

Journal of Medical Law and Ethics

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Preface: Deconstructing Donation¹

In the twenty first century, it seems that the body parts, tissue and fluids that can be donated are limitless, and the purposes for donation have extended beyond our imaginations. We can donate milk teeth, urine and tears to art exhibitions such as *Palaces* or *Museum of Water*, which have prompted researchers to consider the ethics of these donations as illustrated by the project titled *Trust me I'm an artist*. When we look at how we make sense of 'donation' in the 21st century, we are right to question if the ideas, themes and approaches from the past still apply to how donation is practiced today.

Donation and Altruism

As researchers in the field of donation, we have become entrenched in the same dialogue. The act of donation continues therefore to be presented as one that is altruistic, and one that the public are struggling to sustain – a topic that Emma King refers to in her article on cultured red blood cells using stem cell technology for this special issue. This dominating influence of the altruistic nature of donation is today reflected in the policy relating to gamete donation for example, in that 'payment' to egg and sperm donors should be classified as 'reimbursement' for the expenses incurred during the donation i.e. travel or childcare costs. Whilst the difference in language might be small, the implications for society can be deemed to be significant. Paying donors for their donation would not only put a price on human body parts, but also in the case of donating gametes, on the basis of 'life'. Donors, in turn, would *benefit* from their donation, and therefore no longer be altruistic in their act of donation. Yet, the evolution of practices within clinics, such as egg-sharing between women with fertility problems in return for a reduction in the cost of fertility treatment, illustrates the need for a critical approach to re-imagining donation to generate alternative understandings of donation in the twenty first century.

Donation and a Right to Donate

Attention to some concepts, such as a right to donate, has been reignited as new uses for previously 'wasted' blood have been generated. Women who wish to store the cord blood as result of giving birth to their baby, but are unable to afford the cost of commercial cord blood banks, view the option to donate to the English public bank as an opportunity to also gain inexpensive storage. So, if their baby or a family member requires the cord blood due to a future illness, then the cord blood might be available for use, without incurring the cost of commercial bank storage. In essence, the women perceive gains resulting from their donation. However, donating to the public 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

¹ DOI 10.7590/221354015X14488767262750

near a maternity ward that acts as a collection site, a right to donate emerges in order to acquire the benefits they perceived arise from affordable storage.

Donation and Autonomy

Consent has been considered king when discussing the donation of body parts, tissue and fluids, with the intention that they are given freely and voluntarily – a topic Charlotte McLachlan and Gemma Potts apply to their paper on prisoners donating their kidneys for this special issue. But this perception of donation is challenged when we consider companion animals as blood or organ donors or the introduction of the opt-out policy for organ donation in Wales. No longer can the act of donation be simply considered as one that is active, physical, or conscious. In cord blood donation, where the blood is collected from the placenta that was attached to both the pregnant woman and the foetus, there has been much debate as to whether it is the mother or the baby that has donated. Similarly, in the case of deceased organ donation, healthcare professionals rarely go ahead with a retrieval if the next of kin have not consented to the donation, despite the deceased person being on the organ donation register. It is not always clear then *who* is ‘doing’ the donating – those consenting or those physically giving.

Hierarchies of Donors and their Donations

Policy and practices differ across the types of donation and the purposes of donation. For example, donors are identifiable in some practices, but not in others – a topic that Rebecca Dimond considers in her article on mitochondrial donation for this special issue. The removal of gamete donor anonymity in the UK means that donors are no longer in the shadows, but instead can be identified and acknowledged for their role in the process – a topic that Cathy Herbrand and Nicky Hudson discuss in their paper on information sharing in donor conception in the UK and Belgium for this special issue. However, the practice of identification of donors is not applied to the case for blood or cord blood donation. Through these differences in policy and practices, are we inadvertently privileging some body parts, fluids, tissue above others, constructing a hierarchy of donations and donors? 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, tissue and blood previously considered a ‘waste product’ or ‘replaceable’ *through* the act of donation, so that the body part, tissue or fluid is perceived as life saving or advancing scientific knowledge because of the *purpose* of donation. It is the same body part, tissue or fluid donated, but for different purposes, and therefore generates different meanings. Thereby prompting the questions what can we learn about the body parts, tissue and fluids donated, and the relationships we have towards these body parts, tissue, and fluid – a topic that Patricia Mahon-Daly explores in her article on blood donation for this special issue? All donors and their donations are therefore not equal.

Deconstructing Donation: Continuing the Discussion

The articles that follow in this special issue are the product of the first Deconstructing Donation Conference held at Lancaster University in December 2014. The conference included presentations from practitioner and academic researchers in the field of donation, as well as initiating a week-long writing competition for amateur authors, using a simple statement to create an associated with donation 'organs of donation' (<https://hourofwrites.com/search?t=organ+donation>). The conference, funded by Lancaster University and the Institute of Medical Ethics, led to the British Sociological Association Deconstructing Donation Study Group being established. The Group aims to explore the understandings surrounding 'donation' today and ignite inter- and multi- disciplinary dialogue between researchers and practitioners in the field of donation. Since its inception, a range of activities have taken place, including a Pecha Kucha session at the BSA Medical Sociological Annual Conference (presentation recordings available on the BSA website), and the second Deconstructing Donation Conference is planned to take place on 2016 (<http://www.britsoc.co.uk/groups/deconstructing-donation.aspx>). The articles in this special issue are a part of this continuing discussion of deconstructing donation today.

Dr Laura Machin & Miss Lisa Cherkassky

December 2015

Articles

Biodiversity and perceptions of risk: Reactions to the use of a single donor for stem-cell-derived red blood cell transfusions

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Abstract

Blood transfusion is a well-accepted medical technology that currently relies on a supply of red blood cells from many thousands of altruistic donors. Cultured red blood cells using stem cell technology could offer a replacement technology, providing a limitless supply of red blood cells from a single source. This project used interviews and focus groups to explore the views of a wide range of publics towards cultured red blood cells. This paper explores how participants referred to a lack of biodiversity in cultured red blood cells in three ways. The first was as a comparison to GM crops, with concern over a monopoly on blood supplies. The second was a perceived increased risk associated with a single source of blood. Thirdly participants saw the lack of biodiversity as a threat to the altruistic nature of blood donation from multiple donors.

Introduction

This paper is about a research project which looked at the views of various publics towards the use of stem-cell-derived red blood cells for transfusion. During the course of the research it was found that many participants compared this new technology with that of genetically modified (GM) crops. In this paper I discuss how, in interviews and focus groups, GM crops were used to describe a perceived lack of biodiversity. I introduce the transition to cultured red blood cells as a continuation of historical aspects of blood donation, to show the transition from donor gift to potential laboratory project. I will also look at the attitudes towards GM crops in the UK, to discuss how a perceived lack of biodiversity and the 'scientification' of nature are regarded as inherently more risky.

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The historical context of donor blood transfusion

Although bloodletting was first recorded in 430BC and remained a common practice until the nineteenth century,¹ blood *transfusion* is a relatively recent clinical practice. In 1628 Harvey's² book provided the knowledge needed for early animal transfusion experiments by Lower in 1665 and Cox in 1666-67.³ The recognition of the need to transfuse humans only with human blood 1818 was made by James Blundell, with blood types identified by Karl Landsteiner in 1901.⁴ Routine blood typing was not practised until the 1920s, with the rhesus positive and negative blood types identified in 1941.⁵ Percy Oliver's list of blood donors was started in 1921⁶ but it was not until 1937 that Bernard Fantus set up the blood bank as we now know it, with blood refrigerated for up to ten days. Today blood is one of medicines' 'most vital commodities'⁷ and the UK alone transfuses 2.2 million units of blood each year. Donation and transfusion is overseen by the NHS, with four transplant services covering England and North Wales, South Wales, Northern Ireland, and Scotland. The Scottish National Blood Transfusion Service (SNBTS) is the main focus of the research reported in this paper.

The need for a new method of transfusion

The UK has an established and effective blood donation system but there are challenges which highlight the need for alternative methods of blood transfusion. Preventing contamination of donated blood with transfusion transmitted infections (TTIs) requires large amounts of blood testing, bringing with it associated rises in cost.⁸ Acquiring adequate donors is another major hurdle, with donor numbers falling and the UK transfusion services heading towards a recruitment crisis. Currently only 4% of the UK population are re-

¹ P. Giangrande, 'The history of blood transfusion', *British Journal of Haematology* 110:4 (2000), 758-767.

² W. Harvey, *Exercitatio Anatomica de Motu Cordis et Sanguinis in Animalibus* (1628).

³ H. Brown, 'Jean Denis and Transfusion of Blood, Paris, 1667-1668', *Isis* 39:1/2 (1948), 15-29.

⁴ K. Landsteiner, *Ueber Agglutinationserscheinungen normalen menschlichen Blutes* (1901).

⁵ K. Landsteiner & A.S. Wiener, 'Studies on an agglutigen (rh) in human blood reacting with anti-rhesus sera and with human isoantibodies', *The Journal of Experimental Medicine*, 74:4 (1941), 309-320.

⁶ See footnote 1.

⁷ D. Starr, *Blood: an Epic History of Medicine and Commerce* (Little, Brown and Company, 1999), x.

⁸ E. Ferguson, C. Prowse, E. Townsend, A. Spence, J.A. van Hilten, & K. Lowe, 'Acceptability of blood and blood substitutes', *Journal of Internal Medicine* 263:3 (2008), 244-255.

gistered blood donors,⁹ and the Scottish National Blood Transfusion Service expressed a need to raise the donor levels from 175,000 in 2008 to 210,000 in 2010.¹⁰ Many innovations have been proposed to overcome the dual challenges of donor recruitment and possible infection risk. Haemoglobin-based oxygen carriers (HBOCs),¹¹ derived from human or animal blood and Perfluorocarbons (PFCs),¹² which are synthetic oxygen carriers, were heralded as an alternative to red blood cell transfusion. Unfortunately neither product performed well in clinical trials and are not licensed for use in the UK or USA.^{13, 14}

This paper concerns the Novosang product, which is another proposed technology to overcome both the requirement for donors and the infection risk. Rather than using chemical substitutes for blood, the project goal is to culture red blood cells in the laboratory, providing a limitless and infection free source of blood for transfusion. To date the project has received over £12 million in funding from organisations including the Wellcome Trust, the Scottish Funding Council, Scottish Enterprise, the Scottish National Blood Transfusion Service and NHS Blood and Transplant.¹⁵ By the time the project finishes it is hoped that it will generate small quantities of blood suitable for initial animal and human safety tests.

The reaction of the wider public to this novel method of producing red blood cells was unknown. Blood donations in the UK come from altruistic donors, which has impacted on the interesting 'gift relationship' view of blood transfusions, as was portrayed in Titmuss'¹⁶ book of the same name. Studies have shown that donated blood is still preferable to other forms of blood replacement. Ferguson et al.¹⁷ found that the public viewed blood substitutes as a 'substandard replacement' for actual blood, an unnatural and synthetic alternative. A study carried out by Fleming et al.¹⁸ found that those studied had a preference for donor blood, being regarded as the most effective, most ethically acceptable

⁹ National Health Service, 'Introduction to blood donation', www.nhs.uk/conditions/Blood-donation/Pages/Introduction.aspx (last accessed 18/03/2015).

¹⁰ National Health Service, *Report: Meeting the transfusion needs of patients in Scotland. Scottish National Blood Transfusion Service* (2008).

¹¹ T.A. Silverman & R.B. Weiskopf, 'Haemoglobin-based Oxygen Carriers: Current Status and Future Directions', *Anesthesiology* 111:5 (2009), 946-963.

¹² C.S. Cohn & M.M. Cushing, 'Oxygen therapeutics: Perfluorocarbons and blood substitute safety', *Critical Care Clinics* 25:2 (2009).

¹³ T. Henkel-Honke & M. Oleck, 'Artificial oxygen carriers: a current review', *Aana J.* 75:3 (2007), 205-211.

¹⁴ S.J. Grethlein & A. Rajan, 'Blood Substitutes', *Medscape Reference* (2012).

¹⁵ See more at www.novosang.co.uk.

¹⁶ R.M. Titmuss, *The Gift Relationship: From Human Blood to Social Policy* (LSE Books, 1997).

¹⁷ See footnote 8.

¹⁸ P. Fleming, E. Ferguson, E. Townsend & K.C. Lowe, 'Perceptions in transfusion medicine: a pilot field study on risk and ethics for blood and blood substitutes', *Artificial Cells, Blood Substitutes, And Immobilization Biotechnology* 35:2 (2007), 149-156.

and least 'risky'. This was followed by chemical-based substitutes, bacteria-grown substitutes and finally bovine-derived substitutes, which were seen as being the most risky, least ethically acceptable and least effective. Notably, perceptions of risk correlated with both ethicality and effectiveness for all of the options. The Fleming study shows that human donor blood was still seen as the preferred option by those who were interviewed. Other research on blood and blood substitutes has identified a greater acceptability of blood substitutes amongst medical professionals, when compared to journalists or blood donors.¹⁹ There was also a marked difference between the risk levels perceived by these groups concerning the infection rates through donation. However, none of these papers looked at cultured red blood cells using stem cell technology, and Ferguson et al. argued that a more effective 'marketing' of alternative blood products may change the views that their respondents had expressed. Previous developments in the blood products industry, such as the use of recombinant DNA technology to provide Factor VIII, show that it is possible for an alternative technology to become assimilated into mainstream practice.

This project set out to discover the reactions of various publics in Scotland towards cultured red blood cells. In this paper I report specifically on the theme of biodiversity as it was used by our participants in interviews and focus groups, and particularly as it was used in comparison to GM crops. Given the focus of this paper it is necessary to understand how such crops are viewed in the context of the UK, where this research was conducted.

GM crops in the UK

GM crops in the UK (and in the rest of Europe) have not been publicly accepted in the way that such crops have been in areas such as North America and China.²⁰ Since 2001 only one GM crop has been approved for cultivation in Europe.²¹ Images of protesters in biohazard suits destroying fields of GM crop tests were widely portrayed in the UK media during the late 1990s. The website www.genewatch.co.uk states that currently no commercial GM crops are grown in the UK although testing of such crops does continue. GM products enter the UK from abroad in food, animal feed, and biofuels. At the

¹⁹ K.C. Lowe, K. Farrell, E.M. Ferguson & V. James, 'Current perceived risks of transfusion in the UK and relevance to the future acceptance of blood substitutes', *Artificial Cells, Blood Substitutes, And Immobilization Biotechnology* 29:3 (2001), 179-189.

²⁰ D. Burke, 'GM food and crops: what went wrong in the UK? Many of the public's concerns have little to do with science', *EMBO Reports* 5:5 (2004), 432-436.

²¹ Y. Devos, O. Sanvido, J. Tait & A. Raybould, 'Towards a more open debate about values in decision-making on agricultural biotechnology', *Transgenic Res.* 23:6 (2014), 933-943.

time of writing this paper (August 2015) debates have once again resurfaced in the media after Scotland declared a ban on the growing of GM crops.

Fears about GM crops in the UK have stemmed from a perception that transgenes used in GM crops could transfer into other wild plants or non-GM crop species.²² There has also been a backlash on moral principles towards large commercial companies having control over crop production. Terminator technology, which prevents farmers from storing seed for planting the following year, means that growers must return to the GM company and rebuy seed each year. Some consider this to be locking farmers into a continuing relationship with the commercial company, whilst others see this as the only way to prevent crops spreading in the wild and for companies to guarantee a return on their investment. Some argue that basing a risk assessment of GM crops on public attitudes has distanced the argument from scientific facts, pointing out that many of these risk factors have been founded on human emotions and not on scientific data.²³

Methods

As part of our research into this new method of producing blood, focus groups and interviews were carried out with a variety of publics. The research methods used for this project will be described in more detail elsewhere.

Four key groups were targeted:

- Patients who undergo regular blood transfusions, for example for sickle cell disease or thalassaemia.
- Representatives of religious or moral groups who could contribute to the discussion on cultured red blood cells from an ethical or religious standpoint.
- Clinical groups, such as doctors and nurses, who use blood transfusions in the course of their work.
- Community groups chosen to represent a spread of publics, who may not have a background in science or medicine. These included sports clubs, arts groups, etc.

Interviews were conducted with those who it were felt were ‘experts’ in their field – which included doctors, ethicists, members of religious organisations,

²² A.F. Raybould & A.J. Gray, ‘Will hybrids of genetically modified crops invade natural communities?’, *Trends in Ecology & Evolution* 9:3 (1994), 85-89.

²³ J. Tait, ‘Upstream engagement and the governance of science. The shadow of the genetically modified crops experience in Europe’, *EMBO Reports* 10:S1 (2009).

and patients. Focus groups were used to bring together those who might not have previously considered the issues involved in cultured red blood cells, and included community and sports groups, a college group, and residents in a residential care home for the elderly. The majority of data collection took place in Scotland, apart from a focus group with one patient group which took place in London, and one expert interview in northern England. In total there were 27 data collection sessions, including interviews, full focus groups (approx. two hours) and mini focus groups (which ran from a few minutes to one hour and were often unrecorded). The interviews and focus groups which had been voice recorded were transcribed verbatim and then the transcripts and notes from unrecorded sessions were coded using NVivo software. A grounded theory methodology²⁴ was used, to draw information from the data rather than starting with preconceived theories. In total 22 nodes were used, of which one of these described the views of the interviewees towards the ‘biodiversity’ of the cultured blood product.

Results

The theme of biodiversity was discussed by our respondents in a number of ways. These included feelings of ‘everything being the same’, and of cultured blood production being like ‘GM crops’. These conversations around biodiversity are divided into three interlocking themes of commercialisation, risk associated with a lack of biodiversity, and social considerations.

Theme 1: Commercialisation

The first theme saw participants compare cultured red blood cells to the perceived commercialisation of GM crops. Participants reflected on the way that a ‘free’ product was being turned into a profit making facility – both in the commercialisation of crops which would grow naturally and in the commercialisation of blood which is currently obtained from altruistic donors. This of course glosses over many of the current production costs necessary in both farming and blood transfusion. With increased commercialisation came an appreciation of the rising power wielded by those in control of the product.

‘And my sinister side would say, is there any way that a large corporation could say “and you now need to come back to us” and there would be some kind of power base. Like the genetically modified crop companies in the US who have made it so that any farmer now wanting to farm for the major supermarket chains will then

²⁴ A.L. Strauss & J. Corbin, ‘Grounded Theory Methodology’, in: N.K. Denzin & Y.S. Lincoln (eds.), *Handbook of Qualitative Research* (Sage, 1994).

harvest the grain and will need to go back to the GM company because it only has a rate of regeneration for one year only. And you are then going cap in hand again to buy more seed. And they have deliberately done that in their economic engine of "and you will need us".' (Interview)

Participants raised concerns that the use of blood would be restricted to those who could afford to pay for it, and that the supply of blood might be tied to a particular commercial company who had control over the use of blood by health-care systems. There was also a feeling of unease that commercial companies were profit driven and more likely to cut corners in the pursuit of profits over consumer safety. In contrast there was high trust in public bodies such as the blood transfusion services and the NHS.

However this discussion on commercialisation was tempered in part by a realisation that commercial companies are necessary in the development of healthcare technologies, and that we already rely heavily on such companies to innovate new pharmaceutical products and devices.

'Pretty much all the drugs that have been developed have been developed by industry for commercial gain but it benefited everyone hugely and probably half of these drugs wouldn't be here if it wasn't for the commercial drive to do it. It's all very well saying it's for public good and it should be for everyone but that's not how things get developed, or very expensive things get developed. It seems that the blood thing is coming from this position that we're in now where there's this ethos of giving and it's available to everyone and it's not for profit. There's a sort of a tension.' (Focus group)

'Can I suggest, we're talking from a slightly naïve point. We in the UK have this perception of everything being free on the NHS, albeit we're paying for it through other methods, this is not something that is going to be exclusively done in the UK, this is going to be taken up in America or wherever else, either now or at some point in the future. So whether it's developed in the UK and then licensed out or whether America says we can do this as well. Who's going to pay for that? Is it going to be private companies who see the long-term game plan that would make billions out of it, and without that private money going in, is it ever actually to get to the point of making it to production? I've no idea how much the Wellcome Trust has, and if they're the only body who are involved in this, but sooner or later surely they're going to say, wait a minute we've spent it all, and this is going to run for 20 years until it comes to production.' (Focus group)

There was a lack of awareness amongst many of the participants about the true cost of many healthcare practices in the UK, including blood donation, which the participant is referring to here, and which will be discussed further below.

Theme 2: Lack of biodiversity as increased risk

People also compared cultured blood to GM crops as a view that a lack of biodiversity was somehow riskier. In some unrecorded mini-focus groups the participants referred to the problems of having all the eggs in one basket (what would happen if something went wrong), or of a general (but unspecified) unease about 'everything being the same'.

'I meant in terms of the practicalities, would it not be better to have a cocktail of individuals come together for the red blood cells, for your stock? But I don't know whether that is a technical issue. Just thinking from a general biological perspective, having your feedstock based on a single individual can run into problems, and often unexpected problems. Although I appreciate that with red blood cells you've not got the genetic issue. I don't know enough about the technicalities but just from a general biological perspective I don't know how wise it would be to base it all on a single individual, but I'm sure your guys know what they're doing.' (Interview)

Despite the fact that there might not be a biological basis for a lack of biodiversity to result in increased risk, it was recognised as a legitimate risk factor that many people might identify. This interviewee believed that this stemmed from the fear of the unknown about cultured blood products, although in this case it was compared to irradiated foods rather than GM crops.

'That sense of perception that "I don't know how all this stuff works, but natural to have reactions like thinking this may be passed on". Similar to the reactions to irradiated food etc. In terms of scientific rationale it is completely wrong, but in terms of how people frame issues then that is the way that they think.' (Interview)

Again this was balanced by the view that a lot of the reactions we have to GM crops have been picked up from media stories, and do not necessarily reflect reality.

'You'd think some of the reception in the greater world out there would depend on how the media present this, in focus groups like this we can talk calmly and rationally about it but how would the media present it to the greater population? We've seen the GM foods, Frankenfoods and all this kind of thing, how would that be presented? That would be a concern as to how the scientific world presented it via the media, what the media actually took.' (Focus group)

Theme 3: Cultured blood in a social context

The final theme was that of biodiversity affecting how we view cultured blood in a social context. Currently blood in the UK is given by many thousands of anonymous donors and has a strong sense of 'gift giving'. However as participants raised, this may change if all the blood being produced is coming from one or a small number of stem cell lines.

'But if things, if everything can be bought or sold, if the concept of gift is no longer something that is valued in society, people in America sell their blood, apparently all along the border with Mexico there's a whole lot of blood clinics because they're getting the blood from the poor Mexicans. If this concept of solidarity, a gift is no longer valued or even made possible then I think society as a whole will be weakened.' (Interview)

In this quote the interviewee appears to be relating a change in the social context of blood donation to the increased commercialisation and profit making around blood. Whereas in the quote below the participants are reflecting on the perceived lack of biodiversity, with all the blood coming from a single source rather than the many altruistic donors.

'F1: I guess there's also the point that there might be six or ten nationwide sources of this blood, six or ten people walking around in the UK whose blood is now in the veins of a million people, and that's not how it is at the moment [?] people, whether that would bother people.'

F2: I suppose it's removing diversity, isn't it ...

F1: People would have a problem with that, the way that people have problems with perceiving organs more than they do giving blood for some reason carrying part of that person around with them, does it make a difference if everyone is carrying a part of the same person?' (Focus group)

Although red blood cells only last around 120 days in the body there is still a perception that one is receiving part of another person, although, as is highlighted in the quote, perhaps less than through an organ transplant.

Discussion

Focus group and interview participants discussed biodiversity in the context of cultured blood in three ways. The first was a comparison of cultured blood to GM crops, the second was a perceived increased risk in cultured blood, and the third theme was a supposed social difference between cultured and donated blood.

In the first theme participants compared cultured blood to GM crops as a commercialisation of something which is regarded as intrinsically 'free'. It was argued that this commercialisation might lead to restrictions on access to blood. A socioeconomic concern about GM crops has been the terminator technology put in place by some GM crop companies, which renders GM seeds sterile. If farmers wish to continue with the GM crops they must return to the company each year to buy seeds, which some see as creating a monopoly by the GM seed

companies.²⁵ Similarly participants highlighted the potential risk of a cultured blood company putting a high price on blood which would make it unaffordable for the NHS or for individuals. In comparing cultured blood to GM crops our participants were reacting to what they saw as the restriction of something natural and 'free', a monopoly on something which is currently given as an altruistic gift.²⁶

Such discussions speak to a wider question of commercialisation vs. open source science.²⁷ On one hand technologies such as GM crops, or cultured blood, are seen to commercialise something which is regarded as naturally available. On the other hand a lack of monetary incentive could dissuade commercial involvement in future research.²⁸ In the UK the true cost of blood production remains relatively hidden within the 'black-box' of the NHS. But the large amounts of processing and testing carried out means that blood is essentially already a commercialised product, with a biovalue that is becoming increasingly recognised.^{29, 30} Indeed some participants attempted to raise the issue that we rely on commercialisation all the time for pharmaceutical developments, but that we simply are not aware of this because everything is done through the umbrella of the NHS. They were also aware that the NHS is unlikely to produce all the blood necessary for the entire world, meaning that other countries may be able to set prices for cultured blood which are outside the control of the UK developers.

Cultured red blood cells were perceived by participants to be more risky due to their perceived lack of biodiversity, compared to the current donation system which acquires blood from many individual donors. Increased risk was seen due to the possibility that, with a single stem cell line, if problems were found in this blood then thousands of people would be affected. Participants felt that to produce only one blood source was akin to 'putting all the eggs in one basket', with no knowledge of what might happen in years to come or whether that stem cell line would turn out to have some vital flaw. Conversely one of the aims of cultured red blood cells is to reduce the risk disease transmission due to the current method of obtaining blood from many different donors. The transfer of hepatitis from donor to recipient was an ongoing problem for many years,

²⁵ S. Rastogi Verma, 'Genetically Modified Plants: Public and Scientific Perceptions', *ISRN Biotechnology* (2013), 11.

²⁶ See footnote 18.

²⁷ T. Caulfield, S.H. Harmon & Y. Joly, 'Open science versus commercialization: a modern research conflict?', *Genome Med.* 4:2 (2012), 17.

²⁸ A. Courtney, P. de Sousa, C. George, G. Laurie & J. Tait, 'Balancing open source stem cell science with commercialization', *Nat Biotechnol.* 29:2 (2011), 115-116.

²⁹ H. Busby, J. Kent & A.-M. Farrell, 'Revaluing donor and recipient bodies in the globalised blood economy: Transitions in public policy on blood safety in the United Kingdom', *Health* 18:1 (2014), 79-94.

³⁰ C. Waldby & R. Mitchell, *Tissue Economies: Blood, Organs and Cell Lines in Late Capitalism* (Duke University Press, 2006).

however more widely publicised was the HIV contamination of plasma products, which was first recognised in the early 1980s and affected many haemophiliacs.^{31, 32} The authorities were slow to inform patients or withdraw infected batches, which Starr³³ attributes to the reverence given to blood and its symbolic nature as a social gift, rather than a pharmaceutical product. Previous work, however, has shown that despite infection risks donated human blood is still preferred over any other source,^{34, 35} including bovine derived, and synthetic blood. This work, however, did not take into account the prospect of stem cell derived blood, which is still human blood, just produced in a laboratory.

Finally the participants discussed biodiversity as it affects the social element of blood donation. This theme was heavily intertwined with the perception of risk from a lack of biodiversity, but focused more on the social connections between blood donors and recipients. Red blood cells have no nucleus or nuclear DNA, yet one group specifically said that this did not change their minds because there could be 'something else' (which was undefined) which meant that the blood given by each different individual was unique to them. There was inherent unease about all the blood in the UK potentially coming from a single individual (even if that 'individual' is a stem cell line). For so many years the public in the UK have been used to blood coming from multiple donors, an act of altruism which has led to the many comparisons between blood donation and gift giving. There is still a view that some of the individual is transferred in some way through donation, be that a donation of blood or organs.³⁶ With blood donation in the UK currently using altruistic donors there is an element of 'not knowing' where this blood comes from and who the original donor is. In contrast this cultured blood is a known entity, as every recipient will be getting red blood cells grown from a single (or a small number) of donor lines.

Blood appears to fit a special criteria, especially in the UK, given the attachment to the transfusion services and the gift relationship around blood. Many participants seemed unable to articulate exactly what it was about the lack of diversity in red blood cells that they disliked, almost in the manner of the 'yuck' factor.³⁷ Participants also did not compare the blood to any other technologies, although this may have been for two reasons, one that they were not prompted

³¹ D. Starr, *Blood: an Epic History of Medicine and Commerce* (Little, Brown and Company, 1999), 262.

³² The Penrose Inquiry, *The Penrose Inquiry: Preliminary Report* (APS Group, 2010).

³³ D. Starr, *Blood: an Epic History of Medicine and Commerce* (Little, Brown and Company, 1999), 130.

³⁴ See footnote 18.

³⁵ See footnote 8.

³⁶ M. Lock, *Twice Dead: Organ Transplants and the Reinvention of Death* (University of California Press, 2002).

³⁷ C.W. Schmidt, 'The yuck factor: when disgust meets discovery', *Environ Health Perspect.* 116:12 (2008), A524-527.

down this route by the focus group/interview facilitator, and the other that we tend to compare new technologies with those we are used to or estimate risks based on those technologies which are more prevalent in the media.³⁸ It is perhaps unsurprising that participants were not so well acquainted with other comparable technologies such as synthesised insulin or Factor VIII, but were more aware of higher profile technologies such as blood transfusion and GM crops. This would be a limitation of this study, as it is with all qualitative studies, that the influence of the questions asked and the particular setting of the group or interview can have such a strong influence on the outcomes. However, given that so many of the groups and interviews brought up the issue of GM crops without prompting gives some weight to the idea that this topic was foremost in participants' minds as a comparator technology.

Younger respondents did not appear to have such an attachment to the donation system as the older ones did, and therefore saw the cultured red blood cells as clean, more sci-fi and scientific. This seems to be linked to the general lack of contact with the blood transfusion services compared to older participants, many of whom had either received a transfusion or had been donors for many years. Indeed this compares more with the reaction of the scientists themselves, who see less risk in the standardisation of blood, as it will come from a single 'known' source rather than many 'unknown' donors. With risk perception based on the perceived 'trustworthiness' of companies³⁹ it will be interesting to see how this affects the risk perception of cultured blood, given that both this and donated blood are associated with the SNBTS. One possibility is that perceptions about the role of the blood transfusion services change as cultured blood becomes more prominent. Division in attitudes between younger and older audiences is therefore an area which would benefit from further study. Carrying out this research in the UK has highlighted issues that may have not been expressed elsewhere, because the expectation in the UK is that everybody, regardless of their income, receives all the health care that they require for no cost. This has the additional result of making healthcare in the UK a black-box, with many of us having no idea of the true cost of pharmaceuticals or medical procedures. It is worth noting that if this data had been collected in the US, for example, then reactions to this issue of commercialisation may have been very different. This comparison with other countries is an important area for further study.

³⁸ B. Fischhoff, A. Bostrom & M.J. Quadrel, 'Risk perception and communication', *Annu. Rev. Public Health* 14 (1993), 183-203.

³⁹ M. Siegrist, 'The influence of trust and perceptions of risks and benefits on the acceptance of gene technology', *Risk Analysis* 20:2 (2000), 195-204.

Conclusion

In conclusion, the data show that participants compared cultured red blood cells with GM crops and saw a lack of biodiversity as inherently risky and a threat to the established social ties of donated blood. The commercialisation of a natural product led to concerns about the monopoly of blood, leaving it only available to those with the ability to afford it. Cultured blood was seen as more risky if all the blood came from one stem cell line, despite ongoing problems with infection risks linked to the large number of altruistic donors currently involved in the supply of red blood cells for transfusion. Finally the altruistic and gift-like nature of blood was seen as being replaced by the homogeneous donor blood, and in doing so some of the social interaction of blood transfusion was being removed. Although only a small number of our participants were young adults (18-25 years) they appeared to have a weaker attachment to the transfusion services and viewed the cultured blood as cleaner and more scientific. This was therefore a suggestion for further work, alongside a comparison of the attitudes to cultured blood in countries which do not operate under a system of national health provision.

Techniques of donation: ‘three parents’, anonymity and disclosure

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Abstract

The clinical application of novel in-vitro fertilisation techniques involving mitochondrial donation was legalised in the UK in 2015. Mitochondria contain genetic material and it is possibly not surprising that headlines have described the resulting baby as having ‘three parents’ – the intending mother and father, and the egg donor. The techniques raise important questions, including how do we interpret transfer of biological material from one body to another? What are the implications for identity? And how, whether or when should the use of these techniques be revealed to the child? This article has two aims. First, it sets out the key ethical issues raised by the clinical introduction of mitochondrial donation. Secondly, it presents empirical data to highlight how patients themselves respond to these ethical questions. It concludes by highlighting how the introduction of medical technologies and the relationships between donors and recipients are dependent on the cultural, historical and social contexts.

Introduction

In March 2015, UK Parliament voted to change the law to support the clinical application of novel in-vitro fertilisation (IVF) procedures which involve the transfer of nuclear material into an enucleated donated egg. These techniques are widely known as mitochondrial donation. The result is that the UK is at the cutting edge of mitochondrial science and the only country in the world to legalise germ-line technologies. Scientific, medical and patient communities across the world have closely followed the developments with interest. In September 2015, the Human Fertilisation and Embryology Authority (HFEA) announced their plans for how centres will be licensed and what expectations will be placed on those centres to engage in monitoring babies born using the technique. It is expected that the first cohort of ‘three parent’ babies will be born in the UK in 2016, and as was the case following the birth of the first IVF baby, Louise Brown, in 1978 and again when she gave birth to her first child at the age of 28, it might be expected that the health and development of these children, and potentially their future children will be watched with interest.

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The techniques have attracted intense scientific, media and public interest, with spectres of 'three parent babies', 'slippery slopes' and Frankenstein science competing for headline space alongside stories of women who have experienced the pain of losing a child to mitochondrial disease. Behind the alarming headlines, techniques of mitochondrial donation raise important questions for society. These include how we should understand the transfer of genetic material from one body to another, how this might impact on the child's identity and how, whether or when children should be told about this intervention. This article aims to do two things. First, it aims to set out the key ethical issues raised by the development and clinical introduction of mitochondrial donation. Secondly, based on research exploring the patient experience of mitochondrial disease, it presents empirical data to highlight how patients themselves respond to these ethical questions. Although much has been speculated about the widespread support of these techniques by patients and patient groups, and the importance of listening to those views, this is the first article to present the views of patients in the context of recent legislation. The techniques and the political process have raised many complex issues. This article focuses on three issues: 'three parent babies', anonymity and disclosure. These topics not only illuminate some of the key aspects of the mitochondria debate but also have resonance for exploring the social and ethical aspects of many other techniques involving donation.

Research Methods

This article draws on the analysis of 21 semi-structured interviews conducted with patients diagnosed with maternally inherited mitochondrial disease. The aim of this project was twofold: to explore the patient experience of mitochondrial disease and to understand patients' perspectives on mitochondrial donation. Ethical approval was gained through the North Scotland Research Ethics Committee and participants were contacted through a national mitochondria research clinic. All names have been changed to ensure anonymity. The interviews lasted between one and two hours, and a loosely structured interview schedule was followed. The topics discussed included the experience of diagnosis, health management, communication strategies within the family and the role of reproductive technologies. Based on the author's previous experience of interviewing patients with mitochondrial disease and the difficulties of talking about controversial technologies, small cards were produced with statements printed on them, which were then used to prompt discussion. These

cards were initially prepared as part of Q methodology,¹ an established method within psychology which has now been developed to explore public understanding of science, health behaviours and technologies.² This article also draws on publicly accessible reports prepared by the Department of Health, HFEA and Nuffield Council on Bioethics.

What is mitochondria and mitochondrial disease?

Mitochondria are small structures in the cytoplasm of a cell. The 37 genes contained in mitochondrial DNA are primarily responsible for producing the cell's energy, and make up less than 0.1% of our body's total DNA. Mitochondrial disease is caused when the mitochondria fail to function, the results of which can be extremely variable in terms of symptoms and severity. Symptoms can include diabetes, deafness, epilepsy, digestive disorders and extreme fatigue, and for many patients, the disease is progressive. The term 'mitochondrial disease' encompasses a range of disorders, including mitochondrial encephalomyopathy, lactic acidosis and stroke-like episodes (MELAS) Leber's hereditary optic neuropathy (LHON) and Leigh syndrome.

As mitochondria are derived through the oocyte, disease caused by mutations of mitochondrial DNA are only inherited through the female line. This means that while both sexes can inherit the disease it is only women who are at risk of transmitting the disease to their children. There is no cure for mitochondrial disease and the treatment options, which for most people will be strong vitamins, has limited results. In this context, the development of techniques which can prevent a child from inheriting the disease have been widely welcomed. Scientists at the Wellcome Trust Centre for Mitochondrial Research in Newcastle have developed two related techniques which involve the 'donation' of healthy mitochondria within an IVF cycle. Maternal spindle transfer involves removing the nucleus of the egg and placing it into a donated, enucleated egg. Pro-nuclear transfer involves a similar process but occurs after fertilisation. Both techniques are reported to offer women with mitochondrial disease the only opportunity for having healthy, genetically related children.

As the donor's mitochondria could be inherited by future generations, the techniques are germ-line, and a change in UK law was required for them to be offered to patients. The transition from laboratory to clinic has involved intense

¹ S. Watts & P. Stenner, *Doing Q Methodological Research: Theory, Method and Interpretation* (London: Sage 2012).

² H. Farrimond & S.E. Kelly, 'Public viewpoints on novel non-invasive technologies for prenatal genetic diagnosis', *Public Understanding of Science*, 22:6 (2013), 736-750.

and extensive enquiry and debate, reflecting its controversial nature, and national and international significance. The process involved three scientific reviews by an expert panel,³ a dialogue exercise to assess public attitudes⁴, a call for evidence on the ethical issues organised by the Nuffield Council on Bioethics⁵, a public consultation⁶ and government guidance on draft regulations led by the UK Department of Health,⁷ and several debates at the House of Commons⁸ and House of Lords.⁹

‘Three parent babies’

As mitochondria contain genetic material, it is not surprising that ideas about what this might mean for genetic identity and parentage have captured the imagination, been used in alarmist headlines, and come under scrutiny. ‘Three parent babies’ headlines have primarily dominated the debate,¹⁰ alongside more subtle ideas of ‘three person IVF’, ‘three person babies’ and ‘three person DNA’.¹¹ Based on the extent of the genetic contribution and the function of the genes involved, the Department of Health does not accept that a child born through mitochondrial donation would have three parents:

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- ³ HFEA, *Third scientific review of the safety and efficacy of methods to avoid mitochondrial disease through assisted conception: update 2014*, www.hfea.gov.uk/8807.html (last accessed 22/9/2015).
- ⁴ HFEA, *Mitochondria replacement consultation: Advice to Government. March 2013*, www.hfea.gov.uk/docs/HFEA_Authority_meeting_March_2013_-_Mitochondria_report.pdf (last accessed 22/9/2015).
- ⁵ Nuffield Council on Bioethics, *Novel techniques for the prevention of mitochondrial DNA disorders: an ethical Review* (London: Nuffield Council on Bioethics, 2012), www.nuffieldbioethics.org/mitochondrial-dna-disorders (last accessed 22/9/2015).
- ⁶ Department of Health, *Mitochondrial Donation: A consultation on draft regulations to permit the use of new treatment techniques to prevent the transmission of a serious mitochondrial disease from mother to child* (2014), https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/285251/mitochondrial_donation_consultation_document_24_02_14_Accessible_Vo.4.pdf (last accessed 22/9/2015).
- ⁷ Department of Health, *Mitochondrial Donation: Government response to the consultation on draft regulations to permit the use of new treatment techniques to prevent the transmission of a serious mitochondrial disease from mother to child* (2014), https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/332881/Consultation_response.pdf (last accessed 22/9/2015).
- ⁸ Houses of Commons debate 3 February 2015, www.publications.parliament.uk/pa/cm201415/cmhansrd/cm150203/debtext/150203-0002.htm (last accessed 22/9/2015).
- ⁹ House of Lords debate 24 February 2015, www.publications.parliament.uk/pa/ld201415/ldhansrd/text/150224-0002.htm (last accessed 22/9/2015).
- ¹⁰ ‘Britain is first to legalise three-parent IVF’, *The Times* (25 February 2015), www.thetimes.co.uk/tto/science/article4364732.ece (last accessed 22/9/2015).
- ¹¹ Sulston et al., ‘Three-person IVF’, *The Times* (letter, 28 January 2015), www.thetimes.co.uk/tto/opinion/letters/article4337474.ece (last accessed 22/9/2015).

'Genetically, the child will, indeed, have DNA from three individuals but all available scientific evidence indicates that the genes contributing to personal characteristics and traits come solely from the nuclear DNA, which will only come from the proposed child's mother and father. The donated mitochondrial DNA will not affect those characteristics.'¹²

Many of the participants interviewed for this project were aware of the complexity of the debate and its competing ideas, including the biological significance of genetic material and the role of genetics in influencing our identity. Many highlighted the small contribution of mitochondrial genes that might render it insignificant in transfer, and that overall, the metaphor of 'three parent babies' was not useful:

'[People oppose the techniques] thought there'd be three parents involved and it would pose problems with visiting rights and things, which it wouldn't be anything like that. And I did get annoyed and, and like some of the government parliament people were standing up and arguing their point against it. I thought, well if they had a daughter that was suffering and having problems you wouldn't be so [opposed] [...] they're taking a gene from another lady but as regards to her being a parent, no. It's just like, giving your heart or your lung to somebody isn't it? You don't own them.' [Participant 19]

'The dodgy gene is extracted from the mother who wants a child, isn't it, her egg? And the healthy gene is put into her egg. So the gene is a just a tiny, tiny part of it. An egg is part of you, part of your – Well, it's you. Your hair colouring, your personality, everything. [The donor] has contributed and they've supported and helped somebody, but no, I don't think it's a three-parent [...] But just to take a gene, a healthy gene and take away the bad gene, you're doing it for health reasons. You're not creating somebody else's child. Do you know what I mean? I don't think they can put a claim to it.' [Participant 24]

In some cases, the words of the participants concur with the Department of Health's advice as described previously. Following this advice, the UK government has set an important precedent: the relationship between child and donor has been characterised as one where there is no parental obligation on behalf of the donor.¹³ This means that while donors will be able to find out

¹² Department of Health, *Mitochondrial Donation: Government response to the consultation on draft regulations to permit the use of new treatment techniques to prevent the transmission of a serious mitochondrial disease from mother to child* (2014) 15, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/332881/Consultation_response.pdf (last accessed 22/9/2015).

¹³ The Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015 (SI 2015/572), www.legislation.gov.uk/uksi/2015/572/contents/made?page=5 (last accessed 22/9/2015).

whether a child has been born using their donation, children will only be able to access non-identifying information about the donor.

Donor Anonymity

The system of anonymity that will be introduced alongside mitochondrial donation techniques will have important implications for the child and their family. Many of the participants held the view that the donor should remain anonymous:

‘They [the mitochondria donors] have decided that they will donate to help you have a healthy child, so therefore to me, that’s where the ethics stop. They don’t have any rights to sort of have contact with the child. They’ve decided they want to be a donor, hopefully for the right reasons, not that they then want to have claims on the child that you’re having.’ [Participant 3]

‘It’s like when you give blood; you don’t know where it’s going, but it’s probably saving somebody’s life. But you don’t get to know those people. So, at the end of the day, if you give genes or cells or whatever it is, bone marrow, anything, you know somewhere along the line you’ve done somebody some good, but you don’t know who you’ve done it for. But it’s just something that you feel is right.’ [Participant 25]

Once again, the words of the participants echo the views of the Department of Health and UK government. However, included in the legislation is provision that might open up the opportunity for children and their unknown donors to make contact. Along with their health records, the donor can provide non-identifying information about themselves for the child if they wish, and the clinic can support a voluntary system of contact between the donor and child.

Disclosure

One key recommendation from the Department of Health, and one that relates to the uncertainty about the safety of the techniques, was that the health of any child born through mitochondrial donation should be monitored. Engaging children in follow up naturally raises ethical concerns about the genetic testing of children,¹⁴ and their potential to be medicalised

¹⁴ A.L. Bredenoord & P. Braude, ‘Ethics of mitochondrial gene replacement: from bench to bedside’, *British Medical Journal* (2010) 341.

from a very early age. It is also possible, provided that there is funding in place and the participants are willing, that this follow up will extend to future generations. However, one of the key assumptions on which 'follow up' is based is that families will agree to sustained contact with the clinic. However, another fundamental issue, which might be influential in whether or not families engage in medical services, hinges on disclosure. The participants in this study had differing views about whether the child should be told:

'But I think in a way it would be cruel for the children to be told. Because it confuses things when there's no need for confusion. Because I think the mitochondrial donation should be regarded like any other sort of medical procedure. Because it's not the same as sperm donation where clearly half of the genetic material comes from a parent. I think the percentage is so small that you shouldn't – I think things should be anonymised.' [Participant 8]

'I think they should have a right to know, but I think that it should be explained first, exactly what has been used and the mind and everything else hasn't changed. The only thing that's changed is they've got a healthier life, and that is thanks to the person that donated. But apart from thanking them for giving them a better life, they're not related, it's just like having a heart bypass. Someone's put something into you that makes you function okay.' [Participant 5]

'I think the child and the parent might want to have contact later on. Again, something you might do if you have an adopted child, the child's choice but not until a lot later until they're able to make that choice. I don't think you could say no to them, they're going to have ways of researching and looking.' [Participant 17]

One of the enduring factors about family life is that many children born through assisted reproduction and those who are adopted might not be told of the origins of their birth.¹⁵ Thus even after changes to the anonymity laws in the case of adoption or sperm donation, accessing information about genetic inheritance relies very much on open disclosure practices of families. With the only recent legalisation of the techniques, combined with very little published evidence exploring the patient experience of mitochondrial disease,¹⁶ whether families disclose this information to their child following use of mitochondrial

¹⁵ M. Richards, 'A British history of collaborative reproduction and the rise of the genetic connection', in: T. Freeman, S. Graham, F. Ebtehaj & M. Richards (eds.), *Relatedness in Assisted Reproduction* (Cambridge University Press 2014).

¹⁶ R. Dimond, 'Patient and family trajectories of mitochondrial disease: diversity, uncertainty and genetic risk', *Life Sciences, Society and Policy* 9 (2013) 1-11.

donation is currently an unknown. This study goes some way to contribute to knowledge about how families might manage these processes following use of the mitochondrial techniques, and why some families, despite appearing enthusiastic at first, might in fact lose contact with the 'follow up' clinic.

Discussion

One of the defining characteristics of technologies involving donation is that they have the potential to produce new social relationships. Whereas blood donation might be described as an altruistic and anonymous 'gift',¹⁷ the relationship between a recipient and an organ or tissue donor will depend on many factors including whether or not the donation is from a living donor and whether the donor and recipient are already known to each other. Reproductive technologies are different again, where the relationship between a sperm or egg donor and resultant child is often more clearly defined within a legal framework. Mitochondrial donation, which involves the transfer of genetic but not nuclear material transgresses these boundaries and has led to uncertainty about how the technologies themselves, and the potential relationship between donor and child, should be regulated. The possibility of forging a relationship between donor and recipient, and the meanings that we give to these relationships are of course highly dependent on the kinds of technologies involved and the legal, social and cultural context. The recent legislation, concluding that the mitochondrial donation should not have an obligation towards the child, is important for how families themselves might make sense of these technologies.

The accounts of the participants provide further evidence of the complexity of these decisions. In deciding the role of the mitochondria donor, or whether the child should know about the techniques, participants moved easily between recognising the importance of genetic knowledge and perceiving mitochondrial DNA to have a relatively insignificant role. Importantly, participants made a distinction between donation for reproductive purposes and donation for health or avoiding illness. This distinction also became important when assessing the potential role of the mitochondria donor. Being a donor 'for the right reasons', that is, to improve health, led to the conclusion that the person should not then be allowed to claim a relationship with the child as they might in cases of sperm donation or adoption.

Participant accounts highlight how the meanings we attribute to the techniques of mitochondrial donation, mitochondrial DNA and the mitochondria

¹⁷ R. Titmuss, *The gift relationship: From human blood to social policy* (A. Oakley & J. Ashton eds., London: LSE 1997 [1971]).

donor are developed within a particular context. By frequently comparing mitochondrial donation with other kinds of donation, including heart donation, kidney donation, blood donation and sperm donation, participants revealed the cultural, historical and social backdrop in which relations between donors and recipients are played out. Mitochondrial donation is made sense of because it is categorised as similar, or different, to other kinds of techniques. Mitochondrial donation will allow women with mitochondrial disease the opportunity to have healthy, genetically related children. It is part of a rapidly developing field of mitochondrial medicine, involving the development of diagnostic technologies, risk assessment tools and IVF technologies. However, the techniques have challenged legal and ethical frameworks, and the translation from laboratory to clinical practice has involved a long period of scrutiny. The techniques have attracted intense media interest, and strong views have been expressed by national and international patient and scientific groups. This article has highlighted the views of patients with mitochondrial disease, and this is an important contribution. Although attitudes often differ about the central importance of mitochondrial DNA, this article has shown that patient perspectives, and the debate itself, cannot be reduced to genetic essentialist reasoning. One aspect that appeared prominent in discussions with patients was the perceived motivations of donors and parents. The focus on health rather than reproduction is possibly one of the reasons why the techniques have attracted widespread support. Indeed, although the techniques might have wider benefit than those with mitochondrial disease, other potential uses have been ruled out, including for fertility purposes¹⁸ and for lesbian couples who wish to use the techniques so that both parties can provide a genetic contribution. Of course questions remain about what will happen in practice, and many countries across the world will be watching and waiting with interest as to how children, parents, families, donors and UK institutions negotiate these contentious issues.

¹⁸ C. Smyth, 'Allow three-parent IVF to help older women too, says pioneer', *The Times* (9 February 2015), www.thetimes.co.uk/tto/health/news/article4348194.ece (last accessed 22/9/2015).

Information sharing in donor conception: comparing regulations, ethics and cultural practices in the UK and Belgium

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Abstract

Within the context of donor conception, the significance of knowing about one's genetic origins and the moral and legal status of this information has been the subject of on-going and vociferous debate in a number of Western countries. Ten years on from the removal of donor anonymity in the UK, this paper considers the significance of donor identification law and its relationship to social practices in the UK and Belgium. Despite a similar liberal attitude towards medically assisted reproduction, the UK and Belgium have adopted significantly divergent measures on the issue of donor anonymity. In this paper we describe these regulatory differences and consider the perceptions and experiences of donor identification in each country by contrasting the findings of studies relating to donor conception. We conclude by arguing that greater attention should be given to the complex interplay between legal frameworks and social practices relating to gamete donation and highlight the need for more detailed future research to inform policy-making in assisted reproduction.

Introduction¹

Within the context of donor conception,² the significance of knowing about one's genetic origins and the moral and legal status of this information has been the subject of on-going and vociferous debate in a number of Western countries. For a number of reasons, the importance granted to having information regarding identity, family history, and susceptibility to certain illnesses has burgeoned in recent years, with the associated implication that the anonymity of donors and the issue of access to information about donors has been a major ethical, political and legal challenge. Arguments for

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¹ We would like to thank Prof. Guido Pennings and Dr Lucy Frith for their insightful comments on an earlier draft of this paper.

² A means of achieving pregnancy via the use of a third party donor who provides eggs, sperm or embryos for use by intended parents but who has no legal parental responsibility for the resulting offspring.

a move towards more ‘openness’ in donation systems have also led on occasion to legislative changes, with a number of nations deciding to remove or ban anonymity in favour of identity-release systems³ or those within which both anonymous and non-anonymous donations are possible.⁴

Debate and commentary on this issue in a range of social contexts have tended to conflate a legal position of anonymity for gamete donors with a wider cultural practice of non-disclosure or ‘secrecy’ within families and, correspondingly, have conflated a legal position of identification with a culture of disclosure between parents and donor offspring. As well as creating possible terminological confusion, the suggested alignment of social practices with the law obscures the complexity and diversity of attitudes regarding the possible disclosure of the use of donor conception within families and communities. Ten years on from the removal of donor anonymity in the UK, this paper considers the significance of donor identification law and its relationship to social practices in two European countries.

As two countries that share a common position regarding the political legitimisation of assisted reproduction as a means of family building, and share features of technological innovation and expertise, the UK and Belgium are of particular interest in relation to the articulation between legal policies and social practices in gamete donation. They have similar reputations for pioneering research and facilitating the application of new reproductive technologies and share a similar liberal approach towards medically assisted reproduction by giving access to a wide range of technologies for diverse patient groups.⁵ In particular, they have played a key role in donor conception, permitting and practising sperm donation widely for more than five decades and egg donation for more than two decades.

However, on the issue of donor anonymity, their legislative positions diverge significantly. While anonymity was removed from the UK in 2005 in favour of an ‘identity-release’ system of donation, the Belgian comprehensive law on medically assisted reproduction, adopted in 2007, reaffirmed the obligation for gamete and embryo donation to be anonymous, except in ‘known’ gamete donation where donation results from an agreement between donor and recip-

³ In an identity release system, the donor-conceived child has the right to access to identifying information about their donor at the age of majority. This is for instance the case in Sweden, Norway, Austria, Switzerland, Netherlands and several Australian states (Eric Blyth & Lucy Frith, ‘Access to Genetic and Biographical History in Donor Conception: An Analysis of Recent Trends and Future Possibilities’, in: Kirsty Horsey (ed.), *Revisiting the Regulation of Human Fertilisation and Embryology* (Routledge 2015), 136-52).

⁴ For instance, in Denmark. For more detail on the different systems, see Tabitha Freeman, John B. Appleby & Vasanti Jadv, ‘Identifiable Donors and Siblings: Implications for the Future’, in: Martin Richards, Guido Pennings & John B. Appleby (eds.), *Reproductive Donation: Practice, Policy and Bioethics* (Cambridge, UK: Cambridge University Press 2012), 250-52.

⁵ For example, many clinics in the UK and in Belgium have a long-standing tradition of treating lesbian couples or single individuals.

ient. Researchers in these countries have also been among the first to collect data on social attitudes to the issue of donor identification and disclosure to donor offspring. The availability of these recent empirical studies offers the opportunity to gain an improved understanding about the interplay between legal changes and social attitudes and practices regarding disclosure amongst British and Belgian donor families. A comparison between these countries therefore allows consideration of the ways in which donor identification has been legislated for and experienced in two socio-legal contexts.

The paper begins with an overview of the recent broader trends surrounding donor identification and information sharing within the context of shifting conceptualisations of personhood, genetics and identity. We then describe the recent regulatory changes relative to gamete donation, first in the UK and then in Belgium. This is followed by a consideration of the perceptions and experiences of donor identification in each country by contrasting the findings of studies relating to donor conception. The penultimate section focuses on the current debates and challenges in relation to donor identification. We conclude by arguing that greater attention should be given to the complex interplay between legal frameworks and social practices relating to gamete donation and highlight the need for more detailed future research to inform policy-making in assisted reproduction.

Shifting mores in relation to disclosure and donor identification

During the 1980s, a discourse in favour of access to information about one's genetic origins emerged in various Western countries. This discourse, which asserted the child's right to personal identity, first developed in relation to adoption in the US and Canada where adoptees and birth parents were pushing for the removal of confidentiality in the adoption registry.⁶ Not only did this movement lead to the creation of 'open adoptions' in the US and the UK where biological and adoptive parents know their respective identity and can (under certain conditions) contact one another, but also to the adoption of international and national laws, similar to the adoption law in the UK, giving adopted children the right to access information about their origins. Overall, this movement contributed to an increasing political and discursive shift in the significance given to knowing one's family origins.

This trend towards 'openness' progressively extended to the field of gamete donation on a number of grounds including the need for knowledge about one's 'genetic' identity as well as a desire not to withhold information about a person's

⁶ Wayne E. Carp, *Family Matters: Secrecy and Disclosure in the History of Adoption* (Cambridge, Massachusetts: Harvard University Press 1998).

life story.⁷ Yet a number of authors have highlighted the substantial differences between adoption and gamete donation.⁸ Donor-conceived children have been planned by intending parents well before conception, whilst adopted children have, in contrast, been relinquished by their birth parents and as a result have been raised by another individual.⁹ In addition, adoptees often report feeling aware of the fact that they are not biologically related to adoptive parents due to physical differences within the family. They may also have to deal with the stigma associated with this lack of physical resemblance, unlike donor-conceived children who may have been conceived with the genetic material of one of the intending parents and may have increased resemblance to their parents due to any ‘matching’ done at the fertility clinic. While both adopted children and donor-conceived children may desire more information about genetic origins, their conception circumstances are quite different and concerns may be distinct, especially in terms of disclosure and identity. It is well documented that some adoptees search for their birth parents in order to understand the context of and reasons for the adoption.¹⁰ Notwithstanding these differences in context, a parallel has been drawn between practices of information sharing in adoption in order to implore the need for more openness in gamete donation.¹¹

This shift towards identification and greater information sharing in gamete donation has also been reinforced by the increasing attention given in recent times to genetics, especially in terms of medical history and family knowledge.¹² With regard to medical progress on genetic disorders, the need to have access to or knowledge about one’s own genetic and genealogical history is increasingly significant.¹³ This is also apparent in the proliferation of related phenomena such as ‘popular genealogy’, involving a search for one’s ancestors and mapping of family trees.¹⁴ This shift in thinking about origins as ultimately determinable

7 Richards et al., ‘Introduction’, in: Martin Richards, Guido Pennings & John B. Appleby (eds.), *Reproductive Donation: Practice, Policy and Bioethics* (Cambridge, UK: Cambridge University Press 2012), 1-12.

8 Françoise Shenfield, ‘Truth or Dare? Anonymity: The Case For’, *Progress in Reproduction* 3:8 (1999); Lucy Blake et al., “‘I Was Quite Amazed’: Donor Conception and Parent-Child Relationships from the Child’s Perspective”, *Children & Society* 28:6 (November 2014), 425-37.

9 Jesús Palacios & David Brodzinsky, ‘Review: Adoption Research: Trends, Topics, Outcomes’, *International Journal of Behavioral Development* 34:3 (1 May 2010), 270-84.

10 Janet Carsten, “‘Knowing Where You’ve Come From’: Ruptures and Continuities of Time and Kinship in Narratives of Adoption Reunions’, *The Journal of the Royal Anthropological Institute* 6:4 (2000), 687-703.

11 Julia Feast, ‘Using and Not Losing the Messages from the Adoption Experience for Donor-Assisted Conception’, *Human Fertility* 6:1 (February 2003), 41-45.

12 Dorothy Nelkin & Susan M. Lindee, *The DNA Mystique. The Gene as a Cultural Icon* (New York: Freeman and Company 1995).

13 Kaja Finkler, *Experiencing the New Genetics: Family and Kinship on the Medical Frontier* (Philadelphia: University of Pennsylvania Press 2000).

14 Fenella Cannell, ‘English Ancestors: The Moral Possibilities of Popular Genealogy’, *Journal of the Royal Anthropological Institute* 17:3 (September 2011), 462-80.

has inflected public and policy discourses related to family relations, kinship and gamete donation.

The emergence of demand for non-anonymous donors amongst certain social groups has also added to the shifting landscape of donor anonymity. An increasing number of lesbian and single women have accessed reproductive technologies over the last two decades, creating family situations where the biological (donor) father is not an active presence. For some of these women, having medical information about the donor as well as information about his interests and personality traits to provide to the future child was of significance.¹⁵

Changes in the uptake of egg donation may also have contributed to changes in practices around donor anonymity. As demand has grown and freezing technologies have advanced, egg donation has become more widely used and, in many contexts, the number of donated eggs is not sufficient to meet the increasing demand. This means that waiting times can be considerable, something which in turn has contributed to a rise in the number of women asking a close relative or friend to become their donor¹⁶ and indirectly, has facilitated known donation and donor identification.

Within this wider context, the culture of anonymity and non-disclosure that had once prevailed appears to have been subject to notable change, as disclosure and identification have increasingly been debated and encouraged in gamete donation.¹⁷

The legal perspective: anonymity vs. identifiability

As countries at the heart of technological developments and ethical debates regarding assisted reproductive technologies, both the UK and Belgium have been exposed to shifting values and trends regarding information about genetic inheritance. Legal decisions regarding the identification of donors in these countries have, however, taken somewhat differing paths. These divergent regulatory positions offer a fruitful opportunity to examine the ways in which laws and social practices may, or importantly, may not be, co-constitutive.

¹⁵ P. Baetens & A. Brewaeys, 'Lesbian Couples Requesting Donor Insemination: An Update of the Knowledge with Regard to Lesbian Mother Families', *Human Reproduction Update* 7:5 (October 2001), 512-19.

¹⁶ P. Baetens et al., 'Counselling Couples and Donors for Oocyte Donation: The Decision to Use Either Known or Anonymous Oocytes', *Human Reproduction (Oxford, England)* 15:2 (February 2000), 476-84.

¹⁷ John B. Appleby, Lucy Blake & Tabitha Freeman, 'Is Disclosure in the Best Interests of the Children Conceived by Donation?', in: Martin Richards, Guido Pennings & John B. Appleby (eds.), *Reproductive Donation: Practice, Policy and Bioethics* (Cambridge, UK: Cambridge University Press 2012), 231-49; Nuffield Council on Bioethics, 'Donor Conception: Ethical Aspects of Information Sharing' (London, April 2013).

In the following section, we present some of the key features of the debates in each country in order to highlight the differing ways information sharing in gamete donation have evolved in each context.

The UK regulation

In 1990, the UK pioneered the legal regulation of assisted reproduction by adopting the Human Fertilisation and Embryology Act. This Act made anonymity mandatory for donor conception¹⁸ but fertility clinics were required to collect some non-identifying information about the donor which could be released upon request by the donor offspring at the age of 18. There was, however, no state mandated possibility to identify the donor at this time. Moreover, parents were usually advised not to tell the children about the circumstances of their conception.

Fifteen years later, the Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulation 2004 abolished donor anonymity in the UK. This change meant that from 2005, offspring conceived through gamete donation were given the right to access identifying information about their donor and thus to make it potentially possible for them to contact their donor at the age of 18 (if their details are up to date). This ‘identity-release’ donation system was henceforth mandatory for everyone who wished to use gamete or embryo donation in a clinical setting. This also meant that people who wanted to donate gametes must also agree to be identifiable and to accept the possibility of being contacted by the offspring at some point in the future.¹⁹

In the policy debates which led to the removal of donor anonymity in the UK, a number of claims were made regarding the need for donor offspring to be able to access identifying information about their donor. As described above, those lobbying for the rights of adoptees also advocated for the rights of donor-conceived people to have equivalent information about their origins. Progar (the British Association of Social Workers’ Project Group on Assisted Conception) and the national charity, the Children’s Society, advocated for legal changes with regard to the removal of donor anonymity in the interests and rights of donor-conceived individuals and succeeded in raising public and political attention on this issue.²⁰ The public awareness actions started by the Children’s

¹⁸ Previously the Family Law Reform Act adopted in 1987 had allowed the intended parents to be the legal parents of the resulting child, while preventing the donor from making claim to or assuming any rights or responsibilities towards any resulting children.

¹⁹ It is also possible in the UK for ‘known’ donors to be used, whereby the identity of the donor (often a family member) is known to the recipients at the point of treatment, unlike the identity release system in which intending parents are only given non-identifying information at the point of donation.

²⁰ Ilke Turkmendag, ‘The Donor-Conceived Child’s “Right to Personal Identity”: The Public Debate on Donor Anonymity in the United Kingdom’, *Journal of Law and Society* 39:1 (2012), 58-75.

Society occurred almost simultaneously as two donor-conceived individuals (Joanna Rose and ‘EM’) went to court in order to claim access to information about their donor under the Human Rights Act 1998.²¹ These two factors led the UK government to launch a public consultation in 2002, followed by consultation exercises by the HFEA with clinics and donors, designed to consider the amount of information that should be made available to donor-conceived people and their parents.²² Though responses to the consultation were mixed, following this exercise, the UK government revised the law in order to make anonymous gamete donation illegal. As Frith has suggested, these legal changes were therefore based on a parallel being drawn between gamete donation and adoption, as well as the principle that the ability to identify one’s donor was in the ‘best interests of the child’.²³ Donor anonymity therefore emerged in the UK as a social problem and saw legal change on the basis of these conceptualisations.²⁴

According to advocates of the removal of donor anonymity, granting donor-conceived individuals access to information about their conception would allow them access to their medical history, information about family relatedness, and would ensure fulfilment of identity.²⁵ These arguments were also in line with the concern about the risks of genetically related sexual partners and the desire to avoid unwitting incest at a time when the number of offspring conceived with gamete donations was increasing.²⁶

Overall, the government emphasised the priority granted to the child’s interests in its decision to change the law in 2004 ‘rather than the best interests of the medical profession or the best interests of those going for treatment’.²⁷ It has been argued that the debates were ‘conducted with very limited empirical

²¹ Nuffield Council on Bioethics, ‘Donor Conception: Ethical Aspects of Information Sharing’ (London, April 2013), 22.

²² ‘Donor Information Consultation: providing information about Gamete or Embryo Donors’, UK Department of Health, 20 December 2001. Available at: http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005810.

²³ Lucy Frith, ‘The Limits of Evidence: Evidence Based Policy and the Removal of Gamete Donor Anonymity in the UK’, *Monash Bioethics Review* 33:1 (March 2015), 29-44.

²⁴ Turkmendag, ‘The Donor-Conceived Child’s “Right to Personal Identity”: The Public Debate, on Donor Anonymity in the United Kingdom’, *op. cit.*

²⁵ Nuffield Council on Bioethics, ‘Donor Conception: Ethical Aspects of Information Sharing’ (London, April 2013); Turkmendag, ‘The Donor-Conceived Child’s “Right to Personal Identity”: The Public Debate on Donor Anonymity in the United Kingdom’, *op. cit.*

²⁶ Jeanette Edwards, ‘Incorporating Incest: Gamete, Body and Relation in Assisted Conception’, *Journal of the Royal Anthropological Institute* 10:4 (2004), 755-74; Enric Porqueres i Gené & Jérôme Wilgaux, ‘Incest, Embodiment, Genes and Kinship’, in: Jeanette Edwards & Charles Salazar (eds.), *European Kinship in the Age of Biotechnology* (New York & Oxford: Berghahn Books 2009), 112-27.

²⁷ Lucy Frith, ‘The Limits of Evidence’, *op. cit.*, 39.

evidence about the implications of open-identity donation for those involved²⁸ and, some have suggested, without effective consultation processes.²⁹

The direct outcomes of the legal change regarding identifiable donation will remain unknown at least until 2023, when the first donor-conceived individuals will have the opportunity to access identifying information on their donor. Whilst it is currently mandatory for pre-treatment counselling in the UK to include a recommendation that children should be told about their donor-conceived origins,³⁰ there is no legal obligation to do so and therefore children may not be given this information. Open-identity donation can therefore encourage or facilitate the parents' disclosure but it doesn't prevent non-disclosure.³¹ In other words, whether or not parents use an identifiable donor, they will still have to decide to tell the child or not about his or her donor conception.

In the ten years since the removal of donor anonymity in the UK, there has been a shift in the way donor services are organised and a demonstrable will to improve the experience of donors, donor parents and donor-conceived individuals under the new system. Recent initiatives such as the HFEA's Donor Strategy Group³² and the launch of the National Sperm Bank³³ are being implemented in order to further embed the current system and to address donor shortages. Moreover, in 2012, and following public consultation, donor compensation levels were also increased in the UK, in part, to address this shortage.³⁴

The Belgian regulation

While medically assisted reproduction has been widely practiced in Belgium since the 1960s, its regulation has been largely confined to that of professional oversight and guidance. As a result clinicians and researchers were granted a considerable degree of scientific autonomy and any bioethical and religious orientations were respected.³⁵ It was as recently as July 2007 that

²⁸ Freeman, Appleby & Jadva, 'Identifiable Donors and Siblings: Implications for the Future'.

²⁹ Turkmendag, 'The Donor-Conceived Child's "Right to Personal Identity": The Public Debate on Donor Anonymity in the United Kingdom', *op. cit.*

³⁰ A 2008 amendment to the 1990 Act provides legislative endorsement for early parental disclosure (Section 13(6C)).

³¹ Freeman, Appleby & Jadva, 'Identifiable Donors and Siblings: Implications for the Future'; Jennifer Readings et al., 'Secrecy, Disclosure and Everything in-between: Decisions of Parents of Children Conceived by Donor Insemination, Egg Donation and Surrogacy', *Reproductive Biomedicine Online* 22:5 (May 2011), 485-95.

³² See: www.hfea.gov.uk/7138.html.

³³ See: www.veryspecialman.co.uk/.

³⁴ HFEA, CH(12)01 (Implementation of the outcomes of the Donation Review), January 2012. Available at: www.hfea.gov.uk/6966.html.

³⁵ Nathalie Schiffino, Céline Ramjoué & Frédéric Varone, 'Biomedical Policies in Belgium and Italy: From Regulatory Reluctance to Policy Changes', *West European Politics* 32:3 (2009), 559-85.

a comprehensive law on medically assisted reproduction and the disposition of supernumerary embryos and gametes was adopted in Belgium.³⁶ This law primarily aimed at formalising existing clinical practices and limiting possible excesses. The law permits a broad range of reproductive techniques, such as post-mortem insemination or preimplantation genetic diagnosis, and allows these techniques to be offered to any couple and single woman under the age of 48.³⁷ This liberal law is therefore in line with existing clinical practices and attitudes within some Belgian clinics.

The 2007 law also reinforced the obligation for embryo and gamete donation to remain anonymous, after an intense debate on this issue in Belgium. An exception was made for certain cases of gamete donation where donors do not have to remain anonymous provided they result from an agreement between the donor and the recipient. The aim of this exception was, it seems, in reality to facilitate the supply of egg donors, which constitutes a scarce resource, by allowing egg donation from a family member or a friend.³⁸ Indeed, prior to this, most women in Belgium preferred to receive or donate eggs in circumstances where the donors and recipient knew one other.³⁹ This means that in the case of Belgian egg donation, as in 'known donation' in the UK, some intending parents will know who the donor is from the start. This possibility of known donation is regarded and presented as an exception to the prevailing rule in Belgium where clinics are obliged to guarantee the anonymity of donors in rendering inaccessible all information both identifying (e.g. names) and non-identifying (e.g. physical characteristics) relating to donors. The anonymous model generally followed in Belgium contrasts with UK practices where not only do clinics collect and make available medical and physical information about the donors, but also encourage them to provide a personal and biographical description of themselves which will be accessible to donation families at the point of donation.⁴⁰

A crucial argument used to justify the maintenance of donor anonymity in Belgium was the priority given to the autonomy of parents.⁴¹ According to this principle, parents should be able to decide whether or not and how they wish

³⁶ A first law on in-vitro embryos was nevertheless adopted in May 2003. It authorises the procuring of stem cells from residual embryos, therapeutic cloning and the creation of embryos for research purposes. Only reproductive cloning is forbidden.

³⁷ For more details on the content of the new law, see Guido Pennings, 'Belgian Law on Medically Assisted Reproduction and the Disposition of Supernumerary Embryos and Gametes', *European Journal of Health Law* 14 (2007), 251-60.

³⁸ Nicole Gallus, *Le Droit de La Filiation. Rôle de La Vérité Socio-Affective et de La Volonté En Droit Belge* (Bruxelles: Larcier 2009); Pennings, 'Belgian Law on Medically Assisted Reproduction and the Disposition of Supernumerary Embryos and Gametes', *op. cit.*

³⁹ Baetens et al., 'Counselling Couples and Donors for Oocyte Donation', *op. cit.*

⁴⁰ Nuffield Council on Bioethics, 'Donor Conception: Ethical Aspects of Information Sharing', (London, April 2013).

⁴¹ Gallus, *Le Droit de La Filiation. Rôle de La Vérité Socio-Affective et de La Volonté En Droit Belge*.

to tell the child about the nature of their conception. In this model anonymity goes hand in hand with the legislative will to privilege family ties based on parental commitment and daily involvement.

In line with this argument was also the will to respect parents' rights to a private life and to protect their intimacy. The intention of Belgian policymakers was to help donor-conceived children integrate directly into their family without revealing the medical intervention needed for its conception and without the parents fearing the intrusion of the donor in their family. It also intended to prevent the possible disruption to the child and its parents caused by information about and contact with an additional parental figure. Likewise, another aim was to guarantee discretion towards the donor who acted as a genitor and not as a parent. The law was therefore intended to protect the donor against the risk of parental obligations and intrusion in his or her private life at a later stage.

A specific prohibition relating to sharing information about embryo donation was also justified by the need to prevent commercialisation of embryos between donors and recipients. However, as Guido Pennings points out, if this was an important reason for justifying anonymity, this rule should also have been extended to egg and sperm donation.⁴²

The decision to retain anonymity was also made to prohibit access to non-identifiable, non-medical information in order to avoid any genetic determinism, whereby the child's character, for example, might be attributed to the donor's genes.⁴³ This differs from the UK where the significance of genetics has potentially been reinforced through policies which appear to imply determining links between the genetics and personality of the donor: for example, through providing the donor-conceived family with a personal and biographical description of the donor.⁴⁴

Finally, anonymity policies were also justified in Belgium for practical reasons, since they also helped to preserve the number of donations and were therefore suggested as important in avoiding a donor shortage. Although this was also an important concern for medical groups in the UK, this factor was not taken into consideration by the UK government in its consultation.⁴⁵

As in the UK context, practices may not align with laws, meaning that even though Belgian law does not allow access to the donor's identity and may therefore assume a position of non-disclosure within families, this does not

⁴² Pennings, 'Belgian Law on Medically Assisted Reproduction and the Disposition of Supernumerary Embryos and Gametes', *op. cit.*

⁴³ Belgian Chamber, 'Rapport Concernant Le Projet de Loi Relatif à La Procréation Médicalement Assistée et à La Destination Des Embryons Surnuméraires et Des Gamètes', Session 2006/2007, 9 March 2007, 41.

⁴⁴ Though it is also the case that this information is provided in order that donor families can incorporate this information in to coherent 'conception stories'.

⁴⁵ Turkmendag, 'The Donor-Conceived Child's "Right to Personal Identity": The Public Debate on Donor Anonymity in the United Kingdom', *op. cit.*

mean that donor conception parents won't discuss with their children the circumstances of their conception. However, in Belgium, the implication of disclosure is that the child will know about the lack of a biological tie with one of his or her parents, but won't be able to access any information regarding the donor.

Contrasting the UK and Belgian legislative landscapes offer an insight into the differing prioritisation of rights and interests in debates and policy about donor anonymity. We can observe that in the UK precedence was given to the rights and interests of donor-conceived children to know their genetic origins,⁴⁶ whilst in Belgium, the rights of parents and donors superseded the rights of the child on the grounds of the principles of autonomy and a right to privacy.

Disclosure and non-disclosure in practice: research in the UK and Belgium

In this section we consider the practices and attitudes of donor conception parents regarding donor information sharing,⁴⁷ by providing an overview of the studies conducted on this issue in the UK and Belgium. While accurate figures are not available given the difficulties in collecting data about children who have not been told about their donor conception,⁴⁸ the qualitative studies available provide noteworthy insights on perceptions of this issue. There is still a significant gap in the evidence base but these studies offer a valuable snapshot of the complex negotiations and variability surrounding decisions regarding disclosure and non-disclosure within donor conception families and enable a consideration of the ways these practices articulate with local laws.

In the UK, the on-going longitudinal research conducted with donor-conceived families by Susan Golombok and her team from Cambridge University, shows that at age 7, 28% of sperm donation parents and 41% of egg donation parents, were in the process of disclosing information about their conception to their child.⁴⁹ This trend seems to continue at age 10,⁵⁰ with a majority of

⁴⁶ Lucy Frith, 'Gamete Donation and Anonymity: The Ethical and Legal Debate', *Human Reproduction* 16 (2001), 818, 820-22; Lucy Frith, 'Beneath the Rhetoric: The Role of Rights in the Practice of Non-Anonymous Gamete Donation', *Bioethics* 15 (2001), 473, 477.

⁴⁷ In this paper we do not provide a broader discussion about donor-conceived children (see for example Martin Richards, Guido Pennings & John B. Appleby (ed.), *Reproductive Donation: Practice, Policy and Bioethics*, (Cambridge, UK: Cambridge University Press 2012)) but instead focus specifically on the question of disclosure.

⁴⁸ Nuffield Council on Bioethics, 'Donor Conception: Ethical Aspects of Information Sharing', (London, April 2013).

⁴⁹ S. Golombok, J. Readings, L. Blake, P. Casey, L. Mellish, A. Marks & V. Jadva, 'Children Conceived by Gamete Donation: Psychological Adjustment and Mother-child Relationships at Age 7', *Journal of Family Psychology* 25 (2011), 230-239.

⁵⁰ Lucy Blake et al., "'I Was Quite Amazed": Donor Conception and Parent-Child Relationships from the Child's Perspective', *op. cit.*

sperm donor parents in particular choosing not to disclose the conception to the child.⁵¹ This study also highlights the need to distinguish between the initial intention to disclose and the actual process of letting the child know about the use of gamete donation. Indeed, while 37 out of 68 donation parents intended to disclose when the child was aged one, only about half of them had done so six years later.⁵² Moreover, for some of these parents disclosure was only partial. They had told the child about the use of reproductive technologies, but not about the donor.⁵³ Most of these children are therefore not aware that one or both of their legal parents is not his or her genetic parent. Another study conducted by the team at Cambridge on donor-conceived children in several European countries showed that amongst the UK sample, donor-conceived parents who had not disclosed to their children at age 12 tended not to do so later on. At age 18, only about a tenth of the children who had not been told at age 12 knew about the circumstances of their birth.⁵⁴ It is important to note that these trends differ in families formed by single mothers who used sperm donation in which, according to Murray and Golombok's study, 90% of single mothers intended to tell their child.⁵⁵ This proportion is even higher in donor conception families headed by same-sex couples, in which all parents, according to studies conducted in the UK, Belgium and the Netherlands, intended to disclose.⁵⁶

Drawing on interviews with donor conception parents and grandparents, a recent UK sociological study has described how even in family situations where parents are in favour of openness (heterosexual and lesbian couples) telling the child about his or her conception may prove to be much more difficult than

⁵¹ Nuffield Council on Bioethics, 'Donor Conception: Ethical Aspects of Information Sharing' (London, April 2013), 57.

⁵² Readings et al., 'Secrecy, disclosure and everything in-between: decisions of parents of children conceived by donor insemination, egg donation and surrogacy', *op. cit.*

⁵³ *Ibid.*

⁵⁴ L. Owen & Susan Golombok, 'Families Created by Assisted Reproduction: Parent-Child Relationships in Late Adolescence', *Journal of Adolescence* 32:4 (2009), 835-48.

⁵⁵ C. Murray & S. Golombok, 'Going it alone: solo mothers and their infants conceived by donor insemination', *American Journal of Orthopsychiatry* 75:2 (2005), 242-53.

⁵⁶ Fiona Maccallum & Susan Golombok, 'Children Raised in Fatherless Families from Infancy: A Follow-up of Children of Lesbian and Single Heterosexual Mothers at Early Adolescence', *Journal of Child Psychology and Psychiatry, and Allied Disciplines* 45:8 (November 2004), 1407-19; M. Stevens et al., 'Openness in Lesbian-Mother Families Regarding Mother's Sexual Orientation and Child's Conception by Donor Insemination', *Journal of Reproductive and Infant Psychology* 21:4 (1 November 2003), 347-62; K. Vanfraussen, I. Ponjaert-Kristoffersen & A. Brewaeys, 'An Attempt to Reconstruct Children's Donor Concept: A Comparison between Children's and Lesbian Parents' Attitudes towards Donor Anonymity', *Human Reproduction* 16:9 (1 September 2001), 2019-25.

expected in practice, especially given the impact it has on the wider family. Some parents may therefore be hesitant or feel uncomfortable about disclosure.⁵⁷

Overall, it would appear that single women and same sex couples are most likely to disclose, and that whilst the number of heterosexual parents in the UK who are willing to disclose or intend to disclose is increasing, they nevertheless remain a minority of the whole of parents who used gamete donation.⁵⁸ It is also worth noting that the impact of the legal change on disclosure in the families who have used gamete donation after 2005 is still unknown. However, according to the Nuffield Council on Bioethics's report, 'preliminary findings from a study being carried out by Freeman T, Zadeh S, Smith V and Golombok S suggest that the removal of anonymity has not had an immediate impact on disclosure rates'.⁵⁹

In Belgium, an early study by Baetens et al. on egg donation indicated that two thirds of a sample of 144 couples opted for known donation and one third for anonymous donation. One of the main reasons to choose known donation was the fear of using unknown genetic material. Amongst the couples who used egg donation, the proportion of couples intending to disclose later on was similar to those who did not want to disclose (43%).⁶⁰

More recently, another Belgian study on egg donation drawing on interviews with 135 recipient couples and 90 egg donors reported similar rates of disclosure and non-disclosure amongst donor parents, regardless of whether they used an anonymous or identifiable donor.⁶¹ Half of parents using known donation (42 couples) and half of those used an anonymous donor (45 couples) did, indeed, not want to tell the child about his or her conception because of the fear of stigmatisation or rejection within their social circle, as well as to avoid jeopardising the mother-child relationship. Disclosure was also sometimes regarded as a threat to the child's psychological well-being.⁶² The paper also indicates that 'among Europeans (90 couples), 50% were in favour of disclosure compared with only 8.9% of recipients from North or sub-Saharan Africa (45 couples)'.⁶³ In some religious or ethnic communities, using gamete donation was taboo and disclosing the information could be very harmful and stigmatising not only

⁵⁷ Petra Nordqvist, 'The Drive for Openness in Donor Conception: Disclosure and The Trouble with Real Life', *International Journal of Law, Policy and the Family* 28:3 (2014), 321-38.

⁵⁸ Appleby, Blake & Freeman, 'Is Disclosure in the Best Interests of the Children Conceived by Donation?', *op. cit.*

⁵⁹ Tabitha Freeman, personal communication, 11 February 2013, indicated in Nuffield Council on Bioethics, 'Donor Conception: Ethical Aspects of Information Sharing' (London, April 2013), 58.

⁶⁰ Baetens et al., 'Counselling Couples and Donors for Oocyte Donation', *op. cit.*

⁶¹ C. Laruelle et al., 'Anonymity and Secrecy Options of Recipient Couples and Donors, and Ethnic Origin Influence in Three Types of Oocyte Donation', *Human Reproduction* 26:2 (February 2011), 382-90.

⁶² *Ibid.*

⁶³ *Ibid.*

for the child but also for the social father and the mother.⁶⁴ As a result, it remains unclear whether parents who can choose between an anonymous and a non-anonymous egg donor would prefer to disclose more information or not.⁶⁵ The authors therefore recommend ‘maintaining access to different types of oocyte donation’.⁶⁶

As for sperm donation, a qualitative study drawing on interviews with Belgian couples who had used an anonymous sperm donor has shown that once the child was born, most heterosexual couples ‘avoided talking about the donor because it was perceived as disrupting men’s growing confidence in their position as father’.⁶⁷ This was not dependent on whether or not they had disclosed but rather reflected the couples’ priority to protect the father from possible reminders of the donor. By contrast, attitudes towards the donor amongst lesbian couples who were interviewed in the study were more diverse. While disclosure about donor conception was the norm, there were differences in the ways the donor was constructed, with some couples portraying him as a person, especially as the child grew older, and others only considering the male genetic procreator as a means to the conception and tended to ignore him in discussions about family relationships.⁶⁸

The studies conducted to date on gamete donation practices in the UK and in Belgium demonstrate that despite a change of attitudes in professional counselling towards more openness, many heterosexual parents have not disclosed this information to their child or have expressed ambivalence or difficulty in doing so. A currently unknown proportion of donor-conceived children are therefore unaware that one or both of their legal parents is not his or her genetic parent. This proportion seems slightly more significant amongst children conceived using sperm donation than egg donation.⁶⁹ However, studies conducted in several countries also suggest that ‘children who are not informed have positive relationships with their parents and develop normally, which

⁶⁴ Ethnic and cultural differences in public perceptions of disclosure in gamete donation have also been noted in the UK context (see Nicky Hudson & Lorraine Cully, “‘Knock knock, you’re my mummy’”: anonymity, identification and gamete donation in British South Asian communities’, in: Hampshire and Simpson (eds.), *Assisted Reproductive Technologies in the Third Phase. Global Encounters and Emerging Moral Worlds* (Oxford: Berghahn Books 2015) 214-229).).

⁶⁵ This will also be the conclusion of another study conducted later in the US study on disclosure in egg donation (Dorothy A. Greenfeld & Susan Caruso Klock, ‘Disclosure Decisions among Known and Anonymous Oocyte Donation Recipients’, *Fertility and Sterility* 81:6 (June 2004), 1565-71).

⁶⁶ Laruelle et al., ‘Anonymity and Secrecy Options of Recipient Couples and Donors, and Ethnic Origin Influence in Three Types of Oocyte Donation’, 382.

⁶⁷ Elia Wyverkens et al., ‘The Meaning of the Sperm Donor for Heterosexual Couples: Confirming the Position of the Father’, *Family Process* (23 April 2015), 1.

⁶⁸ Elia Wyverkens et al., ‘Beyond Sperm Cells: A Qualitative Study on Constructed Meanings of the Sperm Donor in Lesbian Families’, *Human Reproduction* 29:6 (June 2014), 1248-54.

⁶⁹ Readings et al., ‘Secrecy, Disclosure and Everything in-Between’, *op. cit.* 486.

shows that this specific family secret does not always have an impact on the child's life'.⁷⁰ It is nonetheless worth noting that without more research it is difficult to demonstrate the impact that disclosure might or might not have for those involved and moreover that access to the perceptions of those who do not know they are donor-conceived, is of course impossible.⁷¹

Current debates and challenges

Despite the changes to the legislation of gamete donation in the UK and Belgium described in this paper, debate continues and suggests that there are several issues still at stake in both contexts. First, one effect of the legal shift in favour of open-identity donation is the potential ensuing shortage of gamete donors, which some have argued has been characteristic of the UK context in recent years.⁷² Although evidence suggests that donations are on the increase due to changing donor profiles and improvements in recruitment strategies,⁷³ there is still not sufficient supply to meet increasing demands,⁷⁴ leading some to travel overseas in pursuit of donor treatment.⁷⁵

Moreover, some have proposed that an identity release system has contributed to the genetisation of the family by suggesting that genetic information is crucial for well-being and by giving priority to genetic relationships. Ilke Turkendag notes that 'by marginalizing donor-conceived children, and enforcing a deeply-rooted view that genetic linkage is indeed very important, it is possible that the United Kingdom's disclosure policy compounds stigma and increases subterfuge rather than openness'.⁷⁶

Information sharing and donor identification have continued to be central to regulatory and legal discussions in both countries. In the UK, for example, a call for evidence was launched by the UK Nuffield Council on Bioethics on the ethical aspects of donor information sharing in 2011. It looked at 'issues of privacy, openness, and access to information, and the implications of each of

⁷⁰ Inez Raes, An Ravelingien & Guido Pennings, 'Donor Conception Disclosure: Directive or Non-Directive Counselling?', *Journal of Bioethical Inquiry*, in press.

⁷¹ Nuffield Council on Bioethics, 'Donor Conception: Ethical Aspects of Information Sharing', *op. cit.*

⁷² Theresa Glennon, 'UK and US Perspectives on the Regulation of Gamete Donation', in: Martin Richards, Guido Pennings & John B. Appleby (eds.), *Reproductive Donation: Practice, Policy and Bioethics* (Cambridge, UK: Cambridge University Press 2012), 90-111.

⁷³ Human Fertilisation Embryology Authority, 'Egg and Sperm Donation in the UK: 2012-2013' (London 2014), www.hfea.gov.uk/docs/Egg_and_sperm_donation_in_the_UK_2012-2013.pdf.

⁷⁴ BBC News, 'UK national sperm bank has just nine donors', 1 September 2015, www.bbc.co.uk/news/health-34113080.

⁷⁵ Lorraine Culley et al., 'Crossing Borders for Fertility Treatment: Motivations, Destinations and Outcomes of UK Fertility Travellers', *Human Reproduction* (June 2011), 2373-2381.

⁷⁶ Turkmendag, 'The Donor-Conceived Child's "Right to Personal Identity": The Public Debate on Donor Anonymity in the United Kingdom', *op. cit.* 75.

these for the individuals, families and groups affected by donor conception'.⁷⁷ The working group's conclusions were somewhat controversial in that it argued that it is not the role of state authorities to ensure that donor-conceived individuals are told about the nature of their conception, but rather that efforts should be made to encourage an environment where donor conception could be discussed openly and valued as one amongst a number of ways of family-building.⁷⁸

Presently in Belgium, the issue of information sharing in gamete donation remains controversial, against a growing significance of having information about one's genetic origins. This has been influenced most notably by open donation policies in the Netherlands and claims made by donor offspring which, as in the UK, have requested the ban of anonymous donation and access to the identity of the donor. The question of the regulation of donor conception was also reignited amidst recent discussions about possible future regulation of surrogacy which is currently unregulated in Belgium.

In 2014, a law proposal⁷⁹ was submitted to the Belgian Parliament in order to implement five different possibilities in terms of information sharing: 1) known donation; 2) access to non-identifiable information until the child is 18 and then access to the donor's identity, 3) access to non-identifiable information only, 4) no information on the donor until the child is 18 and then access the donor's identity and 5) anonymous donor. The prospective parent could therefore choose which donation option suits them best, while respecting the donors' preferences in terms of involvement. By offering more flexibility for all involved, this proposal also seeks to avoid significant gamete shortages. The primary aim of this recent law proposal is nonetheless to promote openness, which is illustrated by the suggestion that clinical counsellors be obliged to inform parents-to-be about the possible negative consequences of non-disclosure. In February 2015, a range of experts were invited to share their views on these possibilities. The hearing was followed by the submission of two other, more radical, law proposals, which aimed at banning donor anonymity and at creating a specific organisation responsible for centralising and organising the sharing of donor information.⁸⁰ Researchers at the University of Ghent in Belgium also

⁷⁷ Nuffield Council on Bioethics, 'Donor Conception: Ethical Aspects of Information Sharing', *op. cit.* 31.

⁷⁸ *Ibid.*, xxvii.

⁷⁹ S. Lahaye-Battheu & I. Somers, 'Proposition de loi du 13 novembre 2014 modifiant la loi du 6 juillet 2007 relative à la procréation médicalement assistée et à la destination des embryons surnuméraires et des gamètes, en ce qui concerne l'anonymat dans le cadre d'un don de gamètes', Doc 55/0618.

⁸⁰ V. Van Peel, 'Proposition de loi du 11 mars 2015 créant un Institut pour la conservation et la gestion des données relatives aux donneurs' Doc 54/0952; E. Van Hoof & S. Beck, 'Proposition de loi du 6 mai 2015 modifiant la loi du 6 juillet 2007 relative à la procréation médicalement assistée et à la destination des embryons surnuméraires et des gamètes, réglant le don anonyme de gamètes et instaurant un droit à l'identité pour les enfants issus d'un don', Doc 55/1066.

recently held an international symposium on gamete donation,⁸¹ in which most presentations and discussions focused on the relative challenges and dilemmas associated with anonymous and non-anonymous donation. These political and academic debates reflect the increasing attention granted to this issue in Belgium.

Conclusion

In the UK and Belgium the legal approach to donor identification has evolved in divergent ways, despite the fact that both countries share a common liberal framework regarding assisted reproduction. In Belgium, autonomy and freedom for intending parents have been maintained and prioritised: paradoxically the implication of this being that those who want to use gamete donation to form a family have little choice with respect to donor characteristics and there is no possibility for donor-conceived individuals to access information about the donor, either at the time of donation or in the future. In contrast, in the UK, donation policies place importance on allowing children conceived through gamete donation access to information about their origins. However, by allowing parents autonomy regarding the decision to disclose, this right is not guaranteed. This creates significant disparities, therefore, between donor-conceived children who have been told about their conception and will be able to access information about their donor's identity and those who have not been told.

In the ten years since the removal of donor anonymity in the UK, relative political approaches to donor identification and practices related to information sharing have evolved and are continually challenged by the diversity and complexity of family situations. In attempting to overcome these challenges, some commentators have argued for a 'double track' approach to donation, in which the autonomy of parents and donors could be respected. It is argued that in this model, both parties would have the possibility to choose what suits them best and clinics would match donors and recipients according to their preferences.⁸² One of its main disadvantages however, is the difference between the rights of offspring who have access to their donor's identity and those who don't have this possibility, since the choice about with which method to engage still lies with the recipients and donors. This double-track system was temporarily adopted in the Netherlands and is now on-going in Denmark. In both cases, it

⁸¹ 'Donor conception: An unfamiliar path to a normal family?' Symposium organised by the research group on social and genetic parenthood from Ghent University, 27-28 August 2015.

⁸² Pennings, 'The "Double Track" Policy for Donor Anonymity', *Human Reproduction* 12:12 (1997), 2839-44.

has not been implemented for a long enough period to enable conclusions on the implications to be drawn.

With respect to social practices, research about experiences and perceptions of donor identification and information disclosure remains limited. Almost all of what is known about those who are donor-conceived comes from small-scale studies, even though the UK or Belgium were pioneers in this respect.⁸³ Given this, it is difficult to draw firm conclusions about the implications of donor identification, particularly with regards to the articulation of the law with social practices. Current studies however do appear to illustrate more diversity regarding disclosure practices amongst families, than has been suggested by various stakeholders in public debate. Despite this, the findings of such research has not, to date, played a significant role in shaping policy making,⁸⁴ demonstrating a potential lack of effective and systematic dialogue between social scientists and law-making in this field. This is striking given the vibrancy of the political and legislative debate and change in these countries in recent years. If legislative changes are to be made which are reflective of and consistent with social practices and lived experiences, further detailed, longitudinal research is needed to better understand the social perceptions of those engaged with donor conception and the meanings that people give to disclosure.

⁸³ Nuffield Council on Bioethics, 'Donor Conception: Ethical Aspects of Information Sharing', *op. cit.*

⁸⁴ Frith, 'The Limits of Evidence', *op. cit.*

The Alienation of the Gift: The Ethical Use of Donated Blood

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Abstract

The complexity of the contemporary corporeal gift has ramifications for understanding social exchange mechanisms, donor communities and the potential ethical concerns. This paper deconstructs modern day blood donation and reveals, as a result, tensions in what was once the safe world of the easily identifiable altruistic 'no questions asked' donor, with few ethical problems. It aims to realign classical sociological and anthropological theories of gift exchange to blood donation thus enabling further understanding of the donor world.

This paper focuses on the theoretical implications for reframing the process of blood donation in the UK and the issues concerned with whose blood it is, what relationship the donation has with the donor body and with wider society in the blood product world.

The author re-examines social exchange theory and alienation theory to argue that blood, once donated, has become inalienable from the donor and the nature of donation is today more of a covenant than the unfettered gift that it used to be.

Increasingly, donors want to know where their blood has gone, and who has been given it, thus contesting the notion of alienation in relation to donated blood. This, it is argued, poses ethical issues for the concept of voluntary blood donation, the nature of consent, and the gift relationship today.

I. Introduction

The complexity of the contemporary corporeal gift has ramifications for understanding the concept of the gift exchange mechanisms on which voluntary blood donation is thought to rest. The changing landscape of contemporary blood donation and the ensuing 'blood economies' which have

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emerged raise potential ethical concerns. Previous research¹ has referred to the situation succinctly when saying mistaking an object intended as a gift for a commodity will lead to tensions. Blood commodification has also fallen further under the new auspices of biotechnology; becoming medicalised into a new speciality of 'blood component therapy' with plasma-derived medicinal products being utilised in preference to whole blood transfusions.² As such, the gift relationship as identified by Titmuss now falls under the lens of bioethics for scrutiny.³

This paper deconstructs modern day blood donation against this backdrop of commercialisation of the 'gift', and reveals, as a result, tensions in what was once the safe world of the easily identifiable altruistic 'no questions asked' donor. With little ethical debate, contemporary blood donors are becoming aware of the power and the value of their gift, and acceptance of the gift relationship has become problematic for donors where blood donated at blood donor sessions is used for a purpose unknown by the giver. Contemporary donors want to keep some moral ownership whilst giving, thus indicating that the donation of blood today is more of a covenant than an unfettered gift.⁴ This paper seeks to problematise this area for further debate and queries the nature of blood donation consent in the light of the new bio-value of blood once removed from the host.

The author re-examines social exchange theory⁵ and alienation theory⁶ to argue that blood, once donated, has become inalienable from the donor in a way which changes the concept of blood given as an unfettered gift and re-examines the meanings and purpose behind the new blood donation world where donors have no notion of or say in the intended recipients of their gift, and reflects on the ethics of the contemporary giving relationship.

¹ D. Latiner-Vos, *The Practical Organization of Moral Transactions: Gift Giving, Market Exchange, Credit, and the Making of Diaspora Bonds* (2013).

² www.who.int/mediacentre/factsheets/fs279/en/ World Health Organisation, Fact Sheet No 279, updated June 2014 (last accessed 11/2/2015).

³ R. Titmuss, *The Gift Relationship from Human Blood to Social Policy* (London: London School of Economics and Political Science, 1997).

⁴ M. Petrini, *Between Altruism and Commercialisation: Some Ethics Aspects of Blood Donation* (Ann Ist Super Sanita, 2013).

⁵ M. Mauss, *The Gift Relationship from Human Blood to Social Policy* (London: London School of Economics and Political Science 1997).

⁶ A.B. Weiner, *Inalienable Possessions: The Paradox of Keeping While Giving* (Berkeley: University of California Press 1992).

Demands for blood and blood products increase annually to the point where the United Kingdom uses 8,000 units per day,⁷ meaning that society places a high value on blood.⁸ The average price of blood is £122 per unit in the UK,⁹ with the WHO reporting the number of donations per annum at 108 million.¹⁰ Starr (1998) argues that as blood has become a pharmaceutical product it has come to symbolise a new social system.¹¹ Commodification of blood and its products, and the technology associated with this activity, is a fast growing business. Bio Products Laboratories (BPL) manufactures a range of products from human blood and supports markets in 45 countries.¹² The Blood 2020 strategy has as its aim to provide not only blood, but blood components that are needed for stem cell testing.¹³ All of these changes impact on the social system in which blood donation operates, thus affecting the traditional ambience in which blood is given and collected. Donors potentially understand that they are giving blood and not blood products, and see their gift as inalienable. Thus this new commodified and commercialised social system of blood donation will especially impact the marketing required to retain and attract donors.

2. Reframing the Gift

This paper first focuses on the theoretical implications for reframing the process of blood donation in the UK and the issues concerned with whose blood it is and what relationship the donation has with the donor body and wider society in the spare-part blood product world. Relating classical sociological and anthropological theories of gift exchange to blood donation enables further understanding of the contemporary blood donor world, as understandings of the rationale for becoming and remaining a blood donor being a form of altruism become challenged with the notion of ‘keeping whist giving’ appearing in the narratives of donation. Appadurai has written about the social life of things and blood has entered its own sociability as a result of the new

⁷ www.nhs.uk/Conditions/Blood-donation/Pages/Introduction.aspx/ National Health Service (last accessed 12/10/2015).

⁸ D. Starr, *Blood: An Epic History of Medicine and Commerce* (New York: A. Knopf 1998).

⁹ www.nhsbt.nhs.uk/annualreview/blood-supply/ National Health Service Blood Transfusion Annual review 12-13, (last accessed 12/10/2015).

¹⁰ www.who.int/mediacentre/factsheets/fs279/en/ World Health Organisation, Fact Sheet no. 279 (2015) (last accessed 12/10/2015).

¹¹ D. Starr, *Blood: An Epic History of Medicine and Commerce* (New York: Harper Collins 1998/2002).

¹² www.bpl.co.uk/ Bio Products Laboratories, (last accessed 2/10/2015).

¹³ National Health Service Blood Transfusion, *Blood 20/20. A strategy for the blood supply in England and North Wales* (2014).

life it takes on after leaving the body of its donor.¹⁴ This has relevance when reflecting the social process of donating blood and understanding it through the lens of the gift relationship. Moreover, the nature of the donation is unclear in relation to what the gift becomes as a result of the commodification blood fractionation process and whom the gift ultimately goes to.

Douglas also alludes to the ideas of exchange in society, she argues: 'Gift cycles engage persons in permanent commitments that articulate the dominant institutions.'¹⁵ This can be applied to biomedicine, and for example to the institution for National Health Service Blood and Transplant (NHSBT), and may result in an ethical impasse. Douglas argues that perception of symbols and their interpretation is socially determined and that this perception can alter over time.¹⁶ She goes on to underline that the social body 'constrains' the ways in which the physical body is perceived and that this results in continuous exchanges between the two bodies about the current meaning endowed. Blood, as a natural symbol, undergoes this continuous cycle, thus current meanings of blood need to be reinterpreted. The capacity to buy, sell and commercially fractionate blood has altered the nature of blood from what was a symbol of human kinship and life forces.

This concept of blood being a natural symbol of exchange and kinship can be re-examined in relation to aspects of recent discourse, which is reflective of the ways in which society has begun to use blood and therefore what blood represents.¹⁷ Donated blood is symbolic of both bio-hazard and gift, and is a medicine in its own right. Blood being both a symbol of good and risk brings questions to the understanding of the overly simplistic interpretation of the contemporary gift relationship. Berking argues that the giving of gifts binds everything together, gifts and gifting being representative of social synthesis which irrevocably unifies economics, power and, interestingly, morality.¹⁸

In furthering sociological clarification of the gift relationship, Simmel has argued that society exists where a number of individuals enter into interaction.¹⁹ This interaction is purposeful in achieving desired aims for the mutual benefit of that society, and it creates subsequent unity or socialisation therein. Therefore

¹⁴ A. Appadurai, *The Social Life of Things: Commodities in Cultural Perspective* (Cambridge: Cambridge University Press 1998).

¹⁵ M. Douglas, *Natural Symbols* (London: Routledge 1990), xi.

¹⁶ M. Douglas, *Purity and Danger* (London: Routledge 2002).

¹⁷ J. Kurtzberg, A.M. Lyerly & J. Sugarman, 'Untying the Gordian knot: policies, practices and ethical issues related to banking of umbilical cord blood', *Science and Society* (2005).

¹⁸ H. Berking, *The Sociology of Giving* (London: Sage 1999), 32.

¹⁹ G. Simmel, *The Sociology of Georg Simmel* (translated, ed. and intro K.H. Wolff, Glencoe Ill: Free Press 1950).

unity is derived from the sum of interactions. Simmel's views on exchange are pertinent to this paper, in that a characteristic of pure exchange must be that the sum of value to each party must be greater afterward than before. In the case of donated blood, therefore, the pooling and reconstitution of blood into its products would constitute pure exchange rather than the donation of the blood itself. This is because in contemporary society blood has greater value when out of the body than in it; moreover the value further increases during the process of fractionation. But the donation by the donor may not be pure exchange as the sum of value to the donor after the gift has been made may not be greater, as it was in the past, due to the loss of understanding of where and to whom the gift has been given. Contemporary methods for using and repackaging donated blood change the nature and form of donated blood into a different 'gift' and have shifted much of the value in the gift exchange away from the donor.

Understanding, then, that the gift is altered or changed by becoming commodified, Coleman argued that such commodification would reduce the properties required for blood donation to be a gift and may dilute it.²⁰ Mauss states that the gifts are, in the final analysis, compulsory social actions, even if given in the guise of voluntary politeness; in fact strictly compulsory on pain of private or public warfare. This applies in relative contemporary terms to blood donation as a National Health Service without blood is an unthinkable prospect.

Mauss further tells the observer about the group relationships, in particular the role of gifting in creating and maintaining relationship between groups, arguing that blood has gone further in the medicalisation relationship and that it has indeed become a technical tool separate from, or in addition to, the body. If the body, and therefore blood, has been acknowledged as the 'natural tool of man', it can now also be said to be the natural 'marketplace of man'. Increasingly, donors want to know where their blood has gone, and who has been given it, thus contesting the notion of alienation in relation to donated blood and shifting the paradigm to one of inalienation. This poses ethical issues for the concept of voluntary blood donation and the use of the raw gift for purposes unbeknown to the donor such as re-gifting or selling on.

Moody, also, argues for a rethink on serial reciprocity.²¹ This has ramifications for the concept of inalienability espoused by Weiner and whether blood donors are related to the spirit of their gift after it has been not only donated,

²⁰ S. Coleman, 'The Charismatic Gift', *Journal of the Royal Anthropological Institute* 10 (2004), 421-442.

²¹ M. Moody, 'Serial Reciprocity; A Preliminary Statement', *Sociological Theory* 26:2 (2008), 130-151.

but also altered as a result of the processes used in the redeployment of blood into both the marketplace and the blood supply.²²

Problems arise, then, when the donated blood is alienated from the giver by default as a result of the unidentified reuse of the gift. Therefore, as blood has become more potent as a commodity than a functioning body part following its gifting, it has developed a form of 'sociability'²³ with subsequent bio-value so that blood has become a form of new bio-capital.

Donations vs. Giving: The ethical use of donated blood

Referring to the work of Weiner, blood is described as becoming inalienable, i.e. the donated blood remains in some way related to the donor in spirit after the blood has left the body. This is in contrast to the altruistic paradigm where the gift was of whole blood largely with the popular understanding that the blood became gifted in the same whole state. Weiner argues all personal possessions invoke a connection with their owner, which symbolises the personal experience and adds to their overall identity. Blood donation is an example of this. As blood is increasingly seen as a body-part, its donation or giving can inform us about the donor and what the action of giving holds for them, and about the relationship of blood to the late postmodern body.

The discourse of blood donors about what happens to their blood after donation nowadays progresses this notion that donors now want to keep whilst giving. It is the change to the understanding of the new life that blood has after donation that is entering the donor consciousness which, this paper argues, has made blood inalienable, creating further tensions and instability within the unfettered altruistic paradigm.²⁴

Mauss sets out the obligations and reciprocal requirements that are needed in order for stable gift exchange mechanisms to occur. These entwined obligations, to offer, to give, to receive, to accept and to repay, are crucial to the premise of the gift exchange cycle. This is pertinent to the blood donation system in the UK, which is still regarded today in the same as it was at its inception, i.e. one based on simple altruistic gifting.

In reviewing the current status quo in the newly commercialised blood market, Coleman argues that the process of donation is not able to conform to

²² A.B. Weiner, *Inalienable Possessions: The Paradox of Keeping While Giving* (Berkeley: University of California Press 1992).

²³ A. Appadurai, *The Social Life of Things: Commodities in Cultural Perspective* (Cambridge: Cambridge University Press 1998).

²⁴ K. Arrow, 'Gifts and Exchange', *Philosophy & Public Affairs* 1:4 (1972), 343-362.

the full theoretical application of altruism as laid out by Mauss, as the way in which contemporary societies organise and distribute the gift of blood does not cater for the visual confirmation that the gift has been received.

There has been a change in the way that donated blood is perceived as a quasi-body part in the consumer world. Being duty bound to engage in donating pieces of the body, either in life or after death, has created areas of change in the giving relationship as to how commoditisation influences the understanding of the communal identity of donated blood. This poses further ethical issues requiring reconsideration of the role of understanding donated blood as a gift rather than a more neutral commodity.

3. Ethics and the Corporeal Gift

The Nuffield Report and the Blood 2020 Strategy both look towards increasing use and re-use of a wider range of body parts and organs, which has created a growing percentage of the general population joining the 'donor' fraternity as a result of receiving donor body parts through the impact of rapid technological advances.²⁵ According to the Nuffield Report, paragraph 65, the State remains the 'steward' of public health in relation to the donation of bodily materials including blood. The Report states that no changes are required in the voluntary system presently in place, in which case the gift falls into the hands of this stewardship which may create tension in the future.

Gold offers some ethical commentary on both body and blood. He argues that the body has authentic good conferred upon it by society and this is manifest in diverse ways as well as in intensely personal ways.²⁶ It is a representation of who we are, and for some the body is the expression of a higher order, such as God. Therefore society values the body as a whole, but also increasingly in and for its contingent parts. Whilst these parts are not autonomous, the body is being broken down into both visible and microscopic parts such as DNA. Gold further highlights that this inherent 'goodness' of the body can be used in aiding human health. He cites blood as an example of being symbolically representative of life as well as becoming valuable as a 'health preserving product' once it has been broken into its therapeutic parts (Factor VIII, plasma, etc.) This is an important ethical development in the way societal and individual blood is regarded. While blood parts do not carry the same value as does blood as a whole, it is

²⁵ Nuffield Report (2014), <http://nuffieldbioethics.org/wp-content/uploads/2014/07/Public-health-ethical-issues.pdf> (last accessed 23/9/2015).

²⁶ E.R. Gold, *Body Parts: Property Rights and the Ownership of Human Biological Materials* (Washington DC: Georgetown University Press), 12.

argued by Gold that we do value blood parts for what they represent in being a 'symbol of community', and thereby strengthening the growing link between body components and health.

Gold postulates that, rather than blood as a symbol of life losing its power via its transformation from whole blood to blood parts, in the doing of this the value society places on blood must increase, as blood therefore confers life to the recipient on behalf of society and not the donor. Ethical issues surround the concepts concerning whose blood it is in the first place and who this manifold body part belongs to. The property discourse was embedded in the solid body part donation debate, but it is argued here that the transformation of donated blood increases the original fluid's value more than the volunteer donors understand. The debate concerning ethics of blood parts is not evident in the UK, perhaps because of the voluntary nature of the blood market. Weiss's concept of 'intercorporeality' can be applied to the relationships created by the donating and distribution of the specialist components of blood.²⁷ Weiss is correct when she argues that no one is discrete in their identity, as the new person or 'I' is becoming mediated by the interdependence of what Waldby has called 'biotechnical fragmentation'.²⁸ The NHSBT should therefore make more widely known what happens to the whole blood that is collected, and to ascertain whether donors know what happened to their blood after its donation, to allow for informed consent concerning the gift of blood as one entity and recipients being gifted or charged for a refashioned product of the gift.

Cohen also argues that there has been a development of an 'ethics of parts' in relation to the new divisible, commoditised late modern body.²⁹ By this he means that ethics and ethical stances that used to apply to whole bodies are now applied part by part, thus allowing market forces to dictate the value of individual parts. These ethics are now being applied to blood parts within the Nuffield Report.

Lock argues that market forces make blood donating particularly vulnerable to exploitation due to the fact that donors are made to feel that blood is both a renewable resource from the body and easy to donate.³⁰ This allows both objectification and fetishism for those whose blood is rare, for example. Busby argues

²⁷ G. Weiss, *Body Images Embodiment as Intercorporeality* (London: Routledge 1999).

²⁸ C. Waldby, 'Stem Cells, Tissue Cultures and the Production of Biovalue Health', *An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* 6:3 (2003), 239.

²⁹ L. Cohen, 'Where it Hurts: Indian Material for an Ethics of Organ Transplantation', *Daedalus* 128:4 (1999), 135-65, cited in: Scheper-Hughes & Waquant, *Commodifying Bodies* (London: Sage 2006), 1.

³⁰ M. Lock, 'The Alienation of Body Tissue and the Biopolitics of Immortalised CellLines', *Body & Society* 7:2-3 (2001), 63-91.

that traditional blood services are built on the understanding that everyone is dependent on transfusion and/or transplant medicine.³¹

Waldby and Mitchell postulate that tissue economies, which increasingly include emergent blood-related economies, are about the tense intersection of biological capacities and political systems of power.³² This in itself resonates with the need to rethink the ethical issues with regard to the collection of blood in an altruistic fashion and then alienating the donor from its subsequent re-use. The donated blood, when circulating outside the body, becomes in fact more important, it treats deficient bodies which are in need of its hidden powers. Blood is separated out in order to produce more power parts in the form of fractions of itself, e.g. Factor VIII or white cells. Some of the current donors may understand the developing capacity of their donated blood, understanding that the donation would be separated into parts and used for people with different problems. Although donors may understand blood donation being seen packaged into a new form, however other donors may not know fractionation occurred, for whom there are potential future ethical issues.

4. Commoditisation of the gift

Sahlins stated, prophetically, that ‘one man’s gift should not be another man’s capital.’³³ This can be applied to current controversies over blood donation, the argument being particularly pertinent to the themes identified in this paper, as in relation to blood this is precisely what has occurred. Donors have had very little idea what value others put on their gift, and more importantly, if the end product of the gift was not something that would be recognisable to the majority of donors, then it cannot be the gift as given. Farrell has asked whether blood now is really a gift or a commodity.³⁴ The innocuous donation of blood has turned into an unrecognisable product, and the convention of a voluntary supply of blood does not mean that there is no selling of blood here in the UK, as identified within the Archer Report.³⁵

³¹ H. Busby, ‘The Meanings of Consent to the Donation of Cord Blood Stem Cells: Perspectives from an Interview Based Study of a Public Cord Blood Bank in England’, *Clinical Ethics* 5 (2010), 22:27.

³² C. Waldby & R. Mitchell, *Tissue Economy: Blood Organs and Cell Lines in Late Capitalism* (London: Duke University Press 2007).

³³ M. Sahlins, *Stone Age Economic* (New York: Aldine de Gruyter, 1972) 14, Intro.

³⁴ A.M. Farrell, *Political Scandal and Contaminated Blood in Ireland in Scandals in Past and Contemporary Politics* (J. Garrard & J. Newell (eds.), Manchester: Manchester University Press 2005), 163-176.

³⁵ The Archer Inquiry, *Independent Public Inquiry Report on NHS Supplied contaminated blood and blood products* (2009).

In looking at ways in which contemporary societies manage blood it is possible to say that donated blood has become ‘McDonaldised’.³⁶ Blood is processed and packed in an identical way across the globe, with principles of McDonaldisation applied to the blood service in that the work is related to targets and strict policy.³⁷ The final aspect of the McDonaldisation thesis is that of control being passed from human to non-human. The laboratory-based component services are in the process of becoming non-human operated. The BPL is the embodiment of this aspect. All these processes alienate the giver from their gift, so that the need for re-evaluation of the concept of the gift of blood needs to be acknowledged. How can the donated blood remain in any way related to the giver after these processes?

5. Discussion

Some blood donors may understand this prerequisite relationship between the State and their gift, but not all donors. The body part generation seem to understand that blood is a substance for donating without emotions attached to it, but we still need to reframe the actions from being altruistic or those of citizenship to a half-way house of a covenant relationship. Ethically, there is an issue over the use of donated blood in relation to the spirit of the rationale for giving, thus echoing Titmuss, who predicted that the alienation of the giver from the destination of the product would be problematic in relation to blood donation. This leads contemporary blood donation to become defined as a form of covenanted altruism.

If the NHSBT were to become a non-voluntary institution, there would be serious ramifications for the ways in which the small part of the population who give their blood for free would regard the product of their gift. We can relate this issue to the work of Howson who argues that a key characteristic of the contemporary society is not only the emphasis placed on consumption, but also the sense of ‘self’ which derives from, for example, gifting of donated blood. Therefore damaging the gift relationship could have profound implications for people’s sense of self from their lack of knowledge of the true current market value of their donated blood.³⁸ This argument has relevance for how donors see themselves in relation to the highly commoditised blood donation system. Beck

³⁶ G. Ritzer, *McDonaldisation: The Reader* (London: Pine Forge Press 2006).

³⁷ Joint United Kingdom (UK) Blood Transfusion and Tissue Transplantation Services Professional Advisory Committee, www.transfusionguidelines.org.uk/red-book/ (last accessed 12/10/2015).

³⁸ A. Howson, *The Body in Society* (Cambridge: Polity Press 2004).

further argues that we have become ‘agents of the self’, creating a partnership between the new technologies and the self.³⁹

Further, the cultural value of differing parts of the body for sale or ‘donation’ informs us of the hierarchical regard for relevant parts of the body that different cultures hold, which is well documented.⁴⁰ It invites investigation concerning the relationship between the body and the self in relation to the cyborg culture as well as the concept of bio-value or body capital in the consumerist society.

6. Conclusion

This paper extends the scope of understanding changes in blood donation and the gift relationship on which it depends, in relation to ethics and the gift exchange model. It aims at addressing the impact of developments in biomedicine and consumerism with regard to the self and blood donation and blood products, reflecting on the ethical issues involved in this new type of giving and receiving. Hidden behind a mask of quasi-altruism, donors are shown to be purposeful in their donation behaviour, and as Mauss has argued, there is no such thing as a ‘free gift’. Thus this paper reveals a dichotomy in the interpretation of the action of blood donation – is it an unfettered gift or a covenanted donation? An ethical rethink is required in order to fully understand the new gift relationships that exist in the contemporary world of blood donation.

³⁹ U. Beck, *The Risk Society: Towards A New Modernity* (London: Sage 1992).

⁴⁰ B. Turner, *Medical Power and Social Knowledge* (2nd edn, London: Sage 2001).

Prisoners as Living Kidney Donors: Unlocking the Potential

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Abstract

Living-donor kidney transplantation makes up a large proportion of kidney transplantation in the UK. Kidney donation by prisoners is lawful, and the British Transplantation Society recently compiled guidelines to help indicate the situations in which it is currently considered acceptable and manageable for prisoners to donate. Three main perspectives, that of the transplant recipients, the donating prisoner and the victims of the prisoner's crime, are of particular value and are discussed in this article considering the acceptability of prisoners becoming kidney donors. Ultimately understanding the perspectives of these cohorts would benefit from further research as much of the discussion of literature and views in this article are speculative. This work should be carried out in a timely fashion so that, should the practice of living kidney donation by prisoners be acceptable to these cohorts and the wider public, the British Transplantation Society guidelines can be implemented and a sustainable practice established.

Background

In the UK, 243 people died waiting for a kidney transplant in 2014-15.¹ In the same year, living-donor kidney transplantation made up 34% of kidney transplants in the UK.² The shortage of deceased-donor organs for transplantation means living kidney donation is now a major part of transplan-

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¹ NHS Blood and Transplant, *Kidney Activity* (2015), http://nhsbtmediaservices.blob.core.windows.net/organ-donation-assets/pdfs/kidney_activity.pdf (last accessed 26/9/2015).

² NHS Blood and Transplant, *Organ Donation and Transplantation – Activity Report 2014/15*, http://nhsbtmediaservices.blob.core.windows.net/organ-donation-assets/pdfs/activity_report_2014_15.pdf (last accessed 25/9/2015).

tation practice.³ The increasing practice and awareness of living donation has been accompanied by requests from prisoners to be considered as kidney donors.⁴

As with the general population, there may be a number of physical and mental health reasons that could exclude a prisoner from becoming a donor. However, this exclusion may be over-represented in the prison population due to the health inequalities experienced by offenders.⁵ Beyond these basic health-related exclusion criteria, the British Transplantation Society recently compiled some draft guidelines to assist healthcare practitioners and the Ministry of Justice in dealing with requests from prisoners to become living donors.⁶ The current guidelines are represented in Figure 1. This article aims to consider the potential responses of transplant recipients, prisoners, victims of crime and the wider society to these guidelines, considering:

1. The limitation of prisoners' autonomy, and the appropriateness of permitting or denying donation.
2. The perspective of crime victims on punishment and potential objections about prisoners being allowed the option of donating.
3. The importance of directed and non-directed recipients' access to transplants, and reservations they may have about prisoners donating.

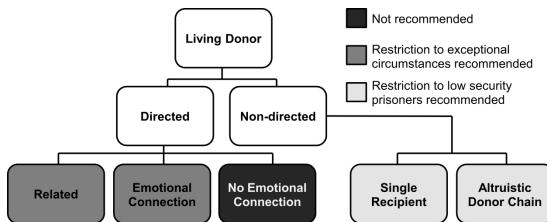


Figure 1: Current British Transplantation Society recommendations for prisoner living kidney donation in the UK. Unrelated directed donation is not recommended. Directed donation to a genetically or emotionally related recipient is possible for prisoners of any security category if the recipient is at high risk without the transplant or no other donor is available. Non-directed altruistic donation is

³ Houses of Parliament, 'Organ donation and Transplants', POST Note, Number 441 (September 2013).

⁴ British Transplantation Society, *UK Guidelines for Living Organ Donation from Prisoners, Consultation Version 2014-01-14*, www.bts.org.uk/Documents/UK%20Guidelines%20for%20Living%20Organ%20Donation%20from%20Prisoners%20Consultation%20version%20January%202014.PDF (last accessed 26/9/2015).

⁵ Public Health England, *Offender health* (2015), www.nepho.org.uk/topics/Offender%20health (last accessed 26/9/2015).

⁶ British Transplantation Society, *op. cit.*

possible for only low security prisoners if the donation cannot be delayed until after release from prison.

Figure adapted from O'Brien et al. (2012)

B. O'Brien & M. Koertzen, 'Anaesthesia for living donor renal transplant nephrectomy', *Continuing Education in Anaesthesia, Critical Care & Pain* 12:6 (2012), 317-321.

The Law Regarding Living Donor Transplantation

Transplantation is regulated by the Human Tissue Authority, through their enforcement of the Human Tissue Act 2004.⁷ The Act requires informed and uncoerced consent from the living donor. The Mental Capacity Act⁸ and common law stipulate the conditions that identify an individual as mentally competent to give consent.⁹ Additionally, the act of donation must be altruistic; no tissue can lawfully be procured and transplanted if the donation will result in any kind of reward for the donor.¹⁰ As long as these statutory and common law requirements are met, prisoners are not categorically excluded from living kidney donation. However, historically, donation by prisoners has been restricted.¹¹

As living kidney donation by prisoners is not prohibited by law, restrictions in place are due to a combination of moral and practical issues. Practical difficulties include:

- Logistical complications in ensuring safe and secure management of donors – i.e. not allowing escape of the prisoner during hospital visits and stays, or any other potential compromise of public and staff security.
- Ensuring donor screening to rule out transmissible disease is valid at the time of surgery, given the high transmission rates of blood-borne diseases in prisons.¹²
- Ensuring valid, uncoerced consent can be obtained from the prisoner.

⁷ Human Tissue Act 2004, part 2, section 33.

⁸ Mental Capacity Act 2005, part 1.

⁹ Human Tissue Authority, *Code of Practice 2. Donation of Solid Organs for Transplantation* (March 2013).

¹⁰ Human Tissue Act, *op. cit.*, part 2, section 33.

¹¹ British Transplantation Society, *op. cit.*

¹² Department of Health, *Tackling Blood-Borne Viruses in Prisons. A framework for best practice in the UK* (May 2011), www.nat.org.uk/media/Files/Publications/May-2011-Tackling-Blood-Borne-Viruses-in-Prisons.pdf (last accessed 26/9/2015).

There are concerns that meeting these requirements in order to allow the few cases of prisoner donation would require allocation of resources, potentially above and beyond that already provided. This could raise moral reservations about directing such valuable resources towards prisoners and for gains that may be outweighed by the public risk (and therefore not in the public interest).¹³

Prisoners

A major concern regarding prisoner living donation is uncertainty about prisoners' ability to give unpressured, uncoerced consent.¹⁴ The concern arises particularly from the need to avoid exploitation of vulnerable prisoners. Because imprisonment takes away autonomy and causes great psychological strain, it may be thought that imprisonment itself limits a persons ability to give valid consent. Prisoners have a high level of dependence on the institution as they are forced to relinquish their autonomy¹⁵ and most of their actions are watched over by prison staff. Prisons also create a large, closed community with their own hierarchy which may make the monitoring and avoidance of coercion difficult to guarantee. However, in the context of psychological treatment of prisoners that benefits others (reduces future offending), which requires consent from the prisoner, it has been found that the treatment does not have to be coercive, even in the context of court-mandated treatment within the prison setting.¹⁶ Hence, donating a kidney or otherwise becoming a living donor can be beneficial to others (and is outside the remit of the courts), and can be considered as unlikely to be directly coerced by the donor being imprisoned.

A further concern is to prevent donation by those with inappropriate motives or unrealistic expectations of the outcomes of donating. The (incorrect) expectation of reward for donation may serve as an inappropriate and possibly coercive motivation for donation. It is illegal for any reward for donation to be monetary,¹⁷ however most would see it as a selfless, 'good' act. The prisoner may therefore expect organ donation to act as 'good behaviour' and potentially be counted towards shortening their prison sentence. This, of course, cannot be the case,

¹³ British Transplantation Society, *op. cit.*

¹⁴ A. Caplan, 'The Use of Prisoners as Sources of Organs-An Ethically Dubious Practice', *The American Journal of Bioethics* 11:10 (2011), 1-5.

¹⁵ C. Haney, 'The Psychological Impact of Incarceration: Implications for Post-Prison Adjustment', *Working papers prepared for the 'From Prison to Home' Conference* (30-31 January 2002).

¹⁶ J. Rigg, 'Measures of perceived coercion in prison treatment settings', *International Journal of Law and Psychiatry* 25:5 (2002), 473-90.

¹⁷ Human Tissue Act, *op. cit.*, part 2, section 33.

and both this situation and concerns about coercion can be addressed by ensuring adequate explanation to any potential donors of what they can and cannot expect as a result of donation.

Yet another inappropriate expectation may be that the donation has a positive effect on the relationship between the donor and recipient in circumstances where the two are related. Imprisonment puts considerable strain on relationships with friends and family, and the prisoner may hope that donating their kidney would help to compensate or alleviate this strain. However, such a positive outcome from kidney donation cannot reliably be predicted, as it has been found that directed donation may have no effect or even in some cases a negative effect on relationships.¹⁸ The compulsory independent assessment process required for all living donors assesses each donor on an individual basis, thereby identifying these potential unrealistic expectations. However, when the donor is a prisoner, the assessor needs to be mindful of the extra stresses and strains the individual and their family are under, providing them with the necessary information to ensure their decision is based upon informed consent.

When considering the extra resources that may be implicated in utilising prisoners as donors, a counterargument to supporting prisoners as donors is that it may be more appropriate to suggest waiting until the prisoner has been released. Based on a Freedom of Information request in 2013,¹⁹ 42 prisoners at the time were serving life sentences in prison, meaning the vast majority of prisoners will serve their sentence then be released, making donation after release an option. However, after their release from prison, integrating back into society and rebuilding their life may be difficult enough without the added burden of undergoing complex medical assessments and procedures. In addition, it has been found that incarceration strongly affects people's health, predominantly caused by stigma associated with imprisonment, and that these effects are most pronounced after release. The timing of these negative health effects is partly attributed to diminished wage growth and marital instability.²⁰ It may therefore be more appropriate for people in prison to donate whilst still in the relatively stable environment of their prison stay. Countering this, it may also be argued that if they are not prepared to commit to the level of effort required to become a donor after their release, then perhaps they are not highly motivated enough to donate in the first place.

¹⁸ G. Heck, J. Schweitzer & M. Seidel-Wiesel, 'Psychological effects of living related kidney transplantation – risks and chances', *Clinical Transplantation* 18:6 (2004), 716-21.

¹⁹ Ministry of Justice Freedom of Information Request, Reference 82302 (May 2013).

²⁰ J. Schnittker & A. John, 'Enduring stigma: the long-term effects of incarceration on health', *Journal of Health and Social Behavior* 48:2 (2007), 115-30.

While much of the discussion around prisoners as organ donors in this article has so far been based on theoretical risk, history has unfortunately shown numerous situations in which prisoners have been exploited in the context of organ donation. For example, in China, there has been long-term reliance on the use of organs for transplantation without consent from executed prisoners, although they are said to have since worked towards an ethical and sustainable organ donation system.²¹ In the USA, there has been a case of 'kidney for parole'.²² In the Philippines, a 'kidney for parole' scheme was considered (it was not implemented because it was considered coercive and unethical).²³ However, it is worth reiterating that it has not been suggested that any type of scheme in which parole is offered in return for donation should be implemented in the UK, despite instances of such proposals elsewhere.

Overprotection (with the aim of protecting those vulnerable to coercion or who are motivated by unrealistic expectations of reward) through unnecessary and paternalistic prevention of all prisoners from donating can be as damaging as underprotection.²⁴ Where it is possible to know that a person is making their own decision to become a living donor, it is logical to support them to accomplish this decision. The British Transplantation Society guidance should assist this process.

After thorough screening, the prisoner donor will be granted or denied the opportunity to donate. We have so far considered the potential harm to the prisoner if permission is granted, but refusal of donation also has the potential to be harmful. However, there is a lack of information on the potential negative effects of refusing donation²⁵ and it has been suggested that thorough explanation is needed in the case of refused donation, in order to help manage reactions of disappointment and distress.²⁶ Guidance supporting the donation of organs from prisoners should also cover this.

²¹ World Health Organization, 'New era for organ donation and transplant in China', *Bulletin of the World Health Organization* 90:11 (2012), 793-868 [online].

²² A.M. Goldberg & J. Frader, 'Prisoners as Living Organ Donors: The Case of the Scott Sisters', *American Journal of Bioethics* 11:10 (2011), 15-16.

²³ L.D. de Castro, 'Human organs from prisoners: kidneys for life', *Journal of Medical Ethics* 29:3 (2003), 171-75.

²⁴ *Ibid.*

²⁵ M.B. Allen, P.L. Abt & P.P. Reese, 'What Are the Harms of Refusing to Allow Living Kidney Donation? An Expanded View of Risks and Benefits', *American Journal of Transplantation* 14 (2014) 531-537.

²⁶ *Ibid.*

Transplant recipients

There are two groups of recipients to consider in the context of prisoner living donation:

- Recipients of a directed donation from an imprisoned friend or family member.
- Recipients of non-directed altruistic donation.

Directed Donation

As represented in Figure 1, the recently prepared *UK Guidelines for Living Organ Donation from Prisoners* do not recommend directed donation from a prisoner to any individual with whom they have no prior emotional or genetic relationship, because of the ‘potential risk of inappropriate and/or complex attachment issues arising from the donation’.²⁷ Avoidance of this consequence is a clearly stated reason not to allow prisoners to donate directly to a named stranger. To those drafting the guidelines, the risks outweighed the potential benefit in this situation.

The guidance also places restrictions on living kidney donation by a prisoner to a named individual they are already emotionally or genetically related to (related directed donation). The guidance recommends related directed donation can be considered for any prisoner if the circumstances are exceptional, meaning specifically if the recipient has no other possible donor or is at unacceptably high risk of ‘severe morbidity or mortality’ without the transplant.²⁸ This implies that a related directed kidney donation from a prisoner is considered a last resort and has the potential to delay the donation.

In general, living-donor kidney transplantation has the advantage of a shorter waiting time between starting dialysis and receiving the transplant, and can even allow pre-emptive transplantation – before the recipient’s kidney function deteriorates to the stage where dialysis is required.²⁹ These factors can improve the likelihood of transplant success.³⁰ Where the donor is a prisoner and the donation is delayed due to the need not being medically urgent – as per the current recommendations – this could negatively impact the recipient’s

²⁷ British Transplantation Society, *op. cit.*

²⁸ *Ibid.*

²⁹ The British Transplantation Society and The Renal Association, *United Kingdom Guidelines for Living Donor Kidney Transplantation* (3rd edn, May 2011), www.bts.org.uk/Documents/Guidelines/Active/UK%20Guidelines%20for%20Living%20Donor%20Kidney%20July%202011.pdf (last accessed 27/9/2015).

³⁰ S.W. Yoo, O.J. Kwon & C.M. Kang, ‘Preemptive Living-Donor Renal Transplantation: Outcome and Clinical Advantages’, *Transplantation Proceedings* 41 (2009), 117-120.

quality of life and may even reduce their chance of a successful transplant. This can be construed as punishing the potential recipient for the past unlawful behaviour of their potential donor.

The situation could also arise where the recipient has two possible matches; a 'perfect' match in an imprisoned donor and a 'less than perfect' match in a donor who is not imprisoned. Should the donor have to wait for the perfect match? Should they have to accept the less than perfect match because of time and cost savings? Any situation where the best medical option might be influenced by the incarceration status of the donor seems untenable, yet one can envision the difficulty of the decision-making process in this situation.

From a societal perspective, the restriction on the situations in which a prisoner can become a directed donor has the potential to contribute to unequal access to living-donor kidney transplants already experienced by people from socially deprived backgrounds.³¹ As well as being less likely to receive living-donor kidney transplants, people from socially deprived communities are more likely to have family or close friends in prison.³² Therefore, although the guidelines to include prisoners as donors act generally to support organ donation from prisoners, these restrictions on related donation may be contributing to inequality. To promote social equality in organ donation (and potentially increase the number of donations) the guidance should allow related directed donation by a prisoner to be considered with an equal level of importance to if they were not in prison.

Non-Directed Altruistic Donation

If prisoners were to be able to be non-directed kidney donors, the point of view of those who may become recipients of such anonymous donations needs to be considered. There is a certain amount of stigma associated with imprisonment and potential recipients may feel that they do not want to be associated with a prisoner, even if it meant having to wait longer for a donation (or perhaps never receiving a transplant). However, it is also possible that potential non-directed recipients of prisoner kidney donation may value the importance of their access to organs for transplantation more highly than whether the donor is a prisoner or not.

³¹ U. Udayaraj, Y. Ben-Shlomo, P. Roderick, A. Casula, C. Dudley, D. Collett, D. Ansell, C. Tomson & F. Caskey, 'Social deprivation, ethnicity, and uptake of living kidney donor transplantation in the United Kingdom', *Transplantation* 93:6 (2012), 610-16.

³² F.C. Bruce, 'Reinvesting in Communities: Community Justice as a Viable Solution to Mass Incarceration', *Internet Journal of Criminology* (November 2012).

There is some evidence to suggest that the opportunity of receiving a transplant would be valued more highly than the background of the donor. In the USA, 13 out of 16 patients on an active waiting list for lung transplants responded that they would accept organs from a death-row inmate.³³ The same survey showed patients waiting for transplants, or who have already benefited from transplant, felt that if even just one person was helped, then donation by a prisoner on death-row would be acceptable.³⁴ Beyond this, there is a lack of evidence on specific attitudes towards prisoners as living kidney donors, and carrying out this research in the form of opinion polls, questionnaires or interviews would be a valuable source of information on the views of the general public and, specifically, potential recipients.

Current practice relating to altruistic non-directed kidney donors ensures the recipient is not aware of who their donor is.³⁵ Therefore, the recipient would not be aware that their donor was a prisoner and this should eliminate any decision-making (and associated stress) to do with accepting an organ donated by a prisoner. However, the uncertainty of not knowing one way or the other could be an issue for some recipients.

It is also known that there is a higher rate of blood-borne virus transmission in prisons than in the general population,³⁶ and therefore an increased risk of blood-borne virus transmission upon transplant due to new infection between donor screening and surgery. Either the screening system would need to be suitably adjusted to be certain the increased risk was ruled out, or recipients would need to be made aware of the increased risk during the operation consent process. In the latter case, this would mean that even though the origin of the organ had not been explicitly divulged, the recipient might infer that the donor was a prisoner. This would then re-open the issues mentioned above and could put an unnecessary burden on the recipient by having to accept or reject the organ if they had moral or other personal beliefs that would question their willingness to accept an organ from a prisoner.

While the choice between good health and personal concern about the origins of an organ might seem easy to some, it is worth considering that if the transplant is successful, the organ will remain in the recipient's body for the rest of their life. A common perception of the imprisoned criminal is of someone of

³³ S.S. Lin, L. Rich, J.D. Pal & R.M. Sade, 'Prisoners on death row should be accepted as organ donors', *The Annals of Thoracic Surgery* 93:6 (2012), 1773-79.

³⁴ *Ibid.*

³⁵ The British Transplantation Society and The Renal Association, *op. cit.*

³⁶ Department of Health, *Tackling Blood-Borne Viruses in Prisons*, *op. cit.*

low social status who is cruel in nature and disliked by the public.³⁷ Therefore it is a reasonable speculation that the idea of receiving an organ from such a person could be troublesome for the recipient and lead to complex and long term internal emotional conflict should they accept the organ donation.

Looking into this, the way a recipient would feel about having a prisoner as a kidney donor may depend on the crime committed. It could be speculated that (if information on a donor's criminal record was available to them) a recipient may be more reluctant about receiving a kidney from someone convicted of one type of crime over another. To address this gradation of type of crime without revealing the exact nature of the donor's crime it may be argued that prisoner living kidney donation should not be permitted beyond low risk prisoners. The reality however, is that prisoners are categorised based on current likelihood of escape and danger to the public, not by the crime committed. This means low risk category prisoners can include, for example, those serving life sentences for murder.³⁸

A counterargument to this concern is that people who have been in prison in the past, or committed crimes and not been convicted or imprisoned, are currently free to become non-directed kidney donors if willing and medically able. In reality, considering that these individuals are not excluded from becoming living donors, the recipient accepting a non-directed altruistic living kidney donation has the chance of receiving a kidney from someone who has committed a serious offence even if prisoners were not included as living donors at all.

Crime victims

Living organ donation involving a prisoner introduces a third party not present when the donor is not a prisoner. This third party is the prisoner's victim(s). There could be several possible reasons for those affected by 'victimful' crimes³⁹ to be against permitting prisoners to become living kidney donors. These include:

³⁷ C. Côté-Lussier, 'The evil, poor, disliked and punished: criminal stereotypes and the effects of their cognitive, affective and behavioural outcomes on punitiveness toward crime', *PhD thesis* (The London School of Economics and Political Science (LSE), 2012).

³⁸ Ministry of Justice, National Offender Management Service, *National Security Framework, Categorisation Function – Categorisation and Recategorisation Of Adult Male Prisoners*. August 2011, www.justice.gov.uk/downloads/offenders/psipso/psi-2011/psi-40-2011-categorisation-adult-males.doc (last accessed 1/12/2015).

³⁹ L. Ellis, 'The Victimful-Victimless Crime Distinction, and Seven Universal Demographic Correlates of Victimful Criminal Behaviour', *Personality and Individual Differences* 9:3 (1998), 525-48.

- Not wanting the person who victimised them to be able to feel they have redeemed themselves.
- Not wanting the person who victimised them to be able to help another (often their own friend or relative).
- Not wanting the prisoner to be able to exercise autonomous control over their own body.
- Not wanting to allow the prisoner to achieve improved self-worth as a result of donation.

A prisoner’s lack of freedom is accompanied by an inevitable loss of opportunity to make autonomous choices. The liberty of choice prisoners may have over becoming a living donor may be perceived as affecting the completeness of their punishment. It could be argued that as a part of punishment, prisoners’ autonomy should be restricted to exclude this type of decision. This could work in two ways, one being to remove their choice to donate and make it compulsory to ‘donate’ a kidney once imprisoned. The implications and moral arguments for and against this go beyond the scope of this essay. The alternative would be to deny the prisoner the choice of becoming a voluntary donor.

Victims may be motivated by revenge, to deny prisoners the choice of donating a kidney because of the possibility that this will cause prisoners distress, or at least prevent them from experiencing a positive outcome. However, there is evidence suggesting revenge is not a highly important punishment outcome for victims. In one study, revenge as an outcome of punishment was rated of intermediate importance by victims of violent crime.⁴⁰ This is shown in Table 1.

Categories	‘M’
‘Just desserts’	3.8
‘Revenge’	3.3
‘Recognition of victim status’	3.5
‘Deterrence of offender’	4.6
‘Rehabilitation’	2.9
‘General deterrence’	3.9
‘Positive general prevention’	3.8
‘Victim security’	4.3
‘Societal security’	4.3

Table 1: In a study by U. Orth in 2003, 171 victims of violent crime were asked to rate the importance of 18 statements relating to punishment goals with

⁴⁰ U. Orth, ‘Punishment Goals of Crime Victims’, *Law and Human Behavior* 27:2 (2003).

regards to the criminal case they were involved in. 'M' is the rating from 0 – 'not at all important' to 5 – 'very important'.

Table adapted from U. Orth, 'Punishment Goals of Crime Victims', *Law and Human Behavior* 27:2 (2003).

A limitation of the study was questionable representativeness of the results. The response rate to the victim survey which was used to collect information was low, and the demographics of respondents was not explored to determine if there was a difference between those who did and those who did not respond.⁴¹ Individuals' responses to being victimised are highly variable, and clearly those responding to the study survived the offences against them. The opinion of someone whose family-member, friend or associate has been murdered for example, could be dramatically different. In the case of a Belgian prisoner who wanted to be euthanised,⁴² the sisters of one of his victims were reported as saying he should 'languish in prison' rather than being given what he wanted, and they pointed out that though a huge amount of consideration was put into whether his wishes would be carried out, no experts asked either their opinion or if they needed help dealing with the situation.⁴³

Limitations aside, the cohort who responded to the survey in Orth's paper placed offender deterrence and security of the victim and society as the most important aims of punishment. Revenge was the second-lowest rated of the punishment goal categories. As the safety of others in society was an important concern, this could be tentatively extrapolated to suggest victims would be considerate of the needs of potential transplant recipients. However, a wide range of crime victims would need to be asked to find a more representative viewpoint.

At the same time, victim and societal safety could be seen as a counterargument to allowing prisoners to be living kidney donors. The British Transplantation Society guidelines recommend that prisoner donation can be permitted from even high risk prisoners (in certain circumstances)⁴⁴ where it can be demonstrated that the process can be appropriately managed, maintaining public and employee safety. As prisoners' risk categories are based on their risk

⁴¹ *Ibid.*

⁴² R. Spencer, 'Belgian rapist and murderer to be put to death by lethal injection', *The Telegraph* (4 January 2015), www.telegraph.co.uk/news/worldnews/europe/belgium/11324579/Belgian-rapist-and-murderer-to-be-put-to-death-by-lethal-injection.html (last accessed 3/10/2015).

⁴³ B. Waterfield & A. Marszal, 'Belgian serial rapist will not be euthanised', *The Telegraph* (6 January 2015), www.telegraph.co.uk/news/worldnews/europe/belgium/11327541/Belgian-serial-rapist-will-not-be-euthanised-as-planned.html (last accessed 3/10/2015).

⁴⁴ British Transplantation Society, *op. cit.*

of escaping incarceration, harming others or themselves⁴⁵ this guidance seems to actively seek putting victims and society at risk – contrary to the victims' values of punishment.

Restorative justice is a process in which people affected by a specific offence work together to deal with its aftermath, and aims to ensure the victim feels 'paid back' for the harm done to them, give the perpetrator the opportunity for redemption, and increase public confidence in the criminal justice system.⁴⁶ This was not covered in Orth's paper, but has been reported in the media to be beneficial for many victims of crime.⁴⁷ Money recovered from offenders is being used to deliver restorative justice in the UK, in order to help find ways to positively move forward from crimes.⁴⁸ Victim participation in restorative justice suggests people wish to help a positive situation arise from a negative one.⁴⁹ This not only indicates that there are victims who want a better outcome for themselves and the offender, but it demonstrates a preference to prevent continuing misfortune. Therefore, victims who support restorative justice would likely be in favour of allowing prisoners to become living kidney donors.

Conclusion

It is possible that, if carefully managed, allowing living donation by prisoners who are motivated and able to do so could increase the potential population of living donors by a small number. However, this is a controversial consideration and there are a lot of perspectives which could challenge the idea of allowing of prisoners to become donors. It would be beneficial to research people's current perspectives on prisoner living donation, including the points of view of transplant recipients, people who have been victims of crime, and prisoners themselves, in order to get a clearer idea of whether those directly affected and members of society in general are accepting of the concept of

45 Offenders' Families Helpline, *Prisoner Category*, www.offendersfamilieshelpline.org/index.php/prisoner-category/ (last accessed 27/9/2015).

46 The Crown Prosecution Service, *Restorative Justice. Legal Guidance*, www.cps.gov.uk/legal/p_to_r/restorative_justice/ (last accessed 13/10/2015).

47 J. Lopez, 'Crime victims find healing through restorative justice', KALW Local Public Radio 91.7FM in San Francisco 7 October 2013), <http://kalw.org/post/crime-victims-find-healing-through-restorative-justice#stream/0> (last accessed 27/9/2015).

48 Ministry of Justice, *New victims' funding for restorative justice*, Press Release (19 November 2013), <https://www.gov.uk/government/news/new-victims-funding-for-restorative-justice> (last accessed 27/9/2015).

49 National Offender Management Service, *Better Outcomes through Victim-Offender Conferencing (Restorative Justice)* (November 2012), <http://webarchive.nationalarchives.gov.uk/2013012812038/www.justice.gov.uk/downloads/about/noms/better-outcomes-victim-offender-conferencing.pdf> (last accessed 27/9/2015).

prisoners donating. However, collecting information about people's opinions on the subject presents another possible issue. Drawing public attention to the subject of prisoner donation could possibly lead to 'backlash' and negative publicity. However, prisoner donation has historically been restricted, so it is unknown what people's responses will be to the concept of officially including prisoners as living donors until the topic is explored further, regardless of the potential and perhaps unsubstantiated reactions. This work should be carried out as soon as possible to aid discussion and decision-making when consulting the currently available guidelines.