong metaphors to underline their appreciation of the functionality of the dead body. Ole, who lost his adult son Tobias, explained his distinction between 'person and part' like this:

I think I have the distinction that as soon as Tobias was declared brain-dead, the person Tobias was gone. The rest is a maintenance box, a spare parts box. And I have never had any problems or scruples about that. To repeat myself, it is with joy and pride I think

about Tobias being so conscious of wanting to help others. All we did was live up to his expectations. That's it. (Ibid: 387)

By conceptualizing Tobias' body as a 'spare parts box', Ole makes it meaningful to pass on the organs. This distinction in turn influences the way he memorializes Tobias. It gives him joy and pride to think about the determination of Tobias to become a donor. As such, organ donation shapes the legacy of the dead and accentuates a new kind of hope at a point in time where hope for survival is gone. This occurs not *despite* but *because of and through* the usability of the body. Though the debate about incentives emphasizes the risk of 'commodification' as a consequence of objectification, we see here that objectification can form part also of social dynamics through which families find hope and construe narratives of dignity. The transformation of a person into an object for transplantation allows families to orchestrate a good death. In many cases, utility and dignity are closely connected in donor family practices of hope (ibid).

In our interviews with registered organ donors, most highlighted a sincere wish to have their bodies used as much as possible (Hoeyer/Olejazz 2020). Benazir, for example, was a young academic woman with an immigrant background who was ambitious and socially engaged. She said: "Well, of course, if I – let's say that I die at the age of 24 – then, of course, I'd really, really hope that I would die in a manner making it possible to help others [brain death]. Compared to ... dying just ordinarily and then lying there in the grave putrefying bit by bit." (ibid: 4). A part of our methodology was in every interview to search for limits to legitimate use as a way of understanding people's moral reasoning. When asking a young father, Jonas, about limits, he explained that he had none. Any kind of use would be better than 'being eaten by worms':

Jonas: 'You may do anything! Feed me to the cats, I'm dead [his emphasis, laughing]. Really, I'd rather not be buried in a coffin; I'd like to be used, for whatever. Bury me under an apple tree then I can be used as fertilizer.'

Klaus: 'What is the difference between fertilizing the graveyard and an apple tree?'

Jonas: 'You eat the apples off the apple tree. A churchyard is not very productive; it's not fertilization, it's waste.' (Hoeyer/Olejazz 2020: 421-422)

In a similar vein, Karen – also a registered donor – said that they could use all of her if they wanted, "...if you want to boil the meat off and make me into a skeleton, that is okay too" (Olejazz/Hoeyer 2016: 23).

Another registered donor, Ingrid, detached her person (or soul) from her dead body. Being a member of an interdenominational Christian movement, Ingrid imagined that the soul leaves the body upon death, living on in Heaven, and that Jesus does not need bodies in Heaven. She said: "You know, when I am dead, then I am in Heaven with the Lord and what happens with my body? If anyone can use it then I think it's wonderful" (ibid: 22). For her, imagining the body being used was not about losing bodily integrity, as some studies have suggested (Santer 1994, Stephenson et al. 2008); rather, it informed the reasoning that made registering as a donor meaningful (Olejazz/Hoeyer 2016, Hoeyer/Olejazz 2020).

### 4.3 Donation Decisions Reflect Relations to Body, Family and Society

When families contemplate donation decisions, their reasoning reflects a wider set of relations between the family and the deceased, relations within the family, as well as broader social relationships to the health care institutions and the welfare state. What might formally be an autonomous decision is embedded in social relations. We now give an example illustrating how donation is not always an easy decision, and how different relations between families and society, each with different temporalities, interact when donor families try to make up their minds.

Alice and Jim lost their 15-year-old son Morten in an accident. They came to Jensen's apartment one winter night and sat across from her with tears in their eyes, holding their coffee cups tight. Alice began explaining the course of events, and when telling Jensen about the question of organ donation, Alice emphasized her considerations about the body of her son:

My first reaction was no. They shall not touch him. It is my child. They shall not start cutting him open. They shall let him be as intact as he is. They cannot cut into my child. I must look after him. I must protect him. It was really, really difficult for me in the time after we said yes to donation. I felt guilty towards my son [...] I really felt I let him down because I left him while his heart was beating. And then again, rationally, I knew that the heart would stop beating as soon as they removed him from the respirator. But at that time, it did not matter. I let him down. (Jensen 2011a: 168)

As his mother, it was almost impossible for Alice to leave Morten and thereby stop protecting the body of her child. Many of the parents Jensen interviewed felt that it was intrinsic to the role of a parent to protect the body of a child. Alice nevertheless explained that she had since come to the realization that organ donation was good because it was what Morten had wanted. A new relation – between Morten and the anonymous recipients – worked with a different temporality, and the mother's short-term urge to protect her child was replaced with a willingness to allow him to do good for others. Donation created a new future for Morten.

Historian Ruth Richardson (1996, 2007) provides a historical and contextual background for understanding such challenges of leaving the dead and transplanting body parts. She describes that in the UK in the early 18<sup>th</sup> and 19<sup>th</sup> centuries, it was considered a duty not to leave a dead body alone. This was based on the assumption that the dead body still had needs, the soul might still be present, and the “hopeful fear that the dead might return to life and require assistance” (Richardson 2007: 6). In addition, people believed that cutting the body could damage the soul, cause haunting, and prevent the possibility of resurrection (Richardson 1996: 71). Centuries later, in our age of modern medical technology and an information paradigm where public campaigns are carefully designed to convince the public to become organ donors (Hansen et al. 2018), it still matters how the body of a family member is handled. Trusting that death has occurred, accepting the need to say goodbye while the heart is beating, and balancing the wish to donate with the urge to keep your family member intact all influence the family's donation decisions and grieving (Jensen 2011a; Sque/Galasinski 2013).

In many instances, the sense of belonging to a particular community features in family reasoning on organ donation. After losing his ex-wife Kate, sixty-eight-year-old

Jens told the story of choosing to donate her kidneys. Jens differed from other donor families in that he did not draw heavily on his emotions when sharing his story, instead focusing on the background of his family's decision and the more general social obligations of donating organs:

I don't see it as a gift; I see it as an attitude. As a natural thing living in the society we do. I mean, we do expect that somebody will come and pick us up if we fall, and take care of us. And if somebody is hurt and needs a kidney, then I find it reasonable if somebody that is passing away can deliver a useable kidney. I find it natural. And based on my own opinion, I have a hard time understanding the debate. [...] I consider it the same as helping an old lady who falls in the street. I would stop my car and help her to her feet. My fundamental attitude is that as a Danish citizen I can use the facilities in this country. And then it is natural for me that I also have an obligation, when I am not here anymore, that they can use whatever parts and bits they like. And I think that should be a part of Danish citizenship or whatever. (Jensen 2011b: 143)

Jens's narrative opens a window to investigate how ideas about social obligations and the perception of duties of citizenship shape his reasoning on organ donation. 'Obligation' is here part of his sense-making, and he associates it with belonging to a place and a community. His recollection connects the personal narrative with the national orchestration of a good death (Jensen 2011b). What we wish to underline here is that reasons for organ donation are deeply intertwined with the ideals and values surrounding the 'good death' in the particular time and society where the decision needs to be reached. They acquire their particular emotional flavor based on the relationships through which people negotiate and make sense of organ donation; and similar reasons might therefore be experienced very differently for different groups of people.

## 5. Conclusion: Lessons for Policymaking

Important prescriptive work in philosophy and other disciplines has established a pool of reasons in favor of organ donation. In particular, reasoning based on notions of altruism, duty and incentives has been influential and shaped scholarly as well as public debates. The various lines of reasoning have supported as well as worked against the idea that donation is the right choice. Conversely, descriptive work exploring how reasoning operates in practice has illustrated the ways in which normative reasons can interact and produce unexpected outcomes. Drawing on our own work, we have shown how people reason in light of context. In practice, potential conflicts and distinctions can dissolve so that utility and objectification can inform attempts to ensure dignity and respect for subjectivity.

Often policy makers define organ donation issues as 'ethical' and include recommendations from ethicists, philosophers, or as in Denmark, an Ethics Council that advises parliament or ministries. While policymaking can benefit from the reasoning developed in normative ethics, we believe that policymaking on organ donation can also benefit from empirical insights into donation reasoning. For instance, Jensen was invited to talk about her research on donor family experiences by the Danish Secretary of Health, when politicians debated whether or not to implement presumed consent.

Insights on family decision-making and grief, topics that politicians usually have no access to explore, might not change political attitudes, but they provide empirically based argumentation to build more socially robust policies. A better understanding of how people in different contexts make sense of organ donation – and sometimes use organ donation to make sense of death – can help build socially sustainable institutions. Sustainability involves trustworthiness and sensitivity towards core values among the citizens affected by the adopted policies. We cannot assume that people weigh up options in uniform ways irrespective of context, and therefore we need to invest in studies of donor reasoning locally to make policies that respect local values. Reasoning also changes over time. There is therefore a need for continuous studies of donor reasoning.

One policy area that might particularly benefit from a deeper empirical engagement is the discussion about presumed consent. Presumed consent policies are associated with increasing donor rates, though it is debatable whether this effect stems from the investment in public campaigns and increased national attention rather than the policy per se (Albertsen 2018; Rhitalia et al. 2009; Sharif 2018; Shaw 2018). Generally, a national policy of presumed consent raises questions regarding the role of the family of the potential organ donor in the organ donation decision (Delgado et al. 2019; Shaw 2017). Should the donor's opinion be overruled? How does this comply with family communication and end-of-life-care in organ donation? Across Europe, presumed consent legislation is organized and practiced in different ways ranging from soft opt-out, where the family is included in decision-making, to hard opt-out, where families cannot veto a donation (Noyes et al. 2019; Prabhu 2019). The same policy, presumed consent, interacts with different values and organizational infrastructures in different countries, and therefore may have different effects. We believe that it is important to study dominant forms of reasoning in local contexts before adopting such policy changes. Policy developments benefit from both prescriptive and descriptive perspectives. It can also help policymakers to articulate criteria of success for a policy change: Is it the number of donations? Or the level of care for relatives? Or, perhaps, sustained public trust and legitimacy?

If national policies consider appropriately how people make sense of death and donation, donor rates can develop in balance with family care and public legitimacy. We believe that this balance cannot be found without a strong empirical engagement. A key task therefore remains to explore how the decision to donate can be made meaningful for those who have to live with it.

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