

Proposing a Sociology of Donation: The Donation of Body Parts and Products for Art, Education, Research or Treatment.

Abstract

This paper advances the case for a 'sociology of donation'. We aim to establish that there is a need for such a sociology, to bring together the many, often disparate, elements that make up the theorizing, practice and experience of donation. We argue that bringing together different forms of donation illuminates the distinctive place both in social meaning and regulation that the body and its products hold. In developing this, we are primarily focusing on the donation of body parts and body products within high-income countries. We will first outline the standard western accounts of donation, and consider how relevant these are to donation practices and policies in the twenty first century. We will then critically discuss how a sociology of donation can be used to further current understandings of 'donation' and identify the challenges facing such a proposal, posing questions to encourage reflection on research practices in this area. Finally, we will explore what a sociology of donation might entail.

Keywords

Body parts, body products, complexity, donation, social structures, sociology, uncertainty

Introduction

This paper contributes to the recent debates surrounding a sociology of donation. International researchers have contemplated a sociology of donation from various standpoints, including morality (Shaw, 2019), gender (Kent et al., 2019), and personal lives of donors (Nordqvist, 2019), and have attempted to bring together the many, often disparate, elements that make up the theorizing, practice and experience of donation (see also Shaw, 2008; Swanson, 2014; Waldby and Mitchell, 2006). We aim to establish that there is a need for such a sociology in order to bring together debates surrounding the donation of different body parts and products for a wide range of different purposes, debates that are often conducted independently of one another. We argue that bringing together different forms of donation illuminates the distinctive place both in social meaning and regulation that the body and its products hold. In developing a sociology of donation, we are primarily focusing on the donation of 'body parts' – tissue, organs – and 'body products' such as aborted fetuses and breast milk. This is partly to delineate the area, but arguably body parts and products raise distinctive sociological and ethical issues, that donation of money or assets do not. We first outline the debates within the donation literature, and consider how relevant these are to current donation practices and policies in westernised high-income countries. We then critically discuss how a sociology of donation might be used to examine current understandings of 'donation' and identify the challenges facing such a proposal. Finally, we explore what a sociology of donation might entail by drawing upon complexity science scholars.

Deconstructing donation

The literature rarely provides generic definitions of 'donation'. Instead, 'donation' is typically deconstructed into its component parts, e.g. recruitment, procurement, transplantation surgery, post-transplant management as in the case of organ donation (Manzano and Pawson, 2014). 'Donation' processes therefore become associated with giving, voluntariness, ownership, costless, and benefit (Gerrand, 1994; O'Neill, 2009). The positive outputs resulting from 'donation' provide insight into how it is defined i.e. life-saving (in transplants and transfusions), life-creating (in assisted conception), life-sustaining (in breast milk), and life-enhancing (in knowledge production and advancing research). The descriptions of the relationships created through the process of 'donation' i.e. gift, or sale and of the people involved (e.g. altruistic relations, stranger), further illustrate how it can be understood. Donation is not always non-financial as clinics and providers sell services that rely on donated body parts, and there are commercial blood, bio and gamete banks. Such understandings surrounding 'donation' have arguably gone on to shape which debates have become prominent in research.

The legacy of Titmuss

Richard Titmuss' (1970) comparative research on blood donation systems in 1960s America and Britain, and the notion of the 'gift relationship' where the act of donation is presented as one that is altruistic (Machin & Cherkassky, 2015) continues to be the starting point for many policy and practice discussions (O'Neill, 2009; Sharp and Randhawa 2014). In the case of organ donation, much pro-donation activism and many campaigns have drawn on a 'gift of life' discourse that sets the gift of the organ apart from other gifts, portraying it as *the* valuable gift of life (Zeiler, 2014). Furthermore, references to Titmuss' work are applied in research irrespective of the body part or product being donated, or the purpose of the donation i.e. treatment, research, education or art.

For Titmuss, the giving of blood to unknown others was understood as the basis for reconciling individual existence with communal life, via acts of altruism towards, and in solidarity with, unknown others. The donation of blood rested upon a sense of intercorporeal connection with others and on an understanding of the vulnerability of ourselves and/or our loved ones who may need this generous gift from others (Titmuss, 1970).

Yet, researchers have argued that articulating body part donation within a 'gift' discourse remains over-simplistic and unrealistic, as it does not reflect the complex and multi-faceted decisions made during the donation process (Sharp and Randhawa, 2014) or what is important for people when making donation decisions (Sque et al., 2007). Ultimately, the 'gift' has been accused of idealizing the donation system and is often seen as an outdated model (Whitfield, 2013). Further, it ignores the political and economic context in which donation takes place (see Champney, 2016; Grace et al., 2019).

Our intention then is not to rehearse these critiques of Titmuss and the 'gift relationship' as this has been extensively carried out elsewhere (see Lamanna, 1997; Mahon-Daly, 2015; Rapport and Maggs, 2002; Tutton, 2004). Instead, we will examine how significant elements of Titmuss' work relates to current donation discourses and how this plays out in practices and policies in westernised societies in order to reinforce the need for a fresh approach to donation.

Reviewing the donation landscape

Altruism

A central part of the 'gift' discourse is the notion of altruism as the appropriate motive for the donation of body parts and products. Altruism can be defined, '...as a supererogatory gift, where donors' altruism leads them to literally give corporeal fragments of themselves to save the life of usually an unknown stranger' (Sothorn and Dickinson, 2011: 890). The Nuffield Council on Bioethics (NCOB) (2011) argues that organ donation should be seen as an altruistic act: it maintains the communal virtue of a 'general disposition to be moved to self-sacrifice by the health needs of others' (NCOB, 2011: 144). Altruism in donation therefore has been described as a form of generalised reciprocity (Miller, 2002). People are urged to donate partly to fulfil their desire to help others, but also because this will promote the kind of community where others would do the same for them (Moorlock et al., 2014).

However, altruism properly defined, is rarely associated with donation, and instead an 'impure' altruism emerges (O'Neill, 2009). Donations of any kind may appear to be altruistic, but a donor's wish for acknowledgment, however trivial, means the gift is never totally free from the social and moral obligations of exchange (Berking, 1999). Equally, some donors view donation as an opportunity to benefit in some way, creating a sense of reciprocity within donation (Locock and Smith, 2011), with donors' motivations understood through weak or conditional forms of altruism (Canvin and Jacoby, 2006; McCann et al., 2010). For example, those who donate tissue for research perceived gaining potential personal benefits through their donation, such as information about their own health, obtaining better care, and assisting the potential development of a cure for their condition (Locock and Boylan, 2015). Similarly, women who donated their aborted fetuses for research purposes were found to feel better about deciding to have an abortion (Martin et al., 1995) or were perceived as seeking redemption by allowing scientists to extract value out of the fetus that they had aborted (Pfeffer, 2008). Consequently, Kanellopoulou (2009) claims that the altruism surrounding the acts of donation reported in studies is a fallacy, and instead argues for a model of mutual exchange, whereby people should be willing to donate to a system that they would be willing to benefit from. Rather than a purely altruistic behaviour, donation could be conceived as a form of beneficent exchange because, 'where there is giving there is also getting' (Lamanna, 1997: 169; see Sharp and Randhawa, 2014 for overview of different perspectives on altruism, reciprocity, and exchange theories).

Community and solidarity

The importance of 'community' has resonated extensively within the literature on donation. The origins of the Red Cross Blood Transfusion Service lie in a duty to a community, rather than a private relation between individuals (Whitfield, 2013). More recently, membership of disease or ethnic communities have been reported to hold a powerful influence on the decision to donate (Sharp and Randhawa, 2016). Governments and charities have created and drawn on a sense of community to generate a sense of solidarity for donors, so they perceive themselves as doing good for those they identify with (O'Neill, 2009). To achieve this sense of solidarity, 'facts' surrounding diseases or ethnic communities are constructed that generate unique needs for that community e.g. rare immunological compatibility, which are presented as currently 'unmet' (Williams, 2015). This places pressure on those facilitating donation, which shapes hospital practices and the interaction between practitioners and potential donors (Kierans and Cooper, 2013), and potential donors with a specific illness or from a particular community are left feeling obligated to express their support through donation (Scully et al., 2012).

However, conceptions of community are fluid and changing. The introduction of hybrid cord blood banks mean a sample is divided and stored for both public and personal use (O'Connor et al., 2012). Unanticipated 'communities' are emerging through the perceived discrimination resulting from contemporary donation infrastructure e.g. donating to the public cord blood bank is restricted according to the location of the collection sites in England. Therefore, for some pregnant women who are unable to donate to the public bank due to not living near a maternity ward that acts as a collection site, a right to donate has emerged in order to acquire the benefit of affordable storage (Machin et al., 2012). Furthermore, a sense of community within donation is now on a global scale through the introduction of European registries and world banks of blood products in order to meet the needs of diverse ethnic populations. As a consequence, donated samples have acquired a price and governments have been able to trade in cord blood (Brown et al., 2011), particularly those of rare blood types that can meet the needs of specific ethnic groups (Brown et al., 2011). Thus, the context of donation is now more globally situated and the development of trans-national donation needs to be recognised.

Voluntariness

In order to encourage the voluntary nature of donation, Titmuss' (1970) work has generated an aversion from policy makers and regulators to financially incentivise or reward donations for fear of establishing tissue-based economies and the resulting commodification or 'marketisation' of human bodies (Lipworth et al., 2011). For example, rather than people receiving payment for their donated eggs or sperm, donors have been reimbursed or compensated for costs incurred in order to donate gametes such as travel, annual leave, or childcare (Human Fertilisation and Embryology Authority, 2019; NCOB, 2011). Some have

argued for retention of individual property rights over donations, particularly biosamples, potentially resulting in paying participants royalties or profit shares (Laurie, 2004; Tutton, 2004).

The voluntary aspect of donation relies heavily on the practice of consent, so that body parts and products are given freely. Yet Hoeyer (2008) accuses researchers as “fixating” on consent, claiming it is a low priority for donors, with programmes often relying on opt-out legislation, as seen in Spanish, Singaporean and British organ donation. Further, who can and should consent is often disputed, as in the case of deceased organ donation, practitioners rarely go ahead with the retrieval of organs if the next of kin have not consented to the donation (Shaw, 2012). No longer can the act of donation be simply considered as one that is active, physical, or conscious. In cord blood donation, there has been much debate as to whether it is the mother or the baby that has donated the blood from the placenta (Kline, 2001). It is not always clear then *who* is ‘doing’ the donating – those consenting or those physically giving – or if a person ‘owns’ his or her body parts and products to give away.

Doubts over how freely donations are given are reflected in how far donors can direct their donations and in what circumstances. For example, donors can choose whether their organs are used for transplantation or research, and specify which organs they are willing to give, which suggests that some constraints are considered socially acceptable (Moorlock et al., 2014). In fertility clinics, donors of embryos are able to place restrictions on who they wish to receive their donation (Frith & Blyth, 2013), as well as which embryos are available for donation (Biggers and Summers, 2004). Yet, deceased conditional and directive donations are prohibited in the UK as they are deemed problematic after a white man’s next of kin requested his organs were only given to white people (Department of Health, 2000).

Anonymity

Titmuss framed blood donation as a relationship between two strangers – the donor and the recipient. To achieve this, the donated blood was given anonymously (Whitfield, 2013). Consequently, donation has been viewed as a one-off act (Shaw, 2014), which is exacerbated by the distance between donors and their donation constructed through the collection, processing, and storage of body parts and products (Whitfield, 2013). In recent years, anonymity has been informally challenged as organ donors’ kin and recipients go to great lengths to find one another and form new kinship relations (Sharp, 2006). Moreover, policy makers, with the support of donor charities, who wish to increase the number of donations and encourage ‘socially responsible’ donations have campaigned for the removal of donor anonymity. In some cases, donors can therefore be identified and acknowledged for their role in the process. Yet, in the instance of donated dental casts made from calcium sulphate marked with the full name of the patient for an art installation, the identification had to be removed (Czarnecki, 2011).

If our individual, social, civil and legal identities are produced by the intertwining of our forenames and surnames with our bodies (Pilcher, 2016), what does this mean then for those donations that are given anonymously such as blood? For Pilcher (2016), identities arise out of the complex meshing of the connections between names and bodies and therefore what does the practice of anonymity 'do' to the people donating, their identity and how we interpret and understand their bodies? What aspects of the person are denied, neglected, or overlooked by the policy of anonymity? Equally, for the recipients of donations, how does the anonymity shape the relationships they can establish with the body part or product? For medical students learning anatomy, allocating names to the dead bodies donated for medical education purposes, enables a relationship to be constructed with their donor (Jones and King, 2016; Williams et al., 2014).

Donation today

Since Titmuss, the landscape of donation within western societies has been dominated by the concept of 'gift' and the associated scripts of altruism, community, voluntary and anonymity. For example, transplantation is understood as an unquestioned good, the shortage of organs is therefore portrayed as tragic, people are depicted as dying unnecessarily, donation is the solution, and donors the heroes (Zeiler, 2014). Zeiler describes the 'darker side' (Zeiler, 2014: 175) of donation, and highlights the need to challenge our assumptions about 'donation'.

Gothic studies researchers have vividly deconstructed the 'state-sponsored' (Wasson, 2015: 105) organ donation process to illuminate the vulnerability of recipients and donors. Fox and Swazey (2002) assert that there is a 'tyranny' inherent in receiving a gifted organ: organ transplantation exerts a powerful influence over the recipients' lives because of the degree of ethical responsibility placed on the recipient to have a successful outcome to the transplant. A 'good recipient' therefore conducts self-care before and after the transplant (Sothorn and Dickinson, 2011). Recipients should also feel gratitude towards the donor for the donation, as they have gone through so much, which highlights the sacrificial element in 'gift-giving' (Mauss, 1966). Viewing donation through the lens of sacrifice rather than the 'gift relationship' or 'gift giving', provides insight into the decisions of families who choose not to donate (Sque et al., 2007). For example to protect the body of a loved one from being cut up during organ retrieval (Sque et al., 2003) or because of religious and cultural understandings around the criteria used to define 'death' (Olick et al., 2009).

Researchers have proposed a need to focus on the ongoing experience of donation (Lipworth et al., 2011), which people 'live' with, and may even come to regret (Burroughs et al., 1998). The donation process is part of an interconnected system of institutions, which form a hierarchy, with the lowest level being represented by the 'institution' of marriage or civil partnership or the family unit, then moving up to a local level e.g. a hospital, the

national level e.g. the NHS within the UK, or the international level e.g. the trade in gametes. Donation then incorporates wider relationships and donors can return to their decision in the future, particularly in the cases of gamete and embryo donations that can produce new and extended kinship relationships and the impact of the donation may not be felt until many years later.

A call for a sociology of donation

What can be donated, to whom, and for what purposes have shifted since Titmuss first wrote about the 'gift relationship'. Research has shown that the meanings and associations with 'donation' no longer seem to adequately capture the act and process. Some have responded to this by challenging if the use of the concept 'donation' is still appropriate (O'Neill, 2009), presenting the term as somehow deficient or lacking in some way, and have gone on to propose alternative descriptors e.g. 'exchange' (Hoeyer, 2013), 'participation' (Haimes and Whong-Barr, 2004), 'transfer' (Sharp, 2006), to capture the diverse elements of donation. However, we argue that 'donation' should not be substituted with another word. The meaning of 'donation' is not static and therefore it can evolve to incorporate the new cultural scripts that better reflect the modern processes around donation. As a dynamic term, its constituent elements have to be recognized, and the complexity of donation, particularly in regard to body parts and products, conceptualized – something that, we argue, can be achieved through a sociology of donation.

Challenges for a sociology of donation

Before contemplating what a sociology of donation might entail, it is worth reflecting on what challenges such a proposal might face. A sociology of donation can be considered to sit between novel and existing fields of study. Yet, proposing a sociology of donation might skirt around the edges of what is significant, or equally it may be considered too narrow in its focus. As researchers, we tend to think and view donation in silos according to what is donated and for what purpose, rather than taking a bird's eye view of the donation landscape to see what can be learned from other forms and purposes of donation. Czarnecki (2011) describes the milk teeth donated by the public used in her art installation, *Palaces*, as a symbol of transition and progress, something that could also be relevant to organ, breast milk or blood donation. Are these silos present because we believe there is something unique about that specific act, process, or body part or product that means the lessons cannot be transferred and applied to the topic under study? Reproductive tissue for example is generally distinguished from other types of donated tissue because eggs, sperm and embryos have the potential to give rise to new individuals, not just to prolong the lives of existing individuals, or used for research (Scully et al., 2012). Further, can we draw inspiration by looking outside of our strict discipline boundaries? After all, anthropologists and ethnographers (see Fox and Swazey, 2002; Lock, 2002; Sharp, 2006) illustrate that the contexts in which different organs and tissues are donated can vary significantly. In turn,

these differences can influence the socio-moral understanding of donation in each case and make them non-comparable in ethical terms.

Therefore, a sociology of donation could be criticized for being too broad and wide ranging in its approach. Indeed, researchers have made multiple attempts to define 'donation', highlighting the challenges to categorically state the origins and end points of the act and process of 'donation'. Drawing inspiration from science and technology studies scholars (see Callon, 1987), 'donation' therefore is a tangled web of people and process, policy and practice, and relationships, that are situated in particular political and economic contexts. Concepts of donation can therefore appear to be without any limits or boundaries. For example, organ donation cannot be understood as the simple agency of the donor because it is always overdetermined by the assemblage of permission from the donors' family, the policies of the hospital, the decisions of the doctors, psychologists, and the work of the algorithms, which assist tissue matching (Sothorn and Dickinson, 2011). Some American healthcare managers perceive participating in some organ donation practices as a matter of conscience, and therefore have either opted to restrict their practices around organ donation and/or enabled staff to opt out (Bramstedt, 2016).

Yet a 'sociology of...' can act as a way of bringing together a set of empirical findings and a collection of scattered writings to propose a distinctive kind of explanatory model for donation. Whilst a 'sociology of...' suggests unity in a field of study, it does not have to be based on a single, general theory. Lipworth et al. (2011), for example, has argued that no single sociological theory or concept can account for the process of donating to biobanks for example. They proposed that any sociology of biobanking would need to be nuanced and to draw upon a variety of social theories in order to account for the donor population, the type of tissue being donated, and the context of the donation. A sociology of donation could be unified by assembling a set of common empirical characteristics that demarcate the field from other types of social phenomena. For example, body parts and products have occupied a distinctive social space, in being generally viewed as outside the realm of market transactions (i.e. prohibitions of selling, fears of commodification and uncertainty over ownership) and concerns over consent and welfare of the donors (and recipients). Hence, in this regard a sociology of donation does usefully delineate an area of social practice.

So, whilst the advantages of a 'sociology of...' are compelling, the question remains if 'donation' warrants its own specialty. After all, what is unique about donation? Does it matter if such a speciality did not exist? What might a sociology of donation entail?

Contemplating a sociology of donation

Donation has, historically, been investigated and framed using a body part or product specific, reductionist approach, which has provided a rich understanding of the social, ethical, legal, and cultural implications of donation for each specific area. A sociology of

donation however, could rise above this reductionism and take a systems-view to provide novel and contemporary insights into the field of donation as a whole. We take inspiration from Capra and Luisi (2014) who have proposed a 'Systems view of Life', which is underpinned by the notion that all living systems are complex, and that this complexity is due to the interconnections between the various networks that span the biological, cognitive, social, and ecological dimensions of life. As such, we believe that a 'sociology of donation' should integrate our 'understanding of social phenomena with the basic ideas about the relevant biological and cognitive phenomena' (Capra and Luisi, 2014: 298) that are inherent to body part or product donation.

Donation as a complex system

The idea that a theory could be constructed and used to explain the mechanistic behaviours and dynamics of complex systems was first advocated by Ludwig von Bertalanffy in the late 1920s, where he stated, 'a system may be defined as a set of elements standing in interrelation among themselves and with the environment' (von Bertalanffy, 1972: 417). He later went on to propose a General Systems Theory which incorporated relationships between components of a system, and that theoretical models be used to explain and predict system-wide processes and events (von Bertalanffy, 1972). By taking inspiration from this early systems thinking, along with the new approach of Capra and Luisi, we conjecture that a systems view would allow us to use a holistic approach for investigating the various dimensions of donation, such as stakeholders and their demographics (e.g. faith, ethnicity and culture), different body parts, institutions and their processes, the wider political and consequent economic structures and the way that social structures constrain people's actions.

[insert Figure 1 Venn diagram of the seven dimensions of complexity here]

We are cognizant that functionality within systems is multi-scale in nature and often hierarchical in the organization of social structures. In addition, we also understand the importance of moving beyond the mere structure and topology of the network of components (i.e. the network of stakeholders within organ donation), which only captures the 'skeleton of complexity', and instead focus on the dynamics and relationships that take place along the links, the environment in which these are situated, and the various factors that are involved in the decision to donate and the decision on who is/are worthy recipients and how these processes are organized and regulated (Allen and Lientz, 1978; Gharajedaghi, 2011). For our proposed 'sociology of donation' we aim to take inspiration from the recent work of Capra and Luisi (2014), which will allow us to include and integrate the various dimensions that make up the complex system of donation, such as biological (body parts), cognitive, social, and institutional dimensions (see figure 1); along with integrating knowledge across the full hierarchy of the complex system of donation, which we term the

‘pyramid of donation’ (see figure 2). For example, by integrating the two key themes of the particular body part and the relevant stakeholders (donors, family of deceased, donation recipients, people produced from donation – that could recognise the inter-sectionality of donation), along a number of dimensions that form the complexity of donation (e.g. faith, culture, community norms), we would be able to form a holistic picture of the reasons why stakeholders make certain decisions around donation.

[insert Figure 2 Pyramid of donation here]

We will now highlight some of these complexities and how our theoretical approach to a sociology of donation could facilitate a richer understanding, by opening up questions and areas of inquiry that were previously not apparent when constrained by the ‘gift’ discourse or a focus on one specific body part or product.

A lens to understand different cultural meanings of the body. A systems-approach to donation will enable us to consider the full spectrum of body parts and products that can now be donated. The recent expansion of what can be donated now represents almost the entirety of the body, including most recently the uterus (Wilkinson and Williams, 2016), and bodily products with tears and water during the birth process donated to the artist, Amy Sharrock’s *Museum of Water*, and urine donation proposed as a possibility for future collection of stem cells (Kloskowski et al., 2015). Certain kinds of donation can be associated with greater repugnance than others might generate e.g. whole brain donation (Lipworth et al., 2011), or the purpose of donation can generate more controversy, such as the donation of dead bodies to the educative art exhibition, Body Worlds (Jones and Whitaker, 2009) or face transplants. Artist, Gina Czarnecki (2011) questions why there is such a taboo about using particular body parts and theorises it is related to our notion of ‘self’ and a reluctance to allow parts of ourselves to be absorbed into ‘others’.

These different forms of donation increase the complexity of the donation system as the donation of different body parts incurs different costs and indeed consequences to the donor. People are willing to donate some body parts and not others, want to have their tissue or embryos used for research but not for treatment, happy to help one particular group of people and not another. In essence, we can be donors in one context, but not in another. There are sliding scales of donation. Donation should be perceived as messy and not straightforward or clear cut and this needs to be reflected in how we research the area as well as how we discuss it. Do body parts used in art exhibitions attach less meaning compared to those used in treatment, education or research? Or do we give meaning to body parts and products previously considered ‘waste’ or ‘replaceable’ through the act of donation, so that the body part or product is perceived as ‘life-saving’ or advancing

knowledge because of the purpose of donation. Does the same body part or product donated for different purposes, generate different meanings? Thereby prompting the questions what can we learn about the body parts and products donated, and the relationships we have towards them. Recognizing the commonalities and dissimilarities between attitudes to the donation of different body parts and products can provide a useful lens to understand different cultural meanings of the body and its constituent parts – that could be lost if donation is not viewed as an inter-dependent system.

Recognizing practices embedded in wider social structures. There are a large number of stakeholders involved in the donation process with a range of motives and requirements. These can include the donor (living or deceased), the recipient, those born from donation and the extended kinship relationships created by gamete and embryo donation, family members, and practitioners (e.g. organ donation nurse, surgeons, bereavement nurses, transplant coordinators, organ retrieval team, fertility specialists). Each of these different stakeholder groups provides their own set of characteristics that add to the complexity of donation. This complexity is multifaceted. For example, in deceased organ donation not only are the next of kin key stakeholders, but their decision process also incorporates various aspects of their identity, such as ethnicity, faith and psychosocial factors (see figure 1), along with the hierarchy of systems that they belong to, such as family, community and culture (see figure 2).

Alongside donations to recipients who need a transplant, there is also a whole industry being developed around the donation of body parts to public and commercial storage banks. These biobanks depend on the donation of tissue and organs for the purposes of scientific research, for example the identification of disease genes, which may lead to the development of personalised treatments. Recognizing the many, different stakeholders involved in donation can shed light on how these practices are embedded in wider social structures that go beyond the act of giving between donor and recipient, and are surrounded by international policy, and regulatory and commercial frameworks. For example, the restriction of men who have had sex with other men (MSM) from giving blood highlights the regulatory power over certain societal groups and the social prejudices influencing the right to donate. This has given rise to debates around inclusions and exclusions of donor screening criteria, who is included and who is not and the development of 'blood activism' (Orsini, 2002). The blood ban, now replayed in women who have slept with MSM unable to donate cord blood, is about how truths are produced, by whom, and for whom (Fisher and Schonfeld, 2010; Valliere, 2005).

Brings areas of uncertainty in 'donation' to the fore. When taking a systems-view to body part or product donation, it is evident that there is a great deal of uncertainty within the system as a whole. This uncertainty can be due to a number of factors, including 1) aleatory uncertainty, such as: the complex human emotions and behaviours that arise during the

decision and consent processes e.g. trust in science, researchers, and institutional governance, and fear of acquiring health problems are significant in determining whether someone donates their embryos, tissue or organs (Andaleeb and Basu, 1995; Lipworth et al., 2011; Scully et al., 2012); the stochastic nature of immunology, in particular the immunological markers that are used in tissue typing, and which are based on the underlying genetic make-up of the donor and recipients and how this genetic make-up is conceptualised; and 2) epistemic uncertainty due to our incomplete knowledge of the system. This is most apparent in the discussions surrounding how 'quality' in donation is determined. In the instances of cord blood or organ donation, quality was once thought to be determined by scientific factors alone e.g. immunological markers and matching, but is now also being influenced by the clinical and social elements of the collection and processing techniques as well as the tacit knowledge that those facilitating donation employ when making decisions (Machin, 2016; Bradley et al., 2016; Sothern and Dickinson, 2011).

Equally, uncertainty is reflected in the discussions surrounding the riskiness associated with donation. For example consideration is given to the possibility of restarting a deceased donor's heart and the subsequent need for them to be intubated again so that a camera can be used when determining the 'quality' of lungs for donation (Edwards et al., 2006; Levvey et al., 2015). There are also risks for those receiving the donated organs. In one case in Wales, the organs transplanted had been refused by other health practitioners (BBC News, 2014), raising the question how do practitioners decide which donations to use when there is a choice. What might be a 'risky' organ for one practitioner, might be acceptable to another. How, then, do healthcare teams determine the quality of donations? A precedent for this way of thinking has been set by Sothern and Dickinson (2011), who discuss the complexity in the donation process of matching organs to recipients due to three uncertainties within the system: medical uncertainty, temporal uncertainty, and geographic uncertainty. Briefly, the former relates to the level of immunological markers (for tissue cross-matching) and the viability of organs; the temporal uncertainty relates to the viability of body parts/products once outside of the body; and the latter relates to the geographical aspects of the donation process, such as the distance between donor and recipient.

We believe that an important research area within this new sociology of donation should therefore be to seek to identify and understand the various uncertainties within the system. A system view of donation will: identify aspects of donation that are not clear-cut and foreground the inherent uncertainties in donation practice; further develop our understanding of the complex interrelationships between the various aspects of donation; and uncover novel areas ripe for future research. By focussing on donation of body parts and products as an activity more broadly located we can pick out common themes, such as anonymity, and see how they play out in different settings. For example, what comparisons can we make between the anonymity of organ versus gamete donors? Are some purposes of donation riskier than others? Is the process and act of donation to art somehow less

risky, or generates fewer ethical issues to consider? By making such comparisons we can see areas where there are similarities and dissonance – this can produce new conceptualisations by disrupting our previously held assumptions and meanings and illuminating how elements such as anonymity function in different contexts.

An example where ‘sociology of donation’ would provide immediate benefit is around deceased donation. The conceptual foundation of modern scientific medicine is firmly grounded in reductionism and relates to the various immunological markers of the donated body part/product and the viability of the donated item with respect to temporal and spatial dimensions. One of the major weaknesses here is that this reductionist approach does not consider the social aspects relating to next of kin consent for the proposed body parts or products to be harvested. The decision by next of kin to donate the organs is a complex decision based on the relative weightings that individuals place on the different dimensions proposed (see figure 1) and the influence from various levels within the pyramid of donation (see figure 2). Figure 3 represents the complex multi-stakeholder environment that relates to the high-level activities involved in deceased donation. Although the activity network appears to be linear and straightforward, we believe that each individual activity has varying forms of uncertainty (and complexity) behind them, that are based upon our proposed dimensions of complexity (e.g. personal psychosocial factors, or social norms through faith, ethnicity or culture), and from the causal relationships introduced from the individual stakeholder’s social identity from their position within the pyramid of donation (e.g. family or community).

[insert Figure 3 Stakeholder environment within deceased donation here]

Conclusion

We have argued that there is a need for a ‘sociology of donation’ to bring together the range of distinctive issues that the donation of body parts and products raise, and open new and productive avenues of research. In advocating a systems view, we have taken inspiration from the early General Systems Theory movement as advocated by von Bertalanffy, along with a more recent interpretation by Capra and Luisi, in order to integrate the external environment of institutions, with the social world of human relationships, and the inner environment of biology and psychosocial factors (as depicted in figures 1-2). The donation of body parts and products raise important social and ethical issues due to the distinctive social meaning and regulation of the body and its products. By placing donation as the central focus of inquiry, we can explore the multi-faceted nature of donation, and bring out commonalties and differences between the social and regulatory structures that govern different forms of donation. Seeing donation as located within broader social contexts and conceiving of it as a complex system, we can begin to address the new

challenges over what can be donated and to whom, and how this will expand and change as medical technologies develop and redraw the horizons of what is possible.

References

Allen, J. & Lientz, B.P. (1978). *Systems in action: A managerial and social approach*. Santa Monica, CA: Goodyear Publishing Company Inc.

Andaleeb, S.S. & Basu, A.K. (1995). Explaining blood donation: The trust factor. *Journal of Health Care Marketing*, 15, 42-48.

BBC News. (2014, November 18). Patients given kidneys rejected 'unfit' by other hospitals. Retrieved from <http://www.bbc.co.uk/news/uk-wales-30086735>

Berking, H. (1999). *Sociology of giving*. London: Sage Publications Ltd.

Biggers, J.D. & Summers, M.C. (2004). When to avoid creating surplus embryos. *Human Reproduction*, 19, 2457-2459. <https://doi.org/10.1093/humrep/deh476>

Bradley, A., Hosgood, S., Nicholson, M., & Watson, C. (2016). Flushed with success. *Research Horizons* [on-line], 30, pp.12-13. Retrieved from https://www.cam.ac.uk/system/files/issue_30_research_horizons.pdf

Bramstedt, K.A. (2016). Exploring the dilemma of hospital refusal to perform controlled organ donation after circulatory death (DCD). *Swiss Bioethica Forum*, 9, 39 – 42.

Brown, N., Machin, L.L., & McLeod, D. (2011). Immunitary bioeconomy: The economisation of life in the international cord blood market, *Social Science and Medicine*, 72, 7, 1115-1122. <https://doi.org/10.1016/j.socscimed.2011.01.024>

Burroughs, T., Hong, B., Kappel, F., & Freedman, B.K. (1998). Organ donor families often question their decision. *Psychosomatic Medicine*, 60, 156-162.

Callon, M. (1987). Society in the making: The study of technology as a tool for sociological analysis. In Bijker, W.E., Hughes, T.P., & Pinch, T.J. (eds) *The social construction of technological systems: New directions in the sociology and history of technology*, USA: MIT Press, pp.83-103.

Canvin, K., & Jacoby, A. (2006). Duty, desire or indifference? A qualitative study of patient decisions about recruitment to an epilepsy treatment trial. *Trials*, 7, 32.
<https://doi.org/10.1186/1745-6215-7-32>

Capra, F., & Luisi, P.L. (2014). *The systems view of life: A unifying vision*. Cambridge, UK: Cambridge University Press.

Champney, T.H. (2016) The business of bodies: Ethical perspectives on for-profit body donation companies. *Clinical Anatomy*, 29, 25-29. <https://doi.org/10.1002/ca.22643>

Czarnecki, G. (2011). *Humancraft: Contaminating science with art*. London: The Bluecoat.

Department of Health (2000) *An investigation into conditional organ donation [Report of the Panel]*. London: Department of Health.

Edwards, J., Mulvania, P., Robertson, V., George, G., Hasz, R., Nathan, H., & D'Alessandro, A. (2006). Maximizing organ donation opportunities through donation after cardiac death. *Critical Care Nurse*, 26, 101-115. <https://doi.org/10.4037/ccn2006.26.2.101>

Frith, L., & Blyth, E. (2013). They can't have my embryo: The ethics of conditional embryo donation. *Bioethics*, 27, 6, 317-324. <https://doi.org/10.1111/bioe.12034>

Fisher, C., & Schonfeld, T. (2010). Sex and blood: A deeper exploration of discrimination in the FDA blood donor policy. *The American Journal of Bioethics*, 10, 40-42. <https://doi.org/10.1080/15265160903506392>

Fox, R.C., & Swazey, J.P. (2002). *The courage to fail: A social view of organ transplants and dialysis*. New Brunswick: Transaction Publishers.

Gerrand, N. (1994). The notion of gift-giving and organ donation. *Bioethics*, 8, 127-150. <https://doi.org/10.1111/j.1467-8519.1994.tb00250.x>

Gharajedaghi, J. (2011). *Systems thinking: Managing chaos and complexity* (3rd ed). Burlington, MA: Morgan Kaufmann.

Grace, D., Gaspar, M., Lessard, D., Klassen, B., Brennan, D.J., Adam, B.D., Jollimore, J., Lachowsky, N.J. & Hart, T.A. (2019). Gay and bisexual men's views on reforming blood donation policy in Canada: A qualitative study. *BMC Public Health*, 19, 772. <https://doi.org/10.1186/s12889-019-7123-4>

Haimes, E., & Whong-Barr, M. (2004). Levels and styles of participation in genetic databases: A case study of the North Cumbria Community Genetics Project. In Tutton, R., & Corrigan, O. (eds) *Genetic Databases: Socio-Ethical Issues in the Collection and Use of DNA*. London: Routledge, pp. 57-77.

Hoeyer, K. (2008). The ethics of research biobanking: A critical review of the literature. *Biotechnology and Genetic Engineering Reviews*, 25, 429-452. <https://doi.org/10.5661/bger-25-429>

Hoeyer, K. (2013). *Exchanging human bodily material: Rethinking bodies and markets*. London: Springer.

Human Fertilisation and Embryology Authority. (2019). Code of Practice (9th ed). Section 13. Retrieved from <https://www.hfea.gov.uk/about-us/news-and-press-releases/2019-news-and-press-releases/new-version-of-the-code-of-practice-has-been-launched/>

Jones, D.G., & King, M.R. (2016). Maintaining the anonymity of cadavers in medical education: Historic relic or educational and ethical necessity? *Anatomical Sciences Education*, 10, 87-97. <https://doi.org/10.1002/ase.1618>

Jones, D.G., & Whitaker, M.I. (2009). Engaging with plastination and the body worlds phenomenon: A cultural and intellectual challenge for anatomists. *Clinical Anatomy*, 22, 770-776. <https://doi.org/10.1002/ca.20824>

Kanellopoulou, N. (2009). Reconsidering altruism, introducing reciprocity and empowerment in the governance of biobanks. In Kaye, J., & Stranger, M. (eds) *Principles and practice in biobank governance*. Farnham: Ashgate, pp.33-52.

Kent, J., Fannin, M., & Dowling, S. (2019). Gender dynamics in the donation field: human tissue donation for research, therapy and feeding. *Sociology of Health and Illness*, 41, 567 – 584. <https://doi.org/10.1111/1467-9566.12803>

Kierans, C., & Cooper, J. (2013). The emergence of the ethnic donor: The cultural production and relocation of organ donation in the UK. *Anthropology and Medicine*, 20, 221-231.
<https://doi.org/10.1080/13648470.2013.845480>

Kline, R.M. (2001). Whose blood is it anyway? *Scientific American*, 284, 42-50.

Kloskowski, T., Nowacki, M., Pokrywczynska, M., & Drewa, T. (2015). Urine – A waste or the future of regenerative medicine? *Medical Hypotheses*, 84, 344-349.
<https://doi.org/10.1016/j.mehy.2015.01.019>

Lamanna, M.A. (1997). Giving and getting: Altruism and exchange in transplantation. *Journal of Medical Humanities*, 18, 169-191. <https://doi.org/10.1023/A:1025637702288>

Laurie, G. (2004). *Genetic privacy: A challenge to medico-legal norms*. Cambridge, UK: Cambridge University Press.

Levey, B.J., Whitford, H.M., Williams, T.J., Westall, G.P., Paraskeva, M., Manterfield, C., Miller, T., McGiffin, D., & Snell, G.I. (2015). Donation after circulatory determination of death lung transplantation for pulmonary arterial hypertension: Passing the toughest test. *American Journal of Transplantation*, 15, 3208-14. <https://doi.org/10.1111/ajt.13388>

Lipworth, W., Forsyth, R., & Kerridge, I. (2011). Tissue donation to biobanks: A review of sociological studies. *Sociology of Health and Illness*, 33, 792–811.
<https://doi.org/10.1111/j.1467-9566.2011.01342.x>

Lock, M. (2002). Human body parts as therapeutic tools: Contradictory discourses and transformed subjectivities. *Qualitative Health Research*, 12, 1406-1418.
<https://doi.org/10.1177/1049732302238751>

Locock, L., & Smith, L. (2011). Personal benefit, or benefitting others? Deciding whether to take part in clinical trials. *Clinical Trials*, 8, 85-93.
<https://doi.org/10.1177%2F1740774510392257>

Locock, L., & Boylan, A-M.R. (2015). Biosamples as gifts? How participants in biobanking projects talk about donation. *Health Expectations*, 19, 805-816.
<https://doi.org/10.1111/hex.12376>

Machin, L.L., Brown, N., & McLeod, D. (2012). Giving to receive? The right to donate in umbilical cord blood banking for stem cell therapies, *Health Policy*, 104, 3, 296-303.
<https://doi.org/10.1016/j.healthpol.2011.11.011>

Machin, L., & Cherkassky, L. (2015). Deconstructing donation, *Journal of Medical Law and Ethics*, 3, 3, 145-147.

Machin, L.L. (2016). The collection of 'quality': Umbilical cord blood for stem cell treatments: conflicts, compromises, and clinical pragmatism, *New Genetics and Society*, 35, 3, 307-326. <https://doi.org/10.1080/14636778.2016.1209109>

Mahon-Daly, P. (2015). The alienation of the gift: The ethical use of donated blood. *Journal of Medical Law and Ethics*, 3, 193-203.
<https://doi.org/10.7590/221354015X14488767262912>

Manzano, A., & Pawson, R. (2014). Evaluating deceased organ donation: A programme theory approach. *Journal of Health and Organization Management*, 28, 366-385.
<https://doi.org/10.1108/JHOM-07-2012-0131>

Martin, D.K., Maclean, H., Lowy, F.H., Williams, J.I., & Dunn, E.V. (1995). Fetal tissue transplantation and abortion decisions: A survey of urban women. *Canadian Medical Association Journal*, 153, 545-552.

Mauss, M. (1966). *The gift: Forms and functions of exchange in archaic societies*. London: Cohen and West.

McCann, S.K., Campbell, M.K., & Entwistle, V.A. (2010). Reasons for participating in randomized controlled trials: Conditional altruism and considerations for self. *Trials*, 11, 31. <https://doi.org/10.1186/1745-6215-11-31>

Miller, D. (2002). Are they my Poor? Critical Review of International Social and Political Philosophy, 5, 106-127. <https://doi.org/10.1080/13698230410001702762>

Moorlock, G., Ives, J., & Draper, H. (2014). Altruism in organ donation: An unnecessary requirement? *Journal of Medical Ethics*, 40, 134-138. <http://dx.doi.org/10.1136/medethics-2012-100528>

Nordqvist, P. (2019). Un/familiar connections: On the relevance of a sociology of personal life for exploring egg and sperm donation. *Sociology of Health and Illness*, 41, 601 – 615. <https://doi.org/10.1111/1467-9566.12862>

Nuffield Council on Bioethics. (2011). *Human bodies: Donation for medicine and research*. London: Nuffield Council on Bioethics.

O'Connor, M.A., Samuel, G., Jordens, C.F., & Kerridge, I.H. (2012). Umbilical cord blood banking: Beyond the public-private divide. *Journal of Law and Medicine*, 19, 512-516.

O'Neill, F.K. (2009). Giving from our bodily belongings: Is donation an appropriate paradigm for the giving of bodies and body parts? *HEC Forum*, 21, 151-174.

<https://doi.org/10.1007/s10730-009-9094-9>

Olick, R.A., Braun, E.A., & Potash, J. (2009). Accommodating religious and moral objections to neurological death. *The Journal of Clinical Ethics*, 20, 183 – 91.

Oltvai, Z.N., & Barabasi, A.L. (2002). Life's complexity pyramid. *Science*, 298, 763-764.

<https://doi.org/10.1126/science.1078563>

Orsini, M. (2002). The Politics of Naming, Blaming and Claiming: HIV, Hepatitis C and the Emergence of Blood Activism in Canada. *Canadian Journal of Political Science*, 35(3): 475-498.

Pfeffer, N. (2008). What British women say matters to them about donating an aborted fetus to stem cell research: A focus group study. *Social Science and Medicine*, 66, 2544-2554. <https://doi.org/10.1016/j.socscimed.2008.01.050>

Pilcher, J. (2016). Names, bodies and identities. *Sociology*, 50, 764 – 779.

<https://doi.org/10.1177%2F0038038515582157>

Rapport, F.L., & Maggs, C.J. (2002). Titmuss and the gift relationship: Altruism revisited.

Journal of Advanced Nursing, 40, 495-503. <https://doi.org/10.1046/j.1365-2648.2002.02406.x>

Scully, J.L., Haimes, E., Mitzkat, A., Porz, R., & Rehmann-Sutter, C. (2012). Donating embryos to stem cell research: The problem of gratitude. *Bioethical Inquiry*, 9, 19-28.

<https://doi.org/10.1007/s11673-011-9352-9>

Sharp, L. (2006). *Strange harvest*. Berkeley: University of California Press.

Sharp, C., & Randhawa, G. (2014). Altruism, gift giving and reciprocity in organ donation: A review of cultural perspectives and challenges of the concepts. *Transplantation Reviews*, 28, 163-168. <https://doi.org/10.1016/j.trre.2014.05.001>

Sharp, C., & Randhawa, G. (2016). The potential role of social capital in the willingness to be a deceased organ donor: A case study of UK Polish migrants. *Transplantation Proceedings*, 48, 680-688. <https://doi.org/10.1016/j.transproceed.2015.10.063>

Shaw, R. (2008). The notion of the gift in the donation of body tissues. *Sociological Research Online*, 13, 41-50. <https://doi.org/10.5153/sro.1832>

Shaw, D. (2012). We should not let families stop organ donation from their dead relatives. *British Medical Journal*, 345: e5275. <https://doi.org/10.1136/bmj.e5275>

Shaw, R. (2014). Live kidney donation as body work. *Critical Social Policy*, 34, 495-514. <https://doi.org/10.1177%2F0261018314538795>

Shaw, R. (2019). Altruism, solidarity and affect in live kidney donation and breastmilk sharing. *Sociology of Health and Illness*, 41, 553 – 566. <https://doi.org/10.1111/1467-9566.12805>

Sothorn, M., & Dickinson, J. (2011). Repaying the gift of life: Self-help, organ transfer and the debt of care. *Social and Cultural Geography*, 12, 889-903. <https://doi.org/10.1080/14649365.2011.624192>

Sque, M., Long, T., & Payne, S. (2003). Organ and tissue donation: Exploring the needs of families. Final report of a three-year study commissioned by the British Organ Donor

Society, funded by the Community Fund, February. Southampton, UK: University of Southampton.

Sque, M., Long, T., Payne, S., & Allardyce, D. (2007). Why relatives do not donate organs for transplants: Sacrifice or gift of life? *Journal of Advanced Nursing*, 61, 134-144.
<https://doi.org/10.1111/j.1365-2648.2007.04491.x>

Swanson, K.W. (2014). *Banking on the Body*. Harvard University Press.

Titmuss, R. (1970). *The gift relationship*. London: Allen and Unwin.

Tutton, R. (2004). Person, property and gift: Exploring language of tissue donation to biomedical research. In Tutton, R., & Corrigan, O. (eds). *Genetic databases: Socio-ethical issues in the collection and use of DNA*. London: Routledge, pp. 19-38.

Valliere, R.W. (2005). The biopolitics of blood donation. In Ivković, M., Draško, G.P., & Prodanović, S. (eds) *Engaging Foucault* (Vol. 2). Belgrade: Institute for Philosophy and Social Theory, pp. 106-113.

von Bertalanffy, L. (1972). The history and status of general systems theory. *The Academy of Management Journal*, 15, 407–426. <https://doi.org/10.5465/255139>

Waldby, C., Rosengarten, M., Treloar, C., & Fraser, S. (2004). Blood and bioidentity: Ideas about self, boundaries and risk among blood donors and people living with Hepatitis C. *Social Science and Medicine*, 59, 1461-1471.
<https://doi.org/10.1016/j.socscimed.2004.01.012>

Waldby, C., & Mitchell, R. (2006). *Tissue economies: Blood, organs and cell lines in late capitalism*. London: Duke University Press.

Wasson, S. (2015). Scalpel and metaphor: The ceremony of organ harvest in gothic science fiction. *Gothic Studies*, 17, 104-123. <https://doi.org/10.7227/GS.17.1.8>

Whitfield, N. (2013). Who is my stranger? Origins of the gift in wartime London, 1939-45. *Journal of the Royal Anthropological Institute*, 19(S1): S95-S117. <https://doi.org/10.1111/1467-9655.12018>

Wilkinson, S., & Williams, N.J. (2016). Should uterus transplants be publicly funded? *Journal of Medical Ethics*, 42, 559-565. <http://dx.doi.org/10.1136/medethics-2015-102999>

Williams, A.D., Greenwald, E.E., Soricelli, R.L., & DePace, D.M. (2014). Medical students' reactions to anatomic dissection and the phenomenon of cadaver naming. *Anatomical Sciences Education*, 7, 169-180. <https://doi.org/10.1002/ase.1391>

Williams, R. (2015). Cords of collaboration: Interests and ethnicity in the UK's public stem cell inventory. *New Genetics and Society*, 34, 319-337. <https://doi.org/10.1080/14636778.2015.1060116>

Zeiler, K. (2014). Neither property right nor heroic gift, neither sacrifice nor aporia: The benefit of the theoretical lens of sharing in donation ethics. *Medicine, Health Care and Philosophy*, 17, 171-181. <https://doi.org/10.1007/s11019-013-9514-0>