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A Critique of the Concept of Autonomy in Organ Donation

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Abstract

The legal requirement for consent or authorization for the use of an organ for transplantation places donor autonomy as the prima facie ethical principle underpinning organ procurement in the UK. Donor autonomy is central to the ethical discourse of transplantation yet this concept remains poorly articulated in the legal and regulatory framework governing organ donation where it is framed narrowly in terms of consent or authorisation.

I analyse the legal framework governing living and deceased organ donation in England, Scotland, and Wales and the regulatory processes for the approval of application for living organ donation and seek to identify whether these are consistent with a particular understanding of autonomy. I consider the adult donor and the child donor separately.

I maintain that the choice to donate an organ is a deeply personal decision based on motivations and values that matter to the donor. I explore the understanding of autonomy in relation to decisions to donate an organ for transplantation from the perspective of the person whose organs are used. I am concerned with a substantive account of autonomy that goes beyond the decisional authority over the use of one's organs. Starting from this premise, I examine the role of self-reflection, personal values and relationships, and moral responsibilities and commitments in decisions to donate an organ and focus on the idea of authenticity understood as a choice that the donor endorses as their own.

I argue that consent or authorization that is lawful from a procedural perspective does not ensure that the decisions of the person whose organs are used for transplantation are respected and does not require that these choices are based on a decision-making process that engages with personal autonomy in a meaningful way.

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Author’s Declaration

I declare that, except where explicit reference is made to the contribution of others, that this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

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1 Introduction

Deceased organ procurement in the UK is governed by the Human Tissue Act 2004 (hereafter HT Act 2004) and the Organ Donation (Deemed Consent) Act 2019 (hereafter OD(DC)A 2019) in force in England, the Human Tissue (Scotland) Act 2006 (hereafter HT(Scotland)A 2006) and the Human Tissue (Authorisation) (Scotland) Act 2019 (hereafter HT(A)(Scotland) 2019), and the Human Transplantation (Wales) Act 2013 (HT(Wales)A 2013). These statutes provide the legislative framework for the removal, storage and use of human tissue and organs and transplantation is one of a range of activities that are regulated, which include post mortem examinations and medical research. Living organ donation in the UK is based on the principle that the use of organs from living persons is generally prohibited unless certain requirements are met and these are set out in the Human Tissue Act 2004 (Persons who Lack Capacity to Consent and Transplants) Regulations 2006 (hereafter HT Regulations 2006), the Human Organ and Tissue Live Transplants (Scotland) Regulations 2006 (HT(Scotland) Regulations 2006), and the HT(Wales)A 2013.

The HT Act 2004 and the HT(Scotland)A 2006 were introduced following the enquiries into the controversial practices of post-mortem organ retention at Bristol Royal Infirmary and the Royal Liverpool Children's Hospital (Alder Hey) in 1999 and 2000.[1] The legislation in place during this time regulating the post-mortem use of tissues and organs was the Human Tissue Act 1961 and this operated on the basis of a 'lack of objection' from relatives to be established rather than a requirement for specific consent.[2] The *Kennedy* [3] and *Redfern* [4] inquiries into practice at these hospitals established that organs and tissue from children who had died had often been removed, stored and used without proper consent. A subsequent census by the Chief Medical Officer for England [5] and the *Isaacs Report* [6] showed that storage and use of organs and tissue from both adults and

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[1] David Price, 'From Cosmos and Damian to Van Velzen: The Human Tissue Saga Continues' (2003) 11 Medical Law Review 1.

[2] 'Human Tissue Act 1961 s 1(2).

[3] Department of Health. *Learning from Bristol: The Department of Health's Response to the Report of the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary 1984-1995.* (London: Stationery Office 2002).

[4] Michael Redfern. *The Royal Liverpool Children's Inquiry Report'* (London: Stationery Office 2001).

[5] Department of Health. *Report of a Census of Organs and Tissues Retained by Pathology Services in England conducted in 2000 by the Chief Medical Officer* (London: Stationery Office 2001).

[6] The Isaacs Report *The investigation of events that followed the death of Cyril Mark Isaacs* (London: Stationary Office 2001).

children without proper consent had been widespread. In Scotland, the Final Report on the Retention of Organs at Post-Mortem,[7] reached a similar conclusion. The strong public reaction to these investigations showed how these practices, once exposed, were widely regarded as unacceptable. The finding that there had been a perceived or actual failure to obtain proper permission to remove and retain the organs, and in particular those of children, had profound ramifications on the development of the HT Act 2004 and on its notion of consent, described as the 'golden thread' of the new legislation.[8] The HT Act 2004 establishes the Human Tissue Authority (HTA)[9] as the regulatory body for activities involving the removal, storage, use and disposal of human material. The HTA also issues Codes of Practice [10] and directions concerning the lawful conduct of the activities within its remit. Specifically, Code of Practice F provides guidance to professionals regarding the proper procedures for securing valid consent in living and deceased organ donation.[11]

The requirement for consent or authorization is a fundamental principle in organ donation from living and deceased persons. The individual may choose whether to donate or not and this prerogative is grounded in the concept that individuals have certain rights of control over what happens to their bodies in life and after their death that deserve respect and legal protection.[12] This approach is consistent with the general patient-centred approach to decision-making in medical ethics where it is widely recognised, at least in western bioethical discourse, that choices are beneficial to the individual's subjective wellbeing because they reflect values and principles that are meaningful to them and that each person knows best what their interests are.[13] However, while the moral basis for consent is concerned with the interests of the patient in making decisions for themselves, the legal doctrine of consent is primarily concerned with the duties and liabilities of medical professionals and consent is framed narrowly in terms of the provision of sufficient

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[7] Independent Review Group. Retention of Organs at Post Mortem: Final Report. (Edinburgh: Stationary Office 2001).

[8] Stephen Layman, 'House of Commons - Health - Minutes of Evidence' [2004] Under-Secretary of House of Commons Standing Committee G, col 66 4.

[9] HTA 2004 s. 13.

[10] HTA 2004 s. 26. The HTA Codes of Practice are available at http://www.hta.gov.uk/legislationpoliciesandcodesofpractice/codesofpractice accessed 4 January 2023.

[11] HTA Code of Practice F: Part 1 Living organ donation (Human Tissue Authority, May 2020); HTA Code of Practice F: Part two Deceased Organ and Tissue Donation (Human Tissue Authority, May 2020).

[12] David Price, *Human Tissue in Transplantation and Research: A Model Legal and Ethical Donation Framework* (Cambridge University Press 2009), 62, 76.

[13] Allen Buchanan and Dan Brock, *Deciding for Others: The Ethics of Surrogate Decision Making* (Cambridge University Press 1990); Eike-Henner Kluge, 'Competence, Capacity, and Informed Consent: Beyond the Cognitive-Competence Model' (2005) 24 Canadian Journal on Aging / La Revue Canadienne du Vieillissement 295.

information, the understanding of this information, and the voluntariness of the decision.[14] The fixation on consent as a free standing justificatory standard and its largely operationalised approach in medical ethics have been criticised for failing to fully account for the underlying interests that consent seeks to protect and the moral and legal duties that it creates.[15]

A unique feature of transplantation is that it involves a procedure to remove an organ or part of an organ from a healthy person in order to treat another person, the recipient. This underlying tension between the needs of patients for a healthy organ and the interests of the individual who is the source of the organ is central to the conceptualisation of the donor autonomy and is captured by Jackson as follows:

> The principle of patient autonomy gives the individual a right to make decisions which may have a profoundly negative impact upon others' well-being. At times, then, there may be a tension between a patient's legal right to determine what is done to her body, and her moral obligations to others.[16]

This thesis examines the understanding of autonomy in relation to decisions to donate an organ for transplantation from the perspective of the person whose organs are used. My starting point is that donor consent is not a freestanding legal principle and that consent matters only in so far as it ensures that underlying interests are protected. The legal requirement for the consent or authorization of the person whose organs will be removed and transplanted places donor autonomy as the prima facie ethical principle underpinning living organ donation and deceased organ procurement in the UK. The fulcrum of this thesis is that while autonomy is central to the ethical discourse in organ donation and permission for the removal and transplantation of an organ is framed normatively in terms of respect for donor autonomy, this principle is poorly articulated in the legal framework governing organ procurement and is largely equated with consent requirements. I claim that a fundamental dimension of the interests underlying organ donation relates to the significance of the act of donation to the donor and the authenticity of the decision in the sense that the choice to donate genuinely reflects the donor's moral principles, values and commitments. Fulfilment of the requirements for consent does not convey the intensely personal and unique way in which the choice to donate is made. Hence, the ethical concern

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[14] Ruth Faden and others, *A History and Theory of Informed Consent* (Oxford University Press 1986).

[15] Roger Brownsword, 'The Cult of Consent: Fixation and Fallacy' (2004) 15 King's Law Journal 223.

[16] Emily Jackson, *Medical Law: Text, Cases, and Materials* (4th edn, Oxford University Press 2016), 239. This idea is rephrased less succinctly in the context of patient's autonomy to refuse medical treatment in Emily Jackson, *Medical Law: Text, Cases, and Materials* (6th edn, Oxford University Press 2022), 254.

is that valid consent or authorization does not ensure that the individual makes a decision according to values and principles that they accept as their own.[17]

I analyse the legal and regulatory frameworks governing organ donation in the UK and seek to identify whether these are consistent with a particular understanding of autonomy. This thesis is narrow in scope and focuses on decision-making from the perspective of the person whose organs will be used for transplantation. I will examine current legislation for deceased organ donation and living organ donation and the regulatory processes for the approval of the applications for living organ donation, and consider whether these are justified by a coherent account of donor autonomy. The focus of my enquiry is whether consent or authorization that is lawful from a procedural perspective ensures that the decisions of the person whose organs are used for transplantation are respected and requires that these choices are based on a decision-making process that engages with personal autonomy in a meaningful way.

I am concerned with a substantive understanding of autonomy that goes beyond the decisional authority over the use of one's organs and examine the role of self-reflection, personal values and relationships, and moral responsibilities and commitments in decisions to donate an organ. While different considerations apply to decisions to donate in life or after death and the circumstances within which decisions are made are unique to the particular individual, I maintain that the choice to donate an organ is fundamentally a personal decision based on motivations that matter to the donor. I explore how these motivations relate to the idea of authenticity and how autonomy of the donor can be conceived as meaning that the individual's choice to donate is authentic in the sense that it is a choice that they endorse as their own. Within this paradigm I focus on the donor as a socially embedded individual and contend that a relational account of autonomy offers a more comprehensive account of authenticity based on the idea that human relationships and the social context within which the prospective donor is situated shape the moral values, interests, and responsibilities and obligations towards others that ground the choice to donate.

The originality of this research lies in the fact that it is an enquiry into the overarching concept of donor autonomy in organ procurement. I seek to understand whether there is a core meaning of autonomy from the perspective of the person whose organs are used for

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[17] Ryan Sauder and Lisa Parker, 'Autonomy's Limits: Living Donation and Health-Related Harm' (2001) 10 Cambridge Quarterly of Healthcare Ethics 399.

transplantation that justifies current practices. The scope of this analysis is intentionally broad. Firstly, it seeks to override the traditional categorisation of the ethico-legal discourse on autonomy according to the type of donation, namely donation in life or posthumous. The HTA is the common regulatory authority responsible both for protecting the interests of living donors and for ensuring that the requirements for consent or authorization to posthumous donation are met. I examine whether the relevant interests that individuals have in relation to the use and control of their bodies in life and after their death are fundamentally different and how these underlying interests affect the individual's decision to donate an organ. These issues are explored in Chapter 2 and 3. Secondly, I consider the full spectrum of donor decision-making abilities and skills, ranging from child donors who are too young to grasp organ donation in any meaningful way, through teenagers and young persons who have the rational and cognitive capacity to understand the donation process and its implications to a variable extent, to adult donors with full legal capacity. This approach requires some adjustments to be made with respect to the understanding of the autonomy of the donor child. Autonomy in the sense of an authentic choice cannot be severed from the maturity of the child and will not apply to the very young. When considering decisions to use an organ from a child or a young person for transplant, a broader construct of autonomy must be considered that goes beyond the limitations of the child's present autonomy and includes their developing autonomy as the child or young person matures, and the autonomy it is anticipated that they will be able to exercise in the future as adults.

1.1 Thesis structure

This thesis is a critique of the understanding of the concept of autonomy under current laws and policies in organ donation and is structured as follows.

This thesis begins with an exploration of the meaning of autonomy. In Chapter 2, I examine the different understandings of individual autonomy in moral philosophy from the perspective of liberal, relational, and communitarian ethical theory and argue that autonomy is a multifaceted principle that is not reducible to the traditional individualist notions of self-determination. I then consider the core elements of autonomy in medical ethics and the meaning of respect for patient autonomy in decisions about treatment. I discuss the connection between autonomy, authenticity, voluntariness, informed consent, and the determination of capacity for the purposes of framing the ethical enquiry within parameters that are relevant to donor autonomy in organ transplantation. A more detailed analysis of these themes and processes will be offered within specific donation contexts, notably living donation, deceased donation, and donation by children. While recognizing the extensive academic critique of the limitations of consent law as a mechanism to ensure respect for patient autonomy, I do not propose to examine these as the constraints of this thesis do not allow for an exploration of the broader debate in medical law about the relationship between autonomy and consent the beyond the specific domain of organ donation.

I consider the meaning of autonomy in living organ donation by adults in Chapter 3. I start by examining recent developments in jurisprudence towards a conceptualization of decisional autonomy as a human right and consider whether a rights-based approach offers useful insights into the understanding of donor autonomy in living organ donation by adults with capacity. Based on the philosophical analysis of donation in Chapter 2, I then discuss how liberal, relational, and communitarian notions of autonomy are relevant to the decision to donate an organ in life and how different elements of these ethical theories apply to donation within the context of a close personal relationship between donor and recipient, and to donation to a stranger. I examine key concepts related to donor motivations namely, altruism, authenticity, self-reflection, and moral obligations towards meaningful others or society in general. I consider whether authenticity is a relevant concept in the approval process of applications for living donation. To this purpose, I examine the legal and regulatory frameworks for living organ donation and the donor screening process by the transplant team and the HTA and consider whether these can accommodate a construct of autonomy based on personal values and moral commitments towards other persons.

In Chapter 4, I explore the meaning and ethical relevance of autonomy in deceased organ procurement from the perspective of the person whose organs are used for transplantation after their death. This requires, first of all, consideration of the interests that living persons have in relation to the posthumous use and control of their body parts. I seek to characterise these interests and develop the idea of how harm or wrong may result by overriding these interests and failing to uphold the wishes of the previously living person. I then set out the consent and authorisation requirements under the opt-out legal and regulatory frameworks for deceased donation in England, Scotland, and Wales and the processes for registering preferences about posthumous donation. In the third and final part of this chapter, I consider whether the opt-out framework is consistent with a particular account of donor autonomy. I analyse how the choice of opt-out as a default relates to consent or authorisation by the individual and examine the shift to an opt-out system of organ procurement from the communitarian perspective of a duty to donate.

In Chapter 5, I examine living organ donation from children and young persons and consider the construct of autonomy that is ethically relevant from the perspective of the child or young person whose organs are to be used for transplantation. There is a fundamental difference in donation practice between England and Wales, where donation by children may be lawful subject to court approval, and Scotland, where living donation by all children is prohibited. Furthermore, in England and Wales, a child, for the purposes of organ donation, is a person under the age of 18 years while in Scotland, a child is a person under the age of 16 years. This means that there is a critical difference in the legal position of 16- and 17-year-olds across the UK: in England, young persons fall within the definition of ‘child’ and the normal requirements for consent to living donation in adults do not apply to them; in Scotland, teenagers within this age range are adults and accordingly, the legal requirements for authorisation set out in Chapter 3 apply. This chapter is substantial in content because in addition to these jurisdictional differences there are a number of concepts that are relevant to our understanding of autonomy in organ donation involving children. I introduce these in the first part of the chapter as these are relevant to all jurisdictions. Firstly, I introduce the social construct of the child and parental authority; the legal concepts of parental responsibility and welfare of the child; the relevance of children’s rights to the principle of respect for children’s autonomy; and the philosophical understanding of future autonomy. The chapter is then structured according to legal jurisdictions. In the second part, I focus on the law in England and Wales. I examine the concept of competence in medical decision-making and set out the legal requirements for the lawfulness of donation by children in England and Wales and examine the concept of the best interests of the child. I then consider best interests from the perspective of relational autonomy, family interests, and the moral duty to donate and how best interests can be reconciled with the developing autonomy of the child. In the third part of this chapter, I examine legal capacity in relation to consent to medical treatment by children and consider how the absolute prohibition of organ donation by children can be reconciled with the understanding of autonomy.

1.2 Limitations

In terms of jurisdiction, this thesis considers current legislation and practice in England, Scotland, and Wales only. At the outset of this research, I specifically choose not to consider Northern Ireland on grounds that this approach offered no additional insight into my analysis of the regulatory framework for donation because the HT Act 2004 regulated deceased and living organ procurement in England and Northern Ireland. This premise changed during the course of my research with the introduction of deemed consent legislation in England in 2020 and at the time of completion of this thesis, Northern Ireland represents the only UK jurisdiction based on an opt-in framework for deceased donation. However, the law in Northern Ireland will align once again with other UK jurisdictions as the Organ and Tissue Donation (Deemed Consent) Bill has passed through its final stage in the Northern Ireland Assembly and will come into effect in 2023. Therefore, I maintain my original jurisdictional limitations as set out above and this thesis covers legislation and practice in England, Scotland, and Wales only.

This thesis considers organ donation in respect of competent adults and children. The focus of my enquiry is on donor autonomy and although there are important differences in how we conceptualise donor autonomy in children, due to particular vulnerabilities associated with limitations in their understanding of donation and their state of dependency on their parents, autonomy, in my view, remains a relevant concept in the context of the use of an organ from a living child for transplantation. I argue that decisions to donate cannot entirely be framed in terms of the best interests of the child and that respect for donor autonomy centres around the idea of the developing autonomy of the child and their future autonomy. However, these specific considerations are unlikely to apply to donation from incompetent adults as it is generally not anticipated that capacity will improve. While acknowledging the possibility of exceptions, for example, preferences regarding donation may have been established before the occurrence of a specific event causing loss of capacity, decisions to use the organs of a living incompetent person for transplantation are framed in terms of their best interests rather than autonomy. This represents a distinct line of enquiry and space does not permit a separate chapter on living organ donation by incapacitated adults. However, I will analyse the judicial interpretation of the best interests of the prospective donor in the limited cases in English jurisprudence in which the courts considered the question of donation of tissue by an adult with incapacity.

My analysis in relation to the use of organs from the child for transplantation focuses on *living* organ donation because living donation provides the proper context that can accommodate ideas of the developing and autonomy of the child and their future autonomy. These concepts apply to children only and not adults and enrich the analysis on the meaning of autonomy by offering a unique perspective. While acknowledging that deceased donation raises important questions regarding the application and relevance of the interests of parents in making posthumous decisions about their child, these issues have been amply discussed elsewhere in the context of the organ retention enquiries and, on balance, offer limited new insights into the concept of autonomy from the perspective of the child donor, beyond the discussion of parental authority for living organ donation by children. In relation to the older child, the ethical concerns about parents making decisions about donation on behalf of an older child where there is no knowledge of the child’s disposition in life towards organ donation also apply to third parties making decisions regarding organ donation on behalf of a deceased adult next of kin and these are discussed in Chapter 4. In relation to the younger child, the position of parents making decisions about posthumous organ donation where the child was clearly too young to have any appreciation in life of transplantation raises fundamental questions about whether posthumous harm and autonomy are ethically relevant concepts. I contend that in these circumstances, the child’s interests in relation to the posthumous removal of their organs cannot be characterized and these decisions shift the focus to parental decisional autonomy rather than on the autonomy of the child who is the organ source. My inquiry in this thesis centres on the concept of autonomy from the perspective of the person whose organs are used for transplantation and I maintain that considerations of the future autonomy of the child donor are an important facet of the decision-making process that should not be excluded from this analysis. Therefore, I will not discuss posthumous donation from children further here.

Finally, this thesis will only consider living donation with respect to organs that are currently lawfully transplanted in the UK, principally the single kidney, as kidneys are duplicate organs, and liver lobes, which can regenerate. Transplantation of lung lobes and small intestine segments from living donors has been successfully performed worldwide but I will not be specifically referring to these procedures as they are not routine practice in the UK. For the same reason I will not be considering living uterine transplantation, currently at the clinical trial phase in the UK.[18] Nonetheless, I contend that the arguments advanced in this thesis are not ‘organ-specific’ and are relevant to the expanding field of living donation. Also, I will not be considering the concept of donor autonomy with respect to the removal of organs which would result in certain death, such as heart or whole liver donation, or certain serious harm, such as dual kidney donation which, although not necessarily fatal, would require the donor to undergo dialysis for the rest of their lifetime.

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[18] Natasha Hammond-Browning and Si Liang Yao, ‘Deceased Donation Uterus Transplantation: A Review’ (2021) Transplantology 2, 140

Examination of donor autonomy in these cases requires a precursory analysis of the ethical acceptability and lawfulness of these procedures, particularly with respect to the limits of consent to harm. This goes beyond the aim of this thesis to deconstruct the meaning of donor autonomy within the existing legal and regulatory framework.

2 The concept of autonomy in organ donation

2.1 Introduction

This thesis explores the meaning of autonomy in decisions regarding organ donation from the perspective of the person whose organs will be used for transplantation. Starting from the analysis of the law and the procedural requirements for consent and authorisation for donation, I seek to identify whether the legal and regulatory frameworks are consistent with particular conceptions of autonomy and whether current practices can be justified by a specific understanding of autonomy. While this chapter does not propose to present an exhaustive review of all theories of autonomy, I seek to identify a sufficiently broad range of perspectives that are relevant to the deconstruction of the meaning of personal autonomy in decisions to donate an organ for transplantation. The aim is to provide the theoretical foundation for the examination of whether there exists a core concept of donor autonomy and autonomous decision-making in organ donation. I will introduce the central themes that emerge from the philosophical and bioethical enquiry into autonomy and link these to the questions and considerations that I see as being ethically relevant in choices about whether to donate an organ or, in the case of children, in permitting the removal of an organ from a child for transplantation. These questions will be analysed in more detail within specific donation contexts in the following chapters, notably where the organ source is a living person, a deceased person, and a child.

In the first part of this chapter, I will examine the three philosophical accounts of personal autonomy that I argue are useful theoretical frameworks to understand the process of making decisions about organ donation. These are the traditional construct of autonomy in liberal political theory, relational theories of autonomy, and communitarian theory. In the second part of this chapter, I will examine the understanding of autonomy in bioethics and the connection between patient autonomy and consent at a philosophical level. I will reserve for the following chapters a more detailed analysis of the legal processes of consent and authorisation within specific donation contexts as this is the basis for my enquiry into whether the legal and regulatory frameworks are consistent with a core understanding of donor autonomy.

2.2 Theories of autonomy

2.2.1 Autonomy: concept and conceptions

Autonomy from *autos* (self) and *nomos* (rule or law) means 'self-governance' or 'self-rule' in reference to the original application of the term to the political independence of the city-state in ancient Greece, where its citizens established their own laws, as opposed to being subjugated by conquering power. However, beyond the etymological use of the term in antiquity, there is no universally accepted definition of 'autonomy'. The understanding of autonomy is context-specific and accounts of autonomy respond to the concerns and questions arising within a specific field of enquiry. Human beings, with their diverse purposes and aims in life and within distinct political, social, cultural, and religious contexts, may analyse and understand autonomy in different ways and value different aspects of autonomy.

A useful starting point for the analysis of autonomy is the distinction between the concept and conceptions of autonomy.[19] In his seminal work, *The Theory and Practice of Autonomy*, Gerald Dworkin draws attention to the broad range of interpretations and uses of the term, identifying a number of meanings, including liberty (positive or negative), dignity, integrity, individuality, independence, responsibility and self-knowledge, self-assertion, critical reflection, freedom from obligation, absence of external causation, and knowledge of one's own interests.[20] Despite the fact that autonomy may refer to actions, beliefs, reasons for acting, rules, the will of other persons, thoughts, and principles, there is a broad consensus that autonomy is 'a desirable quality to have'.[21] Gerald Dworkin emphasizes that there is common ground among these understandings, and individuals with different conceptions of autonomy may share the same concept of autonomy.[22] Applying the distinction between these two ideas first introduced by Hart,[23] he maintains that concept refers to 'an abstract notion that specifies in very general terms the role the concept plays' and accordingly, at an abstract level, different philosophical positions share the same concept of autonomy. However, distinct and conflicting views arise in relation to

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[19] Herbert Lionel Adolphus Hart and Penelope A Bulloch, *The Concept of Law* (2nd edn, Clarendon Press 1998).

[20] Gerald Dworkin, *The Theory and Practice of Autonomy* (Cambridge University Press 1988), 6.

[21] Gerald Dworkin, 'The Nature of Autonomy' (2015) Nordic Journal of Studies in Educational Policy 28479, 28480.

[22] Dworkin (n 20).

[23] Hart and Bulloch (n 19) 241.

'specifying more concretely what principles justify interference with autonomy, what is the nature of the 'self' which does the choosing, what the connections between autonomy and dependence on others are'.[24] This idea of different conceptions of the same concept is described as the 'filling out of an abstract concept with different conceptions of the same concept'.[25] With this distinction in mind, this thesis aims to make clear the specific elements of autonomy that are relevant to decisions about donating an organ for transplantation and examine whether and if so, how, these are taken into account within the legal and regulatory framework for organ donation in the UK.

While recognising the central role of autonomy in the moral philosophy of Immanuel Kant, this thesis is concerned only with personal autonomy. A number of contemporary Kantian scholars have persuasively argued that moral autonomy is, in fact, a distinct idea.[26] Kant writes that '*Autonomy* of the will is the sole principle of all moral laws and of duties in keeping with them'[27] and describes it as 'that property of [the rational will] by which it is a law to itself independently of any property of objects of volition'.[28] Kant's self-legislation is *rational* self-legislation, where rationality requires self-imposition of universal moral law.[29] These self-given laws of the autonomous agent conform with the Categorical Imperative formulated by Kant as 'choose only in such a way that the maxims of your choice are also included as universal laws in the same volition'.[30] Accordingly, Kant's account of autonomy is not one of self-legislation in the modern sense of self-determination[31] and O'Neill distinguishes Kantian autonomy, or principled autonomy,[32] from contemporary accounts of individual autonomy. Kantian autonomy is based upon a normatively dualistic contraposition between desires or inclinations and practical reason and requires conformity with the Categorical Imperative. Only those who choose to act

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[24] Dworkin, (n 21) 10.

[25] Ibid.

[26] Onora O'Neill, *Autonomy and Trust in Bioethics* (Cambridge University Press 2002); Barbara Secker, 'The Appearance of Kant's Deontology in Contemporary Kantianism: Concepts of Patient Autonomy in Bioethics' (1999) The Journal of Medicine and Philosophy 24, 43; James Stacey Taylor (ed), *Personal Autonomy: New Essays on Personal Autonomy and Its Role in Contemporary Moral Philosophy* (Cambridge University Press 2005).

[27] Immanuel Kant, *Critique of Practical Reason* (Bobbs-Merrill Company, Inc 1949).

[28] Immanuel Kant, *Foundations of the Metaphysics of Morals* (The Bobbs-Merrill Company, Inc 1959).

[29] Onora O'Neill, *Constructions of Reason: Explorations of Kant's Practical Philosophy* (Cambridge University Press 1989), 66.

[30] Immanuel Kant, Mary Gregor, Jens Timmermann, et al. , *Groundwork of the Metaphysics of Morals,* (Cambridge University Press 2012)

[31] Joseph Raz, *The Morality of Freedom* (Oxford University Press 1986).

[32] O'Neill, (n 26) 83-86.

according to the moral law (expressed as the Categorical Imperative) from duty are acting autonomously.[33] While, both views may be concerned, in very broad terms, with self-governance, Kant's holds an idealistic conception of autonomy that has little to do with individual autonomy in the sense of self-determination or self-direction.[34] Kant is not concerned with autonomy of persons or of the action but rather with autonomy of the will as the sole principle of morality. In Kantian terms, individuals acting to fulfil personal projects are as heteronomous as those acting under coercion or manipulation.[35]

Autonomy, in this thesis, concerns decisions to donate or not to donate an organ for transplantation, how and why choices are made, and who makes the decision to donate an organ and on what basis. The idea of a moral duty to donate will be discussed in more detail the individual chapters; however, the rigid Kantian moral framework will not be adopted for this analysis for the reasons given and also because Kant's position in relation to the giving away of an integral body part or organ, is not straightforward and remains controversial.[36] Adopting a Kantian perspective for this enquiry into autonomy requires, first of all, an analysis of his views of personhood, dignity, and self-ownership and their relation to the person's treatment of her body parts, in order to determine whether transplantation itself is permissible within his moral theory; for obvious reasons this line of enquiry goes beyond the scope of this thesis and, on this basis, Kantian autonomy will not be examined further.

2.2.2 Liberal theories of autonomy

It is generally held that contemporary accounts of autonomy are grounded in traditional liberal philosophy, which can be traced back to John Stuart Mill's influential work *On Liberty*,[37] encapsulated in the well-known dictum 'over his own body and mind, the individual is sovereign'.[38] Mill's liberty principle is concerned with the person's freedom

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[33] B Secker, 'The Appearance of Kant's Deontology in Contemporary Kantianism: Concepts of Patient Autonomy in Bioethics' (1999) The Journal of Medicine and Philosophy 24, 43.

[34] Diego Gracia, 'The Many Faces of Autonomy' (2012) Theoretical Medicine and Bioethics 33, 57, 58–59.

[35] Kant, (n 30) 58-59.

[36] Nicole Gerrand, 'The Misuse of Kant in the Debate about a Market for Human Body Parts' (1999) 16 Journal of Applied Philosophy 59; Jean-Christophe Merle, 'A Kantian Argument for a Duty to Donate One's Own Organs. A Reply to Nicole Gerrand' (2000) Journal of Applied Philosophy 17, 93.

[37] John Stuart Mill, *On Liberty,* 1859 (Gertrude Himmelfarb ed, Reprinted, Penguin Books 1985).

[38] Ibid.

from external constraints: an individual's choices and actions cannot be overruled, even where these are in conflict with society's views of what is reasonable, morally right, or in the individual's best interests.[39] Mill does not use the term 'autonomy'[40] and his account is more aptly characterised as non-interference, the justification being that individuals are the best judges of their own interests and happiness, and interference is only justified when the actions of the individual cause harm to others, widely referred to as the 'harm principle'.

The harm principle is central to the work of Joel Feinberg in *The Moral Limits of the Criminal Law.*[41] Feinberg draws on the image of the autonomous state to develop a theory of personal autonomy as personal sovereignty, using the principles of harm and offense to define its boundaries. A proponent of liberalism, Feinberg examines the extent to which criminal law should legitimately limit individual liberty. He conceives personal sovereignty as '*de jure* self-government' based on the analogy to a political state, as 'sovereign authority to govern oneself that is absolute within one's own moral boundaries'.[42] Personal sovereignty is the sphere within which the individual decides what happens in relation to what is personal to them:

> the kernel of the idea of autonomy is the right to make choices and decisions – what to put into my body, what contacts with my body to permit, where and how to move my body through public space, how to use my chattels and physical property, what personal information to disclose to others, what information to conceal, and more'.[43]

Feinberg's notion of the autonomous person requires authenticity, self-determination, and a degree of rationality and there are no moral pre-requisites, in the sense that the autonomous individual can equally be moral or immoral. Feinberg identifies four distinct meanings of autonomy: the capacity to govern oneself; the actual condition of self-government; an ideal character; and the sovereign authority to govern oneself.[44] The capacity to exercise autonomy, autonomy as an aspirational principle, and any autonomy rights that the

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[39] O'Neill emphasises that Mill's notion of autonomy is not merely about 'choosing to implement whatever desires they [individuals] happen to have at a given moment, but as taking charge of those desires, as reflecting on and selecting among them in distinctive ways'.

[40] O'Neill, (n 26) 30 notes that Mill's work refers to autonomy once, in the context of states, rather than to individuals.

[41] Joel Feinberg, *The Moral Limits of the Criminal Law: Offense to Others* vol 2 (Oxford University Press 1987); Joel Feinberg, *The Moral Limits of the Criminal Law: Harm to Self* vol 3 (Oxford University Press 1989); Joel Feinberg, *The Moral Limits of the Criminal Law: Harmless Wrongdoing* vol 4 (Oxford University Press 1990); Joel Feinberg, *Harm to Others* (Oxford University Press 1990).

[42] Feinberg, *The Moral Limits of the Criminal Law* vol 4 (n 41) 18.

[43] Feinberg, *The Moral Limits of the Criminal Law* vol 3 (n 41) 54.

[44] Ibid., 27-51.

individual may have do not necessarily coincide with a decision that respects donor autonomy. Autonomy as an actual condition is the meaning I am primarily concerned with here, as I examine how the understanding of autonomy applies to choices about organ donation in clinical practice.

The concept of personal sovereignty and the boundaries between private life and public authority are an important theme in the lectures delivered by Berlin, *Liberty: Incorporating 'Four Essays on Liberty'.*[45] Berlin examines the political meaning of freedom or liberty (terms which he uses interchangeably) and identifies ‘positive liberty’, concerned with who or what controls or interferes with an individual’s life, and ‘negative liberty’, concerned with the sphere within which the individual should be left to live without interference by the state or society. Berlin argues that libertarians, including Mill, were concerned with negative liberty or the safeguarding of an area of life within which the individual, free from external constraints, could flourish and that this was largely founded on the (mistaken) belief that civilization could only advance if individuals were allowed to develop in a distinctive, diversified and original manner. Positive liberty, on the other hand, is centred around the idea of control over one’s life, powerfully articulated as follows:

> I wish my life and decisions to depend on myself, not on external forces of whatever kind. I wish to be instrument of my own, not of other men’s acts of will. I wish to be a subject, not an object; to be moved by reasons, by conscious purposes, which are my own, not by causes which affect me, as it were, from outside. I wish to be somebody, not nobody; a doer – deciding, not being decided for, self-directed and not acted on by external nature or by other men as if I were a thing, or an animal, or a slave incapable of playing a human role, that is, of conceiving goals and policies of my own and realising them.[46]

Autonomy for Berlin is the ‘essence of men’, he identifies it with self-determination, autonomous individuals are ‘authors of values’, ‘ends in themselves’, and the ‘ultimate authority’; it is the opposite of heteronomy, ‘to be acted upon’.[47] Christman refers to the core of this autonomy as the individual’s ‘inner citadel’, the remit within which he exercises self-government.[48] Christman argues that positive liberty is not concerned with the content of desires and preferences but with how these are formed and specifically,

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[45] Isaiah Berlin, in Isaiah Berlin and Henry Hardy (eds), ‘*Liberty: Incorporating ‘Four Essays on Liberty’* (Oxford University Press 2002).

[46] Ibid., 166-217.

[47] Ibid., 183-184.

[48] John Christman, ‘Constructing the Inner Citadel: Recent Work on the Concept of Autonomy’ (1988) 99 Ethics 109.

whether these are forged by pressure, manipulation or ignorance rather than rational reflection of the available option.[49] Yet further questions need to be asked about why the 'doer' is a status we should aspire to. Mill speaks of 'character' and 'individuality',[50] and ascribes value to allowing persons the freedom to develop in different and original ways, value in terms of happiness.[51] However, he does not develop the justification for a connection between the freedom to make one's own choices and happiness, and claims about the association between liberty and utility have been characterized as empirically dubious.[52] A richer insight into why the preservation of an intact inner citadel matters is offered by Ronald Dworkin: a life structured by the individual's own values is relevant to the individual because 'no one treats his life as having any intrinsic, objective importance unless he insists on leading that life himself'.[53] On this view, autonomy has an intrinsic value: it allows the individual to flourish and thrive. Self-authorship is also regarded as a fundamental part of self-realisation in Nozick's understanding of a meaningful life as a life shaped according to an overall life-plan.[54] Similarly, Raz conceives personal autonomy as directing one's life through deliberate choices:

> The autonomous person is a (part) owner of his own life. The ideal of personal autonomy is the vision of people controlling, to some degree, their own destiny, fashioning it through successive decisions through their lives.[55]

The value of autonomy for Raz is embedded in his idea of perfectionism. Autonomy is not simply a goal or project that a person may pursue or reject but has intrinsic value for the person's wellbeing, viewed largely in subjective terms.[56] Autonomy is an important part of leading a good, valuable, and flourishing human life and what matters is the process of setting and evaluating one's goals and interests and the pursuit of self-creation rather than

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[49] John Christman, 'Relational Autonomy, Liberal Individualism, and the Social Constitution of Selves' (2004) 117 Philosophical Studies 143, 343-359.

[50] John Stuart Mill and others, *Utilitarianism: And, On Liberty: Including Mill's Essay on Bentham' and Selections from the Writings of Jeremy Bentham and John Austin* (2nd edn, Blackwell Pub 2003), 126-250, 189, 192.

[51] Although the empirical connection Mill makes between freedom and happiness has been characterised as dubious see Onora O Neill, 'Paternalism and Partial Autonomy' (1984) 10 Journal of Medical Ethics 174, 174.

[52] Ibid.

[53] Ronald Dworkin, *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom* (Harper Collins 1995), 239.

[54] Robert Nozick, *Anarchy, State and Utopia* (Blackwell 1974) 49-50.

[55] Raz *The Morality of Freedom* (n 31) 369-370.

[56] Ibid., 289.

the outcome.[57] This presupposes that the content and ramifications of these choices fit in with valid conceptions of the good and in this sense, Raz's account of autonomy bridges the gap between individualistic and content neutral liberalism and the moral requirements of communitarianism. The central idea is that individuals should be free to pursue their own choices yet value is ascribed to autonomy only where these choices are morally worthwhile.[58] This vision rejects state neutrality to the extent that individuals should not only be free to pursue morally worthy endeavours but should be actively encouraged to do so through soft paternalism.[59]

In *Life's Dominium* Ronald Dworkin observes that the view of autonomy as freedom to make decisions regarding how you live your life is firmly established in 'Western political culture'.[60] In a cogent analysis of why we should ever respect the decisions people make, even when we believe that these are not in their interests, he distinguishes between an evidentiary and an integrity view of autonomy.[61] According to the evidentiary view, autonomy is concerned with a person's welfare and respect for an individual's decisions stems from the fact that people can generally judge for themselves what is in their best interests and interference with their decisions is only warranted when we think that they have made a mistake. However, this account of autonomy struggles to provide a coherent account for situations where the choice made is against the interests of the person but is not driven by an error in the analysis, interpretation, or judgment of facts, risks, and benefits. An example is the person who continues to smoke despite knowledge and acceptance of the health risks of smoking.[62] This raises the question of whether interference with calculated bad choices is ethically justified.

Instead, on an integrity view, which Ronald Dworkin endorses, autonomy requires us to also respect imprudent decisions which may go against an individual's welfare, even where the individual accepts that their choice is not in their interests.[63] This is because the paramount value requiring protection is the integrity of the decision-maker, where integrity is conceived as the capacity of the individual to express their own 'values, commitments,

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[57] Ibid., 375-382.

[58] Heta Gylling, 'Autonomy Revisited' (2004) 13 Cambridge Quarterly of Healthcare Ethics 41, 41 and 45.

[59] Ibid.

[60] Dworkin, (n 53), 166 and 222.

[61] Ibid., 222.

[62] Ibid., 223.

[63] Ibid., 223.

convictions and interests' and live an authentic life according to what is important to them.[64] This view advocates the individual's right of control over their choices in life allowing each of us to shape our lives according to our own coherent or incoherent personality but nevertheless in a distinctive, personal way.[65]

However, the value of shaping one's life may also be understood in an instrumental sense rejecting any intrinsic value in chaotic or inconsistent choices. Rawls propounds an idea of autonomy as a process of deliberation and integration of goals and interests into a life plan.[66] Autonomy is associated with rational choices such as 'the adoption of effective means to ends; the balancing of final ends by their significance in our plan of life as a whole; and the assigning of greater weight to the more likely consequences'.[67] This fits with the broader moral and political theory developed by Rawls that legitimises the use of restricted state paternalism to promote practices for the realization of the agreed best interests of society.

Deliberation and internal coherence are also central to the work of Frankfurt and Gerald Dworkin which provides an account of how instinctive and reflective choices fit in with the concept of personal autonomy based on rationality. In *Freedom of the Will and the Concept of a Person,* Frankfurt develops a model of autonomy based on the structuring of preferences and distinguishes 'first order desires', which are simply desires to do or not to do something, from 'second order desires', which are desires, motives, and preferences resulting from reflective self-evaluation.[68] Second order desires are the desire to have certain desires and involve a process of reflection upon and evaluation of our first order desires to select those desires we want to motivate us. On this view a person is autonomous when acting in accordance with second order desires. Gerald Dworkin also endorses a notion of autonomy as the capacity of persons to critically reflect on the influences that motivate them, such as preferences, desires, values and ideals, and the capacity to either accept them or attempt to change them in light of higher-order preferences or values.[69] This process also requires procedural independence which involves 'distinguishing those ways

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[64] Ibid., 224.

[65] Ibid.

[66] John Rawls, *A Theory of Justice* (Rev ed, Belknap Press of Harvard University Press 1999) 360-361.

[67] John Rawls *Collected Papers* (Samuel Richard Freeman ed, Harvard University Press 1999) 316.

[68] Harry Frankfurt, 'Freedom of the Will and the Concept of a Person' (1971) The Journal of Philosophy 68 5.

[69] Ibid., 20.

of influencing people's reflective and critical faculties which subvert them from those which promote and improve them'.[70]

Within this framework, critical reflection is linked to the idea of authenticity: a person acts authentically when they reflectively endorse the principles underlying their choices and actions.[71] Authenticity gives meaning to these choices and actions and requires that the individual takes responsibility for the kind of person that they are'.[72] Critics of this hierarchical approach to autonomy that focusses on internal consistency question what it is about higher-order desires that confers their legitimacy in overriding other desires.[73] Nonetheless, value neutrality may be seen as a useful attribute supporting an account of autonomy as 'a space in which people are able to pursue their own values' within a society that recognises moral pluralism.[74]

2.2.3 Relational views of autonomy

Any conception of autonomy that is to be of practical value in society cannot circumvent the issue of whether and how personal autonomy can be reconciled with the interconnectedness among individuals based on moral responsibilities, obligations, and ties of affection, which are part of normal human relationships. The liberal idea of autonomy has been criticised for reducing individuals to 'isolated atomistic existences' which do not reflect the real world, characterised instead by an 'interdependent network of relationships' shaping and influencing the choices of the individual.[75]

Against the backdrop of a liberal view of autonomy presenting social relationships as detrimental to individual autonomy, advocates of relational autonomy uphold the idea that social relations can promote the development of autonomy.[76] A relational account of autonomy has gained support amongst feminist scholars denouncing the individualistic notion of autonomy as part of a range of masculine attributes, including power, control,

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[70] Dworkin, (n 20) 18.

[71] Gerald Dworkin Institute, 'Paternalism' (1972) 56 Monist 64; Frankfurt, 'Freedom of the Will and the Concept of a Person' (n 68).

[72] Dworkin, (n 20) 20.

[73] Tom Beauchamp and James Childress, *Principles of Bioemedical Ethics* (8th edn. Oxford University Press 2019), 59.

[74] Robert Taylor, 'Kantian Personal Autonomy' (2005) 33 Political Theory 602.

[75] Alisdair Maclean, *Autonomy, Informed Consent and Medical Law* (Cambridge University Press 2009) 18-19.

[76] Diana Meyers, *Self, Society, and Personal Choice* (Columbia University Press 1989).

invulnerability, aggressiveness, rationality, and emotional detachment, which have traditionally been emulated as they have ‘proven effective in the battle against other men’.[77] This understanding of autonomy does not resonate with the reality of life within the family nucleus, based on values of interdependence and connection, particularly for women in their traditional social role as caretakers.[78] By promoting self-sufficiency as the ideal, the status of persons who are dependent on others is devalued; furthermore, the role of those offering care to dependants becomes antagonistic to the autonomous ideal.[79]

To what extent can the liberal conception of autonomy, as rational self-determination, be reconciled with relational autonomy? Traditional liberals, such as Berlin, reject any relational dimension of autonomy and view the social embeddedness of the self as a form of heteronomy.[80] However, relational autonomy does not necessarily mean that the very existence of individual autonomy is denied, rather, the autonomous agent shapes a life for himself by actively responding to and reflectively engaging with forces of socialisation.[81] A relational approach to autonomy seeks to determine the impact of social conditions on the agency of the person making a decision and accepts that relationships may also be detrimental to autonomy through oppression and manipulation of the self, including influences which become internalised and accepted.[82]

While the broader remit of this strand of the feminist enquiry into how gender socialisation affects the acquisition of autonomy goes beyond the scope of this thesis, an account of autonomy in decision-making should properly recognise that a person’s choices may or may not be free and this depends on the social context within which beliefs, values, desires, interests and identity are formed.[83] This social context is framed by a range of

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[77] Mary Becker, ‘Patriarchy and Inequality: Towards a Substantive Feminism’ (1999) The University of Chicago Legal Forum 21, 21.

[78] Jonathan Herring, ‘Caregivers in Medical Law and Ethics’ (2008) The Journal of Contemporary Health Law and Policy 25, 38.

[79] Jennifer Nedelsky, *Law's Relations: A Relational Theory of Self, Autonomy, and Law* (Oxford University Press) 42-43.

[80] Berlin (n 45) 156.

[81] Linda Barclay, ‘Autonomy and the Social Self’ in Catriona Mackenzie and Natalie Stoljar (eds), *Relational autonomy. Feminist perspectives on Autonomy, Agency, and the Social self* (Oxford University Press 2000).

[82] Susan Sherwin and Meghan Winsby, ‘A Relational Perspective on Autonomy for Older Adults Residing in Nursing Homes: A Relational Perspective on Autonomy for Older Adults’ (2011) 14 Health Expectations 182.

[83] Kim Atkins, ‘Autonomy and Autonomy Competencies: A Practical and Relational Approach’ (2006) 7 Nursing Philosophy: An International Journal for Healthcare Professionals 205.

factors including culture and ethnicity, age, gender, and the dynamics within particular families. [84]

From this perspective, the understanding of the process through which culture and family shape a person's aims, aspirations, and values is crucial.[85] This is relevant to the pluralistic setting of living organ donation in the UK because prospective organ donors and patient-recipients come from different cultural backgrounds and ignoring these different perspectives results in a limited understanding of what autonomy means in the decision-making process. Sociological research conducted by Fox and Swazey on the understanding of ethical issues related to health and illness in a hospital in the People's Republic of China in the 1980s identified how Taoist, Confucian, Buddhist, and Maosit believes affect moral reasoning and represents the first criticism of the dominant secular Western bioethics model, specifically, the assumption that this model is generalizable to different communities worldwide.[86] Decisions about healthcare are influenced by a patient's cultural background.[87] While it is not possible to adequately summarize here the substantial body of research on cultural variations in healthcare decision-making, the theme of the family as the appropriate locus of decision-making concerning the patient-family member emerges as an alternative to the individualistic notion of patient choice predominant in Western bioethics.

A relational understanding of autonomy allows for acceptance of external beliefs and values through a process of critical reflection such that the individual internalises and identifies with them. However, it does not dismiss the self, on the contrary, it places great value on the personal identity and seeks ways to protect it.[88] In this sense, relational autonomy maintains a perspective that is fundamentally grounded in the Western bioethics concept of the self.[89] Relational theorists such as Nussbaum focus on the empowerment of

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[84] Insoo Hyun, 'Waiver of Informed Consent, Cultural Sensitivity, and the Problem of Unjust Families and Traditions' (2002) 32 Hastings Center Report 14.

[85] Robert Young, *Personal Autonomy: Beyond Negative and Positive Liberty* (Croom Helm 1986).

[86] Renée Fox and Judith Swazey, 'Medical Morality is Not Bioethics: Medical Ethics in China and the United States'(1984) 27 Perspectives in Biology and Medicine 336.

[87] Farahd Moazam 'Families, Patients and Physicians in Medical Decision-making: A Pakistani Perspective (200) 30 Hastings Center Report 28.

[88] Sherwin and Winsby (n 83).

[89] Catriona Mackenzie and Natalie Stoljar, 'Autonomy Refigured' in Mackenzie and Stoljar (eds), *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (Oxford University Press 2000).

the individual and the enhancement of autonomy skills.[90] Meyers is concerned with giving the individual the opportunity to maximise autonomy by building up capacities for critical analysis, reasoning, and communication as well as practical skills which include self-discovery, self-knowledge, self-definition, and self-direction.[91] Dodds, on the other hand, is concerned with vulnerable persons and her work on making decisions concerning the healthcare of children advocates active engagement and participation of children in the decision making process.[92]

The concept of individual vulnerability within the context human relationships has attracted considerable academic interest among theorists of relational autonomy. Early work by Goodin[93] broadly interprets vulnerability as harm to one's interests that arises out of relationships between persons such that the interests of a person are subject to a threat or harm by a particular person and that this gives rise to our responsibilities towards those who are vulnerable to our actions and these duties are duties of protection. Fineman developed a different and influential account of vulnerability transcending specific relationships and based on the idea of vulnerability as an intrinsic part of what it is to be human.[94] This conceptualisation reflected Fineman's primary concern about state responsibility, using the idea of the vulnerable citizen to focus on the role of the state in promoting equality through its institutions and structures.[95] Applied to bioethics, Fineman dismisses the idea of autonomy based on the rational, self-sufficient, and independent individual as a 'myth' and advocates a reshaping of bioethical principles, practices and priorities around the ubiquitous vulnerable person as a more accurate and complete representation of the human subject.[96] However, Rogers, Mackenzie and Dodds[97] argue that healthcare ethics requires a more robust exploration of the concept of vulnerability and its connection with autonomy. While accepting that we all share a common biology and

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[90] Martha Craven Nussbaum, *Women and Human Development: The Capabilities Approach* (2000).

[91] Meyers (n 76), 76.

[92] Catriona Mackenzie and Natalie Stoljar, 'Choice and Control in Feminist Bioethics' in Mackenzie and Stoljar (eds) *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self* (Oxford University Press 2000), 229.

[93] Goodin, Robert E. , *Protecting the Vulnerable: A Reanalysis of our Social Responsibilities*, University of (Chicago Press, 1985).

[94] Martha Fineman, 'The vulnerable subject: anchoring equality in the human condition' (2008) 20 Yale Journal of Law and Feminism 1.

[95] Ibid., 19-20.

[96] Fineman Martha 'Vulnerability in Law and Bioethics' (2019) 30 Suppl 52 Journal of Health Care for the Poor and Underserved 60.

[97] Wendy Rogers, Catriona Mackenzie and Susan Dodds 'Why bioethics needs a concept of vulnerability' (2012) 5 International Journal of Feminist Approaches to Bioethics 11.

human embodiment makes everyone vulnerable to pain, disease, and death, they direct the enquiry towards the increased vulnerability of certain individuals or groups and the recognition of vulnerability in terms of the impact of interpersonal and social conditions on the development and exercise of personal autonomy.[98] Rogers and colleagues are concerned with the vulnerability of persons to the actions of others and note that although all persons are vulnerable, vulnerability is a matter of degree at various points in life and universal vulnerability cannot explain why we have specific obligations to persons who are more than ordinarily vulnerable.[99] However, rather than focusing on paternalistic approaches to protect the vulnerable which, they argue, may compound vulnerability, they direct their attention to the societal and relational factors shaping vulnerability.[100] Vulnerability is recognised as arising from biological, social, political and cultural sources and the focus of the enquiry is on the opportunities (be these education, health promotion, access to social services and legal protections) that individuals have to develop and exercise the skills required to foster resilience and reduce vulnerability to need, ill health and exploitation[101]: the obligations arising out vulnerability include a duty to foster autonomy whenever possible.[102] Thus, an important facet of the approach of relational theorists, such as Mackenzie, towards vulnerability is that it dissects the different sources and states of vulnerability to identify different kinds of capability deficits and actual or potential harms they cause.[103] Importantly, this approach rejects the idea of a necessary tension between vulnerability and autonomy because the relational understanding of autonomy is based on the idea that autonomy develops within the context of significant social relationships and is both shaped and constrained by relational connections.[104] Therefore, there is no inconsistency in recognizing vulnerability as a universal condition and recognizing one's duties to mitigate vulnerability while upholding the importance of autonomy and enhancing resilience.[105]

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[98] Wendy Rogers 'Vulnerability and Bioethics' in Catriona Mackenzie, Wendy Rogers and Susan Dodds (eds) *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford Academic Press 2013), 71 and 76.

[99] Rogers, Mackenzie and Dodds (n 98), 20.

[100] Ibid., 26.

[101] Ibid., 12 and 32.

[102] Catriona Mackenzie 'The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability' in Catriona Mackenzie, Wendy Rogers and Susan Dodds (eds) *Vulnerability: New Essays in Ethics and Feminist Philosophy* (online edition Oxford Academic, 2014) 4.

[103] Ibid., 54.

[104] Ibid., 38.

[105] Ibid., 45.

Relational theory can accommodate the self within the notion of a 'relational individual' understood as 'an entity that is produced through, and continually embedded in, relationships, but experienced as a (largely self-directing) individual'.[106] This line of reasoning takes us back to the idea of self-governance in the sense of a person regarding herself as the legitimate source of authority.[107] For Nedelsky 'becoming' autonomous, is being 'able to find and live in accordance with one's own law'.[108] Accordingly, the socially embedded autonomous individual acts according to his own principles, values, and preferences.[109] On this view, autonomy is presented as living in harmony with one's authentic self, which requires a life plan, understood as a conception of the kind of life one wants to lead.[110]

However, as Herring points out, there remains a fundamental difference between the core of traditional and relational autonomy, even where it is accepted by both sides that relationships are valuable and important for the self: the starting point of traditional autonomy is that there exists a self and that the choices made by the self-take into account, to a variable extent, its relationships with others while in relational autonomy, the self is defined by relationships.[111] Importantly, these perspectives explain the shift in balance between rights and responsibilities. The traditional liberal view is based on the presumption of unfettered freedom to act unless there is a particular obligation or duty that arises. Theorists of relational autonomy place emphasis on the responsibilities arising out of relationships and connection between individuals as the norm, dismissing as illusory the liberal claim of freedom to live one's life as one chooses.[112] Herring aptly illustrates this point by juxtaposing the two fundamental questions that encapsulate liberal and relational theory: 'is there a good reason to restrict my freedom?' and 'is it possible to have some freedom, given the responsibilities of those I am connected to?'.[113]

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[106] Jane McCarthy, 'The Powerful Relational Language of "Family": Togetherness, Belonging and Personhood' (2012) 60 The Sociological Review 68, 75-94.

[107] Catriona Mackenzie, 'Relational Autonomy, Normative Authority and Perfectionism' (2008) 39 Journal of Social Philosophy 512.

[108] Jennifer Nedelsky, 'Reconceiving Autonomy: Sources, Thoughts and Possibilities' (1989) Yale Journal of Law and Feminism 1, 31.

[109] Christman (n 49).

[110] Meyers (n 76)

[111] Jonathan Herring, 'Relational Autonomy' in Jonathan Herring, *Relational Autonomy and Family Law* (Springer International Publishing 2014), 21.

[112] Nedelsky (n 79).

[113] Jonathan Herring, 'Forging a Relational Approach: Best Interests or Human Rights?' (2013) 13 Medical Law International 32.

What emerges from relational autonomy theory is that the community, whether this is defined in religious, social or cultural terms, is not perceived as a ‘unit’ in its own rights but as a multitude of individuals with their own interests who through their relationship with the individual shape the individual’s identity and perspective. Thus, the central question regarding autonomy concerns the balance between these influences and the individual as the legitimate source of the authority over matters concerning their own life. However, decision-making in hierarchical communities presents significant challenges in clinical practice in terms of the determination of whether the decision made by the individual is a decision that the individual genuinely endorses as their own. Kuczewski and McCruden highlight the limitations of an analysis of culturally different communities from a Western outsider perspective as this may not properly capture the perspective of the individual within that community.[114] It is important to acknowledge the limitations of applying a Western bioethics-based framework of relational autonomy to healthcare decisions that concern individuals from different cultural backgrounds. As observed by Gilbar and Miola, the requirement for critical reflection my not fit family-orientated approaches of non-Western societies.[115] This poses specific challenges in inter-familial living donation, for example in the context of the disclosure of information to the prospective donor on the risks and benefits of donation. However, the appropriateness of applying this model to decision-making in organ donation is a distinct question that falls outside the scope of this thesis. Here, I focus on the understanding of autonomy within the existing legislation and regulatory framework in the UK which, as I will show in the next chapter on living organ donation, is based on an understanding of the individual prospective donor as the locus of authority for the decision to donate.

2.2.4 Communitarian views of autonomy

Communitarian theory also offers an ethical reappraisal of traditional notions of individual autonomy, based on an understanding of the self as fundamentally social and interconnected with other members of society. The liberal assumption that the interests of the individual are primary and independent of any social connections between members of

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[114] Mark Kuczewski and Patrick McCruden, ‘Informed Consent: Does it Take a Village? The Problem of Culture and Truth Telling (2001)10 Cambridge Quarterly Healthcare Ethics 34.

[115] Roy Gilbar and José Miola, ‘One Size Fits All? On Patient Autonomy, Medical Decision Making and the Impact of Culture’ (2015) 23 Medical Law Review 375.

society is rejected.[116] Communitarian ideology regards communities, be they families or other types of social structures and associations, as an intrinsic part of healthy human existence. However, departing from relational theory, communitarians place a high value on the idea of the common good and the public interest.[117] Social responsibility, collaboration and solidarity are considered prerequisites for a meaningful life.[118] The individual's well-being is seen as dependent on the general well-being of society and while the basic unit of moral agency remains the individual, communitarians recognise that the decisions an individual makes and their impact must be evaluated in the broader context of the public good, accepting curtailment of individual autonomy above and beyond the liberal threshold of actions causing harm to others.[119] A fundamental difference between relational and communitarian views of autonomy is that the former focuses on the impact of social relations on individual decision making, while the latter is concerned with the consequences of the decision or action on society. Communitarians reject liberal neutrality, according to which the state has no role in determining which values and ways of life are better than others, instead they support an active role of the state in promoting shared values. Communitarians reject liberal claims that private choices should be exempt from moral analysis and advocate a broadening of the concept of autonomy to encompass an analysis of what constitutes morally good and bad free choices.[120] An extreme form of communitarianism, authoritarian communitarianism, advocates that the interests of the community should take precedence over the interests and desires of the individual.[121]

A more moderate strand, referred to as responsive communitarianism, seeks to address the tension between the interests of the community and those of individuals and holds that a balance can be achieved. This approach advocates a radical change of the moral culture of society such that donation is genuinely accepted as a social responsibility.[122] It supports the

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[116] Amitai Etzioni 'Communitarianism Revisited' (2014) 19 Journal of Political Ideologies 241.

[117] Amitai Etzioni, 'A Neo-Communitarian Approach to International Relations: Rights and the Good' (2006) Human Rights Review 7, 69.

[118] Daniel Callahan, 'Autonomy: A Moral Good, Not a Moral Obsession' (1984) 14 The Hastings Center Report 40; Daniel Callahan, 'Individual Good and Common Good: A Communitarian Approach to Bioethics' (2003) 46 Perspectives in Biology and Medicine 496; Amitai Etzioni, 'Organ Donation: A Communitarian Approach' (2003) 13 Kennedy Institute of Ethics Journal 1; Raz, (n 31).

[119] Zohar Lederman, 'Communitarianism and Presumed Consent' (2018) 6 Asian Bioethics Review 302, 305.

[120] Callahan (n 120) 505.

[121] Russell Arben Fox, 'Confucian and Communitarian Responses to Liberal Democracy' (1997) 59 The Review of Politics 561; see also Daniel A Bell, 'A Communitarian Critique of Authoritarianism: The Case of Singapore' (1997) 25 Political Theory 6; Bilahari Kausikan, 'Asia's Different Standard' (1993) Foreign Policy 24.

[122] Etzioni (n 120).

internalisation by the individual of the community's interests and goals.[123] The goal of responsive communitarianism is to balance social control and self-determination by changing individual preferences and achieving true voluntary compliance so that the individual remains morally responsible for his choices and actions. Etzioni, a proponent of responsive communitarianism, offers an interesting perspective of how this ethical framework applies to deceased organ procurement and focuses on the use of non-coercive moral persuasion to change individual preferences towards organ donation.[124]

An important aspect in communitarian theory concerns the role played by the family in decisions affecting family members. While dialogue between individuals and their families is encouraged, responsive communitarianism does not advocate family-based decision making, recognising that the decision is the individual's to make, and rejects familism, a distinct strand of communitarianism, that regards the family as the basic moral unit in decision-making.[125] Family-governance, the term coined by Ruiping, one of the key exponents of familism, refers to the dominance of the family over the autonomy of individual family members in medical decision-making.[126] In the United States, the practice of surrogate-decision making on behalf of a patient places decisional authority firmly within the remit of the family; however this concerns decisions involving patients without capacity.[127] This approach is not explicitly recognised as the basis for decision-making in Western bioethics involving adult patients with capacity.

A further strand of communitarian support for a culture change towards a policy of expected donation based on the underlying duty to donate seeks ethical justification in the norm of reciprocity or reciprocal altruism.[128] This perspective differs from the common good principle in so far as it draws upon the reciprocal interest in organs as the motivating factor, which is essentially the idea that everyone is a potential donor and everyone is a potential recipient and that the aggregated effect of individual donations increases the chances of each person of receiving an organ when needed. Siegal advocates an

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[123] Candace Cummins Gauthier, 'Moral Responsibility and Respect for Autonomy: Meeting the Communitarian Challenge' (2000) 10 Kennedy Institute of Ethics Journal 337, 342.

[124] Etzioni (n 120).

[125] Michael Cheng-Tek Tai and Chung Seng Lin, 'Developing a Culturally Relevant Bioethics for Asian People' (2001) 27 Journal of Medical Ethics 51.

[126] Ruiping Fan, 'Self-Determination vs. Family-Determination: Two Incommensurable Principles of Autonomy' (1997) 11 Bioethics 309; Lederman (n 121).

[127] Dan Brock, 'What Is the Moral Authority of Family Members to Act as Surrogates for Incompetent Patients?' (1996) 74 The Milbank Quarterly 599.

[128] Fan (n 128).

incremental approach towards public education, emphasising mutual self-interest and reciprocity in order to strengthen the norm of expected donation. However, once this has been achieved, Siegal, unlike Etzioni, supports the introduction of an opt-out organ procurement policy to give legal effect to the change of the default position to organ donation.

2.3 Autonomy in medical ethics

The notion of respect for patient autonomy dominates the contemporary bioethical debate and largely centres on its relation to medical paternalism and informed consent. What qualifies precisely as autonomous choices or action remains elusive.[129] In *The History and Theory of Informed Consent*, prominent ethicists Faden and Beauchamp examine the different meanings attributed to autonomy in the medical context, which include privacy, voluntariness, self-mastery, choosing freely, choosing one's own moral position, and accepting responsibility for one's choices'.[130] Overall, there appears to be more agreement on the meaning of autonomy in bioethics than in other fields [131] and the patient's right to choose a plan of action and the need to respect the patient's choices feature prominently in the medical literature.[132]

The concept of autonomy gained widespread support in medical ethics largely through the work of ethicists Beauchamp and Childress in the 1970s. In their widely influential work *Principles of Biomedical Ethics,* currently in its eighth edition, four fundamental principles in medical ethics are identified: beneficence, non-maleficence, autonomy, and justice.[133] The principles are presented as a framework for recognising and reflecting on moral problems and its authors emphasise the need for specification, or the process of providing content in order to apply the principles to actual situations, and balancing, the process of identifying the relative weight and strength of the principles in concrete situations.[134] This

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[129] Lucie White, 'The Need for Authenticity-Based Autonomy in Medical Ethics' (2018) 30 HEC Forum 191, 191-193.

[130] Faden (n 14) 7.

[131] O'Neill, (n 26) 23.

[132] Beauchamp and Childress (n 73), 56-57.

[133] Roy Gillon, 'Medical Ethics: Four Principles plus Attention to Scope' (1994) 309 British Medical Journal 184; Beauchamp and Childress (n 73).

[134] Beauchamp and Childress (n 73).

approach has been criticised for providing a mere 'checklist' of disparate issues to consider when faced with bioethical dilemmas and for failing to integrate the principles into an adequate moral theory.[135] In Dworkinian terms the core principle may be seen as the broad concept while specific conceptions of autonomy can be determined from its application to specific clinical scenarios.

While the primacy of autonomy amongst these principles is more accurately described as a trend of the bioethical landscape in the United States,[136] there followed a definite shift in focus on patient autonomy as the dominant value in Western bioethics more generally. This phenomenon was largely a reaction to the existing paternalistic approach to patient care, in which medical professionals were deemed to be the 'proper judges of patients' best medical interests'.[137] Pellegrino and Thomasma characterise the beneficial paternalism underpinning the traditional patient-doctor relationship as follows:

> Paternalism centres on the notion that the physician ... has better insight into the best interests of the patient than does the patient, or that the physician's obligations are such that he is impelled to do what is medically good, even if it is not 'good' in terms of the patient's own value system.[138]

Medical ethicists Buchanan and Brock, interpret autonomy as self-determination or the individual's 'interest in making significant decisions about his or her own life'.[139] This idea finds resonance with the philosophical work of Harris, in which autonomy is encapsulated as:

> […] the values expressed as the ability to choose and have the freedom to choose between competing conceptions of how to live and indeed of why we do so, is connected to individuality in that it is only by the exercise of autonomy that our lives become in any sense our own. By shaping our lives for ourselves we assert our own values and our individuality.[140]

The recognition that patients should be allowed to make medical decisions based on their values and life plans and that these decisions should be respected has led to a more active

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[135] Alfred I Tauber, 'Sick Autonomy' (2003) 46 Perspectives in Biology and Medicine 484.

[136] O'Neill, (n 26) 2.

[137] Ibid., 2.

[138] Edmund Pellegrino and David Thomasma, *For the Patient's Good: The Restoration of Beneficence in Health Care* (Oxford University Press 1988) 7.

[139] Allen Buchanan and Dan Brock, (n 13) 79.

[140] O'Neill, (n 8), 2.

involvement of patients in health care decisions concerning them.[141] Importantly, the principle has been redefined from 'autonomy' to 'respect for autonomy' which distances itself from the ideal of personal autonomy, emphasizing the obligation to respect the autonomous choices and actions of others.[142] The question is framed in terms of respect of an autonomous agent, which is the recognition of the agent's capacities and, importantly, the recognition of the agent's moral right to hold certain views, make certain choices and act upon these choices, and take certain actions, according to personal values and beliefs.[143]

Medical ethicists such as Childress emphasise equally recognise two facets of the idea of respect for patient autonomy: respect as restraint from interfering or attempts to interfere with the decisions and actions of the patient, and respect as a positive obligation to foster autonomous decision-making.[144] However, the principal legal mechanism through which the right of autonomy has been delivered is through the requirement for consent to medical treatment.[145] Waldrop is critical of this notion of 'minimalist autonomy' based on the presumption that any agent is autonomous unless there is clear evidence either of external coercion or an inability to understand or evaluate relevant information in decision-making.[146] Manson and O'Neill challenge the assumption of informed consent as a means to secure autonomy and the acceptance of informed consent as a passive transfer of information from the medical professional to the patient focused largely on information disclosure, followed by a decision.[147] This approach, they claim, fails to contextualise the decision-making process and take into account the commitments and competencies of the those that receive the information.[148]

O'Neill persuasively argues against the perception that medical practice respects a high degree of individual autonomy, maintaining that informed consent simply makes it possible for individuals to choose autonomously but does not guarantee or require that they

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[141] Ibid.

[142] James Childress, *Practical Reasoning in Bioethics* (Indiana University Press 1997) 60.

[143] Tom Beauchamp and Jeffrey Kahn, 'Ethical Theory and Bioethics' in Tom Beauchamp and others (eds), *Contemporary Issues in Bioethics* (8th edn. Wadsworth Cengage 2014) 23-24.

[144] James Childress, 'The Place of Autonomy in Bioethics' (1990) 20 The Hastings Center Report 12, 13 and 15.

[145] Mary Donnelly, Autonomy in the Law in Mary Donnelly (ed.) *Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism* (Cambridge University Press 2011) 52.

[146] Mackenzie and Stoljar (n 90).

[147] Neil Manson and Onora O'Neill, *Rethinking Informed Consent in Bioethics* (Cambridge University Press 2007) 36-37.

[148] Ibid., 39, 47.

do so.[149] O'Neill observes that there is nothing in the informed consent procedure to ensure that the choices made are carefully reflected upon and the process may equally endorse choices that are 'timid, conventional and lacking in individual autonomy.'[150] This idea of authenticity as reflective endorsement of one's wishes and choices in the sense that these are intended and authentically one's own is an important facet of the philosophical enquiry into autonomy.[151] White supports the incorporation of an account of authenticity in the bioethical discourse of autonomy that properly addresses the concerns arising in medical practice that a patient's choices and decisions are not truly their own.[152] White claims that authenticity has been traditionally dismissed in medical ethics and argues that authenticity, understood as choices made according to a coherent and stable set of values, should instead be incorporated into accounts of patient autonomy. On this view, exploring authenticity is particularly important where individuals make choices that are at odds with the views of medical professionals, as competence is more closely scrutinised in these situations and the concern is that the choice may not be truly the patient's own.[153] This allows the evaluation of the individual's decision without relying on a subjective judgment that a decision that is against the person's interests must be irrational or based on inadequately understood premises.[154] White argues that an authenticity-based conception of understanding allows us to place enduring values and beliefs that that are meaningful to individuals beyond scrutiny and accept these values as the basis for health decisions made by the individual .[155] This presupposes some stability of beliefs and values.

Faden and Beauchamp, on the other hand, caution against the use of authenticity in the determination of what constitutes an autonomous decision claiming that people should be allowed to make deliberate choices that are out of character and are not based on any underlying coherent set of values.[156] Nonetheless, where medical decisions have a significant impact, particularly in the long term, it seems important to ascertain that the

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[149] O'Neill, (n 26).

[150] Ibid.

[151] Beate Rossler, 'Problems with Autonomy' (2002) 17 Hypatia 143, 145.

[152] White (n 132).

[153] Ibid.

[154] Ibid., 200.

[155] Faden and Beauchamp (n 132) 200.

[156] Ibid., 266.

values upon which the decision is based are enduring and stable.[157] These critiques highlight the ethical concern about how it is largely the negative autonomy of the patient that is protected from interference, both by ignorance or pressure from third parties, through the requirements for information disclosure and voluntariness.

O'Neill argues that the traditional focus of bioethical discussion on '[w]hat is rather grandly called 'patient autonomy' often amounts to a right to choose or refuse treatments on offer, and the corresponding obligation of practitioners not to proceed without patients' consent' and that it 'say[s] nothing about individuality or character, about self-mastery, or reflective endorsement, or self-control, or rational reflection, or second-order desires, or about any other specific ways in which autonomous choices are to be distinguished from other, mere choices'.[158] Donnelly notes that this is not necessarily an intrinsic flaw in autonomy as a principle but rather at how it is framed and that an account of autonomy incorporating the idea of meaningful choice can and should be developed.[159]

A reconsideration of how autonomy can be reconceptualised in healthcare ethics and law beyond the current prevailing account of autonomy in terms of negative freedom presents considerable challenges.[160] However, the 'ease' with which the ethical concept of autonomy as non-interference can be converted into legal doctrine, is one of the reasons why this account of autonomy currently prevails in law.[161] The focus on the procedural requirements of consent is also driven by the needs of health professionals to establish clear and practical guidance on the approach to medical decision-making.

McLean notes that while recognising a genuinely autonomous decision is relatively straightforward from a theoretical perspective, translating this into legal doctrine is not, essentially because what is required is a normative formula that can accurately and consistently capture 'the nuances of the ethical debate' and evaluate 'the autonomy quotient of the decision' while ensuring that it delivers legal certainty.[162] This consideration is particularly relevant to the practical application of relational theories of autonomy to real

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[157] Dan Brock, 'Decision-making Competence and Risk' (1991) 5 Bioethics 105; Thomas Grisso and Paul S Appelbaum, *Assessing Competence to Consent to Treatment: A Guide for Physicians and Other Health Professionals* (Oxford University Press 1998).

[158] O'Neill, (n 26) 37.

[159] Mary Donnelly Autonomy Variations on a Principle in Mary Donnelly (ed.) *Healthcare Decision-Making and the Law* (Cambridge University Press 2011) 39, 40.

[160] Ibid., 41, 47.

[161] Ibid., 47.

[162] Maclean (n 75) 66.

decisions about healthcare. In relation to medical decision-making, Brazier notes that '[r]eciprocal ethical obligations extend into every area of our lives' and that it is the empowerment of patients which brings these responsibilities to the forefront of decision making.[163] The recognition that persons making a decision about their healthcare have duties and responsibilities towards other people that may potentially conflict with the decision that is most appropriate in terms of their own medical needs is important in order to understand why individuals make the choices that they do. However, translation of these moral duties into legal duties must proceed with caution.[164] Importantly, legitimate ethical concerns about agency within oppressive social conditions could potentially mean that a considerable number of decisions are regarded as non-autonomous, yet it is not obvious that categorising these persons as non-autonomous is desirable as this perpetuates a denial of their decision-making powers.[165]

2.4 Conclusion

Liberal accounts of autonomy as self-determination place value on the authority of the individual over their own life both in terms of capacity and freedom to do so. The following chapters will examine the relevant law and locate the source of the decisional authority in terms of the person whose permission is required for an organ to be removed for transplantation. While this may be relatively straightforward in cases where a person is considering organ donation for themselves, as will be seen, more complex issues arise where decisions are being made for a child.

In this thesis I will examine how choices to donate an organ are made. I start from the premise, as articulated by O'Neill and Manson, that if autonomy is construed

> […] as a question of mere choice, it is necessary to explain why all choices, including superficial and poorly reflected, irrational, and poorly informed choices should be protected; alternatively, if autonomous choice is linked to

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[163] Margaret Brazier, 'Do No Harm. Do Patients Have Responsibilities Too?' (2006) 65 The Cambridge Law Journal 397, 401, 402.

[164] Donnelly (n 167), 36.

[165] Ibid., 34.

> reasonableness or reflectiveness then it is necessary to explain why only these choices should be protected.[166]

I contend that while the ideas of autonomy and choice are inextricably linked, there is a difference between the understanding of autonomy simply as freedom of choice and an understanding of autonomy that is concerned with the decision-making process itself and its relationship with the personal identity, values, and commitments, and with how social and psychological circumstances shape the self and the individual's choices. I will examine the ability and exercise of rationality, self-reflection, and the idea of authenticity in decisions to donate an organ and consider why these matter .

My central argument is that the decision to donate an organ, whether posthumously or in life, is based on values that are important to the donor and almost invariably affects the donor's significant others. It is important to examine what donor autonomy means when choices to donate or not to donate are made, why it matters, and whose views are relevant, particularly in situations where the donor does not fit the traditional template of the rational, independent individual, because the person in need of the organ is a close family member or where there is a strong emotional connection between the donor and recipient.

I argue that a more nuanced understanding of donor autonomy is required, one that can accommodate vulnerability and meaningful relationships within the decision-making process, recognize oppression, and accord the proper weight to moral values and commitments based on genuine ties of love and affection. Substantive accounts of autonomy prima facie appear to offer a more layered understanding of how moral values, responsibilities, and duties result in choices to donate and why meaningful engagement with the person who is the source of the organ to be transplanted is important.

I maintain that relational autonomy offers useful insights into the relevance of the value system of the perspective donor in choices based on moral obligations and responsibilities towards family members, including decisions that may appear instinctive and poorly informed. I use these to explore how the collective and individual interests of individual family members are taken into account when decisions about interfamilial donation are made and how coercion, manipulation, and pressure within the family unit may undermine decisional authority. I accept that it may be challenging to define the boundary between an individual "being deeply embedded within a relationship" and that individual being

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[166] Manson and O'Neill (n 149) 20.

oppressed to the extent that they lose their autonomy[167] and that this difficulty also applies to the evaluation of decisional authority within relationships in non-Western social and cultural communities.

In relation to living non directed donation, I argue that we cannot properly make sense of the decision to donate an organ to a stranger by relying on an individualistic notion of autonomy and that the communitarian ethics perspective is important to understand the moral obligations involved in these choices.

In the context of deceased donation, I discuss how communitarian theory contributes to the analysis of the role of broader notions of human solidarity, reciprocity, and obligations to others following the recent introduction of legislation creating an opt-out system of organ procurement. I challenge the assumption of the public's genuine commitment to donate an organ posthumously and question the justification that opt-out legislation facilitates the realization of society's wish to donate posthumously. I discuss how the obligations and duties underpinning communitarian and relational theory offer a more coherent framework for the analysis of decision-making in deceased organ donation and a more honest justification for the move to an opt-out system of organ procurement.

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[167] Jonathan Herring, *Relational Autonomy and Family Law* (Springer 2014) 23.

3 Autonomy and the living donor

3.1 Introduction

Organs procured through living donation provide an important supplement to the limited availability of organs derived from deceased persons.[168] In the UK, waiting times for a transplant for patients on the deceased donor waiting list are 2-3 years and the scale of the challenge is amplified if we consider that strict criteria apply to wait listing and the waiting list is not an accurate reflection of the number of patients who would benefit from a transplant.[169] Importantly, recipient outcomes in terms of graft survival, mortality rates, and life expectancy using organs from living donors are better than those using cadaveric donors.[170] As a strategy to respond to the shortfall in organs relative to the needs of patients with end-stage organ failure, living donation has the potential to respond 'speedily, flexibly, and effectively'.[171] In this context, the lack of available organs through deceased donation is itself the stimulus for increased reliance on living donors.[172]

The first successful transplant from a living donor involved the transplantation of kidneys.[173] Kidney donation between genetically related donors and recipients gradually expanded beyond the parent-child or sibling-to-sibling blood ties to more distant genetic relationships and donation between spouses, eventually encompassing donation involving all kinds of social relationships and donation between strangers. In the UK, living donation is broadly classified as directed and non-directed donation. Directed donation is donation to a specific and identified recipient with whom the donor has a genetic or pre-existing emotional relationship.[174] Directed altruistic donation is donation to a specified individual

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[168] David Price *Human Tissue in Transplantation and Research: A Model Legal and Ethical Donation Framework* (Cambridge University Press 2010), 198.

[169] https://www.nhsbt.nhs.uk/organ-transplantation/kidney accessed 15 December 2022.

[170] This is due to a number of reasons: living donors are generally healthier than deceased donors, cold ischaemic times are shorter, and operative conditions for the recipient are optimised in an elective setting. Furthermore, transplantation may be timed to avoid dialysis (pre-emptive transplantation) or minimise dialysis duration with improved results as the time on dialysis is associated with poorer outcomes. See Susan Fuggle and others, 'Factors Affecting Graft and Patient Survival after Live Donor Kidney Transplantation in the UK' (2010) 89 Transplantation 694; Kevin Mange and others, 'Effect of the Use or Nonuse of Long-Term Dialysis on the Subsequent Survival of Renal Transplants from Living Donors' (2001) 344 The New England Journal of Medicine 726.

[171] Price, (n 169) 198.

[172] Lainie Friedman Ross and J Richard Thistlethwaite, *The Living Donor as Patient: Theory and Practice* (Oxford University Press 2022).

[173] Marc Shampo and Robert Kyle, 'Joseph E. Murray—Nobel Prize for Organ Transplantation' (2001) 76 Mayo Clinic Proceedings 240.

[174] HTA Code of Practice F: Part 1 (n 11).

with no pre-existing emotional or genetic relationship between donor and recipient with contact mediated by a third party such as a social networking site or a media campaign.[175] Donation to an unknown recipient that the donor has never met and is not genetically related to is referred to as non-directed altruistic donation.[176] While there has also been an expansion, globally, in terms of the types of organs transplanted to include transplants of liver lobes, lung lobes, pancreas islets, and sections small intestine, in the UK living organ donation is largely limited to kidneys and liver lobes.

The removal of an organ is not risk free. The global intraoperative and postoperative complication rates for donor nephrectomy (kidney resection) are 6.8% and 4.9% respectively.[177] Living organ donation is increasingly being normalised, particularly in the case of kidney donation, where it is now portrayed as a mainstream option for the treatment of end-stage renal failure.[178] Nonetheless, the physical risks and the significance of discomfort, encumbrance, and stress associated with the procedure cannot be overlooked and the fact that transplantation turns healthy persons into patients, albeit only transiently in most cases, must be properly recognised when evaluating the ethical justification for allowing individuals to donate.[179]

In the UK, living organ donation by adults is based on the principle that the decision to give or withhold permission for the use of one’s organs for transplantation is the prerogative of the individual, described as a statutory ‘autonomous right’ to give or refuse consent to donation.[180] This reflects the commitment of liberal Western societies to self-determination, based on the idea that choices are beneficial to the individual’s subjective wellbeing because they reflect values and principles that are meaningful to them and that

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[175] Ibid., [28].

[176] For kidney donation, where a living person is unable to donate to their intended recipient due to incompatibility or a poor match they may be matched with another donor and recipient in the same situation in the National Living Donor Kidney Sharing Schemes. The donor organs are then swapped. When two pairs are involved, it is a paired donation and where more than two pairs are involved, it is a pooled donation.

[177] Mireia Musquera and others, ‘Outcomes after 20 Years of Experience in Minimally Invasive Living-Donor Nephrectomy’ (2022) 40 World Journal of Urology 807.

[178] HTA Code of Practice F Part 2 Donation of solid organs and tissue for transplantation (Human Tissue Authority, 2017); British Transplantation Society. *Living Donor Liver Transplantation: UK Guidelines*, July 2015; British Transplantation Society and Renal Association. *Guidelines for Living Donor Kidney Transplantation,* March 2018.

[179] BTS Living Donor Liver Transplantation: UK Guidelines (n 179); Misao Fujita and others, ‘A Model of Donors’ Decision-Making in Adult-to-Adult Living Donor Liver Transplantation in Japan: Having No Choice’ (2006) 12 Liver Transplantation 768.

[180] HTA Code of Practice F Part 2 Donation of solid organs and tissue for transplantation (Human Tissue Authority, 2017) [21].

each person knows best what their interests are.[181] In general, therefore, the state will not intervene to prevent persons from acting on their decisions, even when the choices they make may objectively be thought to be detrimental to them.[182] The fulcrum of this thesis is that decisions to donate an organ are framed normatively in terms of autonomy yet this principle is poorly articulated in the legal and regulatory framework governing organ procurement. My contention is that autonomy matters deeply when a healthy person decides to undergo surgery to resect an organ for transplant to save the life of another[183] and that, however autonomy is conceptualised, it concerns respect for the interests of the donor who is accepting the risks of surgery and respect for the values underpinning their commitment to donate.

The literature on the ethics of living donation largely refers to the transplantation of kidneys as this practice is well established in North America, the UK, and parts of Europe and Far East Asia and provides fertile ground for the development of normative theory on the acceptability of specific practices and restrictions.[184] Many of the themes considered in this chapter stem from the ethical analysis of kidney donation including qualitative research on the psychosocial context of donation involving donors, recipients, families and health professionals. Different surgical risks and greater uncertainty of outcomes apply to other organ transplants and this is ethically relevant to how we conceive the boundaries of the donor’s decisional autonomy. Nonetheless, I maintain that the central ideas pertaining to how decisions are made and the core understanding of donor autonomy are not constrained by the organ itself and are relevant to donation generally.

In this chapter I focus on the meaning and ethical relevance of autonomy from the perspective of the adult living donor. The principle of autonomy is widely regarded as the prerequisite for the ethical acceptability of allowing a person to undergo surgery involving certain and serious physical harm with no medical benefit to themselves to help another

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[181] Buchanan and Brock (n 13) 422; Louis Chariand, ‘Mental Competence and Value: The Problem of Normativity in the Assessment of Decision-making Capacity’ (2001) 8 Psychiatry, Psychology and Law 135; Kluge (n 13).

[182] Appelbaum (n 153).

[183] Or, as in many cases of kidney donation, to enhance their quality of life in a fundamental way.

[184] Peter Reese, Neil Boudville, and Amit Garg, ‘Living Kidney Donation: Outcomes, Ethics, and Uncertainty’ (2015) 385 The Lancet 2003; Peter Singer and others, ‘Ethics of Liver Transplantation with Living Donors’ (1989) 321 The New England Journal of Medicine 620; Aaron Spital, ‘Ethical Issues in Living Organ Donation: Donor Autonomy and Beyond’ (2001) 38 American Journal of Kidney Diseases 189.

person.[185] Taken to its natural conclusion, this approach would seem to endorse the radical libertarian view that the decision is a matter solely for the donor to decide and that a person should be entitled to donate an organ irrespective of the risks and consequences to themselves.[186] This represents a minority view[187] that raises interesting arguments at a conceptual level. However, libertarian claims offer limited insight here because my analysis is rooted in current practice: the UK transplantation services are based on an approach to clinical practice that recognises the constraints of the duties and responsibilities owed by physicians, as moral agents, towards their patients.[188] Elliott articulates this in terms of the moral responsibility that the medical professional shares with the donor: performing surgery to resect the organ for transplant demands that the surgeon is satisfied that their participation is morally justified.[189] Furthermore, the transplant system relies on the trust and support of society and there are valid consequentialist reasons limiting the acceptable degree of harm that donors may undertake as excessive mortality and morbidity after donation is likely to undermine the confidence of the public in transplant programs.[190] For these reasons, I do not pursue libertarian approaches based on a view of autonomy as almost absolute freedom. I focus instead on individualistic notions of personal autonomy as endorsement of personal values and self-reflection and on relational and communitarian accounts of autonomy because these offer a perspective that is more directly applicable and ethically relevant to the *actual* options available to persons seeking to donate an organ and the real-life context within which the decision to donate is made.

In this chapter I will consider the extent to which the legal and regulatory requirements for living organ donation in the UK are consistent with an understanding of autonomy that respects reflected and authentic choices to donate based on values that the individual endorses. As a preliminary issue, I will examine the understanding of autonomy as a human right protected under the European Convention of Human Rights (ECHR) and consider the relevance of a rights-based approach to the deconstruction of donor autonomy.

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[185] Nikola Biller-Andorno and others, ‘Who Should Be Allowed to Give?’ (2001) 22 Theoretical Medicine and Bioethics 351, 361.

[186] C Elliott, ‘Doing Harm: Living Organ Donors, Clinical Research and The Tenth Man.’ (1995) 21 Journal of Medical Ethics 91.

[187] Price, (n 169), 205.

[188] Spital (n 192); Francis L Delmonico and Owen Surman, ‘Is This Live-Organ Donor Your Patient?’ (2003) 76 Transplantation 1257; Elliott (n 187).

[189] Elliott (n 172).p 93

[190] Nicola Williams, ‘On Harm Thresholds and Living Organ Donation: Must the Living Donor Benefit, on Balance, from His Donation?’ (2018) 21 Medicine, Health Care and Philosophy 11, 13

Next, I examine the statutory provisions[191] for consent and authorisation of organ removal and use for transplantation under the Human Tissue Act 2004 (hereafter HT A 2004) and the Human Tissue (Scotland) Act 2006 (hereafter HT(Scotland)A 2006) and under the Human Tissue Act 2004 (Persons who Lack Capacity to Consent and Transplants) Regulations 2006 (hereafter HT Regulations 2006) and the Human Organ and Tissue Live Transplants (Scotland) Regulations 2006 (hereafter HT(Scotland) Regulations 2006), and the understanding of capacity under the Mental Capacity Act 2006 (hereafter MCA 2006) and the Adults with Incapacity(Scotland) Act 2000 (hereafter AWI(Scotland)A 2000). I tease out the requirements in law relating to donor capacity, information disclosure, freedom from interference by third parties, and the prohibition of reward for donation and consider how choices to donate that are informed, voluntary, and not driven by recompense fall short of a substantive approach to autonomy. I then examine the meaning of autonomy in decisions to donate an organ for transplantation, proceeding from the premise that the reasons for donating are central to the understanding of autonomy. I explore donor motivations by focussing on key concepts that emerge from the ethical discourse and the medical literature on living organ donation. These are altruism, authenticity, self-reflection, and a sense of moral duty to donate. In the final part of this chapter, I consider whether consent and authorisation can accommodate a construct of decisional autonomy that places value on self-reflectiveness, on the formation and consolidation of personal motives for donating and moral commitments, and on the coherence in the donor's narrative of how the decision to donate was reached. To this purpose, I examine how the assessment of the prospective donor by medical professionals and by the regulatory body, the Human Tissue Authority (HTA), scrutinises donor motivations, self-reflection, authenticity and moral commitments.

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[191] A review of the medical jurisprudence on the evaluation of capacity goes beyond the scope of this thesis because the courts are not routinely involved in approving applications for living donation by adults and capacity of the prospective donor is assessed by the transplant team on the basis of the statutory tests for capacity. For critiques of the relationship between capacity and patient autonomy please see Charles Foster, 'Autonomy in the Medico-Legal Courtroom: A Principle Fit for Purpose?' (2013) 22 Medical Law Review 48; Jonathan Herring and Jesse Wall, 'Autonomy, Capacity and Vulnerable Adults: Filling the Gaps in the Mental Capacity Act' (2015) 35 Legal Studies 698

3.2 Autonomy rights

Decision-making in the medical context is regulated by the doctrine of consent which constitutes the principal legal mechanism through which the courts have analysed issues concerned with respect for patient choices concerning their healthcare.[192] Ethicists Faden and Beauchamp distinguish between the legal and the moral basis for consent, the first being concerned primarily with the duties and liabilities of physicians, framed in terms of the provision of sufficient information and the avoidance of duress and deception, rather than the interests of the patient in making an autonomous choice.[193] Indeed, it has not escaped criticism that the main focus of the law has traditionally been the protection of negative liberty, in the sense of freedom from interference, rather than the processes necessary to facilitate autonomous decisions.[194]

The principle of autonomy has been poorly articulated in medical jurisprudence and the law's approach to autonomy is first of all to determine the status of the individual in terms of cognitive capacity.[195] Foster takes a rather dim view of what he refers to as the 'thin' approach to autonomy, in which the law delegates the real decision-making to the notion of capacity: if an individual has capacity they have the right to choose what is and what is not done to their body, if not another scheme applies.[196] Capacity in law is 'the line between legally effective and legally ineffective decisions'[197] yet it does not necessarily represent the threshold between a positive action of self-reflection leading to a decision that is authentic and a choice based on a superficial evaluation of the information.[198]

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[192] Donnelly (n 147), 52; I do not propose to trace the legal regulation of consent in English law. The prerequisites for valid consent in law (information, knowledge, and risk) are discussed in Alasdair MacLean 'The Concept of consent: what it is and what it isn't' in *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) 134-136. For a thorough review of the courts' approaches to consent in battery and negligence see 'The legal regulation of consent'. in *Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism* (Cambridge University Press 2010).

[193] Faden (n 14).

[194] Mary Donnelly 'Autonomy in the law', in *Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism* (Cambridge University Press 2010) 49-89.

[195] Sheila McLean, *Autonomy, Consent and the Law* (Routledge-Cavendish 2010), 17-18.

[196] Foster (n 199), 58

[197] Alisdair Maclean, 'Autonomy, Consent and Persuasion' (2006) 13 European Journal of Health Law 321.

[198] Natalie Stoljar, 'Informed Consent and Relational Conceptions of Autonomy' (2011) 36 Journal of Medicine and Philosophy 375, 381.

Recent trends in health law have moved towards a conceptualisation of the duties owed by medical professionals to their patients in terms of patient rights.[199] The obligations of the State to take positive actions to protect individual rights can be located in the protection of the individual's private and family life under Article 8 of the European Convention of Human Rights (ECHR), incorporated into domestic law by the Human Rights Act 1988.[200] Article 8 is broad in scope; it is a qualified right and exceptions apply, including necessary and proportionate actions 'for the protection of health or morals, or for the protection of the rights and freedoms of others'.[201] The protection of private life is taken to include freedom from interference as well as a positive obligation imposed on member states to respect the individual's right to participate in decisions that affect our life[202] which, in the medical context, falls within the remit of making choices about medical interventions or treatment. The case of *Pretty v United Kingdom* represents the first case in which Article 8 was recognised as the basis for the protection of autonomy.[203] The ECHR recognised autonomy as a right falling within the scope of Article 8 and found that Article 8 permitted refusal of medical treatment even if this would lead to death and that the imposition of treatment without consent on an adult patient with capacity constitutes an interference with the patient's physical integrity 'in a manner capable of engaging the rights protected under Article 8(1) of the Convention'.[204] These autonomy rights were expressed as rights of protection for 'the personal sphere of each individual'.[205] Donnelly argues that the recognition of the possibility of conceptualising autonomy as a right of the individual, albeit a right that needs to be balanced against societal interests, represents progress from the traditional legal approach to autonomy simply as a matter of non-interference.[206]

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[199] T Arvind and Aisling McMahon 'Responsiveness and the role of rights in medical law: lessons from Montgomery. 2020 Medical Law Review, 28, 445, 446; Donnelly (n 277) 77-89.

[200] Section 6 of the Human Rights Act 1998 makes it unlawful for a public authority to act in a way that is incompatible with a person's rights under the ECHR.

[201] Article 8(2) ECHR.

[202] Ibid.,

[203] *Pretty v. United Kingdom* (2002) 35 EHRR 1, [61].

[204] Ibid., [63]. In brief, Dianne Pretty, a patient with sever motor neurone disease, sought assurance from the Director of Public Prosecutions that her husband would not be prosecuted were he to provide assistance to her in ending her life by switching off the ventilator as her physical condition precluded her from controlling her accomplishing her aim of avoiding a painful and frightening death. While the ECHR recognized accepted that her autonomy rights were engaged under Article 8 of the ECHR, it also found that the restriction on assisted suicide in UK domestic law could be justified under Article 8(2). Her claim in UK law ultimately failed.

[205] Ibid., [90].

[206] Donnelly (n 277) 79.

While a review of the understanding of patient decisional autonomy in UK case law cannot be conducted within the scope of this thesis[207], the case of *Montgomery v Lanarkshire Health Board* (hereafter *Montgomery*)[208] merits some discussion. Here, the Supreme Court explicitly endorsed the idea of the patients as right-holders rather than 'passive recipients of medical care'[209] and identified the right to respect for private life under Article 8 of the European Convention on Human Rights (ECHR) as underpinning the duty of medical practitioners to involve the patient in decisions regarding their treatment[210]. The case raises important questions regarding the positive duties owed to patients as individuals making decisions concerning their wellbeing. It concerned a claim in negligence brought by Nadine Montgomery, who was diabetic, for the failure of the consultant obstetrician responsible for her care to disclose the risks of vaginal delivery associated with diabetes mellitus, notably the risk of shoulder dystocia, which occurs when the baby's shoulders cannot pass through the mother's pelvis, and offer her a caesarean section. These risks materialised and the baby was born with severe disabilities. The Supreme Court held that information concerning risk that was material to a patient's decision to give or withhold consent should be based on a new two-limbed test of materiality where the risk should be disclosed where in the particular case a reasonable person in the patient's position would attach significance to the risk or a doctor should reasonably be aware that the particular patient would be likely to attach significance to it.[211]

The case ignited considerable academic debate about whether this represented a shift in the law towards a and a conceptualisation of autonomy as a right protected under Article 8 of the ECHR and a more patient-centred approach to decision-making. Dunn and colleagues take the view that the case offers a narrow rights-based account of autonomy that is limited to the determination of what information is owed to patients for them to give meaningful permission to treatment.[212] Montgomery, on the other hand, observes that conceptualising autonomy as an Article 8 right places the emphasis on the positive health rights owed to individuals as citizens rather than as patients and broadens the scope of these entitlements

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[207] For a cogent review of the developments in tort law (pre-*Montgomery*) on the duties of medical professionals to disclose adequate information to the patient see Donnelly (n 277) 80-88. Donnelly argues that a trend in judicial emphasis on professional duties to communicate with the patient rather than merely disclose information can be identified.

[208] [2015] UKSC 11.

[209] [2015] UKSC 11 at paras [56], [75].

[210] [2015] UKSC 11 at [80].

[211] [2015] UKSC 11 at para [87].

[212] Dunn and others (n 275), 112.

beyond the doctor-patient relationship and consent to treatment to claims about the sort of life people wish to live and how these are balanced alongside other rights and concerns.[213] Article 8 also engages the duty to consult, recognised in *Tracey v Cambridge UH NHSFT*[214] and concerning the duty of doctors to be open and transparent about their decisions so that patients have the opportunity to be involved. This duty is broader than the requirements for disclosure of information regarding treatment choices. However, in a thorough review of case law since *Montgomery*, Cave argues that the courts have narrowly interpreted the scope of patient participatory rights and concludes that the power of Article 8 rights should be properly recognised in terms of the principles it endorses that are incorporated into guidance for medical professionals, such as the GMC guidance on consent.[215]

Overall, there is broad academic support for the proposition that the idea of a shared doctor-patient partnership is a more fitting model to respond to the actual needs and expectations of patients.[216] Dunn and colleagues maintain that while Montgomery marks a more patient-centric approach to the determination of what information ought to be disclosed to the patient and how this should be disclosed in the informed consent process, the materiality test does not impose giving *primacy* [my emphasis] to the principle of respect for autonomy.[217] The authors argue that that a primacy approach would prioritise the particular views and values of the patient and require the doctor to ensure that the patient's choices and preferences were, on a proceduralist view of autonomy, aligned with their higher order desires, or, on a relational view of autonomy, an authentic reflection of the patient's moral principles and commitments; this equates to imposing a duty to understand the values held by the patient, how these connect with the question of information disclosure, and why the patient adopted a particular view of the risks involved, requirements that are plainly above the requirement of reasonable awareness set out in the materiality test.[218] Instead, the values of the particular patient are balanced alongside the

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[213] Montgomery and Montgomery (n 288), 108.

[214] *R (Tracey) v Cambridge University Hospital NHS Foundation Trust and others* [2014] EWCA Civ 822

[215] Emma Cave and Nina Reinach 'Patient Rights to Participate in Treatment Decisions: Choice, Consultation and Knowledge' (2019) 7 Journal of Medical Law and Ethics, 7, 157, 177

[216] Cave and Reinach (ibid.); Farrell and Brazier, (n 280); Michael Dunn, and others. 'Between the Reasonable and the Particular: Deflating Autonomy in the Legal Regulation of Informed Consent to Medical Treatment' (2019) 27 Health Care Analysis 110, 113.

[217] Dunn (ibid.).

[218] Ibid., 114-115.

values of a reasonable patient in the patient's position.[219] The very need for the two limbs in the materiality test is taken as a reflection of the fact that there may be differences between what is ethically relevant from the perspective of the reasonable patient, which can be read as including regard for medical evidence, and what is relevant from the particular patient and that these considerations need to be balanced with one another to determine the materiality of the risk.[220] Accordingly, the patient-centric dimension lies in the participation of both parties in a dialogue in which doctors come to understand what matters to the patient explaining the options, and their risks and benefits, consistent with the GMC principles of shared decision-making that underpin good medical practice in the UK.[221]

A similar view was expressed in a paper published soon after the *Montgomery* judgment in which Farrell and Brazier[222] declare that the decision would make little difference to healthcare practice and consent in the UK which largely reflected the patient-centred test for disclosing risk under the GMC guidelines on consent already in place,[223] which were explicitly referred to in the decision delivered by Lord Kerr and Lord Reed.[224] Herring and colleagues also observe that the shared decision-making model is based on the balancing of different, and potentially conflicting, ethical values, interests, and preferences in choosing a course of action and in this sense is different to the consumerist understanding of autonomy as the availability of choice and the freedom to choose amongst a range of

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[219] Jonathan Herring and others. 'Elbow room for best practice? Montgomery, Patients' Values, and Balanced Decision-making in Person-centred Clinical Care' (2017) Medical Law Review 25, 582, 598.

[220] Ibid., 594, 601.

[221] Dunn and others (n 275), 123-125; see also Jonathan Herring and others (n 277).

[222] Anne Maree Farrell and Margaret Brazier, 'Not so new directions in the law of consent? Examining Montgomery v Lanarkshire Health Board' (2016) 42 Journal of Medical Ethics, 85.

[223] General Medical Council, 'Consent: Patients and Doctors Making Decisions Together' (2008) available at https://www.gmc-uk.org/-/media/documents/consent-patients-and-doctors-making-decisions-together-2008---2020_pdf-84769495.pdf accessed 9 September 2022.

[224] The GMC's guidelines on consent were revised in 2020 see 'Decision making and consent: Guidance on professional standards and ethics for doctors' (General Medical Council, September 2020) available at https://www.gmc-uk.org/-/media/documents/gmc-guidance-for-doctors---decision-making-and-consent-english_pdf-84191055.pdf accessed 9 September 2022. According to this guidance all patients have the right to be involved in decisions about their treatment and care and to be supported to make decisions if they are able to (Principle one); decision making is an ongoing process focused on meaningful dialogue (Principle two); all patients have the right to be listened to, and to be given the information they need to make a decision (Principle three); and doctors must try and find out what matters to patients so they can share relevant information about the benefit and harms of proposed options and reasonable alternatives (Principle four). See also 'Consent: Supported Decision-Making – A Guide to Good Practice', (The Royal College of Surgeons of England, November 2018) available at https://www.rcseng.ac.uk/standards-and-research/standards-and-guidance/good-practice-guides/consent/ accessed 9 September 2022. This offers detailed guidance on the implications of *Montgomery* in clinical practice and how surgeons should protect patients' rights to make decisions about their treatment.

options.[225] Jackson examines the duty of care and the relationship between retailer and consumer more in more detail concluding that the comparison is inapt as mandatory disclosures are standardised for all consumers, consumers fail to routinely understand the use of information disclosure, and consumers cannot negotiate the terms and conditions of their contract.[226]

I am not persuaded that the patient-consumer analogy fits the shared partnership model of the doctor-patient relationship endorsed by the GMC or that this approach significantly advances the fundamental assertion made in this thesis which is that autonomy in living organ donation is linked to the idea of authenticity and the making of choices that genuinely reflects the values and principles of the donor. Nonetheless, I accept that *Montgomery* explicitly recognizes the value of genuine dialogue, rather than the unidirectional flow of information, between the patient and the medical professional and sets out requirements that the information is delivered clearly and is understood by the patient.[227] However, I remain cautious about how the requirements articulated in *Montgomery* apply to the decision-making process itself and I share Jackson's concern about any assumption that a the 'neutral presentation of information about material risks and alternatives will seamlessly produce informed patients making informed decisions' because while the disclosure of relevant information in a form that is comprehensible to the patient is important, this may not always be used patients to make an informed choice.[228] This goes back to the fulcrum of the work of O'Neill on the role of autonomy in bioethics, which predates *Montgomery*, about the importance of identifying specific ways in which autonomous choices are to be distinguished from 'mere choices'[229] and her critique that informed consent does not guarantee that individuals make choices autonomously.[230] This perspective remains relevant, in my view, remains relevant today. As Montgomery[231] observes, the Supreme Court model for decision making retains the basic assumption, articulated by Manson and O'Neill[232], that the professional holds the knowledge and is

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[225] Jonathan Herring and others (n 277), 593.

[226] Emily Jackson, Challenging the Comparison in Montgomery between Patients and Consumers Exercising Choices' (2021) 29 Medical Law Review 595, 598, 600-602.

[227] [2015] UKSC 11 at [58].

[228] Emily Jackson (n 283), 611.

[229] O'Neill (n 26), 37

[230] O'Neill (n 26).

[231] Jonathan Montgomery and Elsa Montgomery, 'Montgomery on Informed Consent: an Inexpert Decision? (2016) 42 Journal of Medical Ethics, 89–94. 97.

[232] Manson and O'Neill (n 149), 34-39.

responsible for controlling its flow to the patient, showing little interest in how the information is used beyond a requirement that reasonable care is taken to ensure that the information is not merely disclosed but that the patient is aware of the material facts.[233]

3.3 Legal requirements for living organ donation by adults

3.3.1 Consent: the role of the Human Tissue Authority

The HTA was established as the regulatory body under the HT Act 2004[234] and is responsible for assessing all applications for organ donation from living people in the UK. Living donation may proceed only if the HTA has given its approval. Here, I set out the legal and procedural requirements for the referral of donor candidates by the transplant team and the HTA assessment and approval of applications for living donation. In the third part of this chapter, I will consider the extent to which these requirements are consistent with a substantive understanding of donor autonomy that respects and protects authentic choices to donate based on values and commitments that the individual endorses.

In England and Wales, consent for the removal of organs from living donors, for the purposes of transplantation, must comply with the requirements of the HT A 2004, and the MCA 2005, the HT Regulations 2006, and the common law. Consent in Scotland must comply with the HT(Scotland)A 2006, the AWI(Scotland)A 2000, and the HT(Scotland) Regulations 2006.

Section 33 of the HT Act 2004 provides an exception to the general prohibition on the use of organs from a living person for transplantation provided that there is no reward for the organ[235] and that the requirements set out in the HT Regulations 2006 are met. These regulations require that the registered medical practitioner with clinical responsibility for the donor refers the application for living donation to the HTA.[236] Referral to the HTA

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[233] [2015] UKSC 11 at [87].

[234] The Human Tissue Act 2004 s 15

[235] ibid. s 33(3)(a)

[236] Human Tissue Act 2004 (Persons who Lack Capacity to Consent and Transplants) Regulations 2006 11 (2)

requires confirmation from the medical practitioner that they are satisfied that the prospective donor is medically suitable for organ removal and donation.[237] The transplant team is also responsible for seeking informed consent or authorisation from the donor.[238]

The role of the HTA is to act 'as an independent check that legally valid consent is in place'.[239] HTA members responsible for approving or dismissing the application for living donation do not assess the prospective donor directly but base their decision on a report by an Independent Assessor (IA)[240] who is trained and accredited by the HTA.[241] For approval, the HTA must be satisfied on the balance of probabilities that no reward has been given or promised in relation to the transplanted organ[242] and that consent to remove the organ for transplantation has been given.[243] Regulations 11(8) and (9) set out the following mandatory issues to be covered in this report: any evidence of duress or coercion affecting the decision to give consent, any evidence of an offer of a reward, the information given to the person interviewed about the nature of the surgery to resect the organ and to implant it into a recipient and the risks involved, and the capacity of the donor to give consent.

The HT(Scotland)A 2006 also contains a general restriction on transplants involving living adult donors.[244] This restriction does not apply if the Scottish Ministers are satisfied that no reward has been given for the organ and that specific requirements set out in the HT(Scotland) Regulations 2006 are met.[245] To achieve consistency, an agreement between the Scottish Executive and the HTA establishes that the HTA will assess prospective living donors on behalf of the Scottish Ministers.[246]

Therefore, the HTA will require to be satisfied that the provisions of the HT(Scotland)A 2006 and the respective regulations have been met before living donation can proceed.

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[237] HTA Code of Practice F: Part 1 (n 11) [75]

[238] HTA Guidance for Transplant Teams and Independent Assessors (Human Tissue Authority, updated 2017)

[239] HTA Code of Practice F: Part 1 (n 11) [63]

[240] HT Regulations 2006 (n 195) 11(4).

[241] HTA Code of Practice F: Part 1 (n 11) [36]; Guidance for Transplant Teams and Independent Assessors (n 197) [53].

[242] HT Regulations 2006 11(3)(a).

[243] HT Regulations 2006 11(3)(b)(i).

[244] Human Tissue Scotland Act s 17(1)(b), s 17(2)(b).

[245] HT Regulations 2006 17(3).

[246] The HTA's remit in Scotland is described in a document titled *Human Tissue (Scotland) Act 2006: A guide to its implications for NHS Scotland*, issued by the Scottish Health Department on 20 July 2006 [23].

These requirements are as follows: that the donor is not an adult with incapacity;[247] that the application for living donation is referred to the HTA by a registered medical practitioner with clinical responsibility for the donor;[248] and that interviews with the donor and, in case of directed donation, with the recipient, were conducted.[249]

The decision to approve or reject applications for living donation hinges on a number of criteria that rely on facts to be established in the course of donor and recipient interviews. Therefore, the regulations are prescriptive in terms of the specific matters to be covered in the report based on these interviews. Under regulations 2(6) and (7) the interviews must cover: any evidence of duress or coercion affecting the decisions of the donor to authorise organ removal and use for transplant; the information given to the donor regarding the nature of surgery to resect the organ and to implant it into the recipient, and the risks involved; and the capacity of the donor.[250] Once the report has been finalised, under regulation 2(5), approval of applications for living donation requires that the HTA is satisfied that no reward is given for the organ, that the donor authorised the removal and use of the organ for transplantation, that there is no evidence of duress or coercion affecting the decision to donate, and that the donor has the required capacity.

The opening statement on the regulatory framework for living organ donation in the HTA Guidance document for transplant teams and independent assessors states

> The purpose of regulating living donation in the UK is to make sure that donors are not forced to act against their wishes, and to safeguard against people trafficking for the purpose of organ donation.[251]

This statement emphasises the focus on the voluntariness of the decision and on the non-commercialisation of organs. The definition of valid consent requires that the prospective donor is informed and has the capacity to make the decision. These requirements say nothing about why or how individuals choose to donate in the first place. To explore this aspect of decision-making it is necessary to examine the donor assessment process, and specifically the psychosocial evaluation.

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[247] HT Regulations 2006 2(1), 2(2).

[248] HT Regulations 2006 2 (3).

[249] HT Regulations 2006 2 (4).

[250] I will discuss the specific capacity requirements in the next section.

[251] Guidance for Transplant Teams and Independent Assessors (n 197) [21].

3.3.2 Consent: the role of the clinician

As noted, the role of the HTA is to independently verify that legally valid consent is in place once a referral is made.[252] The referring medical practitioner is responsible for seeking informed consent or authorisation for donation [253] and for assessing the capacity of the prospective donor.[254] In the referral letter to the IA before the interview,[255] the medical practitioner is required to confirm that they have provided information to the donor that is required to understand the consequences of donation and that they are satisfied that the donor has capacity to consent to donation.[256] I will examine these requirements in turn.

The clinician must provide prospective donors with sufficient information to reach an informed decision about donation before the IA interview takes place.[257] The HTA Code of Practice F requires the medical practitioner to discuss specific 'areas' with the donor.[258] This requirement is essentially a duty to convey information to the donor, specifically: the nature of the surgical procedure; any material short and long terms risks; the chances of success of transplantation; any significant side effects or complications for the recipient, specifically including the risk of graft failure; the right to withdraw consent at any time before organ removal; that the decision to donate must be free of duress or coercion; that it is a criminal offence to give or receive a reward for the organ.[259] A material risk, which includes the risk of death to the donor, is where a reasonable person would attach significance to the risk or the transplant team is or should be reasonably aware that the donor would be likely to attach significance to it.[260] HTA guidance on valid consent in living organ donation was revised following the UK Supreme Court judgment in *Montgomery v Lanarkshire Health Board*[261] to include a requirement that the donor understands *both* the generic risks and the individual risks of donation.[262] Generic risks are those risks to which all donors would attach significance, while individual risks are those

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[252] HTA Code of Practice F: Part 1 (n 11) [63].

[253] Ibid. [67].

[254] Ibid. [63].

[255] Guidance for Transplant Teams and Independent Assessors (n 197) [92].

[256] HTA Code F: Part 1 (n 11) [75] , [76].

[257] Ibid. [67].

[258] Ibid. [70].

[259] Ibid [70].

[260] Ibid. [70]

[261] *Montgomery v Lanarkshire Health Board* [2015] UKSC 11.

[262] Guidelines for Living Donor Kidney Transplantation (n 179) [2.4].

risks to which the particular person considering donation is likely to attach significance because they concern specific medical risks or considerations related to lifestyle that are relevant to the donor candidate.[263]

Similarly, in Scotland, the medical practitioner must state that they are satisfied that the donor has capacity to authorise donation[264] and that they have provided the prospective donor with 'sufficient information as to the nature of the medical procedure for, and the risk involved in, the removal of the organ'.[265] Information must be sufficient 'to reach an informed decision about whether they wish to donate an organ'.[266] The same guidance applies in Scotland regarding the specific information (set out above) to be disclosed to the prospective donor by the medical professional.[267]

Professional guidance by the General Medical Council on patient decision-making advises medical professionals to provide information about risk in a balanced way to avoid bias, explaining the anticipated benefits as well as potential burdens and risks of the proposed intervention, and to communicate this information in ways that are easily understandable.[268] Conveying the chances of an adverse event occurring is not straightforward. For example, reported donor mortality from kidney removal is 0.03%,[269] and outcome data following surgery indicate low donor morbidity,[270] with a <1% chance of developing end-stage-renal disease over 15 years.[271] These findings can be broken down further to provide statistics according to a variety of different criteria: specific conditions, such as increased blood pressure or the development of diabetes; time-frame within which the adverse outcome manifests itself, such as short-term and longer-term; pre-existing medical conditions; sex

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[263] Ibid. [2.4].

[264] HTA 2017 Guidance for Transplant Teams and Independent Assessors (n 197) [41].

[265] Ibid.

[266] Ibid., [67].

[267] Ibid., [68], [69]

[268] General Medical Council, Guidance on Professional Standards and Ethics for Doctors: Decision Making and Consent, (September 2020), 17-19 available at https://www.gmc-uk.org/-/media/documents/gmc-guidance-for-doctors---decision-making-and-consent-english_pdf-84191055.pdf accessed 15 December 2022.

[269] Arthur Matas and others, 'Morbidity and Mortality after Living Kidney Donation, 1999-2001: Survey of United States Transplant Centers' (2003) 3 American Journal of Transplantation 830; Dorry Segev, 'Perioperative Mortality and Long-Term Survival Following Live Kidney Donation' (2010) 303 JAMA 959.

[270] Linda O'Keeffe and others, 'Mid- and Long-Term Health Risks in Living Kidney Donors: A Systematic Review and Meta-Analysis' (2018) 168 Annals of Internal Medicine 276; Matas and others (n 228).

[271] Musquera and others (n 185).

and ethnicity of the donor.[272] The quantification of the risks of surgery to the donor goes beyond the remit of this thesis, the point being made here is that the data that can be conveyed to a prospective donor are complex and must be put into perspective to be meaningful to the decision-making process. Perspective refers to the donor's point of view and donors will assign different weight to the same risk according to the significance of successful transplantation to them. While these balancing considerations apply to the majority of medical decisions, living donation is unique because the intervention is not recommended by medical professionals for the treatment of the patient or the management of a medical condition. For the surgeon seeking consent for a procedure, the medical benefit to a patient is more easily determined and quantifiable relative to the risks involved than the fulfilment of the non-medical interests of the prospective donor because the latter require scrutiny of the donor's value systems and motivations for donating. The ethical concern is that the evaluation of the relative importance of the risks and the value of donation to the donor is conducted from the perspective of the medical professional rather than the donor and this compromises the donor's entitlement that their decision, based on reasons that matter to them, is respected.

With regards to legal capacity, this is a prima facie requirement for valid consent to a medical intervention. Establishing a standard for capacity involves setting out minimum requirements that the individual must fulfil in order to make a decision that is legally effective. In living organ donation, the referring clinician is required to assess capacity and confirm, in the referral letter to the HTA, that they are satisfied that the donor has capacity to consent to donation.[273] In practice, transplant teams adopt a multidisciplinary approach to donor screening for medical suitability for donation and mental health assessment may be undertaken by a qualified mental health clinician, including psychiatrists, psychologists, nurse specialists, and counsellors, with experience in the field of living donation.[274] The mental health assessment is no longer mandatory for all donors although it is recommended for all donations to an unknown recipient.[275] The MCA 2006, in force in

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[272] Krista Lentine and Anita Patel, 'Risks and Outcomes of Living Donation' (2012) 19 Advances in Chronic Kidney Disease 220.

[273] The medical practitioner with clinical responsibility for the prospective donor must refer the matter to the HTA for consideration under Regulation 11(2) of the Human Tissue Act 2004 (Persons who Lack Capacity to Consent and Transplants) Regulations 2006; See also HTA Code of Practice F Part 1 (n 11)[63], [76].

[274] Guidelines for Living Donor Kidney Transplantation (n 179) .

[275] Ibid. [8.4].

England and Wales, and the AWI(Scotland)A 2000 set out a functional test for capacity[276] that is task-specific in the sense that a determination of capacity is made in relation to the decision under consideration.

In England and Wales, the MCA 2005 regulates medical decision-making involving individuals lacking capacity. Under s.1(2) all persons are assumed to have capacity unless it is established that they lack capacity. While capacity itself is not defined, the MCA 2005 sets out a two-tiered test for incapacity. A person lacks decision making capacity in relation to a matter if they are unable to make a decision for themselves due to an 'impairment of, or disturbance in the functioning of, the mind or brain'.[277] This disturbance may be permanent or temporary and the range of conditions which may result in impaired capacity is set out in the MCA 2005 Code of Practice.[278] This inability to make a decision for themselves is defined as the inability to understand, retain, use the relevant information and weigh up the risks and benefits to make a decision.[279] The statutory approach aims to promote independent decision making as far as possible so that information must be provided in a way that is accessible to the specific individual before a determination of incapacity can be made.[280]

Similarly, in Scotland, s.1(6) of the AWI(Scotland) Act 2000 defines being 'incapable' as a lack of capacity to act, make communicate or understand decisions, or retain memory of decisions due to mental disorder or inability to communicate due to a physical disability. Understanding a decision includes being able to understand or remember information relevant to the decision, including information about the foreseeable consequences of deciding one way or another, or of failing to make the decision altogether.[281] With respect to the determination of capacity, the focus is on information disclosure, ability to understand the information provided, and use of the information to make a decision.

The skills required to fulfil the legal concept of capacity show, at most, how an individual comes to a decision in operational terms. The possession of cognitive skills to understand and appreciate the information provided by medical professionals and the demonstration of

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[276] Mary Donnelly, 'Capacity Assessment under the Mental Capacity Act 2005: Delivering on the Functional Approach?' (2009) 29 Legal Studies 464

[277] Mental Capacity Act 2005 s 2(1).

[278] Ibid. s 2(2); Mental Capacity Act (London: Stationary Office 2007) [4].

[279] Ibid. s 3(1).

[280] Ibid s 3(2).

[281] Adults with Incapacity (Scotland) Act 2000 Explanatory Notes to s 1 [14].

rational skills in balancing the risk and benefits of the organ removal and transplantation demonstrate that the individual has the ability to process facts and figures but say little about why an individual chooses to donate an organ and whether the choice made by the individual is authentic. It is important to note that how the individual uses the information provided to make their choice is closely linked to how specific information is prioritised relative to other concerns and commitments that the donor may have. Rationality is not the only 'processing modality' and, as will be discussed below, in situations where the donor and the recipient are in a close relationship, affective reasoning is another processing modality that challenges the traditional assessment of capacity and deserves careful attention.

3.3.3 Consent: the role of the Independent Assessor

The HTA reaches its decision to approve or reject an application for living donation on the basis of a report [282] compiled by an IA, who does not need to be medically qualified and is trained and accredited by the HTA.[283] The report is based on interviews conducted by the IA with the donor and the recipient, separately, and together if donation is directed. IAs are independent of the transplant team and their report is the primary source of evidence enabling the HTA to make a decision on whether to approve or deny approval of the application to donate, although the HTA is free to seek additional information from the donor, the recipient and from the referring medical professional.[284]

Specific guidance on the role of the IA and the remit of the IA interviews and reports is set out in HTA Code of Practice F part 1 and HTA guidance documents for transplant teams and IAs.[285] The IA must provide a comprehensive account of the interviews and the rationale for any conclusions drawn from these interviews.[286] These interviews are confidential and the contents of the report are not shared with the transplant team.[287] The IA report must include any evidence of duress or coercion affecting the decision to give

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[282] The Human Tissue Act 2004 (Persons who Lack Capacity to Consent and Transplant Regulations 2006) 11(4); Guidance for Transplant Teams and Independent Assessors (n 197).

[283] Ibid. [25], [41].

[284] Guidance for Transplant Teams and Independent Assessor (n 197) [25], [41].

[285] HTA Guidance for Transplant Teams and Independent Assessors and Accredited Assessors in Scotland (Human Tissue Authority, November 2018)); Guidance for Transplant Teams and Independent Assessors' (n 197).

[286] HTA Code of Practice F Part 2 Donation of solid organs and tissue for transplantation (Human Tissue Authority, 2017) [98].

[287] Ibid., [100].

consent[288] and any evidence of an offer or a reward.[289] Duress or coercion are interpreted as meaning that the will of the prospective donor has been compromised so that they can no longer make an independent decision.[290] The report must also include the following: any difficulties with communication with the donor and an explanation of how these difficulties were overcome;[291] details of the information given to the donor regarding the nature and risks of surgery[292] to remove the organ for transplant, and details of the person providing that information;[293] and the capacity of the donor to understand the nature and risks involved in surgery[294] and that consent may be withdrawn at any time before surgery.[295]

Details of the IA's role and the requirements for the IA report are set out in an HTA guidance document specific for Scotland.[296] The HTA must be satisfied that the prospective donor is not an adult with incapacity[297] and that the prospective donor gives authorisation for removal and use of the organ for transplantation with no evidence of duress, coercion, or reward.[298] More specifically, on the basis of the IA donor interview, it must be established that the donor understands the medical procedure and risk involved and that authorisation may be withdrawn at any time before surgery,[299] has been given sufficient information about the surgical procedure and risk involved,[300] and has considered the wider implications arising from the intended donation, including any effect on children or dependants.[301] In relation to the interview with the donor, the report must cover the following items: any evidence of an offer or reward for donation; in directed donation, the relationship between donor and recipient; any evidence of duress or coercion affecting the

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[288] Human Tissue Act 2004 (Persons who Lack Capacity to Consent and Transplants) Regulations 2006 11(3)(a).

[289] Ibid., 11(3)(b).

[290] Guidance for Transplant Teams and Independent Assessors (n 197) [27].

[291] Human Tissue Act 2004 (Persons who Lack Capacity to Consent and Transplants) Regulations 2006 11(3)(c).

[292] Ibid., 11(9)(a)

[293] Ibid., 11(9)(b).

[294] Ibid., 11(9)(c)(i).

[295] Ibid., 11(9)(c)(ii).

[296] Guidance for Transplant Teams and Independent Assessors and Accredited Assessors in Scotland (n 244).

[297] Human Tissue Act 2004 (Persons who Lack Capacity to Consent and Transplants) Regulations 2006 2(2).

[298] Ibid., 2(5)(a), (c) and (d).

[299] Ibid., 2(5)(e).

[300] Ibid., 5(2)(f).

[301] Guidance for Transplant Teams and Independent Assessors and Accredited Assessors in Scotland (n 244) [39].

donor's decision, the information provided to the donor regarding the surgical procedure and the risks involved and the donor's capacity to understand this information; the donor's understanding of the wider implications of donation and that authorisation can be withdrawn at any time before surgery.[302]

Details of the donor evaluation by the IA are set out in the HTA Code of Practice F applicable in England and Wales.[303] The primary role of the HTA is stated as ensuring that valid consent is in place for organ removal; the IA should report evidence of any pressure to donate placed on the donor by any third party, which is used by the HTA to make a judgment on whether the will of the donor 'has been so overborne such that they can no longer make an independent decision'.[304] The IA report should also include any concerns that are relevant to the HTA's assessment of whether or not the legal requirements for approval of the application are satisfied.[305] Comparable requirements apply in Scotland where the IA report must confirm the following: any evidence of an offer or reward for the organ, any evidence of duress of coercion affecting the person's decision to authorise removal and use of the organ for transplantation, the information given to the donor as to the nature and risk of the surgical procedure, the person's capacity to understand this information and that their authorisation may be withdrawn at any time before organ removal, and the person's capacity to understand any wider relevant implications arising from donation such as the effect on any children or dependent relatives of the donor.[306]

The HTA describes its role as firstly, ensuring that there has been no reward sought or offered for the organ and secondly, providing an 'independent check to help protect the interests of living organ donors'.[307] However, these interests are only expressed in terms of giving the donor the opportunity to speak to the IA as a person who is not connected to the transplant unit so that the IA can confirm that the wish to donate is 'free from any pressure to act against their will'.[308] I argue that the formulation of this statement is significant because it highlights that the primary concerns of the HTA are the non-commercialisation of organs and the voluntariness of the decision to donate as freedom from external

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[302] Human Tissue Act 2004 (Persons who Lack Capacity to Consent and Transplants) Regulations 2006 5(6).

[303] HTA Code F: Part 1 (n 11) [37], [38].

[304] Ibid., [89].

[305] Ibid., [87].

[306] Guidance for Transplant Teams and Independent Assessors and Accredited Assessors in Scotland (n 244). [49], [50].

[307] Guidance for Transplant Teams and Independent Assessors' (n 11) [7]

[308] Ibid., [37].

pressure. The HTA's definition of voluntariness is simplistic and inadequately captures the complexity of the decision to be made, particularly in the context of close emotional or family relationships where the donor feels a moral duty to donate to the recipient and the pressure to donate is derived from the donor's own values and responsibilities. I will explore the moral burden of familial duties in more detail below. The point being made here is that these forms of pressure should not necessarily be characterised as third-party interference because they involve more complex processes of internalisation of expectations to donate that may or may not undermine the donor's ability to make an authentic choice.

3.3.4 Procedural autonomy

As discussed above, the HT A 2004, HT(Scotland)A 2006, HT Regulations 2006 and the HT(Scotland) Regulations 2006 set out requirements for disclosure of information and risks of organ removal and transplantation by the medical professional with clinical responsibility for the donor, the prohibition of payment, inducement or reward for the organ, and the duty of the HTA to exclude undue pressure or coercion by third parties. These provisions are concerned with the adequacy of consent, in the procedural sense, rather than the meaning of consent:[309] consent is valid if the prospective donor is informed, makes the decision to donate voluntarily with no expectation of a reward for the organ, and has the required capacity. However, these requirements say nothing about how the decision is or should be made in the first place.

In the context of organ transplantation, the decision to undergo a surgical procedure to resect an organ so that it can be transplanted into a person who is ill and needs it, in the knowledge that surgery carries only risks and no medical benefits to themselves, is a decision of a deeply personal nature. I argue that analytical and cognitive capacity cannot capture the underlying moral values, principles, and commitments that drive a decision to donate. The skills required to fulfil the legal concept of capacity demonstrate, at most, how an individual comes to a decision in operational terms. Understanding and appreciation of information, and balancing risk and benefits are processes but say little about why an individual makes the particular decision. Thus, there is force in the argument that by overlooking whether the choices made are those which the person values and genuinely

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[309] Price (n 176), 109.

wants,[310] capacity is committed to ostensible rather than substantive protection of autonomy.[311]

I take the view that conceptually, donor autonomy in living organ donation cannot be reduced to liberal arguments of freedom of choice and freedom from interference and that the decision to undergo inevitable and serious physical harm for no direct medical benefit to oneself should properly be regarded as a positive act of self-realisation and of fulfilment of one's purposes. The cognitive and analytical skills required for a determination of capacity to understand and process information about risk do not necessarily ensure that the decision accords with the individual's underlying values and their view of what risks are worth taking and how balancing of these risks should occur. In this sense, procedural requirements do not ensure respect for donor autonomy in a substantive sense. In the second part of this chapter, I will explore a range of motivations for living organ donation that I consider to be valuable elements for the understanding of a substantive account of donor autonomy. I then examine whether, despite these prima facie limitations in the legal and regulatory framework, the psychosocial evaluation by the transplant team as part of the donor screening process has due regard for a substantive understanding of donor autonomy.

I conclude that the idea of the patient as a rights holder cannot fully account for the substantive understanding of living donor autonomy that I explore in this thesis. When considering the prospective adult donor wishing to donate an organ, the concept of autonomy as a human right does not create a free standing right to demand that transplantation is carried out if this is not supported by the medical professional.[312] Under Article 8(2) of the ECHR, considerations of harm related the pre-existing health of the prospective donor or to the nature of the transplant requested, for example, donation of two kidneys[313] with the donor accepting the prospect of life-long dialysis need to be carefully balanced against any rights for respect of a choice to donate. In inter-familial donation, circumstances in which there is a strong preference towards donation among decision to

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[310] Coggon and Miola (n 291).

[311] Herring and Wall (n 192).

[312] In this sense there is an analogy with patient demands for treatment and as Brazier notes there is observes an understanding of autonomy as a positive obligation does not mean that '[w]hat I want should be delivered' see Brazier (n 171) 400.

[313] The issue of dual kidney donation materialised in the US where a bioethics committee rejected the offer of a father wishing to donate his single remaining kidney to his daughter following transplant failure of his previously donated kidney. See Philippa Bailey and Richard Huxtable 'When Opportunity Knocks Twice: Dual Living Kidney Donation, Autonomy and the Public Interest' 2016 30 Bioethics 119.

donate an organ On this view, the ethical concern lies more in the infringement of the patient's rights to be free from ignorance (liberty)[314] rather than in the how the use of this information relates to the exercise of autonomy.

3.4 The meaning of donor autonomy

3.4.1 Introduction

I contend that the traditional construct of autonomy in Western bioethics based on the patient-decision-maker as the self-interested, independent, and rational moral agent[315] offers limited insight into the meaning of autonomy for the living organ donor. The starting point for my arguments in this chapter is that an account of transplantation as a transaction in which the competent adult exercises their decisional authority to consent to the removal of an organ, freely and voluntarily, does not fully convey the intensely personal and unique way in which the choice to donate is made and how the act of donation affects the lives of the donor, the recipient, and the persons to whom they are close. Majeske argues that this reflects an 'impartialist' understanding of autonomy that compartmentalises the decision maker, disregarding the value of personal relationships in shaping the values and goals of the donor and how these influence the decision of whether to donate to a particular recipient.[316] Crouch and Elliott also highlight this ethical concern claiming that an individualistic construct is flawed because the donor is not acting in a vacuum; they propose an alternative analysis of living organ donation based on a relational concept of moral agency that takes into account how commitments and responsibilities within the donor-recipient relationship affect and shape the donor's interests.[317]

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[314] For a cogent analysis of the concepts of autonomy and liberty in medical decision see John Coggon and José Miola, 'Autonomy, Liberty, and Medical Decision-Making' (2011) 70 Cambridge Law Journal, 523.

[315] Ian Kennedy, *Treat Me Right: Essays in Medical Law and Ethics* (Clarendon Press 1988).

[316] RA Majeske, LS Parker, JE Frader JE 'In search of an ethical framework for consideration of decisions regarding live donation' in Spielman B (ed) Organ and Tissue Donation: Ethical, Legal and Policy Issues (Southern Illinois University Press), 89-101.

[317] Robert Crouch and Carl Elliott, 'Moral Agency and the Family: The Case of Living Related Organ Transplantation' (1999) 8 Cambridge Quarterly Healthcare Ethics, 284-285.

To be clear, an approach that values relationships and moral duties does not necessarily dismiss the values of freedom and liberty or detract from the focus on fostering decisions based on the individual's own standpoint.[318] I do not dispute that the voluntariness of a decision to donate is paramount and must be protected in law. However, setting aside radical libertarian claims, my starting point is that liberty to act and freedom from interference are not absolute entitlements and living donation requires a construct of autonomy that draws out the nuances of negative liberty, rather than adopting a binary approach in which liberty or freedom are seen as something that the individual either has or does not have. Emotional and social connections between persons have the potential to undermine self-determination but do not necessarily do so and decisions that are driven by relationships and moral responsibilities may still be autonomous if there is genuine acceptance of these commitments. A substantive view of autonomy goes beyond the individual's ability to choose and the freedom to act as one wishes and includes the decision to do so.[319] Here, I will focus on this decision to act or, more precisely, the decision-making process leading up to the action that the donor takes. Respect for donor autonomy requires medical professionals to take the wishes of the prospective donor seriously and to prioritise the donor's values.[320] Substantive autonomy places significant value on self-reflectiveness and the coherence in the donor's narrative of how the decision to donate was reached, focussing on the formation and consolidation of personal motives for donating an organ. It is substantive in its scrutiny of the content of the motivations for donation in order to determine whether these are problematic or unproblematic for decision-making.[321] Motivations are relevant to the determination of decision-making capacity because exploring the donor's perspective on how donation will affect their life [322] may reveal expectations based on false beliefs, or inconsistencies between the donor's stated goal and the likelihood of achieving this through the choice they are making, indicative of irrational thought processes, a manifestation of underlying psychopathology,

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[318] The authors also note that the community is not viewed as a unit but rather as a group of individuals with different personal interests and desires. This distinction is important as it marks distinction between socio-relational and communitarian approaches to autonomy. The relevance of communitarian accounts of autonomy to organ donation will be discussed in Chapter 3, in the context of deceased organ donation.

[319] Lars Øystein Ursin, 'Personal Autonomy and Informed Consent' (2009) 12 Medicine, Health Care and Philosophy 17.

[320] Richard Steiner and Arthur Matas, 'First Things First: Laying the Ethical and Factual Groundwork for Living Kidney Donor Selection Standards' (2008) 8 American Journal of Transplantation 930.

[321] Helena Hermann and others, 'Emotion and Value in the Evaluation of Medical Decision-Making Capacity: A Narrative Review of Arguments' (2016) 7 Frontiers in Psychology, 2.

[322] Margareta Sanner, 'The Donation Process of Living Kidney Donors' (2005) 20 Nephrology Dialysis Transplantation 1707.

or poor understanding of the risks.[323] Motivations may also be problematic because unmet expectations have psychosocial repercussions on the donor and may be associated with poor donor outcomes.[324] This highlights the need to thoroughly explore the reasons for seeking to donate an organ and the anticipated outcomes.

However, where motivations are based on values, any evaluation to determine those that are acceptable and those that are not, invariably presupposes an ideal system of moral values against which choices and actions are measured yet there remain fundamental questions regarding the ethical acceptability of certain motivations. There is minimal consensus in many areas, such as the degree of acceptable familial influence on autonomous decision making, the extent to which an external observer can adequately appreciate the emotional structure and dynamics of a particular family, whether expectations of advantages or other ‘secondary gains’ should rule out a prospective donor, and whether acceptability of the motivation for donation be judged independent of the particulars of the donor’s situation.[325] The lack of consensus on these issues means that there is a real risk that the evaluation of the prospective donor’s reasons for donating is based upon the assessor’s personal values and judged against their standards rather than considering the reasons according to donor’s own value system. This approach conflicts with the ethical concern that decisions to donate are made authentically, according to the values that the individual accepts as their own and upon which the decision to donate is based.

In the second part of this chapter, I set out the central ethical ideas emerging from the literature concerning motivations in living organ donation and specifically, altruism, personal values, and moral obligations. These are not distinct categories and the confluence between these motivations demonstrates the challenges involved in understanding the reasons individuals wish to donate and in making decisions regarding whether these individuals should be allowed to donate. This overview will serve as the theoretical basis for the final part of this chapter which examines whether the legal and regulatory framework requires authenticity in decisions to donate an organ and to what extent

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[323] Hannah Maple and others, ‘Motivations, Outcomes, and Characteristics of Unspecified (Nondirected Altruistic) Kidney Donors in the United Kingdom’ (2014) 98 Transplantation 1182; Giuliano Testa, ‘Ethical Issues Regarding Related and Nonrelated Living Organ Donors’ (2014) 38 World Journal of Surgery 1658 ; Antonia Henderson and others, ‘The Living Anonymous Kidney Donor: Lunatic or Saint?: Living Anonymous Kidney Donor’ (2003) 3 American Journal of Transplantation 203.

[324] Stephen Potts, ‘Transplant Psychiatry’ (2009) 39 The Journal of the Royal College of Physicians of Edinburgh 331.

[325] Biller-Andorno and others, (n 193), 353.

motivations are taken into account in the psychosocial screening of donor candidates by the transplant team and in the HTA approval process.

3.4.2 Authenticity and the role of emotions

The informed consent process requires medical professionals to disclose information, risks, and benefits of treatment and to ensure that the prospective donor understands and evaluates the information provided in reaching a decision.[326] This theoretically removes interference with decision making due to ignorance. The determination of capacity involves an assessment of the donor's understanding and processing of the information and of whether they have actually integrated it in their decision making.[327] Under the MCA 2005 and the AWI(Scotland)A 2000 this approach predominantly focusses on cognitive capacity,[328] ignoring non-cognitive factors such as emotions and moral values.

Critics of the exclusive focus of consent on deliberative rationality support the inclusion of the affective dimension of moral judgment for a more complete understanding of autonomous decision-making.[329] Silverman claims that the affective system plays a role in promoting a person's wellbeing because individuals pursue specific goals, values and interests because they feel differently about them.[330] On this view, an individual's preference for certain courses of action rather than others is not reducible to a rational calculation. In a persuasive critique of the failure of the legal concept of capacity to capture the nuances of autonomy, Herring and Wall[331] maintain that the assessment of rationality cannot account for emotions and 'affective attitude' understood as the desires, preferences, values, goals or commitments which are necessary to evaluate outcomes or consequences in order to effect preferences. Their argument is based on Charland's emotion theory construct[332] which recognises that emotions are crucial in giving priority to specific values

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[326] General Medical Council (n 232) .

[327] Rebecca Hays 'Contraindications to Living Donation from an ILDA Perspective' in Jennifer Steel (ed), Living Donor Advocacy: An Evolving Role Within Transplantation (Springer New York 2014), 206-207, 217.

[328] See Natalie Banner, 'Can Procedural and Substantive Elements of Decision-Making Be Reconciled in Assessments of Mental Capacity?' (2013) 9 International Journal of Law in Context 71.

[329] For an in-depth analysis see Carol Gilligan, *In a Different Voice: Psychological Theory and Women's Development* (Harvard University Press 2003); Eva Feder Kittay *Women and Moral Theory* Diana Meyers (ed.) (Rowman & Littlefield, 1987) Mackenzie and Stoljar (n 90).

[330] Henry Silverman, 'The Role of Emotions in Decisional Competence, Standards of Competency, and Altruistic Acts' (1997) 8 The Journal of Clinical Ethics 171.

[331] Herring and Wall (n 192), 703-704.

[332] Louis Charland, 'Appreciation and Emotion: Theoretical Reflections on the MacArthur Treatment Competence Study' (1998) 8 Kennedy Institute of Ethics Journal 359.

and preferences. The central idea is that emotions contribute to decision making in a distinctive way: they are complementary to cognitive and rational capacities by helping the individual understand personal values and the meaning of aspects of life which are essential to the pursuit of personal goals and preferences and allow the individual to make authentic choices which are consistent with their principles and values.[333] Accordingly, cognitive abilities assessed under the MCA 2006[334] are necessary to understand the nature and the likely consequences of an action but not sufficient to make a choice autonomously because this also requires the individual to appraise the action and its consequences according to their preferences, values, and goals.[335] Emotions play a complementary and constructive role in the processing of information,[336] the appreciation of a current situation and possible options,[337] and in the determination a person's goals and in motivating action.[338]

The structuralist focus on self-reflection appears to exclude impulsive choices from the sphere of autonomy: acting autonomously is conceptualised as acting in accordance with second order desires based on reflected values.[339] In a cogent critique of the judicial interpretations of autonomy refusal of treatment cases in English law, Coggon seeks to integrate behaviours that are calculating and those that are spontaneous within an overarching account of autonomy. He distinguishes between best desire autonomy, which broadly corresponds to actions that are consistent with the agent's value system and may go against the agent's immediate inclination, and current desire autonomy, defined as conscious but unreflected or poorly reflected choices.[340] Best desire autonomy, Coggon claims, is to be preferred for 'serious decision-making'.[341] However, instinctive actions should not be dismissed as irrelevant to autonomous decision-making and Friedman makes two important points: firstly, self-reflection need not occur closely prior to the decision-

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[333] Ibid. See also Silverman (n 322).

[334] These arguments also apply to the assessment of capacity under the AWI(Scotland) 2000.

[335] Herring and Wall (n 192), 704.

[336] PaulAppelbaum, 'Ought We to Require Emotional Capacity as Part of Decisional Competence?' (1998) 8 Kennedy Institute of Ethics Journal 377.

[337] Charland (n 324), 359-376.

[338] Silverman (n 222).

[339] Harry Frankfurt, 'Freedom of the Will and the Concept of a Person' (1971) 68 The Journal of Philosophy 5.

[340] John Coggon, 'Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?' (2007) 15 Health Care Analysis 235. Coggon also identifies a third category of ideal desire autonomy which requires decision-making to accord with an objective set of ideals and is compatible with Kantian autonomy.

[341] Ibid., 241

making process and may in fact have occurred in the distant past;[342] and secondly, the value or importance of what matters to a person does not need to be explicitly articulated and actions that 'express an agent's emotions and character' can still reflect deeper values if they reflect coherence with attitudes over time.[343]

Friedman's claims are critical to my analysis because they challenge traditional assumptions that instinctive reasoning and action are incompatible with the demands of substantive autonomy that I claim are relevant in living donation. Emotional decision-making can be autonomous in a substantive way when choices express what genuinely matters to the person and are informed by feelings attached to preferred options, outcomes or states of affairs.[344] Therefore, at the very least, careful scrutiny of decisions that appear prima-facie instinctive and precipitous is required to identify deeper unarticulated motives and the aim of my enquiry in the third part of this chapter is to explore how decisions to accept or reject a donor candidate take into account affective factors.

Hellman et al. recognise the importance of understanding the role of emotions and values in medical decision-making and the challenges of incorporating these into evaluations of consent that are predominantly based on rational and cognitive elements.[345] Early studies of decision-making processes among prospective living donors identified a disregard for information and data on risk. In the 1970s, Fellner and Marshall reported that most interviewed kidney donors made an immediate decision without considering information provided by medical professionals or weighing alternatives.[346] In their classic work on the sociology of transplantation, Simmons and colleagues found that the majority of donors made a decision as soon as they became aware of the recipient's need for an organ.[347] The made the important distinction between moral reasoning, or decisions to donate based on the donor's hope and willingness to help, and deliberative reasoning which involves a careful analysis of the real risks and benefits of donation.[348] These findings are corroborated by post-transplant interviews with donors revealing that their decision to

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[342] Marilyn Friedman. A Conception of Autonomy, *Autonomy, Gender, Politics* (Oxford University Press 2003), 8.

[343] Ibid., 9.

[344] Silverman (n 282).

[345] Hermann and others (n 271), 2.

[346] Carl Fellner and John Marshall, 'Kidney Donors--the Myth of Informed Consent' (1970) 126 The American Journal of Psychiatry 1245.

[347] Roberta Simmons, Susan Klein Marine, and Richard Simmons, *Gift of Life: The Effect of Organ Transplantation on Individual, Family, and Societal Dynamics* (Transaction Books 1987), 233-285.

[348] Ibid.

donate is often made instinctively before being given medical information,[349] they are fully committed to donation by the time surgery and eligibility are discussed with the transplant team,[350] the immediate decision does not change when they are informed of the risks of surgery,[351] and they are unreceptive of medical information or of any suggestion that they should make a more informed decision in the light of further counselling.[352]

These findings raise concerns about the validity of consent as the decision to donate appears to be made with incomplete information on the procedure, inadequate understanding of the risks of donation, and limited deliberation. It is important to consider whether respecting decisions which do not meet the traditional informed consent criteria would allow individuals to sacrifice their own welfare too radically or whether this allows individuals to pursue deeply held values and ultimately serve a deeper sense of autonomy and a higher sense of well-being.[353] Some commentators argue that such decisions should be dismissed because in living organ donation compliance with the requirements for informed consent is non-negotiable.[354] Yet many are sceptical of the 'myth of informed consent' as far as organ donation is concerned.[355] In the healthcare context more generally, Beauchamp and Childress argue that full understanding of the information pertaining to a medical decision is impractical and unrealistic and that less than fully informed consent may still be valid as long as there is substantial understanding.[356] This is consistent with the approach of the Nuffield Council on Bioethics that fully informed consent remains largely an unattainable ideal while the ethically significant requirement is that consent is genuine.[357] In living organ donation, Spital makes a compelling argument against the

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[349] Sam Goldman, 'Liver Transplantation Using Living Donors. Preliminary Donor Psychiatric Outcomes' (1993) 34 Psychosomatics 235; Megan Crowley-Matoka, Mark Siegler, and David Cronin, 'Long-Term Quality of Life Issues Among Adult-to-Pediatric Living Liver Donors: A Qualitative Exploration' (2004) 4 American Journal of Transplantation 744.

[350] Jochen Schweitzer and others, 'Psychological Consultation before Living Kidney Donation: Finding out and Handling Problem Cases' (2003) 76 Transplantation 1464; Reese, Boudville, and Garg (n 185); Lynn Stothers, William Gourlay, and Li Liu, 'Attitudes and Predictive Factors for Live Kidney Donation: A Comparison of Live Kidney Donors versus Nondonors' (2005) 67 Kidney International 1105.

[351] Sanner (n 272), 1707-11.

[352] Sue Russell and Rolf Jacob, 'Living-Related Organ Donation: The Donor's Dilemma' (1993) 21 Patient Education and Counseling 89.

[353] Sauder and Parker (n 17), 405-407.

[354] Peter Reese and others, 'Creating a Medical, Ethical, and Legal Framework for Complex Living Kidney Donors' (2006) 1 Clinical Journal of the American Society of Nephrology, 1148.

[355] Fellner and Marshall (n 338).

[356] Beauchamp and Childress (n 73).

[357] Nuffield Council on Bioethics, *Human Tissue, Ethical and Legal Issues* (KKS Printing 1995), 199.

traditionally held view[358] that consent must always be fully informed consent. This, he writes, would only be justified if fully informed consent were the 'sole medium through which a potential donor can express his autonomy'.[359] Spital's central claim is that autonomy and informed consent are not the same and that not-fully-informed consent, at least in the context of personal relationships between the donor and the recipient, may still be valid consent where it is a genuine expression of the care and concern for the recipient; in this sense immediate decision-making can be properly regarded as 'an expression of autonomy'.[360] On this view, the value of autonomy lies in the authenticity of the decision understood as reflecting the donor's values. This point is central to the question posed by O'Neill and Manson[361] about the importance of considering why certain choices should be protected and not others. I contend throughout this thesis that the meaning of autonomy in decisions to donate an organ in life to another person is inextricably linked to the reasons for donation and that respect for the autonomy of the donor means identifying choices that are authentic and carefully considering even those that appear impulsive at first glance. Veatch and Ross also support the view that an instantaneous decision is not necessarily inadequately informed:

> Some offers are so obviously compatible with one's basic commitments and life plan that very little if any information is needed. Such poorly informed decisions may nonetheless be autonomous and consistent with one's life plan[362]

Authenticity means that the person's decision must be their own in the sense that the person identifies with these values and commitments and that these are coherent with the person's sense of identity and what matters to them.[363] Unlike objective tests of capacity based on the ability to understand and use information to make a decision, authenticity requires the individual to evaluate their decision against the values and principles that are important to them. Foster questions whether there exists a core self which can be unequivocally identified as the author of the life-plan upon which autonomy rests.[364] He notes that individuals have a multitude of roles, considering the example of the terminally

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[358] The Authors for the Live Organ Donor Consensus Group, 'Consensus Statement on the Live Organ Donor' (2000) 284 JAMA: The Journal of the American Medical Association 2919.

[359] Spital (n 192).

[360] Ibid.

[361] Manson and O'Neill (n 149).

[362] Robert Veatch and Lainie Friedman Ross, *Transplantation Ethics* (2nd edn, Georgetown University Press 2015), 210.

[363] Catriona Mackenzie and Wendy Rogers, 'Autonomy, Vulnerability and Capacity: A Philosophical Appraisal of the Mental Capacity Act' (2013) 9 International Journal of Law in Context 37, 43.

[364] Foster, '(n 199) 61.

ill patient who wishes to die peacefully yet as a religious follower declines palliation, and as a mother wants to prolong life with her children.[365] It is important to recognise that values and commitments change during a lifetime and that this can be a challenge in defining who the authentic person is. However, the fluid nature of these values and duties can be accommodated. Within a structuralist framework, Frankfurt emphasises that autonomy is acting in accordance with a value system (second-order desires) that need not be permanent but is settled in the sense that it is recognised by the individual as their own value system[366]; similarly, Dworkin identifies a 'sense of the self' and that individuals have the ability to act out of genuine conviction or preference, although he admits that competent persons do not always have consistent values, make consistent choices, or lead reflective lives.[367]

I argue that affective decision-making and the authenticity of choices to donate, in so far as these relate to moral standards and priorities, can be properly identified by diligent mental health evaluation. In many cases, at least within established donor-recipient relationships, values are reasonably settled and reflected in the prospective donor's way of living and interacting with significant others. Where there are concerns about erratic behaviour, inconsistent beliefs and values, and unstable personal relationships, exploration of these issues with the prospective donor is required. However, this task by no means unconventional as in the broader context of mental health, evaluations are routinely conducted by professionals who are trained to engage with patients on these matters. In the following sections I explore the motivations underpinning affective decision-making and consider how these motivations relate to the authenticity of the decision to donate.

3.4.3 Motivations: altruism and self-interest

The obvious starting point in the analysis of motives for organ donation is altruism as this has been endorsed as a fundamental principle of organ donation in the UK.[368] The Nuffield Council on Bioethics recognised that 'the notion of altruism as underpinning important communal values expresses something very significant about the kind of society in which

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[365] Ibid., 61.

[366] Frankfurt, 'Freedom of the Will and the Concept of a Person' (n 331).

[367] Ronald Dworkin, *Life's Dominion: An Argument about Abortion and Euthanasia* (HarperCollins 1993), 224-225.

[368] 'Nuffield Council on Bioethics (n 349); Guidelines for Living Donor Kidney Transplantation (n 179); Guidelines Living Donor Liver Transplantation (n 179); Marie-Chantal Fortin and others, 'The Enigmatic Nature of Altruism in Organ Transplantation: A Cross-Cultural Study of Transplant Physicians' Views on Altruism' (2010) 3 BMC Research Notes 216.

we wish to live'.[369] This reflects entrenched views within the transplant community that altruism is the only acceptable motive for living donation.[370] However, critics question the unqualified use of altruism as the ethical justification for living organ donation on grounds that it is a concept with many different interpretations and there is no convincing reason to place altruism above other reasons for donating.[371] Here, I explore the use of altruism in organ donation policy in the UK and its relationship with other motivations for donation.

From a philosophical standpoint there are divergent views on whether pure altruism exists and whether mixed motivations are coherent with altruism. For Derrida absolute altruism is an impossible paradox. Genuine giving must remain beyond self-interest and egocentric calculations so it cannot be understood to be giving: altruism is annulled by any recognition or even apprehension of the good deed.[372] It is hard to see how a construct of altruism based on such uncompromising requirements may apply to the reality of transplantation. Even in non-directed donation, where anonymity is preserved and there is no direct or indirect communication between the donor and the recipient, the consent giving process requires the donor to confront questions about the goodness of the donation in terms the benefits to the recipient, and to consider the risk to themselves. A more relevant characterisation of altruism as a motive for living organ donation is based on whether it is pure, in the sense of donation that is exclusively motivated by concern for the needs of others, or mixed, in the sense of altruism that also accommodates other self-serving interests in donation. Nagel conceptualises altruism as objective and rational behaviour: it is acting in the interests of others without the need for further motives.[373] On this view, the interests of the recipient are the reason for acting altruistically and other partial reasons, traceable to the relationship with the recipient and sympathy with their plight are not.[374] Similarly, Gauthier conceives altruistic behaviour purely as a rational capacity.[375] Blum does not dismiss rational altruism but also recognises altruism as action based on altruistic emotions, such as sympathy compassion, and concern, towards another

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[369] 'Nuffield Council on Bioethics, Human Bodies: Donation for Medicine and Research. London: Nuffield Council on Bioethics, 2011', 5

[370] Michael Abecassis and others, 'Consensus Statement on the Live Organ Donor' (2000) 284 JAMA 2919.

[371] Gregory Moorlock, Jonathan Ives, and Heather Draper, 'Altruism in Organ Donation - An Unnecessary Requirement' (2012) 94 Transplantation Journal 143; Ben Saunders, 'Altruism or Solidarity? The Motives for Organ Donation' (2012) 26 Bioethics 376.

[372] Jacques Derrida, 'Given Time: I. Counterfeit Money'. Peggy Kamuf (translator) (The University of Chicago Press 1992), 23.

[373] Thomas Nagel, *The Possibility of Altruism* (Princeton University Press 1978), 1.

[374] Ibid., 16.

[375] David Gauthier, *Morals by Agreement* (Reprint [der Ausg] 1986, Oxford University Press 2006), 238.

person.[376] These emotions blur the line between pure and mixed altruism because of the positive effects that the donor may derive from doing the right thing. Frankfurt wrote extensively on the relationship between self-interest and other-regarding interests within loving relationships, although primarily from the perspective of developing a coherent theory of personal autonomy that could accommodate our commitments towards the flourishing of persons we care about. For Frankfurt, caring for others is not antithetical to personal autonomy, rather the act of caring for someone that is important to a person constitutes part of that person's identity: the individual identifies with the interests of a loved one because they are invested in the person they love, invested in the sense that the individual's life is enhanced when the interests of a loved one prevail and harmed when these are defeated.[377] This account of altruism accepts that the partiality of relationships can be a strong motivating factor for our actions.

However, it is not always clear that altruism in the sense of other-regarding attitude is the central concern in transplantation from a policy perspective. In fact, a different understanding of altruism that is largely identified with voluntariness and non-commercialisation seems to pervade the UK transplantation context.[378] For example, the British Transplant Society (BTS) guidelines on living donor kidney and liver transplantation state that altruism 'reinforces the philosophy of voluntary […] donation'.[379] In my view, this is not a necessary connection and the two concepts should not be conflated: voluntariness means that the decision to donate is deliberate and free from undue pressure or coercion and says nothing about whether a particular decision is made for the benefit of others. In fact, a decision to donate made freely and voluntarily by the individual may be driven by self-interest. The interests driving the choice to donate, whether these are self-regarding, other-regarding, or a combination of both, are relevant to authenticity because in recognising these interests and in acting upon them the individual makes a choice that is genuinely theirs and autonomous in a substantive way.

This raises the question of what altruism is understood to be in the UK transplantation context. The term 'altruism' is used in relation to donation to strangers, referred to as

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[376] Lawrence Blum, *Friendship, Altruism and Morality* (Routledge Revivals 2010).

[377] Harry Frankfurt, *The Reasons of Love* (Princeton University Press 2019), 61-62.

[378] Moorlock, Ives and Draper (n 391).

[379] William Plant, Murat Akyol, and Chris Rudge. The Ethical Dimension to Organ Transplantation in John Forsythe (ed) Transplantation Surgery (2nd edn). (WB Saunders 2002) referred to in the Guidelines for Living Donor Kidney Transplantation' (n 61), 24.

'altruistic living donation' by the BTS and in NHS policy documents.[380] Members of the European Platform ELPAT (Ethical, Legal and Psychosocial Aspects of Organ Transplantation) published a revised classification of living organ donators in which the use of the term 'altruistic donation' is replaced by 'unspecified donation' to provide legal clarity, the idea being that the term 'unspecified' is objective and neutral because it simply describes the fact that the donor is donating an organ anonymously to a stranger.[381] Removing all connotations linked to altruism was considered important because altruism makes assumptions about motives and it was recognised that pure altruism may not exist and some form of personal gain may occur with anonymous donations to strangers. Nonetheless, in the UK, the term 'non-directed altruistic living donation' persists and this characterisation of donation types is used in HTA documents and professional guidance by the BTS.[382]

Intuitively, the idea that an individual donates an organ anonymously to an unknown person appears to fulfil a stringent interpretation of altruism as a selfless and gratuitous act primarily undertaken to help another human being. The anonymity of the recipient means that the donor relies on the abstract idea of human suffering rather than acting in response to the particular suffering and need of an identifiable person.[383] Glannon and Ross characterise non-directed living organ donation as a form of 'cosmopolitan altruism' which is 'directed toward the human race as a whole, and hence toward individuals toward whom one has no special ties'.[384] Empirical evidence indicates that the motives of most non-directed donors are based on a sincere desire to help another person.[385] Persons willing to

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[380] The preferred term is now unspecified donation although the use of altruistic donor still figures in the online materials available on NHSBT 'BTS UK Guidelines Living Donor Liver Transplantation, July 2015' (n 164); 'British Transplantation Society and Renal Association. Guidelines for Living Donor Kidney Transplantation' (n 164).

[381] Frank Dor and others, 'New Classification of ELPAT for Living Organ Donation' (2011) 91 Transplantation 935.

[382] See NHSBT https://www.organdonation.nhs.uk/become-a-living-donor/donating-your-kidney/donating-a-kidney-to-someone-you-dont-know/ Organ Donation Scotland accessed 15 December 2022

[383] Paweł Łuków, 'Pure Altruistic Gift and the Ethics of Transplant Medicine' (2020) 17 Journal of Bioethical Inquiry 95, 98.

[384] Quoting Galston W. Cosmopolitan altruism. In: Ellen Frankel Paul, Fred D Miller, and Jeffrey Paul (eds), *Altruism* (Cambridge University Press 1993), 123.

[385] Rebecca Gare and others, 'Understanding Barriers and Outcomes of Unspecified (Non-Directed Altruistic) Kidney Donation from Both Professional's and Patient's Perspectives: Research Protocol for a National Multicentre Mixed-Methods Prospective Cohort Study' (2017) 7 BMJ Open e015971; Roy Gohh and others, 'Controversies in Organ Donation: The Altruistic Living Donor' (2001) 16 Nephrology, Dialysis, Transplantation: Official Publication of the European Dialysis and Transplant Association - European Renal Association 619; James Rodrigue and others, 'Altruistic Kidney Donation to a Stranger: Psychosocial and Functional Outcomes at Two US Transplant Centers' (2011) 91 Transplantation 772; Allison Tong and others, 'It Was Just an Unconditional Gift.' Self Reflections of Non-Directed Living Kidney Donors: Perspectives of Altruistic Donors' (2012) 26 Clinical Transplantation 589.

donate an organ to a stranger are moved by a general desire to help someone in need with donation making little difference to them directly and are more likely to engage in other forms of altruistic behaviour, such as charity work or blood donation.[386] This suggests that the choice to donate reflects a broader predisposition towards helping others.

However, qualitative research on the attitudes of medical professionals toward donor candidates indicate that some have reservations about the practice and there is generally poor understanding of the motives of individuals wishing to donate to a stranger and a presumption of underlying mental health issues.[387] This appears consistent with donor accounts that the psychological evaluation elicited feelings of vulnerability[388] and was often the most concerning part of the screening workup[389] with donors feeling that they were having to repeatedly justify their wish to donate against efforts to dissuade them.[390] Careful examination of the reasons for donating appears to be justified for the protection of the donor and to ensure that their motivation is not to fulfil some psychological need.[391] However, it is important to acknowledge that there is likely to be a threshold for the level of scrutiny of these reasons beyond which choices, and therefore autonomy, are de-valued.[392]

There appears to be a tension between the ostensible emphasis on altruism from a policy perspective and the perception by persons donating to strangers that their reasons for donation are viewed with suspicion or a with a presumption of underlying mental health issues. Paradoxically, non-directed donation is regarded by some commentators as the only form of living donation in which consent can be fully autonomous: the choice is authentic because the donor-recipient relationship is not relevant to the decision to donate[393] and third-party pressure is less likely to be a relevant factor. If respect for donor autonomy

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[386] Hannah Maple and others, ‘Donating a Kidney to a Stranger: A Review of the Benefits and Controversies of Unspecified Kidney Donation’ (2020) 272 Annals of Surgery 45.

[387] Steel (n 319).

[388] Alexis Clarke, Annie Mitchell and Charles Abraham, ‘Understanding Donation Experiences of Unspecified (Altruistic) Kidney Donors’ (2014) 19 British Journal of Health Psychology 393.

[389] Ibid.

[390] Ibid.

[391] Francis Kane, Grace Clement and Mary Kane, ‘Live Kidney Donations and the Ethic of Care’ (2008) 29 Journal of Medical Humanities 173.

[392] The point that investigations into treatment refusal may diminish self-determination was made by McLean (Autonomy, consent, and the law p.107) in the response to the assertion by Callahan that the decision-making process and the choice itself should be taken into account over the more general right to choose see Daniel Callahan, The troubled dream of life: in search of a peaceful death (Georgetown University Press, 2000), 36.

[393] Gohh and others (n 376), 619-621.

matters, it is important to examine on what principles acceptability of certain motivations and certain relationships rather than others is based.

Nevertheless, the use of altruism to differentiate between donation to a specific recipient and donation to an unknown person is problematic because by seemingly inferring that the latter is more altruistic, it makes assumptions about the reasons a person chooses to donate to a stranger. While prima facie, the prioritisation of other-regarding interests over self-regarding interests is easily reconcilable with non-directed donation, empirical evidence shows that donors also report positive feelings after donation such as improved self-esteem, fulfilment, contentment, empowerment, and a sense of peace.[394] Non-directed donors describe the reward for donating in terms of the meaningfulness of making a profound difference to another person's life and personal satisfaction.[395]

Of course, any psychological benefit derived from donation should be properly distinguished from the expectation to fulfil a self-regarding interest, a sort of quid pro quo in which the donor expects to derive some benefit in return.[396] Nonetheless, it is not clear that the use of the label 'altruistic' in relation to donation to an unknown person properly reflects the fact that pleasure or reward may be derived both from helping a stranger and from helping a particular person. Furthermore, the endorsement of solidarity and reciprocity is also well documented and non-directed donation has been variously described by donors as 'giving back to the community', a means to convey the person's gratitude and appreciation for a good life,[397] and 'doing something which you would want others to do for you'.[398] Again, references to altruism do not properly account for these aspirations.

Recognising that a genuine desire to help another person may be the primary or one of the reasons for organ donation is important because it is the first step in the attempt understand the decision and ensuring that the choice is authentic. However, there is no convincing explanation for why altruism should be regarded as the paramount motive for donating

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[394] Allison Tong and others (n 376).

[395] Annika Kisch and others, 'The Meaning of Being a Living Kidney, Liver, or Stem Cell Donor—A Meta-Ethnography' (2018) 102 Transplantation 744..

[396] Walter Glannon and Lainie Friedman Ross, 'Do Genetic Relationships Create Moral Obligations in Organ Transplantation?' (2002) 11 Cambridge Quarterly of Healthcare Ethics 153, 154

[397] Ibid.

[398] Lindsey Dorflinger and others, 'Assessing Living Donor Priorities Through Nominal Group Technique' (2018) 28 Progress in Transplantation 29.

over solidarity, moral obligations, and self-interested motives. A range of motivations based on the donor's self-interest have been identified.[399] Taking aside financial and non-financial rewards, which are unlawful, these relate to donor expectations regarding the relationship with the recipient post-transplantation. These motivations include strengthening or repairing the relationship with the recipient and restoring family connections, gaining recognition from others for their sacrifice, and also more practical considerations, such as improving the recipient's participation in family life and the recipient's capacity to financially contribute to the household income, and seeking relief of the donor's social caregiving burden.[400] A recent meta-analysis of the experience of both non-directed and directed donors identified a sense of duty to do what they felt they had to do as the overriding drive for donation.[401] In the context of donation to close family Glannon and Ross reject the idea that donation carried out to fulfil moral responsibilities towards a specific recipient is altruistic, notwithstanding its moral worth.[402] Familial obligations will be examined in more detail next but for the purpose of this discussion, it is important to acknowledge the individual's perception that donation is discharging a personal duty to ensure the recipient's wellbeing is another facet of the increasingly diverse narratives underpinning a choice to donate. These findings do not negate a wish to help the recipient for the recipient's sake but do support a reconsideration of traditional assumptions of altruism as the only ethically acceptable reason for donation. It must be recognised that the heterogeneity of living donors cannot be reduced to a homogenous attitude towards donation[403] and that the specific focus on altruism is a simplistic view of the mixed and complicated reasons for donating.[404] My contention is that unpacking the motivations for donation is a crucial function of the donor screening process in order to understand whether the choice to donate is authentic and determine whether these motivations are accepted or rejected in the HTA approval process.

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[399] Myriam Guedj, Maria Sastre, and Etienne Mullet, 'Donating Organs: A Theory-Driven Inventory of Motives' (2011) 16 Psychology, Health & Medicine 418.

[400] Angelique Ralph and others, 'Donor and Recipient Views on Their Relationship in Living Kidney Donation: Thematic Synthesis of Qualitative Studies' (2017) 69 American Journal of Kidney Diseases 602, 612.

[401] Kisch and others (n 386), 754.

[402] Glannon and Ross (n 387), 154.

[403] Price, *Legal and Ethical Aspects of Organ Transplantation* (Cambridge University Press 2000).

[404] Williams (n 176).

3.4.4 Motivations: moral obligations and interfamilial donation

I discussed in Chapter 2 how individualistic accounts of autonomy look at the decision-maker in isolation and regard external sources of pressure as undermining the self-determination of the individual. Clearly, there are important questions to be asked regarding the proper boundaries of ‘persuasion’, ‘manipulation’, and ‘influence’ by third parties. Spital observes that these concepts are relevant to donation to unrelated persons as a crucial role of informed consent in this context is to prevent the exploitation of the donor.[405] However, in donation between donors and recipients who share a close personal relationship, framing the question in terms of exploitation, Spital claims, is not appropriate because the central ethical concern is whether the decision to donate is genuine.[406] This is not to deny the possibility of external pressure by family members, the point is to avoid preconceptions that influence necessarily diminishes voluntariness and scrutinise how the influence is perceived by the prospective donor. It is important to examine whether the person can separate their wishes and values from those of other family members and whether they have insight into the fact that others, consciously or unconsciously, are exerting pressure to make the decision they see as right.[407] The degree of intimacy between family members plays a significant role in determining how a prospective donor perceives their obligations to other family members.[408]

In the context of donation involving ties of affection between the donor or the recipient, the characterisation of the sense of pressure to donate mainly as a form of external pressure does not fully capture the complexity of the relationship dynamics. Influence may be reflectively internalised so that the donor genuinely endorses action that conforms with the expectations of family members.[409] The blurring of the boundaries between external and internal pressure to donate represents a considerable challenge in the assessment of whether the decision that the donor makes is truly theirs. External influences will be perceived differently or even not at all by each potential donor and may exist alongside

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[405] Spital (n 192), 189

[406] Ibid., 190.

[407] Betsy Johnson ‘A Practical Guide: Role of the Independent Living Donor Advocate: Protect or Advocator Is it Both?’ in Jennifer Steel (ed), *Living Donor Advocacy: An Evolving Role Within Transplantation* (Springer 2014), 316.

[408] Glannon and Ross (n 387), 157.

[409] Rosamond Rhodes Autonomy, Agency and Responsibility: Ethical Concerns for Living Donor Advocates in Steel (n 358). p 305-6

personal motivations to donate so it is important to carefully explore these influences and evaluate their real impact on the decision-making process.[410]

The mere existence of living donation as a treatment option for end-stage organ failure can itself place pressure upon individuals to donate to a loved one.[411] For example, interviews with prospective donors reveal that despite their understanding that deceased donation is an alternative, living donation is perceived as the only option for the recipient that is acceptable in the circumstances.[412] This internal pressure arises from the donor's moral values, conscience or love for the recipient and plays a critical role in the decision-making process yet it is not clear whether we are willing to accept it as a more benign form of pressure compared to pressure from external sources and if so, on what basis.[413] In the context of interfamilial donation, the pressure to donate has been framed in terms of a moral duty.[414] There is considerable divergence of opinion on the impact of moral obligations towards the recipient on the ability of the individual to make an autonomous decision to donate.[415] An extreme view regards the sense of duty as a coercive force.[416] However, even where donors perceive that there is no choice other than donation this does not necessarily mean that the individual is not acting autonomously.[417] Rhodes, drawing on her experience as an independent living donor advocate, offers an insightful analysis of statements made by prospective donors, such as 'my family expects this of me', and emphasises the importance of probing these testimonials because while many donors may conform to family expectations they may also genuinely endorse these commitments.[418] From this perspective, genuine endorsement of one's responsibilities may be an expression of autonomy.

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[410] Cindy Koslowski Brown 'Pressure and Coercion' in Jennifer Steel (ed.) *Living Donor Advocacy: An Evolving Role Within Transplantation* (Springer 2014), 275.

[411] Ibid.

[412] Annette Lennerling, Anna Forsberg, and Gudrun Nyberg, 'Becoming a Living Kidney Donor' (2003) 76 Transplantation 1243.

[413] Marjorie Clay 'Education of the Donor by the ILDA (Psychosocial Aspects)' in Jennifer Steel (ed.) *Living Donor Advocacy: An Evolving Role Within Transplantation* (Springer 2014), 76

[414] Arthur L Caplan, 'Am I my brother's keeper?' (1993) 27 Suffolk University Law Review 900.

[415] Spital (n 192).

[416] Anna Forsberg and others, 'The Essence of Living Parental Liver Donation - Donors' Lived Experiences of Donation to Their Children' (2004) 8 Pediatric Transplantation 372.

[417] Faden, Beauchamp and King (n 14), 344-345.

[418] Rosamond Rhodes 'Autonomy, Agency, and Responsibility: Ethical Concerns for Living Donor Advocates' in Steel (n 358), 305-6.

Moreover, the argument that familial donations are not made freely is frustrated by the reality that intimates may not want to separate their interests from those of the recipient.[419] The intertwining of individual interests is a manifestation of family dynamics and emotional bonds between family members more generally.[420] The need to balance these interests is a universal feature of any decision-making within family relationships[421] and is not unique to donation.[422] Prospective donors are individuals with lives of their own who have duties and responsibilities towards other family members and personal relationships and commitments that will be affected by donation and these should be taken seriously.[423] It must be recognised that a sense of a moral duty to donate is a strong motivating factor.[424] Nowhere is perception more acute than in the case of parents seeking to donate an organ to their child.

Organ donation by parents to their children illustrates the futility, in practice, of approaches focussing on the separation of individualistic rational choice from moral obligations. The acceptance by parents of donation as an extension of the familial duty of care towards the child in need is well recognised.[425] The first live liver transplants performed in the United States in the 1980s and involving parent donors and child recipients triggered intense ethical debate regarding the issue of the validity of consent. In 1989, ethicist Arthur Caplan, questioned whether parents could realistically refuse to undergo a procedure when the alternative was certain death for their child. In a comment in the New York Times on a mother to daughter transplant performed by a team at the University of Chicago, Annas wrote ‘The parents basically can’t say no’.[426] These concerns have been echoed in more recent times in the context of both liver and kidney transplants, with studies reporting the perception among parents that donation is the only option

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[419] Lainie Friedman Ross and others, ‘Should All Living Donors Be Treated Equally?’ (2002) 74 Transplantation 418, 419.

[420] Singer and others (n 170).

[421] Ross and Thistlethwaite (n 158).

[422] Singer and others (n 170), 320.

[423] Medard Hilhorst, Leonieke Kranenburg and Jan Busschbach, ‘Should Health Care Professionals Encourage Living Kidney Donation?’ (2007) 10 Medicine, Health Care and Philosophy 81.

[424] Mare Knibbe, Els Maeckelberghe, and Marianne Verkerk, ‘Confounders in Voluntary Consent about Living Parental Liver Donation: No Choice and Emotions’ (2007) 10 Medicine, Health Care and Philosophy 433, 435.

[425] Simmons, Marine, and Simmons (n 368).

[426] Crouch and Elliott (n 338).

available.[427] The scale of the issue is difficult to ascertain as studies generally involve small samples of donors and there are significant methodological differences in the way donor perceptions are explored.[428] Nonetheless, these findings do raise concerns regarding the voluntariness of the consent process when parents agree to donate an organ to their child.

Siegler and Lantos warn against the 'internal coercion' exerted by conscience and guilt.[429] However, Crouch and Elliott claim that the idea of moral obligations generating internal coercion is based on an understanding of moral agency which equates freedom with independence from others and self-interest: moral commitments associated with intimacy are regarded as coercive because they result in a course of action which a completely independent individual would not take.[430] This view, the authors argue, disregards the fact that moral and emotional commitments are part of ordinary human life and that most parents make sacrifices for their children unhesitatingly.

A sense of a moral responsibility to donate to a loved one is a natural instinct that does not necessarily mean that the decision-making process is non-autonomous.[431] Furthermore, questioning the freedom of the decision in the context of living organ donation would necessarily involve questioning a range of decisions involving sacrifice by parents for the benefits of their children, including, for example, financial sacrifices to pay for college fees.[432] Crouch and Elliott argue that duties and responsibilities, rather than constraining a parent's autonomy, 'give voice to [her] autonomy and say something about the kind of agent [she] is and the kind of family of which [she] is a member'. So rather than dismissing the idea of obligation towards another as coercion, these responsibilities must be taken seriously if we want to understand how family members can make free choices about organ donation.[433] Burnell and colleagues conducted semi-structured interviews of parent donors

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[427] Lennerling, Forsberg, and Nyberg (n 363); Patricia Franklin and Alison Crombie, 'Live Related Renal Transplantation: Psychological, Social, and Cultural Issues' (2003) 76 Transplantation 1247; Fujita and others (n 165); Forsberg and others (n 367).

[428] Steel (n 358).

[429] Mark Siegler, John Lantos. Commentary: Ethical justification for living liver donation. (1992) 1 Cambridge Quarterly of Healthcare Ethics 320, 323.

[430] Crouch and Elliott (n 338).

[431] Singer and others (n 243), 620-622; Emma Massey and others, 'The ELPAT Living Organ Donor Psychosocial Assessment Tool (EPAT): From "What" to "How" of Psychosocial Screening - a Pilot Study' (2018) 31 Transplant International 56; Crouch and Elliott (n 129), 275-287.

[432] Crouch and Elliott (n 338), 276-278.

[433] Ibid.

to explore whether they felt that they had a genuine choice to donate.[434] Observing that parents perceived a sense of obligation to donate which was rooted in the fact that they identified their interests with those of their children, the authors make a compelling argument that to conclude that this sense of duty negates voluntariness would imply that all behaviour that is morally motivated and precluding alternative courses of action would be, by default, coerced.[435]

Research exploring statements that there was no choice but to donate have revealed that what parents really mean is that there is no acceptable alternative and offering to become an organ donor out of a moral duty to save one's child, may still be a choice for many adults, albeit a reluctant choice.[436] Parents may find themselves in the position of having to make a choice that they would prefer not to make. Statements from interviews conducted with prospective parent donors that the parent has no other option but to donate express in strong terms how unwavering commitment to the child is the parent's highest priority and that there is no other realistic option because nothing else is as important to them than saving the child's life.[437] While this may be seen as evidence that the choice to donate cannot be free in these circumstances, others consider this an authentic manifestation of the parent's wishes based on definite and clearly recognised priorities.[438]

Price notes that the parents, the very people who feel the responsibility to donate to their child most strongly, are the most willing, determined donors and the least ambivalent.[439] The decision to donate is grounded in the parent's awareness of how a transplanted organ will improve the child's life and a sense of responsibility for the child's welfare, which is consistent with norms widely accepted by society that parents should make sacrifices for their children.[440] In such circumstances, moral decision-making, based upon the awareness of the consequences of transplantation for the recipient, an assumption of personal

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[434] Philippa Burnell, Sally-Anne Hulton and Heather Draper, 'Coercion and Choice in Parent–Child Live Kidney Donation' (2015) 41 Journal of Medical Ethics 304.

[435] Ibid., 307.

[436] Cara Cheyette, 'Organ Harvest from the Legally Incompetent: An Argument Against Compelled Altruism', 502.

[437] Rosamond Rhodes Autonomy, Agency, and Responsibility: Ethical Concerns for Living Donor Advocates in Steel (n 277), 306

[438] Ibid.

[439] David Price, 'Living Kidney Donation in Europe: Legal and Ethical Perspectives--the EUROTOLD Project' (1994) 7 Suppl 1 Transplant International: Official Journal of the European Society for Organ Transplantation S665, 107-121.

[440] Allan Bennett and Jennifer Harrison, 'Experience with Living Familial Renal Donors' (1974) 139 Surgery, Gynaecology & Obstetrics 894.

responsibility towards the donor, and an assessment of moral norms, can be an acceptable alternative to the traditional informed consent approach.[441] The point made here is that decision-making based on moral duties and responsibilities that the individual genuinely endorses leads to authentic choices and that the individual's recognition of the weight of these commitments does not negate authenticity. Respect for substantive autonomy requires us to accept how these choices are made and in the third part of this chapter I will examine how the psychosocial evaluation of the donor takes into account moral decision-making.

3.5 The assessment of the living donor

3.5.1 The purpose of psychosocial screening

Taking into account the legal and regulatory requirements for the approval of applications for living donation discussed in the first part of this chapter, I now examine whether the evaluation of the donor candidate by medical professionals and the HTA through the IAs is based on a particular interpretation of donor autonomy. I will consider to what extent scrutiny of donor motivations is to ensure that the decision is authentic and consistent with underlying moral values and commitments.

Comprehensive international and national guidelines for the psychosocial evaluation of the living donor are lacking. In response to the need for a clear and coherent approach to mental health assessment many transplant centres adopt internal protocols.[442] Considerable variability has been reported between transplant centres regarding the components of the psychosocial evaluation such as the timing, content, duration, and specificities of this process, and also regarding outcomes such as absolute and relative contraindications to donation following the evaluation.[443] A systematic review of psychosocial screening guidelines for living kidney and liver donor candidates identified inconsistency in both the content and process of the evaluation and found that there was a lack of consensus on the concept of psychosocial screening itself which was reflected in the lack of standardised

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[441] Fellner and Marshall (n 298).

[442] Stephen Potts and others, 'Mental Health Assessment of Altruistic Non-Directed Kidney Donors: An EAPM Consensus Statement' (2018) 107 Journal of Psychosomatic Research 26.

[443] Annette Lennerling and others, 'Living Organ Donation Practices in Europe - Results from an Online Survey' (2013) 26 Transplant International: Official Journal of the European Society for Organ Transplantation 145.

psychological testing and agreement on contraindications for donation.[444] The research group subsequently identified the specific 'clusters' for the psychosocial evaluation of the living donors including: 'psychopathology', in reference to the identification of mental health illness; 'information and risk processing', comprising the assessment abilities to make decisions, process and understand information on risk, surgery and the donation process, capacity to give informed consent; and 'motivation and decision making'.[445] The latter focused on exploring pressure to donate, conflicts or dependencies in the donor-recipient relationship, subordinate donor-recipient relationships, how the decision to donate is made, motivations for donation, and ambivalence.[446] Motivation and decision-making was identified as a distinct theme in the donor evaluation, separate from mental health illness and considerations of capacity, although there is no elaboration on whether motivations should play a distinct and specific role in the donor evaluation. From the perspective of donor autonomy, it is important to regard motivations as a dimension of the decision to donate in their own right because they are relevant to the authenticity of the choice. However, motivations are often evaluated for the purpose of identifying mental health illness or making a determination of capacity. I return to these points below.

Recognising these shortcomings, the UK and Ireland Group of Renal Transplant Psychiatry produced a Consensus Guidance Statement on the Mental Health Assessment of Altruistic Donors which is included in the appendix to the BTS Guidelines on living donation.[447] This statement was further developed in the course of a workshop in conjunction with the annual meeting of the European Association of Psychosomatic Medicine and eventually consolidated into a guidance document for clinical, research, and regulatory bodies.[448] The purposes of the assessment are listed as follows: exploration of motivation, resilience, expectations about donation; clarification of the availability of emotional support for the donor; identification of any concurrent severe psychosocial stressors and risk factors for relapse of recurrent psychiatric illness; identification of individuals whose wish to donate arises from mental disorder and should therefore be excluded.[449] Assessment of the donor's

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[444] Nathalie Duerinckx and others, 'Predonation Psychosocial Evaluation of Living Kidney and Liver Donor Candidates: A Systematic Literature Review' (2014) 27 Transplant International 2.

[445] Sohal Ismail and others, 'Toward a Conceptualization of the Content of Psychosocial Screening in Living Organ Donors: An Ethical Legal Psychological Aspects of Transplantation Consensus' (2015) 99 Transplantation 2413.

[446] Ibid.

[447] British Transplantation Society and Renal Association. Guidelines for Living Donor Kidney Transplantation. 4th ed, 2018 [8.2].

[448] Potts (n 464).

[449] Ibid., 31.

capacity is also included as a specific purpose of the mental health evaluation and this is defined as ‘their ability to understand, remember and weigh the information presented to them, and to then make and convey their decisions’.[450]

On close inspection, these guidelines appear to be primarily concerned with the identification of pre-existing psychiatric or psychological disease or risk factors for such illness manifesting post-donation and establishing absolute contraindications to donation or identifying the need for support where these contraindications may be relative. It is important to note that the guidelines are for altruistic donors rather than directed donors and this approach may be justified by the evidence indicating that mental health disease may be more prevalent in this subset of donor candidates, as discussed above. While the donor’s motivations for choosing to donate are clearly explored in the psychosocial assessment, there is no indication that self-reflection or moral commitments towards donation are specifically discussed with the donor and the guidelines do not explicitly deal with the issue of authenticity of the decision.

The BTS published guidelines on donor evaluation to determine the medical suitability of the donor candidate for donation. Separate guidelines are available for kidney and liver donation. However, as the sections relating to autonomy, informed consent, and voluntariness of the decision are duplicated, for the purposes of this discussion, I will refer to the guidelines for living kidney donation. The guidelines stipulate that donor evaluation should be completed within 18 weeks and this time-frame ensures that the donor has adequate time to make a decision and includes a ‘cooling-off period’ that allows the donor to re-evaluate the choice made and withdraw if they no longer wish to proceed.[451] A multi-disciplinary team approach and independence between the clinicians responsible for the evaluation of the donor and those responsible for the recipient are strongly recommended.[452] Originally, the HTA required formal mental health assessment of all living donor candidates by a psychiatrist or a psychologist. Since 2012, this is only mandatory for directed altruistic donation (donation to a specified recipient with no pre-existing emotional or genetic relationship to the donor or a genetically related recipient

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[450] Ibid., 31.

[451] British Transplantation Society and Renal Association. Guidelines for Living Donor Kidney Transplantation. 4th ed, 2018 [5.2].

[452] British Transplantation Society and Renal Association. Guidelines for Living Donor Kidney Transplantation. 4th ed, 2018 [3.4].

who does not fall within the category of close genetic relationships) and non-directed altruistic donation (unspecified donation to an unknown person).[453]

It is notable while the HTA guidance documents and Code of Practice on living donation do not mention the term ‘autonomy’, the BTS guidelines contain an ethics section and refer to autonomy as one of the key ethical principles in living donation:

> Autonomy is the right of an individual to self-determination. Autonomy underpins our entitlement to control our own body, because it is ‘ours’. Valid consent must be given by the living donor before an organ can be removed; a primary aim is that such decisions are freely and autonomously made to offset concerns about coercion and ‘undue inducement’ that undermine valid consent.[454]

However, on close inspection, this statement strips autonomy of any substantive attributes linked to self-reflection, the authenticity of choice, and endorsement of values, presenting an impoverished account of self-determination as a right of control over the use of our body parts and freedom from interference. The ‘donor perspective’ section states: ‘[t]he principle of autonomy provides a legitimate basis for supporting living donation. Living donor surgery is morally acceptable when carried out with informed consent, freely given’. This statement equates autonomy with free and informed consent and the focus turns to these aspects: highlighting the distinction between conveying information to the prospective donor and acceptance and processing of this information, the guidelines acknowledge the challenges presented by individuals who make a decision to donate early in the process and are ‘impervious to or oblivious of any suggestion that they should make a more informed decision following counselling’.[455] This is immediately followed by the following comment: ‘[T]he consent may be real, but whether it is truly informed may be questionable’ conveys the idea that real consent is inadequate relative to informed consent. While the reference to ‘real consent’ appears to implicitly acknowledge the role of affective decision-making in living donation, the meaning of ‘real’ is not discussed and seems to reduce this idea to a hastily made and impulsive decision. The guidelines say nothing about how consent that falls short of informed consent is regarded by those

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[453] British Transplantation Society and Renal Association. Guidelines for Living Donor Kidney Transplantation. 4th ed, 2018 [8.2].

[454] British Transplantation Society and Renal Association. Guidelines for Living Donor Kidney Transplantation. 4th ed, 2018 [3.2].

[455] British Transplantation Society and Renal Association. Guidelines for Living Donor Kidney Transplantation. 4th ed, 2018 [3.4].

assessing the prospective donor and whether real consent is acceptable to clear the screening process, allowing the donor candidate to proceed with the HTA evaluation.

Ethical analysis of what real consent is taken to mean is absent and the section moves on to consider the second aspect of consent, that is, 'freely given' consent. The guidelines acknowledge the difficulties with the identification of subtle yet compelling forms of external pressure on individuals to donate which make it 'difficult or impossible for a potential donor not to proceed through the assessment process'.[456] The connection between autonomy and informed and voluntary consent is reinforced by a further statement:

> It is important to recognise that the concept of 'Informed consent, freely given' will vary according to the donor-recipient pair involved. In most situations, the motives and autonomy of the donor will be beyond question but, in others, it can be more difficult to establish that consent is both informed and voluntary.[457]

Together, these statements suggest that the primary purpose of the donor assessment is to ensure that the legal requirements for valid consent are met and specifically, that consent is informed and free from undue pressure and coercion. Here, I am not concerned with the adequacy of the information conveyed to the donor or with effectiveness of the donor assessment by the transplant team and the IA to identify unwilling donors. I broadly accept that these ends are achieved. My central concern is whether the assessment of the donor requires genuine consent that justifies proceeding with transplantation in situations where the decision to donate is not based on strict fulfilment of informed consent criteria.

In such circumstances, medical professionals or transplant authorities approving the procedure should be satisfied that the donor-recipient relationship is sufficiently clear and meaningful to the donor to justify the acceptance of consent that appears to be based primarily on care and concern rather than on full understanding of the nature and risks of the procedure.[458] To this purpose the psychosocial evaluation needs to address the donor's self-understanding as an autonomous moral agent as well as the relationships and social context within which decisions are made.[459] The legal and regulatory framework and the BTS guidelines are primarily concerned with undue pressure to donate or coercion of the

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[456] British Transplantation Society and Renal Association. Guidelines for Living Donor Kidney Transplantation. 4th ed, 2018 [3.4].

[457] British Transplantation Society and Renal Association. Guidelines for Living Donor Kidney Transplantation. 4th ed, 2018 [3.4].

[458] Spital (n 192).

[459] Biller-Andorno and others (n 193).

donor by third parties yet as discussed above, the emotional connection with the recipient involves blurring of the boundaries between meeting the expectations of others to donate and fulfilling one's own moral commitments. The process of internalisation, whereby the donor accepts these duties and responsibilities is a crucial part of what it means to donate out of care and concerned for a significant other. Part of the challenge is that evaluation of the donor requires the assessor to judge the extent to which personal obligations are internalised and willingly accepted by the individual wishing to donate.

With respect to the IA interview, the duties of IAs to exclude undue pressure and coercion, assess the capacity of the donor and ensure that consent to donation is valid have been described above. Nonetheless, in a rare deviation from the focus on pressure to donate from third parties, concern about internal pressure to donate is specifically raised in the HTA guidance to IAs: 'Many donors place pressure on themselves, both as the person selected to donate and for the donation to be a success'.[460] IAs are instructed to note these issues in their report because these are a key aspect of the discussion with the donor about factors influencing their decision to donate. However, unlike coercion and undue pressure from third parties which overpower the donor's volition, the HTA states that '[i]t is unlikely that such personal pressure would lead to the HTA making a decision not to approve a case'.[461] While this statement clearly shows that there is recognition of the pressure to donate arising out of the donor's own expectations, there is no elaboration about the endorsement of a sense of responsibility or moral duty to donate. The statement appears to imply that internal pressure to donate is a more benign form of pressure yet unless the individual genuinely accepts their responsibilities and commitments as valid reasons for donating an organ, the decision cannot be authentic and this is problematic for autonomy. The IA interview represents an important opportunity for the exploration of motivations and authenticity with the donor and, from the donor's perspective, it may be perceived by the donor as a less formal setting than that of the psychosocial evaluation. The IA is required to include statements from the donor interview regarding discussions about duress and coercion to clearly demonstrate that these issues are properly explored.[462] Ultimately, the ethical relevance of motivations appears to be more concerned, at least formally, with the voluntariness of the decision than with the authenticity of the choice to

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[460] Human Tissue Authority Guidance for Transplant Teams and Independent Assessors (updated December 2017) [164].

[461] Human Tissue Authority Guidance for Transplant Teams and Independent Assessors (March 2015, updated December 2017) [164].

[462] HTA Assessment process for living donor transplant cases (Human Tissue Authority Stnadard Operating Procedures-111, Version 25, February 2022).

donate although the internal pressure to donate is singled and distinguished from the pressure to donate by third parties. This does not detract from the fact that in person interviews with the donor by a person who is not a member of the transplant team represent opportune conditions for the exploration of the authenticity of the decision to donate. I return now to the issue of the purpose of the exploration of motivations during donor screening and specifically, the association between motivations, mental health illness, and capacity.

3.5.2 Motivations and psychosocial outcomes

An important reason for careful scrutiny of motivations is the association between certain motives and expectations, and poor psychosocial outcomes post-donation and it has been reported that 8.2% of all living donor candidates are rejected due to psychosocial issues.[463] There are valid reasons why medical professionals assessing donors are concerned about certain expectations. Firstly, motives are relevant to the determination of decision-making capacity because exploring the donor’s perspective on how donation will affect their life[464] may reveal unrealistic expectations, expectations based on false beliefs, or inconsistencies between the donor’s stated goal and the likelihood of achieving this through the choice they are making, indicative of irrational thought processes. A further important concern, particularly in non-directed donation, is that the decision to donate is a manifestation of an underlying psychopathology, or poor understanding of the risks.[465] Donor candidates have been declined in cases where donation was perceived as an act of self-promotion or where it was used to boost self-esteem, seek approval, atonement or redemption from others or where there were unrealistic expectations that transplantation would be successful or where donation was in response to psychological illness, such as depression or low self-esteem.[466] Unrealistic and unmet expectations can negatively affect donors leading to poor psychosocial outcomes after transplantation and deterioration of donor-recipient relationships.[467]

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[463] Mark Nickels and others, ‘A Psychosocial Evaluation Process for Living Liver Donors: The University of Rochester Model’ (2011) 41 International Journal of Psychiatry in Medicine 295-308.

[464] Sanner (n 272), 1707-13.

[465] Maple and others (n 345); Testa (n 273).

[466] Emma Massey and others, ‘Encouraging Psychological Outcomes After Altruistic Donation to a Stranger: Altruistic Donor Follow-Up’ (2010) 10 American Journal of Transplantation 1445.

[467] James Rodrigue and others, ‘Measuring the Expectations of Kidney Donors: Initial Psychometric Properties of the Living Donation Expectancies Questionnaire’ (2008) 85 Transplantation 1230.

This highlights the need to thoroughly explore the reasons for seeking to donate an organ and the outcomes anticipated by the prospective donor. However, it is not always clear on what basis personal expectations should be declared unrealistic or unacceptable and some commentators have questioned whether the risk of psychological harm should preclude an individual from donating where there is valid consent.[468] The identification of non-altruistic motives, such social recognition or expectations of changes within their interpersonal relationships, are considered important elements of the evaluation of the prospective living kidney donor and have been associated with poor psychosocial outcome after transplantation.[469] However, some commentators accept that these factors, while putting the donor at increased risk of psychological harm, do not necessarily invalidate informed consent and should not preclude an individual from donating.[470] It is important to examine whether the prospective donor's goals are achievable and whether these are consistent with other values and goals that the donor holds as part of the risk assessment process.

The NHSBT justifies the psychological assessment by to ensure that 'the risk of any psychological harm […] is acceptably small'.[471] The definition of 'acceptably small' is open to question yet transplant psychiatrists note that while these judgments are necessarily paternalistic, they are not intrinsically different from the assessments that other medical specialists make as part of the medical screening of a donor, for example in the case of a cardiologist assessing a donor candidate with a history of cardiac disease.[472] Potts, a UK-based transplant psychiatrist, argues that 'the purpose of psychiatric review is not to approve or disapprove a potential donor's motives', rather the aims are two-fold: to identify patients for whom transplantation may be inappropriate because the wish to donate arises from an identifiable mental disorder, such a mood or personality disorder, and to identify individuals who may need additional support before or after donation and provide that support.[473] On balance, this view seems to support the idea that the psychosocial evaluation of the patient has an essentially clinical purpose which is to exclude pathology precluding donation.

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[468] MA Dew and others, 'Guidelines for the Psychosocial Evaluation of Living Unrelated Kidney Donors in the United States' (2007) 7 American Journal of Transplantation 1047.

[469] Rodrigue and others (n 488), 'Measuring the Expectations of Kidney Donors: Initial Psychometric Properties of the Living Donation Expectancies Questionnaire' (2008) 85 Transplantation 1230.

[470] Dew and others (n 420).

[471] NHS Blood and Transplant 'Can I be a Living Kidney Donor?', compiled by a sub-group of the Living Donor Kidney Transplantation 2020 Strategy Implementation Group, 5.

[472] Potts (n 464).

[473] Ibid.

3.5.3 Motivations and capacity

The psychosocial evaluation also considers motivations to donate as part of the determination of capacity. A decision to donate an organ based on underlying values that affect how the donor balances risk or rejects information, as in the case of donation by parents to their children, or based on specific self-interested motivations, such as rekindling a failed marriage or improving one's self-esteem, may be of concern to the medical professional. The concern may be justified; however, the MCA 2005 is clear and recognises that all individuals have their own 'values, beliefs, preferences and attitudes' and that a person should not be categorized as lacking capacity merely because the decision is unwise from the perspective of third parties, including family members and healthcare professionals.[474] Furthermore, even where a decision is unwise and is obviously irrational, this does not necessarily mean that the person lacks capacity.[475] However, empirical research suggests that persons assessing capacity find it difficult to distinguish between 'incapacitous' and 'unwise' decisions.[476]

Critics note that the assessment of capacity is inevitably a normative process filtered through the values and biases of the person assessing capacity [477] and that the rationality of the individual concerned is generally established by reference to its consequences.[478] From the narrow perspective of the autonomy of the living donor, it is important that the assessment of capacity does not introduce a value-system that is different to that of the patient concerned. Qualitative research on the application of the MCA 2005 for the assessment of capacity by health professionals has found that lack of capacity is associated

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[474] Section 1(4) MCA 2005 and MCA 2005 Code of Practice [2.10].

[475] MCA 2005 Code of Practice [2.11]

[476] 'Mental Capacity Act 2005' (n 222); Natalie Banner 'Unreasonable reasons: normative judgements in the assessment of mental capacity' (2012) 18 Journal of Evaluation in Clinical Practice 1038; Natalie Banner 'Can procedural and substantive elements of decision-making be reconciled in assessments of mental capacity?' (2013) 9 International Journal of Law in Context 71; Emma Cave, Protecting Patients from their Bad Decisions: Rebalancing Rights, Relationships, and Risk, (2017) 25 Medical Law Review 527; Coggon, John, and Camillia Kong. 'From Best Interests to Better Interests? Values, Unwisdom and Objectivity in Mental Capacity Law', (2021) 80 Cambridge Law Journal 245; Charlotte Emmett and others, 'Homeward Bound or Bound for a Home? Assessing the Capacity of Dementia Patients to Make Decisions about Hospital Discharge: Comparing Practice with Legal Standards' (2013) 36 International Journal of Law and Psychiatry 73; David Gibson, 'Conceptual and Ethical Problems in the Mental Capacity Act 2005: An Interrogation of the Assessment Process' (2015) 4 Laws 229; Timothy Thornton, 'Capacity, Mental Mechanisms, and Unwise Decisions' (2011) 18 Philosophy, Psychiatry & Psychology, 127.

[477] Donnelly Capacity Assessment under the Mental Capacity Act 2005: Delivering on the Functional Approach (2009) 29 Legal Studies 464, 466.

[478] Val Williams and others, 'Best Interests Decisions: Professional Practices in Health and Social Care' (2014) 22 Health & Social Care in the Community 78, 247.

with unwise or irrational decisions and that assessors face difficulties in clinical practice in applying the test for capacity without factoring in the determination that will ensure an outcome that meets the clinical needs of the patient.[479]

It is important to note that the statutory test for capacity requires an inability to make a decision and that this inability is caused by an impairment of, or a disturbance in the functioning of, the mind or brain and cannot be overcome by presenting the information in a way that is accessible to the particular donor candidate. Where there is no psychological or psychiatric condition affecting the functioning of the brain or mind or where there is no impairment of the brain or mind it cannot be concluded that the individual lacks capacity. Clearly, a declaration of incapacity is not a panacea to resolve concerns over an individual's determination to donate an organ. Medical professionals, as moral agents, are under no obligation to proceed with surgery. If the multi-disciplinary team has concerns about the suitability of a potential donor, even where capacity is not disputed, and feels that proceeding with donation is inappropriate, the team is under no obligation to proceed and referral for a second opinion may be appropriate.[480] There is no need to resort to a determination of incapacity.

Nonetheless, the transplant team have a duty to make a genuine attempt at understanding the decision from the donor's perspective and take this viewpoint into account in the decision-making process.[481] It should be noted that medical professionals are not necessarily qualified to balance the medical risks against the psychosocial benefits to the donor of donation[482]. Value systems vary widely so the benefit of donation to the donor may be different even where the medical risks are the same.[483] Transparent discussion of these values during donor screening and interviews, coupled with critical reflection of subjective views, and a genuine attempt to make explicit the reasons for a determination of

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[479] Val Williams and others, 'Best Interests Decisions: Professional Practices in Health and Social Care' (2014) 22 Health & Social Care in the Community 78, 84-85.

[480] British Transplantation Society and Renal Association. Guidelines for Living Donor Kidney Transplantation. 4th ed, 2018 [3.5].

[481] David Levine 'When a stranger offers a kidney: Ethical issues in living organ donation' (1998) 32 American Journal of Kidney Diseases 676, -684.

[482] Robert Veatch, 'The Foundations of Bioethics' (1999) 13 Bioethics 206.

[483] Jerome Kassirer, 'Adding Insult to Injury. Usurping Patients' Prerogatives' (1983) 308 The New England Journal of Medicine 898.

capacity, may help to minimise the risk of arbitrariness and personal bias in assessments of capacity.[484]

The transplant team should understand the donor's motives, commitment to donation, and views on the trade-off between the personal risks and benefits of donation. It is argued that proper consideration of the benefits of donation should not require transplant professionals to adhere to or share the donor's moral value system but simply to understand motivations and the context within which the decision is made, assess whether the wish to donate is genuine, and whether the donor has considered the risks involved.[485] It is important to ascertain that the decision to donate is enduring, well-considered, and consistent with the donor's own views and moral convictions as this will increase the confidence of transplant professionals that expectations are realistic and outcomes are acceptable to the donor.[486]

3.6 Conclusions

The regulation of living donation is dominated by consent law which is concerned with upholding decisions made by competent adults in the absence of ignorance, undue influence or coercion. The focus is on the cognitive abilities of the individual in relation to the understanding and processing of the information about surgery and its risks and the benefits of the transplantation process. Consent law protects voluntary and informed choices rather than autonomous choices in the sense of choices made which the person values and endorses as their own. However, the evaluation of motivations for donation conducted as part of the psychosocial evaluation of the donor and during the IA interview places living organ donation in a unique position to bridge the disconnect between the philosophical nuances of autonomy and legal definitions of capacity and consent.

Relational autonomy emerges as an alternative framework for the analysis of the decision to donate an organ to a loved one, offering a richer and more nuanced account of the role of personal relationships and emotional attachment in the decision to donate an organ than

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[484] Helena Hermann and others, 'Decision-Making Capacity: From Testing to Evaluation' (2020) 23 Medicine, Health Care and Philosophy 253; Fabian Freyenhagen and Tom O'Shea, 'Hidden Substance: Mental Disorder as a Challenge to Normatively Neutral Accounts of Autonomy' (2013) 9 International Journal of Law in Context 53.

[485] Medard Hilhorst and others, 'Can We Turn down Autonomous Wishes to Donate Anonymously?: Turn down Wishes' (2011) 24 Transplant International 1164, 1168.

[486] Ibid.

the traditional approach for seeking informed consent based on the assessment of cognitive abilities, while maintaining the donor as the decision-maker. In the words of Nedelsky, a relational analysis 'provides a better framework for identifying what is really at stake' and 'for making judgments about the competing interpretations of rights involved'.[487] While most people agree that the risk of complications and predicted outcomes after donation are relevant to the decision to donate an organ, there will be different views regarding the importance of these risks relative to the ill health of a spouse or a child or one's deeply held commitment to help a stranger in need. An individualised approach which recognises the importance of thorough contextual analysis of the individual's narrative and experiences is necessary for a fuller understanding of the individual's perspective.[488] In directed donation, the assessment of proportionality of the risks and benefits cannot be performed in a vacuum but requires consideration for the moral responsibilities and duties on which the donor recipient relationship is based.[489] However, the evaluation of donor candidates, seems to predominantly focus on one dimension of relational ethical theory which is how relationships exerting pressure on the individual to donate invalidate consent. I have discussed how third-party expectations about the donor's role and a sense of a personal responsibility towards the recipient can be reconciled with a decision-making process that is autonomous. This approach requires the internalisation of moral commitments and responsibilities by the donor so that they accept the decision to donate as theirs.

From the perspective of the person assessing the donor, there needs to be an honest recognition that the candidate may not fulfil the procedural requirements for informed consent because their primary reason for donating is based on a sense of moral responsibility that cannot be reduced to the rational balancing of the risks and benefits of donation. This concession, has been carefully analysed and justified in the ethical literature on donation where it is argued that the context within which a decision to donate an organ is made is fundamental and dismissing choices because they are not based on a rational analysis of the risk and benefits of donation violates the 'spirit' of the informed consent doctrine which is to respect autonomy by ensuring that the individual makes decisions that reflect their deeply held values.[490] This concession is alluded to but not comprehensively

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[487] Jennifer Nedelsky, *Laws Relations: A Relational Theory of Self, Autonomy, and Law* (Oxford University Press, 2011), 4.

[488] Gareth Owen and others, 'Mental Capacity and Decisional Autonomy: An Interdisciplinary Challenge' (2009) 52 Inquiry 79..

[489] Caplan (n 437).

[490] Sauder and Parker (n 17).

addressed in the guidance documents for transplant professionals and IAs. It seems reasonable to assume that transplant teams are sensitive and responsive to family dynamics in interfamilial donation and that, at least in donation from parents to their children, the moral duty donate is accepted and that duties generally are carefully considered within the particular donor-recipient relationship. What appears to be lacking is an alternative legal tool to replace informed consent and this raises questions about the ethical relevance of the validity of consent where this is merely procedural. While these questions should be properly acknowledged in this critique of the concept of donor autonomy, this thesis does not seek to propose an alternative consent framework.

I have examined whether the assessment of the prospective donor by the transplant team and by the IA goes beyond the limited aims that are explicitly set out in clinical practice and HTA guidelines and scrutinises donor motivations, authenticity, self-reflection, and moral commitments. The psychological assessment of donors by mental health specialists scrutinises the motivations for donation. However, in the determination of capacity, motivations are examined with reference to the individual's ability to appreciate the risks and consequences of surgery and balance the risks and benefits of transplantation rather than to establish whether the decision that the individual reaches is authentic. Motivations are also specifically examined to exclude pre-existing pathology that precludes donation.[491] Here, the purpose of the psychological assessment is to identify non-autonomous decisions, such as a decision to donate driven by a pathological need or by a mental condition such as depression. This, I have argued, is a particular concern in non-directed donation, where motivations for donation to a stranger are often poorly understood. Donors view risk based on their own value system and acceptance of risk depends on how this incorporates actions conducted for the benefit of others. It is important not to medicalise divergent moral predispositions. I maintain that the exclusion of underlying conditions addresses different concerns and does not necessarily mean that the decision to donate is authentic and based on values that the individual genuinely endorses. On balance, at least formally, the donor assessment process supports an account of donor autonomy that is largely reducible to ensuring that decisions are informed, voluntary, and free from coercion.

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[491] Potts (n 464).

4 Autonomy and the deceased donor

4.1 Introduction

Drawing on the philosophical and bioethical perspectives on autonomy identified in Chapter 2, this chapter explores the meaning and ethical relevance of autonomy in deceased organ procurement from the perspective of the person whose organs are used for transplantation once they have ceased to exist. The aim is not a theoretical enquiry per se, rather I seek to determine whether the opt-out legal and regulatory frameworks for deceased donation in England, Scotland, and Wales are justified by a particular account of donor autonomy. This necessarily involves some reflection upon the differences in the understanding of autonomous decision-making in living organ donation and with respect to the posthumous removal of an organ for transplantation.

Establishing who should provide permission for organ removal and on what basis, is central to any discussion of donor autonomy. My starting point is that the authority for donation derives from the organ source, in the sense of the person whose organs are removed posthumously for transplant.

This chapter is structured in three parts. In the first part, I start from the premise that, however autonomy is understood, it must be connected to the interests that living persons have or perceive to have in relation to the posthumous use and control of their body parts. My enquiry is primarily philosophical and I seek to characterise these interests, how these may change with death, and how harm may be caused by failing to uphold the individual's preferences and choices regarding donation once they are deceased. The aim is to capture the sense in which these interests are relevant to choices and decisions about the removal of organs for transplantation after death without making assumptions that all persons recognise the same interests or any interests at all. In the second part of this chapter, I will set out the consent and authorisation requirements under current opt-out legislation and the processes for registering preferences regarding posthumous donation. This will serve as the foundation for my arguments in the third part of this chapter about whether and how the choice of the default – donation versus non-donation - shapes individual preferences, how decisions about posthumous organ donation are made, and whose decisional autonomy is upheld. I will then situate the purported justification for the shift in policy in the different

UK jurisdictions within the broader ethical discourse on the legitimacy of organ procurement frameworks based on consent that is not explicitly given by the person whose organs will be used for transplantation after their death. This raises the question of the ethical relevance of individual libertarian autonomy to decisions to donate posthumously. This section will mainly centre on the understanding of organ donation as a moral duty or an act of solidarity from the perspective of communitarian theory and I argue that the language of responsibilities, values, and obligations, discussed in Chapter 2, provides a coherent fit with the statutory law setting of donation as the default position. Finally, I will consider whether the current legislation and practices can and do discern between choices that are superficial, uninformed, and poorly reflected upon, and those that are based on scrupulous deliberation and reflect the deeply held and authentic values of the donor. Following a similar approach to that developed in Chapter 3 on living donation, I contend that the analysis of decisions about posthumous donation engages substantive accounts of autonomy. This builds towards my overarching aim which is to consider whether the legal framework for the procurement of organs for transplantation is based on a coherent account of autonomy.

Of note, while I explore the fundamental ethical principles underpinning opt-in and opt-out systems of organ procurement, I will not be considering whether the opt-out framework based on a sense of duty to donate is justifiable or whether there is an ethically preferable solution between opt-in and opt-out frameworks. These questions remain the subject of polarizing debates among policymakers, academic scholars, and organ transplant specialists, with no consensus achieved between the divergent ethical positions. These questions, while interesting, are distinct lines of enquiry that do not directly advance the issue I am concerned with, notably the meaning of donor autonomy under the present framework, and cannot be accommodated within this analysis.

At the outset of this research, an opt-out framework for deceased organ procurement was in place in Wales under the Human Transplantation (Wales) Act 2013 (afterwards HT(Wales)A 2013). Under this legislation, an adult is deemed to have consented to donation unless there is evidence that they objected. On the other hand, in England and Scotland, deceased organ procurement was based on an opt-in framework under the Human Tissue Act 2004 (afterwards HT Act 2004) and the Human Tissue (Scotland) Act 2006 (HT(Scotland)A 2006) requiring the express permission from the person in life for posthumous organ removal and transplantation.[492] In the course of writing this thesis, opt-out legal frameworks were introduced in England under the Organ Donation (Deemed Consent) Act 2019 (afterwards OD(DC)A 2019, on 20 May 2020, and in Scotland under the Human Tissue (Authorisation) (Scotland) Act 2019 (afterwards HT(A)(Scotland)A 2019), on 26 March 2021. As a result, an opt-out legal framework for posthumous organ procurement is now in force across all three jurisdictions. This shift in policy is significant, for reasons that will become clearer in this chapter, and has required substantial revision of my original analysis and reconsideration of my arguments about the interpretation and boundaries of the decisional autonomy of the donor.

Originally, my critique of autonomy in deceased donation centred around the question of whether the opt-in and opt-out legal frameworks operating in parallel within different legal jurisdictions but within a single national organ procurement system managed by NHS Blood and Transplant,[493] could be reconciled into a coherent account of donor autonomy or whether these practices reflected fundamentally different ideas of donor autonomy. An important part of my analysis was a critique of the legal powers of the next of kin to give consent or authorise donation on behalf of the deceased under the HT Act 2004 and the HT(Scotland)A 2006. This was routine practice, as the wishes of the vast majority of the members of the public regarding donation were not registered. I challenged the justification for the legal powers of the next of kin to make decisions on behalf of the donor with no explicit delegation of authority from the person in life and the lack of legal requirement for the next of kin to make the decision on the basis of clear evidence of a wish, preference or intent to donate. I argued that the opt-in system was based on the principle of 'no-objection-to delegation'[494] rather than explicit consent and that it did not reliably ensure that the wishes of the donor were respected.

Crucially, the legal authority of the next of kin has changed under the opt-out framework and I will discuss below the effects of these changes in terms of the respect accorded to the decisional autonomy of the donor. Further arguments concerned the limitations of the process of registration of preferences on the organ donation register (ODR) as a tool to give consent or authorisation to donation and the permissibility of allowing the next of kin

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[492] In the absence of express permission from the previously living person, transplantation could proceed with the permission of the next of kin (discussed below).

[493] In its role as a special health authority, sponsored by the Department of Health and Social Care.

[494] Govert Den Hartogh, 'Can Consent Be Presumed?: Can Consent Be Presumed?' (2011) 28 Journal of Applied Philosophy 295..

to override consent or authorisation given by the person in life on personal grounds. These concerns remain relevant under the opt-out legislation and will be addressed below.

I contend that under legislation that was in force only two years ago in England and one year ago in Scotland, there were significant flaws in the regulation of the procurement system. These flaws related to the limited, largely procedural interpretation of donor autonomy and the failure to consistently protect and uphold the decisions of the donor. While the purpose of this chapter is not to evaluate whether one framework is preferable to the other, the analysis of the meaning of donor autonomy within the present opt-out framework cannot completely ignore its pre-existing conceptualisation.

With the introduction of the OD(DC)A 2019 and the HT(A)(Scotland)A 2019, I have refocused my angle of inquiry towards an evaluation of the meaning of donor autonomy within the opt-out framework only. Organ procurement systems differ not only in the way they secure consent but also in the strategies used to influence decision making.[495] Changing the default from non-donation (opt-in) to donation (opt-out) has the potential to generate significant shifts in public behaviour while maintaining the choice set (donation or non-donation) unchanged.[496] In this chapter I will consider how accepting donation as the default interferes with the decision-making process and what this means for autonomy.

4.2 Posthumous interests and posthumous harm

4.2.1 Posthumous interests

A legal framework for organ procurement based on consent may be irrelevant for donor autonomy if we take the view that the deceased have no interests in need of protection after death or that no harm or wrong results from the frustration of any interests that the person may have had during life. Therefore, it is important to consider the relevant interests and interest holders and question how harm or wrong follows where these interests are not upheld. Bodily integrity in the sense of the right of the individual to be free from physical

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[495] Douglas Mackay and Alexandra Robinson, ‘The Ethics of Organ Donor Registration Policies : Nudges and Respect for Autonomy’ (2016) 16 The American Journal of Bioethics 3, 3.

[496] Jennnifer Blumenthal-Barby and Hadley Burroughs, ‘Seeking Better Health Care Outcomes: The Ethics of Using the “Nudge”’ (2012) 12 The American Journal of Bioethics, 1; Scott Halpern, Peter Ubel, and David Asch, ‘Harnessing the Power of Default Options to Improve Health Care’ (2007) 357 The New England Journal of Medicine 1340.

interference and their right of exclusive use and control over their body is clearly relevant to the excision of a body part, the organ, for transplantation into another person. While the understanding of bodily integrity is straightforward for living persons, the interest in bodily integrity changes after death and may no longer be relevant.[497] At a basic level, the idea of burying the body intact appears illusory if we consider that the process of decomposition of the human body occurs immediately after death and loss of physical integrity is inevitable.[498]

Here, I examine the philosophical basis on which individuals can be conceived of as having interests in relation to posthumous uses of their bodies. I consider whether there are other relevant interests besides interference with bodily integrity that account for the harm resulting from the use of organs without appropriate permission. Specifically, I will examine the interests in the control of the posthumous use of one's body.

The concept of posthumous interests in our bodies appears prima facie plausible. In his influential account of interests and harm, Feinberg defines interests as those in which one has a stake: a person has an interest in Y when he stands to lose or gain according to the condition or outcome of Y; a harm is the blocking or thwarting of an interest.[499] Welfare interests are distinct from ulterior interests,[500] the former being material interests of a practical nature, such as the interest in material goods or health which are means to satisfying ulterior motives understood as more subjective preferences, such as those relating to family, career, or personal interests.[501] Importantly, Feinberg maintains that a person's interests generally go beyond the person's immediate experience or concern to some point in the future and this point may lie beyond death, so these interests are posthumous in the sense that they survive death.[502] Glannon notes that 'because the body is so closely associated with who we are, we can have an interest in what is done to it even after we cease to exist'.[503] The idea that our control over the use of our bodies during life,

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[497] Thomas Wilkinson, 'Last Rights: The Ethics of Research on the Dead' (2002) 19 Journal of Applied Philosophy 31.

[498] Muralitharan Nair and Ian Peate *Fundamentals of Applied Pathophysiology: An Essential Guide for Nursing and Healthcare Students* (2nd ed, Wiley-Blackwell 2013).

[499] Feinberg and Feinberg, *Harm to Others* (n 41).

[500] Ibid.

[501] HLA Hart, PMS Hacker and Joseph Raz (eds), *Law, Morality, and Society: Essays in Honour of H. L. A. Hart* (Clarendon Press 1977). p 285-286

[502] Robert M Veatch, 'Autonomy's Temporary Triumph' (1984) 14 The Hastings Center Report 38.

[503] W Glannon, 'Do the Sick Have a Right to Cadaveric Organs?' (2003) 29 Journal of Medical Ethics 153, 154.

particularly in terms of our rights against third parties, should not be extinguished by death holds a strong appeal in liberal societies.[504]

This is articulated by the Scottish Executive in the concept of authorisation for organ donation as ‘an expression which is intended to convey that people have the right to express, during their lifetime, their wishes about what should happen to their bodies after death, in the expectation that those wishes will be respected’.[505] Price notes that this is consistent with the Report of the Independent Review Group on the Retention of Organs at Post-Mortem which shaped Scottish legislation[506] and articulates the deeply felt sense that taking organs without permission is morally wrong.[507] This perception is based on the ‘widely shared and basic intuition that my body is mine and I should decide what happens to it’.[508] Transposed into the procurement of organs, this rationale dictates that my permission for organ removal for transplantation is required because the organ is mine to give. This view does not necessarily imply a property relationship in law between the individual and one’s body parts.

The difficulty with the analysis of any power or entitlement of control that the donor may have over the posthumous use of their organs largely stems from the fact that the specific relationship between the individual and the human body is not explicitly set out in legislation or in its background legal principles.[509] There has been growing academic support for a property-based approach to account for the individual’s rights of control over the posthumous use of their body parts.[510] The idea of ownership interests in excised organ and body parts challenges the established common law principle that there is no property in

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[504] Hart, Hacker and Raz (n 454).

[505] ‘Human Tissue (Scotland) Act 2006: A Guide to Its Implications for NHS Scotland’; ‘Payne, J. Scottish Parliamentary Debate on the Organ Donation Taskforce (2008a) Report, ‘Organs for Transplants: A Report’, SPICe Briefing, 5th March 2008’.

[506] Price, (n 176).

[507] Ibid., 90.

[508] Thomas Wilkinson, *Ethics and the Acquisition of Organs* (Oxford University Press 2011); Glannon (n 13); Paula Boddington, ‘Organ Donation After Death — Should I Decide, or Should My Family?’ (1998) 15 Journal of Applied Philosophy 69.

[509] Shaun D Pattinson, ‘Directed Donation and Ownership of Human Organs’ (2011) 31 Legal Studies 392. p 395

[510] Shaun D Pattinson, ‘Directed Donation and Ownership of Human Organs’ (2011) 31 Legal Studies 392; For a comprehensive analysis of the legal treatment of human biological materials in common law jurisdictions and a framework for the creation and allocation of property rights in separated biological materials Rohan Hardcastle, *Law and the Human Body: Property Rights, Ownership and Control* (Hart Publishing 2009).

the human body or its parts[511] and is reflected in the recent judicial decision in *Yearworth v North Bristol NHS Trust.*[512] The 'rule-preclusionary' conception of property developed by Beyleveld and Brownsword is based on the idea that ownership of an object confers a prima facie right to legitimately use or exclude others from using that object on the basis of the relationship between the individual and the object.[513] The advantage of a property approach is that this precludes others from using the body part and places the burden of proof on others wishing to use it or restrict the owner's use of it such that they have to show that their interest overrides the interests of the owner. Nonetheless, the concept of the human body as property remains a polarising subject and an analysis of the prolific academic debate surrounding its merits and application lies beyond the scope of this thesis.

Irrespective of any recognition of the human body as property, property does not fully account for why it is important to respect the wishes of deceased persons regarding donation. The physical transfer of the organ to another person clearly represents a dimension of the posthumous interests involved in donation if we think of the retrieval process as the removal of an organ from the body of which it was part and its implantation into another living person, such that it becomes an integral part of the recipient. Importantly, the view of organ donation as a process akin to the testamentary disposition of personal property fails to capture the spectrum of interests involved in decisions to donate. A fundamental dimension of the interests underlying organ donation relates to the significance of the act of donation to the donor. Feinberg observes that interests which transcend death include the person's 'publicly oriented and other-regarding interests, and also "self-centred" interests in being thought of in certain ways by others'.[514] Altruism and solidarity but also societal recognition and personal fulfilment are recognised as important motivating factors in organ donation.[515]

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[511] David Price, *Human Tissue in Transplantation and Research: A Model Legal and Ethical Donation Framework* (Cambridge University Press 2010), 230-270

[512] [2009] EWCA Civ 37, [2010] QB 1. For challenge to the interpretation of *Yearworth* as creating property rights human material see Luke Rostill, 'The Ownership That Wasn't Meant to Be: Yearworth and Property Rights in Human Tissue' (2014) 40 Journal of Medical Ethics 14.

[513] Deryck Beyleveld and Roger Brownsword, 'My Body, My Body Parts, My Property?' (2000) 8 Health Care Analysis 87.

[514] 'Harm and Self-Interest' in Hart, Hacker and Raz (n 454), 308

[515] Ben Saunders, 'Altruism or solidarity? The motives for organ donation and two proposals: The motives for organ donation' (2012) 26 Bioethics 376.

The self and personhood are bound up in donation as a form of personal legacy.[516] For Belliotti, the idea of a personal legacy which survives death represents an important dimension of the interests of the previously living person.[517] His claim that a person's biographical life transcends their biological life is based on the idea that, while biological life is extinguished by death, our biographical life, which is bound to our identity and created by our choices, endeavours, and actions in life, persists for some time after death and may be affected by how persons regard us after our death.[518] For example, the act of donating an organ may change the way those close to the donor, as well as recipients and their families or society at large, view the person and remember them after death. Tomasini argues that the meaningfulness of life extends beyond death, as manifested by our transcendent interests or desires, such as the honouring of death bed promises; the disposal of property and belongings after death; the preservation of the integrity of one's reputation posthumously; the respectful disposal of our corpse; the flourishing of children, relatives and friends; and the successful completion after death of creative endeavours or projects begun in life.[519] These interests are a strong indication that we care about those we leave behind when we die, that we want to be remembered for what our life stood for, and that we care that our body is treated with respect.[520] By respecting the premortem aspirations, preferences, and decisions of persons after their death, society recognises that death does not extinguish all 'moral traces' of the person.[521] Young encapsulates this concept as follows:

> we may protect an interest in posthumous bodily integrity because, as a society, we wish to see ourselves as people who respect the wishes of the dead. This could be because we believe the dead have moral interests and we want to act morally by respecting those interests, or because we think the living will benefit if we respect the prior wishes of the dead. It could be because we promise people that we will respect their wishes, and we want to be a society that keeps our promises. It could also be because we perceive that respecting the wishes of the dead honours the lives of those who have died. The reasons need not be determined: what matters on this approach is that the importance of an interest in posthumous bodily integrity derives, at least in part, from the fact

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[516] Price, *Human Tissue in Transplantation and Research: A Model Legal and Ethical Donation Framework* (n 464).p 54.

[517] Raymond Belliotti, (1970) 60 'Do Dead Human Beings Have Rights?' The Personalist 201, 206.

[518] Raymond Belliotti, *Posthumous Harm: Why the Dead Are Still Vulnerable* (Lexington Books 2013), 102 and 138.

[519] Floris Tomasini, *Remembering and Disremembering the Dead* (Palgrave Macmillan UK 2017) 29

[520] Ibid., 30.

[521] Mark Wicclair, 'Ethics and Research with Deceased Patients' [2008] Cambridge Quarterly of Healthcare Ethics 87, 89

> that we as a society want to see ourselves in a certain light: it is society that benefits by respecting the wishes of the dead.[522]

If we accept the existence of posthumous interests, harm is understood as frustration of these interests. However, although the idea that posthumous events can institute harms appears inherently plausible,[523] there are important theoretical difficulties with application of this model that require some consideration. Firstly, the lack of a proper subject who is the interest holder and who may experience actual harm. Secondly, the issue of backward causation, which arises when harm occurs retrospectively because the set back of ante-mortem interests occurs after death.[524] I will consider these in turn.

4.2.2 Who is the interests holder?

While intuitively the existence of posthumous interests appears straightforward, ascribing a subject holder to the interests is not. It is generally held that the deceased are not persons in their own right and have no interests.[525] On this view, any surviving interests cannot be attributed to a subject that no longer exists.[526] Partridge rejects the possibility of posthumous interests on the grounds that the deceased has ceased to exist and that interests cannot be disassociated from the subject holder of the interests because they can only be interests insofar as they matter to someone.[527] While recognising that persons care about circumstances beyond one's death and that keeping promises posthumously when these were made to an individual in life may even be morally right or desirable, Partridge claims these actions cannot be *in the interests* of the deceased because the interest is extinguished with the interest bearer.[528] He argues that the relevant interests are those of other living persons and that it is in the interests of living persons generally, out of concern for their own 'to-be-posthumous interests' that legal institutions, such as testamentary provisions,

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[522] Hilary Young, 'The Right to Posthumous Bodily Integrity and Implications of Whose Right It Is' 14 72. p 201

[523] CL Hamer, 'A Stronger Policy of Organ Retrieval from Cadaveric Donors: Some Ethical Considerations' (2003) 29 Journal of Medical Ethics 196 <https://jme.bmj.com/lookup/doi/10.1136/jme.29.3.196> accessed 13 March 2022.

[524] Price, *Human Tissue in Transplantation and Research: A Model Legal and Ethical Donation Framework* (n 464).p 56-57

[525] Ibid.p 55.

[526] Wellman C, *Real Rights* (Oxford University Press 1995). p 155

[527] Ernest Partridge, 'Posthumous Interests and Posthumous Respect' (1981) 91 Ethics 243, 246-7

[528] Emma Partridge, 'Posthumous Interests and Posthumous Respect' (1981) 91 Ethics 243.p 253-254, 258-259

are in force to ensure that the wishes expressed by persons during their lifetime are honoured after death.[529]

Nevertheless, some commentators maintain that the dead do possess interests. Kramer defines interest in terms of an event or a state of affairs that can improve the condition or avert a deterioration in the condition of an entity X but does not presuppose any cognitive ability of the entity.[530] On this view, even inanimate objects can be interest holders and the deceased state poses no particular theoretical difficulty. Brecher conceives the dead as dead persons, not merely memories, whose identities extend into the future and remain part of a transgenerational moral community.[531] Obligations towards dead persons are grounded in their contribution to the development of the community in which we live and in their role in shaping our identities as members of this community; therefore, as members of a particular community, the dead can be said to have interests.[532] Sperling circumvents the theoretical problem of the lack of a subject-holder by conceptualising a largely symbolic posthumous existence with a subject (the 'Human Subject') holding all the interests of the person after death.[533] However, there are significant limitations in this approach as it is not clear how the Human Subject relates to the person nor how, in practice, the Human Subject could acquire legal status.

Callahan notes that tracing the interests of the deceased to the living person reveals that the ethical concern is for the interests of the living and merely shows that the deceased in their post-mortem state have no interests.[534] Yet this does not solve the question of how the antemortem person can be the holder of interests surviving beyond his death. Adopting a more pragmatic approach, Belliotti proposes that surviving interests are merely transcendent interests that people hold when alive that centre on events extending beyond death, without claiming that the interests themselves survive death and continue to be

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[529] Ibid.p 260-61

[530] Matthew Kramer, 'Do Animals and Dead People Have Legal Rights?' (2001) 14 Canadian Journal of Law & Jurisprudence 29 , 33 Kramer attributes rights to the deceased for as long as the person retains a presence in the lives of survivors to the extent that the deceased can be "morally assimilated" to the person he was before death (p.46-7).

[531] Barbara Brecher, 'Our Obligation to the Dead' (2002) 19 Journal of Applied Philosophy 109.

[532] Ibid., 115-116.

[533] Daniel Sperling, *Posthumous Interests: Legal and Ethical Perspectives* (Cambridge University Press 2008). The Human Subject is timeless and also exists before birth holding the interests of the person before he is born.

[534] Joan Callahan, 'On Harming the Dead' (1987) 97 Ethics 341, 345-346.

embodied in an interest bearer.[535] Similarly, Glannon does not reject the notion of posthumous interests but conceives these simply as surviving interests, interests which a person has in states of affairs which will materialise or fail to materialise after their death; this account does not presuppose that the content of the interest is restricted to the existence or experience of the interest holder.[536]

This is broadly consistent with Ronald Dworkin's framework of experiential and critical interests. The former are felt experiences associated with a specific time that are perceived by the individual as pleasurable or exciting and, in any case, positive. Critical interests are based upon critical judgments about what makes life good, and satisfying these interests is important to the individual.[537] They are deeply personal and can be an integral part of one's life plan.[538] Unlike experiential interests, critical interests are not extinguished with death. Accordingly, a critical interest in the welfare of others may be the motivation for organ donation. In this sense critical interests have considerable explanatory potential because they provide the reason an individual decides to donate their organs after death.

4.2.3 Who is harmed?

Acceptance of the idea that interests in the control of the use of one's body remain relevant after the death of the individual raises the question of whether the posthumous frustration of these interests harms the deceased or the previously living person. This issue has attracted considerable academic debate. The idea that the deceased cannot be harmed is rooted in the experience requirement of epicurean philosophy,[539] accordingly, 'to be harmed a person has to first *be*'.[540] Callahan maintains that if death is the first moment of non-existence, then at that point there is no longer a person to harm.[541] Therefore, if the set back of interests occurs posthumously when there is no subject that can suffer harm, there can be no harm. The experience requirement was challenged by Nagel in his well-known

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[535] Dworkin, (n 53), 58

[536] Walter Glannon, 'Persons, Lives, and Posthumous Harms' (2001) 32 Social Philosophy, 127.

[537] Dworkin, (n 53), 203-230.

[538] Ibid., 199-217.

[539] Epicurus maintains that biological death is the total annihilation of the subject and that 'death is nothing to us,' because there is no subject to experience good or bad. His argument is founded upon what is known as the "existence condition", a term coined by Fred Feldman (see 'Feldman F. Some Puzzles about the Evil of Death. 1991 Philosophical Review, 100, 205–227'.), exemplified by the following proposition: 'nothing either good nor bad can happen to a subject *s* at time *t* unless *s* exists at *t*' (cited in Geoffrey Scarre, *Death* (1. publ, Acumen 2007).

[540] Tomasini (n 472).

[541] Callahan (n 487), 343.

brain-injury scenario, in which he argues that an adult whose mental state has been reduced to that of an infant has nevertheless been injured, irrespective of the fact that he is contented and oblivious about the change in his condition.[542] By removing the experience requirement, the idea of harm to the deceased appears theoretically plausible. The philosophical impasse set by Epicurus was finally circumvented by a novel perspective developed by Pitcher. Pitcher accepts the death-annihilation thesis but distinguishes between two kinds of subject: the post-mortem subject and the ante-mortem subject; while the former cannot be harmed, posthumous events can harm the ante-mortem subject.[543] This theory was further developed by Feinberg in a comprehensive account of ante-mortem harm caused by posthumous events.[544] A key element of this theory is the distinction between want fulfilment and want satisfaction.[545] Essentially, fulfilment of a want is the coming into existence of that which is desired, while want satisfaction is the experience of contentment or gratification that normally occurs in the mind of the person when he believes that his desire has been fulfilled. Fulfilment and satisfaction do not necessarily coincide. Fulfilment of a desire may occur yet the person may derive no pleasure from it; conversely, satisfaction may occur when the person erroneously believes that there has been fulfilment of the goal or desire. Feinberg accepts that death is the total and final end of the individual, although he argues that harm may still occur after death, for example, through the abrogation of one's will, the voiding of contracts, the breaking of promises, or the spreading of false rumours.[546] He contends that harm is the objective blocking of goals and thwarting of desires rather than the harm subjectively perceived and that, similarly, enhancement or benefiting of an interest is the objective fulfilment of well-considered wants.[547] Price notes that the idea that a person can be harmed despite lack of awareness has been applied to the judicial analysis of the interests of persons lacking capacity, for example, those in persistent vegetative states, in relation to previously expressed wishes.[548] Harm is taken to be the frustration of the autonomous wishes of the individual expressed

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[542] Thomas Nagel, 'Death' (1970) 4 Noûs 73 <https://www.jstor.org/stable/2214297?origin=crossref> accessed 13 March 2022, 77

[543] Gary Pitcher, 'The Misfortunes of the Dead.' (1984) 21 American Philosophical Quarterly, 183.

[544] Feinberg and Feinberg, *Harm to Others* (n 41).

[545] This builds on the theory developed by William D. Ross*, 'Foundations of Ethics: The Gifford Lectures Delivered in the University of Aberdeen, 1935-6'*, Oxford, Clarendon Press, 1939.

[546] Joel Feinberg, 'The Rights of Animals and Unborn Generations. in Philosophy and Environmental Crisis', William Blackstone (ed.) (University of Georgia Press, 1974), 43-68'; Hart, Hacker and Raz (n 454). p 284-308

[547] Hart, Hacker and Raz (n 454). p 303

[548] Price, *Human Tissue in Transplantation and Research: A Model Legal and Ethical Donation Framework* (n 464).p 58

while competent. However, the analogy between the interests of a previously autonomous person and those of a previously living person is not straightforward because, in the first case, any entitlement to have one's wishes respected is held by a living, albeit incompetent, person.[549] The incompetent interest holder is a legal person and frustration of the person's interests can give rise to a valid claim in law.

Nonetheless, the idea that harm to a person can occur independently of experience has been rejected. Building on the premises that a person is nothing more than a body and a mind, Glannon maintains that harm is harm to the well-being of a person and can only be understood as something causally affecting the body or the mind of that person.[550] He argues that proponents of the independence theory erroneously equate a bad unexperienced state of affairs about a person with harm to that person. A state of affairs may affect the life of a person even if they are unaware of this. However, in these circumstances their well-being is not affected and therefore, this does not constitute harm to the person. Furthermore, on this view, posthumous harm cannot exist because after death there is no mind and, therefore, no person. Partridge also contends that interests cannot be detached from the subject bearer so that if death removes the personal concern or the stake in an event, the event remains a mere happening rather than a harm.[551]

However, Feinberg uses the concept of harm as arising out of non-fulfilment per se, regardless of the awareness of the subject, to develop a theory of harm affecting previously living persons.[552] He articulates this as follows:

> All interests are the interests of some person or other, and a person's surviving interests are simply the ones that we identify by naming him, the person whose interests they were. He is of course at this moment dead but that does not prevent us from referring now, in the present tense, to his interests, if they are still capable of being blocked or fulfilled.[553]

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[549] Ibid., 58.

[550] Glannon (n 535), 134-137.

[551] Partridge (n 480), 249.

[552] The irrelevance of the awareness of the subject is apparent in Feinberg's analogy with defamation. Feinberg contends that the defamation of a living individual without the individual's knowledge constitutes harm simpliciter. It is harm because it thwarts the individual's interest in a good reputation even though he is oblivious to being the object of contempt. Feinberg "Harm and Self-Interest," in Law, Morality and Society: Essays in Honour of H. L. A. Hart, ed. P. M. S. Hacker and J. Raz (Oxford: Clarendon Press, 1977), 305-6.

[553] Feinberg, *Harm to Others* (n 41), 83.

This approach has found resonance with many contemporary philosophers. Belliotti identifies harm as frustration of the wishes or desires of the antemortem person.[554] Similarly, Kamm refers to harm in the context of actions taken after a person's death which destroy the projects that they completed in their lifetime.[555] Tomasini, referring to transcendent interests, notes how treatment of a dead body against the wishes of the previously living person can harm the ante-mortem person who holds certain beliefs about how their corpse ought to be treated post-mortem.[556] Callahan acknowledges that there is genuine confusion about whether it is the dead or the living who are harmed:

> For when we say that we feel sorry for the *dead* Smith because of some posthumous event, we generally do mean it is the dead Smith we feel sorry for […] If we feel at all sorry for the dead in such cases, it is not because we think that *while alive* the person was harmed – indeed , it is common to express relief that the living (antemortem) person was not harmed by whatever the event is.[557]

Yet when we feel sorry for the dead person, writes Callahan, we identify with the antemortem person in the sense that we visualise the antemortem person and direct our feelings towards them.[558] Wilkinson deals with the existence of the subject by observing that 'we can make sense of harming someone after her death in the same way that we can make sense of remembering someone after her death'.[559] On this view, we can remember now a deceased relative as they were when alive (our memories are of the living person, not the corpse), similarly we can do something now which causes harm to the person as they were in the past.

There is also another sense in which posthumous harm may occur. Tomasini considers the harm to posthumous reputation as a form of (second order) symbolic harm to the biographical life of the person. However, Partridge claims that no posthumous event can affect the events that constitute a completed life.[560] Glannon concedes that the biographical life of the individual is distinct from their biological life and may include states of affairs which occur posthumously yet while these events may affect the individual's biographical

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[554] Belliotti (n 516), 201.

[555] Frances Kamm, 'Morality, Mortality Volume I: Death and Whom to Save From It', (Oxford University Press 1993) 209.

[556] Tomasini (n 472).

[557] Callahan (n 487), 346

[558] Ibid., 347.

[559] Wilkinson, 'Last Rights: The Ethics of Research on the Dead' (n 450), 34.

[560] Partridge (n 481), 253.

life, they do not harm him.[561] The idea of a biographical life has intuitive appeal; however, as Belliotti notes, the relationship between a person and their biographical life is not clear and the question of whether and how the symbolic harm affects the antemortem person remains.[562]

I accept the mainstream view that the relevant interests are those of the previously living person which may be promoted or frustrated by the actions of others after their death.[563] From this perspective, respect for the individual's preferences in organ donation is derived from the autonomy of living persons to make decisions about what happens to their bodies after death, rather than from any autonomy rights of the cadaver.[564]

4.2.4 Backward causation

The Feinberg-Pitcher claim that the frustration of surviving interests after death results in harm to the antemortem person requires us to consider how events occurring in the future can causally affect events that took place in the past. Taking the point in time, after death, in which the frustration of interests occurred as the first time the antemortem person is harmed inevitably causes difficulties with backwards causation because it presupposes that a posthumous event may cause retroactive harm. Li observes that the question of when the harm event occurred is conceptually different from the question of 'when was the person harmed by it?'[565] For Pitcher, the fact that the event was going to happen means that the harm occurred before the person's death.[566] Feinberg expands upon this idea and states that a person who is harmed ante-mortem was going to be harmed 'all along' by the future event, essentially, 'the ante-mortem person was harmed in being the subject of interests that were going to be defeated whether he knew it or not'.[567] There is no retroactive harm as causation is logical rather than physical.[568] The Pitcher-Feinberg account of ante-mortem harm not only bypasses the philosophical impasse of explaining harm to a non-existent person but also purposely avoids the pitfalls of backward causation. However, as Belliotti

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[561] Glannon (n 535), 129.

[562] Belliotti (n 516), 143.

[563] Glannon (n 535).

[564] Adnan Sharif and Greg Moorlock, 'Influencing Relatives to Respect Donor Autonomy: Should We Nudge Families to Consent to Organ Donation?' (2018) 32 Bioethics 155, 156 .

[565] Jack Li, *Can Death Be a Harm to the Person Who Dies?* (Kluwer 2002), 93.

[566] Pitcher (n 496), 187.

[567] Feinberg and Feinberg, *Harm to Others* (n 41).

[568] Raymond (n 471), 50.

notes, a consequence of this account is that virtually all human beings are harmed to a degree throughout their lives because they hold interests which will be defeated posthumously.[569] Waluchow disagrees with this conclusion:

> […] when I do whatever it is that sets back the interest of the antemortem person […] I do not make it true that his interests *were* set back. Rather, I make it true that the interests he had are *now* set back. The setting back takes place now, not then. At most, we can say that back then it was true that the interests were going to be set back.[570]

For Glannon, the issue of backward causation does not exist: harm to a living person cannot occur when the body or mind are not affected[571] so the future frustration of interests cannot harm the (living) individual in the present. Price notes that the common law is 'inherently flexible in order to accommodate intended policy' and that in cases involving prenatal injuries the harm is applied prospectively to new-borns in order to circumvent the difficulties with ascribing liability where the victim is an unborn child and not a person in law; harm could similarly be attributed retrospectively to previously living persons.[572] Wellman develops the idea of 'rights that impose future duties': death extinguishes the individual right but the duties arising out of this right persist beyond death creating obligations upon others, notwithstanding the fact that rights cannot be ascribed to the deceased.[573] The idea of rights creating duties which persist beyond the death of rights-holder obviates the theoretical difficulty of the lack of subject for persisting interests. The duties persist because they are based on the grounds of the rights. Considering promises made to person prior to death, promise keeping, and reneging are moral grounds of the right of the person that the promisor act as promised.[574] However, while this compromise appears attractive, Sperling highlights the inconsistency in the acceptance of the idea that duties persist after death while rights do not.[575]

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[569] Belliotti (n 516).

[570] Wil Waluchow, 'Feinberg's Theory of "Preposthumous Harm" (1986) 25 Dialogue 727, 731.

[571] Glannon (n 535), 127, 128.

[572] *B v Islington Area Health Authority* [1992] 3 All ER 832 (CA).

[573] Wellman (n 42), 156.

[574] Ibid., 156

[575] Sperling (n 486), 61.

4.2.5 Conclusions

I return to the point raised at the outset of this analysis that conceptually, the requirement for consent to posthumous organ removal for transplantation cannot be separated from underlying interests that consent seeks to protect. Consent is described as the fundamental guiding principle under the HT Act 2004.[576] However, Price notes that an element of 'back-to-front thinking' has permeated the development of legislation from its inception, with the Human Tissue Bill parliamentary debates fixating primarily on consent as the legal and ethical justification for the removal and use of human material while failing to address first the fundamental question of whether any interests are implicated in these procedures, and largely ignoring that these interests are the basis of the requirement for consent.[577]

The HT Act 2004 and HT(Scotland)A 2006 do not explicitly set out the relationship between a person and their body parts or the rights of control that persons have over the use of material removed from their bodies, despite the fact that interests in the control of posthumous uses of body parts recognised during the organ retention enquiries were affirmed during the Parliamentary debates on the Human Tissue Bill.[578] This point is important because consent (or authorisation) is not a 'free-standing ethic or justificatory standard' but is necessarily linked to underlying interests requiring protection.[579] Establishing the relative weights of the interests that living individuals have in their bodies after their death and of any interests that the next of kin or society may have in the body of a deceased is crucial to determine why it is necessary to obtain permission for organ retrieval and from whom.[580]

It is clear that from a philosophical perspective there remains considerable disagreement surrounding the conceptualisation of the holder of posthumous interests and how harm may be caused by the frustration of these interests after death. I am not concerned here with proposing a solution for this theoretical impasse because this is not necessary to justify my

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[576] 'HTA Code of Practice A Guiding Principles and the Fundamental Principle of Consent' (Human Tissue Authority, 20 May 2020) https://content.hta.gov.uk/sites/default/files/2020-11/Code%20A.pdf accessed 10 December 2022.

[577] Brownsword (n 15), 230 referring to the Explanatory Notes to the Human Tissue Bill. Brownsword describes the fixation on consent as the legal and ethical justification for an act as the fallacy of sufficiency whereby an act is deemed right or wrong on the basis of whether consent is present or absent.

[578] See Dr Ladyman, House of Commons Hansard Debates, Standing Committee G, col. 65, 29 January 2004.

[579] Price, *Human Tissue in Transplantation and Research: A Model Legal and Ethical Donation Framework* (n 464), 104.

[580] Ibid., 62.

focus on autonomy in posthumous organ donation as a concept connected to decisions affecting the interests that living persons have in relation to the posthumous use of their body parts. The remit of this discussion on posthumous interests is more modest: I seek to draw attention to the fact that, despite the lack of a common consensus on these philosophical questions, there is considerable force in the intuition that the corpse is intimately connected to our essential 'selves'[581] and that living persons have interests in what happens to their bodies after death.[582] I accept the broad proposition that any critical interests that the individual may have in relation to organ transplantation can be promoted or frustrated by actions conducted posthumously. In other words, whether the posthumous use of one's organs for transplantation is consistent with the individual's values, principles, or life plan or conversely, or whether the prospect of surgical removal of one's organs after death is unacceptable for personal reasons, respecting (and disrespecting) the person's preferences about donation matters deeply.[583] I seek to identify what types of choices are protected under the law as it currently stands and this analysis does not require definitive answers to the questions of how critical interests may be frustrated and who suffers harm.

Be this as it may, I argue that respect for the wishes and choices of the previously living person is central to what we understand autonomy to be in organ donation. Taking these interests seriously requires us to examine how decisions to donate or not to donate are made, whether the current legal framework supports and protects genuine and authentic choices, and what the consequences are of making superficial and poorly reflected choices or uninformed choices or not making choices at all.

4.3 Deemed consent and authorisation:

4.3.1 Statutory requirements

The HT Act 2004 requires 'appropriate consent' for the removal and use of an organ from the body of a deceased person for transplantation.[584] Appropriate consent is the consent of

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[581] Ibid., 62.

[582] Sheelagh McGuinness and Margaret Brazier, 'Respecting the Living Means Respecting the Dead Too' (2008) 28 Oxford Journal of Legal Studies 297.

[583] Price, *Legal and Ethical Aspects of Organ Transplantation* (n 354).

[584] Section1(1)(c) and (f) HT Act 2004.

the deceased person if this was in force immediately before death[585] or, in its absence, the consent of a nominated representative.[586] As originally enacted, the HT Act 2004 stated that in the absence of the consent of the previously living person or that of an appointed representative, appropriate consent was the consent of a person standing in a qualifying relationship to the deceased.[587] Consent was required from the person whose relationship to the deceased was accorded the highest ranking according to a hierarchy of relationships.[588]

The implementation of opt-out legislation in Wales and, later in England, modifies the definition of what constitutes appropriate consent by introducing the concept of deemed consent. Deemed consent was introduced by the HT(Wales)A 2013. Accordingly, consent by competent adults is deemed unless express consent to organ removal for transplantation was given while the person was alive,[589] in which case this express consent is required for transplantation to proceed. In England, the OD(DC)A 2019 introduced deemed consent through an additional clause, s.3(ba), whereby if there is no express consent of the deceased or of a nominated representative in force, then appropriate consent is the deemed consent of the deceased.

Of note, the introduction of deemed consent does not displace the validity of the person's own consent or refusal to consent expressed in life or the validity of the consent given by a representative appointed by the adult: these forms of express consent prevail and it is only where there is no express consent that deemed consent applies. However, the introduction of deemed consent does change the legal authority of third parties under the qualifying relationship rules to give consent on behalf of the deceased. The HT(Wales)A 2013, which sets out the main provisions relating to specifically to consent to transplantation replaces the corresponding consent provisions in the HT Act 2004[590] and does not contain provisions for consent to be given from persons in a qualifying relationship.[591] Similarly, the OD(DC)A 2019 replaces the provision for consent from the person in a qualifying relationship with the application of deemed consent. As a result, the role of any adult in a

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[585] Section 3(6)(a) HT Act 2004.

[586] Section 3(6)(b) HT Act 2004.

[587] Section 3(6)(c) HT Act 2004.

[588] Section 27(6) HT Act 2004.

[589] Section 4(2)(a).

[590] Of note, other provisions of the HT Act 2004 not directly related to consent but applicable to transplantation, have not been restated in the HT(W)A 2013 but continue to apply in Wales.

[591] However, under s4(3) if the deceased appointed a person to give consent and no one is able to give consent under the appointment, consent is given by a person standing in a qualified relationship with the deceased.

qualifying relationship with the deceased is now limited to blocking the application of deemed consent in situations where the third party has evidence that the previously living person would have objected to donation or, at the very least, where there is reasonable doubt about the person's support for donation.[592]

Deemed consent does not apply to excepted adults defined as those who not meet the criteria for residency within the relevant jurisdiction[593] or the criteria for capacity to understand the concept and legal effects of deemed consent and that organs can be removed on this basis for transplantation.[594] These exceptions are consistent with the idea that information disclosure about opt-out systems of organ procurement and understanding of the donation process and the legal consequences of deemed consent are essential for the legitimacy of organ procurement.

Under the HT(Scotland)A 2006, as originally enacted, organ removal for transplantation required authorisation by the deceased[595] or in its absence, authorisation by the nearest relative[596] according to a hierarchy of relationships. The HT(A)(Scotland)A 2019 introduces the concept of deemed authorisation amending the section on authorisation in the HT(Scotland)A 2006 and is broadly aligned with deemed consent legislation in England and Wales. An adult is deemed to have authorised the removal and use for transplantation of a body part if there is no express authorisation of the deceased in place regarding the removal and use the part for transplantation, and there is no opt-out declaration regarding the removal and use of the part for transplantation.[597]

As in England and Wales, deemed authorisation is subject to residency requirements.[598] It does not apply to adults who are incapable of understanding the nature and consequences

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[592] Under s.3(6B) of the Organ Donation (Deemed Consent) Act 2019 consent cannot be deemed and transplantation cannot go ahead if the next of kin can provide information that would lead a reasonable person to conclude that the person concerned would not have consented to organ removal. Similar provisions apply under s.4(4) of the HT(W)A 2013.

[593] Resident in England or Wales for a period of at least 12 months immediately before dying under s.3(9)(a) HTA 2004 and s.5(3)(a), respectively.

[594] The excepted adult is an adult who lacked capacity in the sense described above for a significant period before dying. 'Significant' is interpreted as a sufficiently long period as to lead a reasonable person to conclude that it would be inappropriate for consent to be deemed to be given. In Wales is Section 5(3)(b) HT(W)A 2013

[595] Section 6 Human Tissue (Scotland) Act 2006.

[596] Section 7 Human Tissue (Scotland) Act 2006.

[597] Section 6D(1) Human Tissue (Authorisation) (Scotland) 2019.

[598] Under s.6D(2)(a) the Human Tissue (Authorisation) (Scotland) 2019 only applies to persons ordinarily resident in Scotland for a period of at least 12 months ending immediately before death.

of deemed authorisation[599] and in circumstances where evidence is provided to a health worker that would lead a reasonable person to conclude that the adult was unwilling for the part to be used for transplantation or that unwillingness is likely.[600] The role of the nearest relative is also now limited to providing evidence that the deceased person objected or evidence of their likely unwillingness to donate.[601]

Express consent or authorisation to donation can be registered in a centralised database, the NHS ODR managed by NHS Blood and Transplant (NHSBT), the executive non-governmental public body responsible inter alia for improving the supply of organs for transplantation.[602] Persons can join the register at any age. It is important to note that the national ODR continues to operate despite the introduction of the opt-out system of organ procurement and the NHSBT encourages the public to use the ODR to record their decision regarding organ donation, even under the opt-out system. The electronic ODR is easily accessible online on the NHSBT organ donation website[603] and individuals may register a decision to donate or a decision not to donate.[604] They may also amend previously recorded decisions or withdraw from the ODR.

4.3.2 Procedural autonomy

The NHSBT places a strong emphasis on the fact that despite the changes in the law, the choice about whether or not to donate remains and this decision is the individual's to make.[605] Information about organ donation is provided and the public is encouraged to use this information to make an informed choice about organ donation and register this choice. The fact that registration continues to be encouraged by the NHSBT, despite the introduction of the opt-out framework, indicates that explicit consent is still regarded as a preferable way to convey an intent to donate. It is important to consider this claim carefully

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[599] Section 6D(2)(b) Human Tissue (Authorisation) (Scotland) 2019.

[600] Section 6D2(d)(i) and (ii) Human Tissue (Authorisation) (Scotland) 2019 respectively.

[601] Section 8 of The HT (Authorisation)(S) A 2019. This provides for a section 6E to this effect to be inserted in the HT(Scotland) A 2006. This evidence may be provided by any person, not specifically the nearest relative).

[602] See www.organdonation.nhs.uk and www.organdonationscotland.org last accessed (both documents) 25 May 2021.

[603] See www.organdonation.nhs.uk and www.organdonationscotland.org last accessed (both documents) 25 May 2021.

[604] When the ODR was first introduced, there was no formal process to register an objection to donation such that a preference not to donate could only be established where this was conveyed by the next of kin of the deceased.

[605] See https://www.organdonation.nhs.uk/register-to-donate/.

and examine what registration actually involves. I am not concerned with whether active registration is a clearer way of giving permission to organ donation, my focus is on whether the process of registering consent or authorisation to donation, or an objection, requires a minimal level of appreciation of organ donation and commitment to becoming a donor.

When the individual gives or refuses consent to posthumous donation by registering their preferences on the ODR, there is no requirement to meet the criteria for capacity, understanding, and voluntariness normally taken to be essential requirements for valid consent to treatment or medical procedures.

Online registration on the ODR is simple and initiatives have been introduced to ensure that the process is convenient and widely accessible, by allowing individuals to join through the Driving and Vehicle Licensing Agency when applying for or renewing their driving licence, or when registering with a GP practice, or signing up for a Boots advantage card.[606] Some commentators have expressed reservations regarding this approach that introduces registration for organ donation in the context of an unrelated task and caution that what is taken to be consent is, at most, a positive disposition towards donation at that particular time.[607]

Joining the ODR is essentially a process of self-registration which involves no oversight of the decision-making process. There is no provision for any assessment of capacity, and individuals lacking capacity to make a decision regarding donation cannot be reliably identified at the stage of selecting the relevant options. Any doubts regarding the capacity are likely to arise, around the time of death of the person when organ donation is discussed with the next of kin. As discussed above, reasonably robust evidence of an impairment of capacity would preclude deemed consent or authorisation.[608] With regards to information disclosure, while information about donation and transplantation is available on the NHSBT registration website, selecting the option of donation does not require any knowledge or understanding of the organ donation process. Also, the process cannot identify whether decisions are made voluntarily by the person consenting to donation.

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[606] www.organdonation.nhs.uk and www.organdonationscotland.org last accessed (both documents) 25 May 2021.

[607] Robert Truog, 'When Does a Nudge Become a Shove in Seeking Consent for Organ Donation?' (2012) 12 The American Journal of Bioethics 42.

[608] Department of Health, 'Organs for Transplants. A Report from the Organ Donation Taskforce', 2008' [4.8].

Overall, registration as a donor conveys no information about the underlying decision-making process and how the particular individual reaches a decision to donate is irrelevant.

In this respect, giving consent or authorisation to organ donation is significantly different to giving consent to medical interventions. This inconsistency has been highlighted by the UK Organ Donation Taskforce responding to the concerns of clinicians that carrying a donor card or registering with the ODR falls short of the definition of consent in the medical setting.[609] The obvious difference between these situations is that the procedure (organ removal) takes place after death. This raises the question of whether the individual's interests in the use and control of their body after death are genuinely held to be important and whether harm resulting from the frustration of these interests matters.

The minimal requirements for the provision of appropriate consent to donation are difficult to reconcile with a view that attaches importance to the individual's interests in the control over the posthumous use of their body and that supports the protection of these interests. The use of the term 'authorisation' under the HT(Scotland)A 2006 rather than consent properly distinguishes between giving permission for organ donation and giving consent to medical procedures and interventions, circumventing the inconsistencies between these processes. The Scottish Review Group rightly noted that while 'valid consent is generally expected to follow the provision of information, authorisation is not constrained by this requirement'.[610] While the choice of the term 'authorisation' may be more coherent from a semantic perspective, registration of consent and authorisation equally fail to ensure that choices to donate are based on critical reflection and genuinely represent the wishes of the individual. If the individual's interests in what happens to their body after death matter from a normative perspective, arguably the process of organ procurement should do more to ensure that the individual has real understanding of the donation process and that their choice is well considered choice.

However, if we consider the common law dictum that individuals may give consent for any or no reason at all,[611] respect for autonomy should also include the right to ignore information or make a decision with minimal self-reflection. It is widely recognised that individuals are generally reluctant to contemplate the physical process of organ retrieval

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[609] Ibid.

[610] Scottish Review Group on Retention of Organs at Post-Mortem: Final Report, 2000 s.1 [17].

[611] Price, *Legal and Ethical Aspects of Organ Transplantation* (n 354).

and transplantation into another human being.[612] Arguably, respect for autonomy should also accommodate the preferences of those who wish to help persons in need of an organ at a more abstract level but don't want to know the details and don't wish to dwell on death or the dying process. This aptitude does not necessarily mean that the desire to do good is any less genuine or meaningful to the person.

The broad range of attitudes towards posthumous organ donation present significant challenges to the analysis of what donor autonomy means for the person whose organs are removed for transplantation. There are profound differences between persons in their understanding, appreciation, and perceptions about organ donation; their willingness to engage with themes such as illness and death and reflect upon choices that they may face; and in terms of value systems and sense of commitment to moral principles. Furthermore, religious beliefs, culture, and social and personal factors profoundly affect the way people regard the dying process and how any concerns about what happens after death are shaped. The arguments raised in this chapter highlight the difficulties in attempting to apply a system of organ procurement that is a good fit to all and properly takes into account the interests that individuals have relation to the removal of their organs for transplantation.

4.4 Opt-out and autonomy

4.4.1 The gift concept

The concept of organ donation as gift-giving has traditionally been accepted as the sociological explanation for organ transplantation.[613] Slogans such as 'give the gift of life after your death' are an intrinsic part of the narrative surrounding transplantation.[614] However, where organ procurement is based on deemed rather than explicit consent (or authorisation) questions arise about whether the idea of a life-saving gift is an appropriate concept to use. While deceased persons are clearly always the *source* of the organs, arguably, the term 'donor' should properly imply an *intent* to bequeath one's organs to patients in need of a transplant. Conceptually, intent to donate is clearer where consent or

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[612] Joan Costa-Font, Caroline Rudisill and Maximilian Salcher-Konrad, '"Relative Consent" or "Presumed Consent"? Organ Donation Attitudes and Behaviour' (2021) 22 The European Journal of Health Economics 5.

[613] Orit Ben-David, *Organ Donation and Transplantation: Body Organs as an Exchangeable Socio-Cultural Resource* (First, Praeger 2005), 49.

[614] See https://www.nhsbt.nhs.uk/what-we-do/transplantation-services/organ-donation-and-transplantation

authorisation is based upon active steps taken by the individual to register their preference on the ODR, rather than where permission to use organs for transplantation is accepted as the default position.

I would argue that this is not simply a matter of semantics because the concept of ‘donor’ and ‘donation’ have specific implications in terms of an individual’s commitment to bequeath an organ to persons who need transplantation and in terms of how we understand personal autonomy in decisions about the uses of our body parts after death. The concept ‘provision of organs’, while potentially less palatable to society, may be a more honest representation of an organ procurement system that is prepared to accept that the use of organs for transplantation is justified in the absence of the individual’s objection.

An alternative narrative, which I argue is more coherent with the current legal and procedural framework, is one based on organ donation as a moral duty. This will be discussed below.

4.4.2 Is it consent?

Appreciation of what decisional autonomy means within an opt-out framework from the perspective of the person whose organs are used for transplantation requires an examination of the understanding of deemed consent and authorisation. Within an opt-in framework, the requirement for express consent or authorisation is regarded as important because it indicates that a decision has been made.[615] The central concern regarding opt-out frameworks is that they do not guarantee that the individual has actively made a choice about what can or cannot be done with their bodies after death. I will look more closely at the idea that not registering an objection to donation is taken to mean that the individual is giving their consent or authorisation for organ removal and transplantation.

Setting aside the issue of the effects of opt-out on transplantation rates, the key question, argues Chris Rudge, National Clinical Director for Transplant 2008-2011, is ‘not whether presumed consent is a better way of getting organs for transplant, but whether it is a better way of getting consent’.[616] In other words, the paramount concern should be whether

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[615] Sheila McLean, ‘Consent and the Law: Review of the Current Provisions in the Human Fertilisation and Embryology Act 1990 for the UK Health Ministers’ (1997) 3 Human Reproduction Update 593; Deryck Beyleveld and Roger Brownsword, *Consent in the Law* (Hart 2007), 187

[616] Chris Rudge. ‘Giving organs must be seen as being in the donor’s best interests,’ says new transplant director. The Times 4th August 2008.

deemed consent or authorisation is an ethically superior means of gaining consent than explicit consent, ignoring any increase in the number of transplants. There is force in the argument that if consent does matter normatively only explicit consent can legitimise posthumous removal of organs.[617] Price maintains that the right system, ethically and legally, is a system in which the true wishes of all individuals are definitively and accurately recorded pre-mortem, such that no assumptions regarding the deceased's wishes need to be made.[618] This is consistent with the view of Beyleveld and Brownsword that silence is an unreliable indicator of consent and that ideal consent should be conveyed by clear signalling in the form of opting in because this allows the individual personally and unequivocally to consent.[619] Therefore, if the primary ethical concern is to ensure that organs are removed from persons who made a choice in life to donate posthumously, the requirement for explicit consent is prima facie the preferable mechanism. Joining the ODR is a clear signal that the person is acting upon their preference to donate for the simple reason that it is an active step taken to indicate intent to donate. In principle, an opt-in system respects the decisional autonomy of the person whose organs will be used because their explicit permission is required for organs to be transplanted.

The OD(DC)A 2019, the HT(Wales)A 2013, and the HT(A)(Scotland)A 2019 are based on the principle that both action and non-action involve the exercise of choice: by doing nothing i.e., failing to object, the individual chooses to donate and by registering an objection the individual refuses to donate. The default position is regarded as a choice because by choosing to do nothing individuals are taken to knowingly consent to donation.

Opt-out systems are frequently referred to as 'presumed consent' systems.[620] The concept of a presumption to characterise consent is controversial and presumed consent has been rejected by many critics as deception[621] or consent that is not real.[622] Garwood-Gowers, argues that 'there is no such thing as "presumed consent" in philosophical or legal terms

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[617] H McLachlan 'Presumed consent is no consent at all' see Danielle Hamm and Juliet Tizzard, 'Presumed Consent for Organ Donation' (2008) 336 BMJ 230.

[618] Price, *Human Tissue in Transplantation and Research: A Model Legal and Ethical Donation Framework* (n 464), 126.

[619] Beyleveld and Brownsword (n 569), 188 and 197.

[620] Hamm and Tizzard (n 571).

[621] Den Hartogh (n 446).

[622] John Saunders, 'Bodies, Organs and Saving Lives: The Alternatives' (2010) 10 Clinical Medicine (London, England) 26. See also J Saunders Written Evidence to the National Assembly for Wales www.assemblywales.org/bus-home/bus-committees-third1/bus- paras 13-14.

and that consent is either implicit or explicit or it doesn't exist at all'.[623] While the term 'presumed consent' is pervasive in the literature on posthumous organ procurement the interchangeable use of presumed consent and opt-out is inaccurate and fails to capture an important distinction. Price rightly differentiates between opt-out models based on implicit (or tacit) consent, which is the *actual consent* of the deceased person, and those based on imputed (presumed) consent, which is based on the wishes *attributed* to the individual.[624] He cautions that 'consent should not be inferred from silence unless there is good reason to believe that this was reflective of actual acquiescence'.[625] Pattinson defines implicit consent as consent signalled through 'suggestive conduct' and implied consent as 'a necessary means of fulfilling a purpose for which express consent has been obtained and the patient is reasonably expected to be aware of this connection'.[626] An example of giving implied consent is when a patient told by their doctor that a blood test is required then rolls up their sleeve and extends their arm so that blood can be drawn.

Irrespective of labels, there are clearly important conceptual differences between implicit consent and consent that is attributed or implied. Establishing whether deemed consent falls within the first or the second category is not straightforward. Considering implicit consent, its application to the context of organ procurement is problematic for a number of reasons. It is consent applied impersonally to the general public on the basis of inaction rather than to the specific patient who actively rolls up their sleeve. Furthermore, it is not possible to pinpoint the time when implicit consent is actually given as inaction may cover months or even years. Arguably, this may be taken as the date deemed consent or authorisation legislation came into force on the basis that the individual would have known then that from that point onwards a failure to opt-out would be regarded as valid consent in law. Ultimately, the level of knowledge and understanding of deemed consent or authorisation and the legal consequences for the specific patient cannot be conclusively established from inaction alone. Individuals, with their different priorities, personal commitments, and moral values, may or may not engage with the idea of posthumous organ donation. On balance, it is hard to see how deemed consent (or authorisation) is

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[623] Extraction and use of body materials for transplantation and research purposes: the Impact of the Human Rights Act 1998 in Austen Garwood-Gowers, *Healthcare Law: The Impact of the Human Rights Act 1998.* (Routledge-Cavendish 2002), 310

[624] Price, *Human Tissue in Transplantation and Research: A Model Legal and Ethical Donation Framework* (n 464), 114-116

[625] Price, *Human Tissue in Transplantation and Research: A Model Legal and Ethical Donation Framework* (n 459), 114-116

[626] Pattinson, *Medical Law and Ethics* (Sweet & Maxwell (UK) 2020), 8.

implicit consent and, in my view, at most, it is consent that can be attributed to the individual.

The grounds for accepting consent that is attributed to the individual rather than consent that is explicitly given require careful scrutiny because they go to the heart of the issue of whether the wishes and preferences of the individual regarding the posthumous use of their body genuinely matter from an ethical perspective.

4.5 The ethical basis for the shift to opt-out

4.5.1 Public support

Ethical arguments used to justify opt-out systems of consent include those based on the idea that most people are supportive of organ donation.[627] The Explanatory Notes to the OD(DC)A 2019 state public support as the justification for the opt-out legislation,[628] quoting evidence from an attitudinal survey conducted by NHSBT that 80% of the population supports organ donation in principle.[629] The empirical evidence that most people are supportive of donation is controversial. It is not clear that public opinion surveys are reliable indicators of real levels of willingness to donate because surveys often ask about support for donation in general, rather than about the individual's own wish to donate; research suggests that positive responses are more likely to be elicited when the issue is framed in theoretical terms and when those interviewed feel the need to conform to societal values.[630] The presumption that the majority of the public is willing to donate an organ is problematic because it relies on the accuracy of opinion polls that conflate a disposition of being in favour of organ donation generally with choosing to become an organ donor and acting upon this choice by registering a preference to donate. The polls may not be representative of the public's actual preferences and, in any event, they say nothing about the preferences of the particular individual. Proceeding with transplantation on the presumption that an individual wished to become an organ donor *because* most people support organ donation does not take seriously the interests of the particular person over

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[627] Ben Saunders, 'Opt-out Organ Donation without Presumptions' (2012) 38 Journal of Medical Ethics. p 69, 71.

[628] See Explanatory Notes para 5 https://www.legislation.gov.uk/ukpga/2019/7/notes/division/3/index.htm last accessed 8 March 2022.

[629] See https://archive2021.parliament.scot/S5_HealthandSportCommittee/BHF_Submission.pdf last accessed 26 February 2022.

[630] David Price, *Human Tissue in Transplantation and Research: A Model Legal and Ethical Donation Framework* (Cambridge University Press 2009), 141.

the use and disposition of their body. If these interests matter, it is imperative that the procurement system ensures that the actual preferences of the individual are identified and protected in all cases.

Even at a population level, assumptions about the wishes of the public can be misleading in a multicultural and multifaith society. The concept of the UK public as a homogenous entity is challenged by small-scale studies that have identified disparities in attitudes towards organ donation among different ethnic or religious groups in the UK.[631] The DonaTE project, a project undertaken before the introduction of opt-out legislation to identify barriers to registration as an organ donor and to family consent, found that many people from minority backgrounds did not identify with media messages on donation or felt that these were not relevant to them and the authors concluded that engaging members of minority communities, particularly community and faith leaders, was paramount in designing targeted strategies to raise awareness and normalise conversations about organ donation within these groups.[632] Randhawa and Gardiner recently observed that a more 'granular approach' to specific ethnicity to properly understand the heterogeneity in attitudes towards donation among ethnic minority communities in the UK.[633] However, current NHS Blood and Transplant statistics remain concerning because they show that minority ethnic groups are underrepresented in ODR registrations and 80% of transplants in people from ethnic minority backgrounds are from white donors.[634] These findings have important clinical implications if we consider that in many cases donors of the same

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[631] Wazim Ahmed, Susie Harris, and Edwina Brown, (1999). Attitudes to Organ Donation among South Asians in an English High Street' 1999 (12) Journal of the Royal Society of Medicine, 626; Fawzi AlKhawari, Gerry Stimson and Anthony Warrens, 'Attitudes Toward Transplantation in UK Muslim Indo-Asians in West London' (2005) 6 American Journal of Transplantation, 1326; Salman Gauher and others, 'The factors that influence attitudes toward organ donation for transplantation among UK university students of Indian and Pakistani descent' (2013) 27 Clinical Transplantation 359; Gurgh Randhawa and James Neuberger, 'Role of Religion in Organ Donation—Development of the United Kingdom Faith and Organ Donation Action Plan' 2011 48 Transplantation Proceedings 689; For a summary of the position of different faiths regarding organ donation see Michael Oliver and others, 'Organ Donation, Transplantation and Religion' (2011) 26 Nephrology Dialysis Transplant 437.

[632] Myfanwy Morgan and others, 'Increasing the acceptability and rates of organ donation among minority ethnic groups: a programme of observational and evaluative research on Donation, Transplantation and Ethnicity (DonaTE)' (2016) 4 Programme Grants for Applied Research 1.

[633] Gurch Randhawa and Dale Gardiner 'Tackling organ donation among minority ethnic communities in the UK—a whole systems approach ' (2022) 142 British Medical Bulletin 142.

[634] NHS Blood and Transplant, 'Annual Report on Ethnicity Differences in Organ Donation and Transplantation: Report for 2021/2022', Statistics and Clinical Research, NHS Blood and Transplant available at https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/28457/annual-report-on-ethnicity-differences-2021_2022.pdf accessed 15 December 2022. This report is published as a supplementary report of the Organ and Donation Transplantation Activity Report 2020/22 by the NHS BT. These findings are consistent with earlier figures, for example, Office for National Statistics, Ethnicity and National Identity in England and Wales (2011) https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/articles/ethnicityandnationalidentityinenglandandwales/2012-12-11 accessed 12 December 2012.

ethnicity as the recipient provide the best match for an organ increasing the chances of successful transplantation. While recognising that further time is necessary to assess the impact on donation rates of the recently introduced opt-out legislation in England and Scotland, these figures highlight the fact that claims of public support for organ donation used to legitimise the introduction of an opt-out system of organ procurement are not straightforward and are not based on a clearly defined notion of the 'public' that takes into account the multicultural fabric of UK society.

4.5.2 Social utility

The analysis of decision-making within opt-out organ procurement systems is further obfuscated by arguments conflating the issue of the normative validity of deemed consent with the social utility of this type of consent in terms of increasing the numbers of transplanted organs. Therefore, the potential of these opt-out strategies to increase the number of transplanted organs is used to confer legitimacy upon the consent giving process. However, the success of opt-out systems in improving transplantation rates is controversial[635] and there is limited evidence that changes in the way consent can be obtained, alone, result in increased donation rates.[636] For example, it is generally recognised that high rates of donation and transplantation in Spain, a country widely regarded as a model of successful organ procurement, is principally attributable to its well-organised infrastructure and the proactive role of transplant coordinators rather than its opt-out system of organ procurement.[637]

There are mixed views on whether the introduction of the opt-out system in Wales has translated into increased donation rates.[638] In England and Scotland, the impact remains to

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[635] Albertsen (n 663); Saunders (n 647).

[636] Brian Willis and Muireann Quigley, 'Opt-out Organ Donation: On Evidence and Public Policy' (2014) 107 Journal of the Royal Society of Medicine 56.

[637] Rafael Matesanz, Blanca Miranda, and Carlos Felipe, 'Organ Procurement and Renal Transplants in Spain: The Impact of Transplant Coordination. Spanish National Transplant Organization (ONT)' (1994) 9 Nephrology, Dialysis, Transplantation 475; Rafael Matesanz and others, 'Spanish Experience as a Leading Country: What Kind of Measures Were Taken?' (2011) 24 Transplant International 333; John Fabre, Paul Murphy and Rafael Matesanz, 'Presumed Consent: A Distraction in the Quest for Increasing Rates of Organ Donation' (2010) 341 BMJ c4973; Anne-Maree Farrell, David Price and Muireann Quigley, *Organ Shortage Ethics, Law and Pragmatism* (Cambridge University Press 2011); Andreas Albertsen, 'Assessing Deemed Consent in Wales - the Advantages of a Broad Difference-in-Difference Design' (2019) 45 Journal of Medical Ethics 211 .

[638] Albertsen (n 662); Jordan Parsons, 'Ensuring Appropriate Assessment of Deemed Consent in Wales' (2019) 45 Journal of Medical Ethics 210; Adnan Sharif, 'Presumed Consent Will Not Automatically Lead to Increased Organ Donation' (2018) 94 Kidney International 249; Jane Noyes and others, 'Short-Term Impact of Introducing a Soft Opt-out Organ Donation System in Wales: Before and after Study' (2019) 9 BMJ Open e025159.

be assessed due to the combination of recently implemented legislation and cuts to transplantation activity across the UK due to the COVID-19 pandemic.[639] Utilitarian arguments for opt-out systems of organ procurement place are based on the imposition of rules through legislation to maximise the number of organs available for transplantation. I will not be exploring these arguments further here as these principles remove the locus of the decision-making away from the individual. This thesis is concerned with decisions to donate from the perspective of the person whose organs are removed and transplanted: how decisions are made and whether choices that genuinely reflect personal values and commitments matter within the existing legal framework. My analysis of whether deemed consent and authorisation legislation can be reconciled with a particular account of donor autonomy focuses on collective values that are internalised and accepted by the individual as a moral duty to donate.

4.5.3 Moral duty

Opt-out systems are broadly based on the premise that donation is the morally right thing to do although this is not explicitly recognised as the normative basis for the policy. A statutory duty to 'promote transplantation as a means of improving the health of the people of Wales' is set out in section 2(1)(a) of the HT(Wales)A 2013. Statements such as this, frame the duty in terms of a duty to promote organ donation rather than a duty to donate an organ and it is said that donation awareness has increased as a result of the implementation of deemed consent legislation.[640] However, Price claims that opt-out systems go beyond the promotion of donation and organ removal for transplantation is regarded as a form of moral requirement or entitlement of others.[641]

Farrell argues that, as a matter of general principle, it is important that organ donation is seen, and indeed promoted, on the basis that it is a moral obligation of citizenship, and an important aspect of participating in the community.[642] However, there are divergent views regarding how far the law should go to promote these values and whether the imposition of moral obligations upon the individual is justified. For Machado, deemed consent or

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[639] Jordan Parsons, 'Deemed Consent for Organ Donation: A Comparison of the English and Scottish Approaches' (2021) 8 Journal of Law and the Biosciences lsab003; The number of deceased donor transplants across the UK decreased by 68% Alex R Manara and others, (2020) 396 Lancet 'Donation and Transplantation Activity in the UK during the COVID-19 Lockdown' 465.

[640] Albertsen (n 662), 318.

[641] Price, (n 176), 127.

[642] Anne Maree Farrell, 'Time for Change: The Need for a Pragmatic Approach to Addressing Organ Shortage in the UK' (2008) 3 Clinical Ethics 53.

authorisation legislation is not ethically problematic and should properly be regarded as a 'quasi-civic duty in donating organs, grounded on notions of social solidarity in society'.[643] This position broadly aligns with claims by Lindeman that opt-out frameworks are an expression of the community's acknowledgment of the 'profound significance of each member's life and health' and of the shared lives of community members and its commitment to a common good.[644]

Commitment to the common good is the central tenet of communitarian ethical theory and is based on notions of social solidarity rooted in the collective obligation to respond to the needs of others. Moral responsibility plays a significant role and is understood as care and concern for other members of the community, and awareness of one's obligations to others and of the impact of one's choices and actions upon others.[645] Beyond these general ethical commitments, communitarianism is a broad church so here, I focus on the work of Etzioni who has developed a sophisticated account of moderate communitarianism in deceased organ donation, known as responsive communitarianism. Starting from the point that individuals in Western countries generally support organ donation and that no principled objections to donation have been identified, Etzioni advocates a change of existing predispositions towards donation into active choices to donate organs placing the emphasis on the development of a community appreciation that donation is the morally right thing to do.[646]

The process of moral persuasion goes beyond the mere provision of information on the benefits of transplantation. In practical terms, Etzioni seeks to promote visible commitment to organ donation and engagement with the public by community leaders, such as members of the clergy, politicians, members of the media community; increased persuasiveness of organ donation forms; and the introduction of electronic books to document donor status of individuals who are willing to share this information.

However, he distinguishes the social pressure required to change individual preferences from a 'top-down approach' involving the introduction of opt-out organ procurements

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[643] Nora Machado, *Using the Bodies of the Dead; Legal, Ethical and Organisational Dimensions of Organ Transplantation.* (Routledge 2019),193.

[644] James Lindemann Nelson, 'Internal Organs, Integral Selves, and Good Communities: Opt-out Organ Procurement Policies and the "Separateness of Persons"' (2011) 32 Theor Med Bioeth 289, 290-291.

[645] Cummins Gauthier (125), 346.

[646] Gil Siegal and Richard Bonnie, 'Closing the Organ Gap: A Reciprocity-Based Social Contract Approach' (2006) 34 The Journal of Law, Medicine & Ethics, 416.

systems, which he claims are not based on a shared understanding of organ donation as a social or moral responsibility. This distinction is central to the questions I examine in this chapter about the understanding of donor autonomy within the opt-out legal framework because it maintains the individual at the centre of the decision-making process. A key concern is that the change of preferences is based upon a genuine recognition by individuals that organ donation is the right thing to do. In this sense, Etzioni seeks to achieve a balance between respect for personal autonomy and achieving the common good: his proposal is for a radical change of the moral culture of society yet donation must be genuinely accepted by the individual as a moral responsibility.[647] Moral responsibility requires an awareness of one's obligations to others and of the impact of one's choices and actions upon others.[648] The rejection of the law as a means of achieving the common interest is based on the assumption that the imposition of a legal framework removes the individual as the person who makes their own choices,[649] negating moral responsibility.[650] Nonetheless, some communitarian exponents do support the implementation of opt-out systems of procurement and the justification for this is firmly grounded in a moral duty to donate, rather than in a presumption of consent.[651]

4.6 Defaults and donor autonomy

An opt-out framework introduces changes to the requirements to secure valid consent. Although the individual is presented with the same choice set of donation or non-donation, from the perspective of donor autonomy it is important to consider whether consent secured by default reflects differences in the decision-making process that are relevant to a substantive conceptualization of autonomy and whether it achieves shifts in individual preferences.

Opinion polls indicate that the majority of individuals are supportive of donation yet there is widespread apathy among the general population in registering wishes to donate.[652] In recent years, strategies to increase donation rates have been re-examined in light of the

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[647] Etzioni (n 120).

[648] Cummins Gauthier, (n 125), 337, 346.

[649] Mark Kuczewski, 'Reconceiving the Family: The Process of Consent in Medical Decisionmaking' (1996) 26 The Hastings Center Report, 106-108.

[650] Cummins Gauthier, (n 125), 344-345.

[651] Lindemann Nelson (n 643), 290-291.

[652] Alberto Molina-Pérez and others, 'Public Knowledge and Attitudes towards Consent Policies for Organ Donation in Europe. A Systematic Review' (2019) 33 Transplantation Reviews 1.

application to organ procurement of psychological theories of behaviour modification,[653] and specifically nudge theory.[654] Nudge theory, developed by leading American academics, Thaler and Sunstein, in their influential book *Nudges*, is based on the idea that decision-making involves two components: a reflective system based on decision-conscious processing of information and an automatic system resulting in instinctive choices made with minimal cognitive engagement.[655] Nudges target the automatic system and alter behaviour in a noncoercive manner by introducing subtle changes to the context within which choices are made.[656]

Supporters of nudge theory claim that predictable cognitive biases cause individuals to make choices that are contrary to their best interests or the interests of others/society. By presenting choices in different ways individuals can be steered towards better decisions. A relevant consideration is whether nudges cause the infringement of rights or harm.[657] While nudges are a form of libertarian paternalism, supporters argue that individual liberty is not infringed because the same choices are available and choosing differently from what the nudge suggests is easy.[658] It is paramount that making a different choice to the one supported by the nudge is not more burdensome and although there is no definition of 'easy', there is a broad consensus that communicating one's preference by phone is considered onerous, while a mouse click is easy.[659]

On this view, the harm of opt-out systems depends on the proportion of people for whom the default would make it harder for them to choose their preferred option not to donate.[660] This requires fair consideration of whether registration of an objection to donation is more demanding than not taking any action, being mindful that the simplicity of an online registration system may be irrelevant to those for whom internet access or internet literacy is a challenge. It is fair to say that while registering an objection may be relatively easy, the

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[653] Sharif and Moorlock (n 563); Anne-Maree Farrell, 'Addressing Organ Shortage : Are Nudges the Way Forward' (2015) 7 Law, Innovation and Technology 253, 254.

[654] Richard Thaler and Cass Sunstein, *Nudge: Improving Decisions about Health, Wealth, and Happiness* (Yale University Press 2008).

[655] Theresa Marteau and others, 'Judging Nudging: Can Nudging Improve Population Health?' (2011) 342 BMJ, 263.

[656] Thaler and Sunstein (n 653).

[657] Karen Yeung, 'Nudge as Fudge' (2012) 75 The Modern Law Review, 139-142.

[658] Douglas Mackay and Alexandra Robinson The Ethics of Organ Donor Registration Policies: Nudges and Respect for Autonomy' (2016) 16 The American journal of bioethics 3.

[659] Shlomo Cohen, 'Nudging and Informed Consent' (2013) 13 American Journal of Bioethics.

[660] MacKay and Robinson, (n 657).

default of not taking any action at all is undoubtedly the easiest and most convenient option.

However, from the perspective of donor autonomy and how decisions to donate are made, there are deeper concerns. Nudges take advantage of the status quo bias, which is the tendency of individuals to stick with existing circumstances and choose the default [661] that is attributed to a combination of inertia,[662] view of the default as the officially endorsed choice,[663] and risk aversion.[664] The potential of nudge theory to increase numbers of organs made available becomes apparent if we consider that despite evidence of support for donation among the public, this support is often in the abstract and actual decisions regarding donation are generally not formed.[665] Switching the default to donation allows apathy to be channelled towards donation.

In general terms, the use of defaults is ethically problematic for individual autonomy because it takes advantage of the status quo bias without awareness of the individual.[666] Critics point out that setting defaults does not foster decisions made according to one's values and preferences because there is no engagement with the rational capacity of individuals.[667] Truog is sceptical of this approach in deceased organ donation because it is designed to maximise organ donation registrations rather than optimising decision-making.[668] From this perspective, the legitimacy of nudges as a strategy to change behaviour depends, to some extent, on whether these are accompanied by policies to

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[661] Cass Sunstein, 'Deciding by Default' (2013) 162 University of Pennsylvania Law Review, 1-57.

[662] In the organ donation context, inertia is particularly relevant as individuals are generally reluctant to contemplate their own death and think about the ethical issues surrounding transplantation.

[663] Organ donation is perceived as endorsed by the state and/or society.

[664] Shai Davidai, Thomas Gilovich and Lee D Ross, 'The Meaning of Default Options for Potential Organ Donors' (2012) 109 Proceedings of the National Academy of Sciences of the United States of America 15201.

[665] James Douglas and Antonia Cronin, 'The Human Transplantation (Wales) Act 2013: An Act of Encouragement, Not Enforcement: The Human Transplantation (Wales) Act 2013' (2015) 78 The Modern Law Review 324.

[666] MacKay and Robinson (n 657), 4.

[667] Mackay and Robinson (n 657).

[668] Robert Truog, 'The Ethics of Organ Donation by Living Donors' (2005) 353 New England Journal of Medicine 444.

promote deliberative participation, transparency and accountability[669] and on the presence of clear boundaries about the nature, scope, and limits of state intervention.[670]

An adequate information campaign on organ donation is generally regarded as an absolute pre-requisite for legally valid consent in an opt-out organ procurement system, otherwise opt-out policies effectively become mechanisms for avoiding consent altogether.[671] Informational campaigns, public debates, and debates in the National Assembly for Wales and the Scottish and British Parliament played a pivotal role in the development of legislation and in promoting public awareness about donation generally and engaging the public in discussions about the proposed changes to legislation.

Clearly, the delivery of information to the public about the type of permission that is regarded as sufficient for organs to be removed for transplantation is pivotal. However, achieving an adequate information campaign represents a significant hurdle. There are real concerns that some persons will invariably be bypassed and remain ignorant of the law and that public education campaigns cannot guarantee that every member of society is aware that inaction is treated as consent or authorisation to donation.[672] Furthermore, while the initial fervour of organ donation campaigns which accompany the introduction of an opt-out system may satisfy the duty of information disclosure, questions arise about whether this duty is consistently discharged in the long term, once legislation has been implemented and the policy is established. To this effect, the HT(Wales) A 2013 imposes a duty upon Welsh Ministers to promote a public informational campaign on deemed consent every 12 months and submit annual reports regarding these initiatives to the National Assembly of Wales until 2020 (s.2(2) and (3)).[673]

Information and awareness campaigns plays an important role not only in ensuring that the decision to donate is informed and that the individual is aware of the legal implications of registering consent or objection to donation and of failing to register a preference.

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[669] Anne-Maree Farrell, 'Time for Change: The Need for a Pragmatic Approach to Addressing Organ Shortage in the UK' (2008) 3 Clinical Ethics 278.

[670] Muireann Quigley, 'Nudging for Health: On Public Policy and Designing Choice Architecture' (2013) 21 Medical Law Review 588.

[671] Ben Saunders, 'How Altruistic Organ Donation May Be (Intrinsically) Bad' (2018) 44 Journal of Medical Ethics.

[672] Mark Schweda and Silke Schicktanz, 'The "Spare Parts Person"? Conceptions of the Human Body and Their Implications for Public Attitudes towards Organ Donation and Organ Sale' (2009) 4 Philosophy, Ethics, and Humanities in Medicine 4.

[673] There is no equivalent statutory duty in England and Scotland.

However, from the perspective of the autonomy of the donor, it important to consider whether the choice of donation as the default position and the public education campaigns can achieve real shifts in attitudes towards donation and not merely an increase in the numbers of organs available for transplantation.

Farrell questions the legitimacy of the use of nudges to induce behavioural changes in areas of public policy where differing values, beliefs and preferences are at stake.[674] The point being made is that the proper approach should be to actively promote serious engagement with the decision-making process, rather than facilitating unreflected registration of the default, so that the choices of the individual genuinely reflect their values and ethical priorities. In response to this, it could be argued that there is broad consensus that deceased organ donation is a good thing as there is no evidence in the literature that refusal of an organ as a matter of principle is an area of ethical concern. Furthermore, the information campaigns preceding and accompanying the changes in legislation engage the public in organ donation and encourage individuals to express their preferences regarding donation and join the ODR.

Another relevant consideration in terms of the autonomy of the donor is that the previous opt-in system was not neutral in the sense that this was also based on a default and this was non-donation. Jacobs argues that there has been limited academic debate on the presumption of refusal to organ donation on which opt-in frameworks are based and critiques the general perception that violations of a desire to donate are as less serious than those of a desire not to donate.[675] Within an opt-in framework, the assumption that individuals who do give express consent or authorisation do not wish to donate is equally open to challenge. Any procurement system that is based on a binary option yet does not require a preference to be registered must account for silence: the failure to choose must be categorised either as a willingness to donate or an unwillingness to donate.[676] I do not intend to compare the merits of opt-in and opt-out systems for organ procurement. I highlight the point made earlier that there were significant flaws in the pre-existing opt-in system and intrinsic contradictions with respect to the proper source of the authority to

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[674] Farrell, (n 652).

[675] Marie Andrée Jacob, 'Another Look at the Presumed-versus-Informed Consent Dichotomy in Postmortem Organ Procurement' (2006) 20 Bioethics, 297-299.

[676] According to Mackay and Robinson this also applies to opt-in systems which use non-donation as the default. The authors conclude that mandatory choice systems are ethically preferable because, while they involve coercion to the extent that a choice is imposed, they do not impose registration as a donor and the requirement to indicate a preference is implemented in order to promote individual autonomy.

make decisions about organ donation and the relevance of substantive autonomy in the consent or authorisation process. When we examine the meaning of donor autonomy within the current opt-out system we cannot ignore it conceptualization in the first place under the opt-in system. There was and remains a fundamental mismatch between the procedural and unreflected registration of a donation preference in life and the deeper level of engagement and personal involvement of the next of kin when organ donation is being considered around the point of death. I will turn to this aspect now.

4.7 The role of the next of kin

Realistically, an opt-out organ procurement system cannot reliably identify whether a specific individual who fails to object to donation is giving actual consent. This deficiency is compensated for, to some extent, by the assigning the next of kin[677] a statutory role in conveying any objection to donation based on their knowledge of the deceased person. Clearly, evidence of an objection to donation is important because this is incompatible with an assumption that the individual consented. Indeed, s.24(2) of the HT(A)(Scotland)A 2019 creates a 'duty to inquire' about the deceased's views on organ donation. Accordingly, the clinician has a duty to consult with the nearest relative as far as is reasonably practicable, although there is no provision stipulating that donation should not proceed without consultation.

The fact that deemed consent or authorisation do not apply where the next of kin adduce evidence that the deceased objected to donation properly recognises that persons close to the deceased may have knowledge of the person's true and most recently held preferences regarding donation. At the same time, the role of the next of kin has been significantly re-dimensioned as their legal authority to provide consent on behalf of the deceased, a key feature of earlier opt-in legislation, is no longer recognised under deemed consent legislation. This removes the problematic practice that allowed family members, with no formal delegation of authority from the deceased, to make decisions about donation based on inferences about the preferences of the deceased or based on their own views surrounding posthumous organ donation.

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[677] I use the term "next of kin" to include "persons standing in a qualifying relationship" (under the HT Act 2004 and the HT(Wales)A 2013) and "the nearest relative" (under the HT(Scotland)A 2006)

The HTA Code of Practice highlights that the role of persons in qualifying relationships is important and that sensitive communication and engagement with them is paramount.[678] The NHSBT encourages individuals to involve their families in their choices about organ donation and this approach may be seen as broadly consistent with relational accounts of decision-making in so far as it recognises the moral interests of family members in the knowing the preferences of their loved one and ensuring that their choices are upheld and the interests of the living person in knowing that their wishes are clear and will be respected after their death. However, where there is limited discussion about organ donation within the family, concerns remain that family members with no direct knowledge of the person's wishes, may view the apparent acquiescence of the deceased with suspicion and that they may object to donation proceeding on the basis of deemed consent. Where uncertainty does not amount to robust evidence of an unwillingness to donate, the decisional remit of family members becomes blurred.

In a public consultation conducted before the introduction of deemed consent legislation in England, the question was asked about whether the family should have the final say in the absence of a recorded objection from the deceased. Parson notes that deemed consent legislation departed from the result of this question: only 25 per cent of respondents felt that the family should make the final decision, while a far more decisive 48 per cent answered 'no'.[679] He claims that there was an attempt to achieve the best of both worlds in allowing those in qualifying relationships to demonstrate the deceased's objection rather than explicitly allowing them to make the choice on behalf of the deceased.[680]

The practical effect of this distinction is questionable as, ultimately, the current system operates as a 'soft opt-out' which ultimately respects the family's wishes not to proceed with donation. The next of kin are effectively afforded a power of veto as transplantation will not proceed without their support. These powers are not based on knowledge or concern about the genuineness of the deceased's consent and do not constitute a form of legal authority to make decisions for the deceased, they are a de facto power to override the consent of the deceased. There is extensive criticism of these veto powers in the medico-legal literature, with broad support for the liberal view that the individual's wish to donate should not be overridden by third parties. Den Hartogh maintains that while the

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[678] HTA Code of Practice F: Part 1 (n 11).

[679] Department of Health & Social Care, 'The New Approach to Organ and Tissue Donation in England: Government Response to Public Consultation' (August 2018).

[680] Parsons, 'Deemed Consent for Organ Donation' (n 638).

next of kin have strong interests arising out of their special ties to the deceased, these cannot be the basis for any moral or legal entitlement to make decisions.[681] Kamm is more specific: ‘Neither caring most, nor the fact that they [the relatives] will be comforted by keeping or giving an organ would seem to be a strong enough basis for a moral and legal right to decide’.[682]

I do not propose to rehearse these arguments further here. Be that as it may, in the real world of clinical practice, transplantation will not supersede the objections of the family and the NHSBT states unambiguously that family will always be involved if donation is a possibility and donation will not proceed if the family or a loved one object.[683] The HTA also recognises that where objection to donation exists, proceeding with retrieval may not be appropriate.[684] Objection to donation by family members is not limited to situations in which the objection is clearly derived from knowledge that the deceased person would have objected to donation. Research shows that within the opt-out legal framework, reasons for these objections include uncertainty about the wishes of the deceased person which, together with the perception of donation being against their religious or cultural beliefs, and that these are particularly prominent reasons given by families within ethnic minority groups to justify their opposition to the removal of an organ from a loved one.[685] These findings highlight the need for greater engagement with minority groups to explore perceptions about the role of religion and culture in decisions to donate an organ posthumously and encourage dialogue about posthumous donation within families and communities.

In practice, organ transplantation relies on the goodwill and support of the public and proceeding with organ removal despite the objection of family members is not an approach endorsed by transplant professionals due to the real risk of erosion of public trust in the transplant system.[686] Accordingly, deference to the wishes of the next of kin, where these

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[681] Govert Den Hartogh, ‘Is Consent of the Donor Enough to Justify the Removal of Living Organs?’ (2013) 22 Cambridge Quarterly of Healthcare Ethics 45, 38 and 54.

[682] FM Kamm, *Death and Whom to Save from It* (Oxford University Press 1998).

[683] https://www.organdonation.nhs.uk/talk-to-your-loved-ones/ last accessed 15 February 2022.

[684] ‘HTA Code of Practice F Part 1 (n 11), [100].

[685] NHSBT (n 632), 9 and 28 (Table 3.3).

[686] Ibid. [92].

go against the decision of the deceased to donate, is widely seen as a necessary concession to avoid public backlash.[687]

In the absence of an appointment as a representative under s.4 HT Act 2004 or s.8 HT(Wales) Act 2013, the next of kin have no legal authority to consent on behalf of the deceased. The HTA Code of Practice F on deceased donation states that legally valid consent (which includes deemed consent or express consent of the previously living person) cannot be revoked by the next of kin and is sufficient to allow the lawfulness of the donation.[688] Nonetheless, under deemed consent legislation, the next of kin still retain significant powers to determine the course of events and indeed the HTA Code of Practice F recognises that the presence of valid consent does not mandate that donation must proceed.[689] Two points should be noted. Firstly, at the end-of-life stage in hospital, the next of kin are normally actively involved in the management of the patient. If organ donation is a possibility, specialist nurses approach the family to discuss this option, explain what is involved in donation, and explore the views of the family and the dying patient. Engagement with families of potential donors is an intrinsic part of the donation process and while it is made clear to them that they are not being asked for legal consent, because this has been given either expressly by the individual in life or their consent can be deemed, their role in the process is otherwise comparable to that of a patient asked to make a decision about their own treatment. In effect, they are more directly involved and more specifically informed about organ donation than the person who, in life, registered a preference by making a selection with a click of a mouse pad. Secondly, the objection to donation by families is not limited to circumstances in which consent is deemed but also where the deceased has given express consent to donation, either under the previous opt-in system or as part of the NHSBT drive to register preferences under the present opt-out system.

It is clear that concerns about respect for the autonomy of the donor persist under opt-out legislation because the decisional authority of the previously living person is not exclusive yet most people would reasonably assume that registration of a preference would ensure that their wishes are respected. Arguably, the interests of the previously living person and of family members could be seen as grounding a right to private life and family life, under

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[687] Price, *Human Tissue in Transplantation and Research* (n 256), 88.

[688] HTA Code of Practice F Part 2 Donation of solid organs and tissue for transplantation (Human Tissue Authority, 2017) [89]

[689] Ibid.

Article 8 of the ECHR.[690] The legal and HTA regulatory framework seemingly do not recognize a free-standing right of the family to make a decision about donation where valid consent is in place. It is hard to see how respect for the views of the family could be construed as a right to reverse the deceased's decision to donate under the Article 8 right to respect family life or the Article 9 right to respect for religious beliefs, as any autonomy rights of family members would have to be balanced against the respect to private life owed to the previously living person. Furthermore, the European Court of Human Rights in *Elberte v Latvia* found that the 'surviving relative acts as the depositary of the rights of the deceased' casting doubt over the existence of any free-standing rights of family members to make a decision about donation involving the organs of their deceased next of kin.[691]

4.8 Conclusions

In this Chapter I have examined the interests that persons may hold with regards to the use of their organs for transplantation after their death. In liberal societies, there is a strong sense of entitlement to make decisions about what happens to our bodies after death based on the idea that our bodies belong to us. On this view, the choice is the individual's to make. The principle that preferences about organ donation expressed in life by the previously living person should be respected was openly endorsed in the HT Act 2004 and still holds following the introduction of the deemed consent in England, Scotland, and Wales, as demonstrated by the fact that express consent and objection always prevail over deemed consent. Opt-out systems present the individual with the same choice as opt-in systems and it is claimed that they are consistent with the exercise of autonomy where the individual understands the following: that donation remains voluntary and that they have the right to refuse consent, with no negative ramifications; that objection to donation

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[690] For an discussion about the distinction between Article 8 ECHR rights based on 'private' and on 'family life' and the connection between the autonomy of the deceased and the autonomy of the family in deceased organ donation see Emma Dove et al., 'Elberte v. Latvia: Whose Tissue Is It Anyway - Relational Autonomy or the Autonomy of Relations?' (2015) 15 Medical Law International 79 and Sarah Fovargue and Lucy Hogg, 'Mine, Yours, Ours? Autonomy and the Removal and Use of Organs and Tissues before the European Court in Petrova v. Latvia and Elberte v. Latvia' (2017) 1 Journal of Trafficking and Human Exploitation 143.

[691] Application no. 61243/08, January 2015 [2]. I cannot accommodate this analysis here; however, see Fovargue (n 714) for a critique of *Petrova v Latvia* and *Elberte v Latvia* about giving priority to the autonomy of the deceased while recognising the relational context within which the decision is taken.

requires positive action to formally register the objection; and that inaction will be regarded as consent to posthumous organ donation.

However, the introduction of deemed consent as the default position raises questions about whether this form of consent, when express consent is not in place, protects the underlying interests of the individual, however these are understood, and whether these interests matter. Broadly, interests surrounding the use of our bodies after death may be self-regarding or other-regarding and these are not mutually exclusive. Self-regarding interests may be narrowly conceived as quasi-property interests over our bodies, essentially an interest in the exercise of control per se, or may be related to the idea of personal legacy and how we wish to be remembered by significant others. Other-regarding interests are driven by an underlying moral duty towards helping other members of society ranging from individual altruistic commitments to collective forms of moral responsibility based on solidarity and reciprocity. These ethical frameworks are relevant to this discussion only insofar as they inform the discussion about the type of interests that individuals may have in relation to the posthumous use of their bodies, although these are not specifically examined in this thesis.

Intuitively, there is a strong sense in which overriding or failing to uphold and respect the individual's preferences regarding organ donation is morally wrong, notwithstanding the conceptual difficulties articulating how removing or failing to remove an organ for transplantation actually harms the person after their death. This is supported by the fact that the opt-out framework allows the next-of-kin to override deemed consent or authorisation where they have evidence that the deceased objected. It is also supported, to some extent, by the re-framing of the legal powers of the next of kin who no longer have the authority to give consent or authorisation to donation on behalf of the deceased. Arguably, by removing the next of kin as a source of authority for consent or authorisation, the position is formally more coherent with the idea that the decision rests with the donor.[692] However, the legal position and clinical practice are not consistent on this point and where dialogue with the next of kin and persuasion fail, the importance of maintaining public trust in transplantation takes priority, overriding the wishes of the deceased.

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[692] Arguably, the law does not go far enough because although they have no legal right to override the consent or authorisation of the deceased, in practice transplantation will not proceed without their support.

Within the current opt-out framework, as in the previous opt-in system, giving express consent or authorisation to donation is reducible to a registration of a preference. Joining the ODR is a perfunctory process designed to be simple and accessible. With no external oversight, there is no mechanism to establish whether the choice is informed and voluntary or whether the individual has any understanding of the donation process and the implications of registering a preference on the ODR. Whether the decision is based on any underlying motivations and what these motivations are is irrelevant in law: there is no requirement that the decision genuinely reflects the individual's moral values. The only condition is that there is no evidence to displace the consent registered on the ODR as the individual's settled preference before death.

The recognition of the diverse interests that an individual may have in relation to whether their organs are used for transplantation does not displace the fact that many people do not make a decision in life about whether they intend to donate posthumously. Failure to make a decision may reflect very distinct positions, such as unwillingness to commit to making a choice, apathy prevaricating over willingness or unwillingness to donate, indecisiveness or ambivalence towards donation, or lack of engagement due to other priorities in life. Ultimately, it is important to openly acknowledge that some individuals may be indifferent to or unconcerned about organ transplantation irrespective of the promotion of organ donation in the media. The failure to make a choice is problematic for claims that the decisional authority lies with the person whose organs could be used for transplantation. In a procurement system based on binary choice, not making a choice, whether deliberately or by inertia, must be categorised either as giving consent or refusing consent. Failure to make a choice is problematic because if the possibility of transplantation arises at the end of life, a decision about whether to proceed with donation or not has to be made.

Opt-out systems interpret failure to object as consent to donation. However, it does not automatically follow that donation proceeds in these circumstances. In practice, there is a deep level of engagement and personal involvement of the next of kin around the point of death when organ donation is being considered. The collaboration and input of the family is required for medical reasons to determine the suitability of the patient as a donor. as the determination of the medical suitability of the individual as a donor. However, there was and importantly, remains, a fundamental mismatch between the procedural and unreflected registration of a donation preference in life that allows organ removal to proceed in the absence of a clear commitment to transplantation and simply require a lack of evidence of any objection, and the degree of engagement of the next of kin during the dying process.

The circumstances in which the family are approached appear to promote actual decision making. Medical professionals and specialist nursers approaching the family are required to discuss the possibility of transplantation and provide sufficient information on the organ retrieval process such that they understand what is involved and which organs may be removed if donation. It is important to note that direct discussion offers relatives the opportunity to understand and question the organ donation process and that, unless they specifically decline information, they are likely to be better informed about organ donation than persons who join the ODR in life. Seeking consent or authorisation to donation from the next of kin is, de facto, a process of seeking consent to a medical intervention and follows the established principles of valid consent in law, particularly with regards to the provision of information.

There is a fine line between the idea that donation is the right thing to do and the idea that there exists a moral duty to donate posthumously. Irrespective of the validity of evidence showing a public predisposition towards donation, the change in the legal system is based on the premise that posthumous donation is morally right and should be encouraged. While this does not amount to a legal duty to donate because the system allows choice and encourages individuals to register their preferences, including their objection, the acceptance of silence as consent is hard to justify without considering the broader good that donation can achieve. This would tantamount equate to accepting the opt-out system as a legal mechanism to redress any wrong caused by a failure to uphold the positive yet silent wish to donate of the majority of individuals. A moral duty to donate offers a more coherent account of why we accept donation by default. Opting-out systems based on a moral duty to donate are not intrinsically problematic for autonomy and how the individual internalises this duty remains paramount. This depends on whether the choice of donation as the default position and public education campaigns can achieve real shifts in attitudes towards donation and not merely an increase in the number of donated organs because of the apathy effect.

5 Autonomy and the child donor

5.1 Introduction

The use of an organ from a living child for transplantation necessarily involves physical harm and poses risks to the child's future health raising important questions regarding the role of the state, through the courts, and the boundaries of parental rights and responsibilities in respect of their children. Transplantation involving the living child donor routinely occurs with donation of regenerative tissue, such as bone marrow harvesting to treat a sibling with a haematological malignancy, which is potentially curative.[693] Living donation of solid organs from children remains controversial and has rarely been reported in the UK or Europe.[694] A number of live kidney transplants were performed in the U.S. in the 1970s and in the majority of cases the recipient was a sibling, although kidney donation from minors to parents and grandparents have also been reported.[695] For practical reasons, here I refer to sibling recipients and, unless otherwise specified, I use the term 'sibling' loosely to indicate a relationship between minors that may or may not be genetically related.[696]

The justification for exposing children to the risks of surgery and largely unknown long-term effects for the exclusive clinical benefit of another person has caused considerable division among policymakers, medical professionals, and academics worldwide. At some level there is an intuition that donation from a child to save the life of sibling should at least be considered and may be the right thing to do. At the same time there is ethical concern regarding the justification for allowing a healthy child to undergo irreversible surgery which carries potentially life-limiting or life-threatening consequences for no therapeutic benefit to himself. This is reflected in international guidelines.

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[693] Myriam Weyl-Ben-Arush, 'The Price of the Successful Treatment of Pediatric Malignancies' (2017) 13 Current Paediatric Reviews

[694] Francis L Delmonico and William E Harmon, 'The Use of a Minor as a Live Kidney Donor' (2002) 2 American Journal of Transplantation: Official Journal of the American Society of Transplantation and the American Society of Transplant Surgeons 333; M Campbell and others, 'How Young Is Too Young to Be a Living Donor?: Young Living Donors' (2013) 13 American Journal of Transplantation 1643.

[695] R Aulakh, 'Too Young to Save His Mother's Life? Hospital Changes Policy for Teen' *Toronto Star* (Toronto, ON, 2011).

[696] This acknowledges the fact that contemporary notions of the family are no longer limited to the traditional nucleus comprising a mother, a father and their biological offspring and that the family has become an increasingly complex and fluid structure of biological and sociological relationships.

The 2010 WHO Guiding Principles set out a general prohibition on the transplantation of solid organs from minors, although kidney transplantation between identical twins may be authorised.[697] The rationale for this exception is the high chance of an exact tissue match and successful outcome in kidney transplantation. The Council of Europe Convention on Human Rights and Biomedicine [698] prohibits the donation of non-regenerative tissue and organs by persons who are not able to give their consent (Article 20(1)). Donation of regenerative tissue is permitted (Article 20(2)) from a person who cannot give consent, provided that they do not object to donation and that the following criteria are satisfied: there is no compatible donor available with capacity to consent, the recipient is a sibling of the donor; the donation is potentially life-saving, and written authorisation is provided in accordance with national law and with the approval of the relevant regulatory body. This view was also expressed by the Ethics Committee of the Transplantation Society Amsterdam Forum, which included kidney transplant surgeons and physicians representing more than 40 countries worldwide.[699] The World Medical Association states that persons lacking capacity to consent should not be considered as living organ donors although exceptions are conceded in ‘very limited circumstances’ subject to legal and ethical review.[700]

In England and Wales, organ donation involving the living child donor, where ‘child’ is defined as a person under the age of 18 years, is governed by s.2 of the HT Act 2004[701] and the Human Tissue Act 2004 (Persons who Lack Capacity to Consent and Transplants) Regulations 2006 (hereafter HTA Regulations 2006) established under the HT Act 2004. According to the BTS guidelines, donation of solid organs by a living child may occur ‘only in extremely rare circumstances’.[702] There are no restrictions on the permissible donor-recipient relationship and both the approval of the courts and of the HTA are

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[697] Sixty-Third World Health Assembly, World Health Organization, ‘WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation’ (2010) 11 Cell and Tissue Banking 413.

[698] Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine Oviedo, 4.IV.1997 European Treaty Series - No. 164.

[699] Francis Delmonico and Council of the Transplantation Society, ‘A Report of the Amsterdam Forum On the Care of the Live Kidney Donor: Data and Medical Guidelines’ (2005) 79 Transplantation S53.

[700] WMA Statement on Organ and Tissue Donation Adopted by the 63rd WMA General Assembly, Bangkok, Thailand, October 2012 and Revised by the 68th WMA General Assembly, Chicago, United States, October 2017.

[701] Section 2 of the Human Tissue Act defines ‘appropriate consent’ in the context of activities involving bodily material from a living child as the consent of the child (s.2(2)) or the consent of the person with parental responsibility where the child is not competent to give consent (s.2.(3)).

[702] ‘British Transplantation Society and Renal Association. Guidelines for Living Donor Kidney Transplantation’ (n 164) [2.9].

required.[703] Importantly, approval is required *before* cases are referred to the HTA.[704] Applications for living organ donation by children are evaluated by a panel of three HTA members rather than by a single member. In Scotland, transplantation involving a living child donor is permissible only for regenerative tissues[705] while organ transplantation is prohibited. The HT(Scotland) Act 2006 and the Live Transplants (Scotland) Regulations 2006 (hereafter HT(Scotland) Regulations 2006) define 'child' as a person under the age of 16 years. The only permissible exception is when an organ retrieved from a child is transplanted as part of a domino organ transplant operation:[706] the child is the recipient of a heart-lung transplant for lung disease which requires the removal of the healthy heart[707] which, in turn, may be transplanted into another recipient.[708] A heart-lung transplant is more successful clinically than a bilateral lung transplant and donation of the healthy heart is effectively an incidental outcome of a procedure which has clear therapeutic benefits to the sick child. The official position of the British Medical Association, which aligns more closely with the Scottish approach, is that 'it is not appropriate for live, non-autonomous donors (minors) to donate non-regenerative tissue or organs'.[709]

The possibility of a child becoming a living organ donor in England and Wales, subject to the statutory requirement for court approval and enhanced oversight of the application by a panel of three HTA members, contrasts with the position in Scotland characterised, on one hand, by an absolute prohibition on the use of organs for transplantation from a child under the age of 16 years and, on the other, a lack of any legal restrictions on donation from young persons aged 16 and 17 years old. The child has interests that are complex and evolve with their development and a deeper understanding of these interests is essential to grasp the moral claims that children may have.[710]

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[703] British Transplantation Society and Renal Association. Guidelines for Living Donor Kidney Transplantation' 2018. [2.9.1] BTS UK Guidelines Living Donor Liver Transplantation, July 2015 [3.9.1]

[704] HTA Code of Practice on the Human Transplantation Wales Act 2013 (Revised July 2017) [45] [56].

[705] s.17(1) of the HT(Scotland) Act 2006 and regulation 5(1) and 5(5) and 5(6) of the Human Organ and Tissue Live Transplants (Scotland) Regulations 2006.

[706] s.17(4) of the HT(Scotland) Act 2006 and regulation 5(1-4) of the Human Organ and Tissue Live Transplants (Scotland) Regulations 2006.

[707] The healthy heart is removed on grounds that a combined heart-lung transplant has greater chances of success than a lung transplant.

[708] s.17(10) of the HT(Scotland) Act 2006.

[709] Veronica English and others (eds), *Medical Ethics Today: The BMAs Handbook of Ethics and Law* (3rd edn, Wiley-Blackwell 2012).

[710] David Archard and Colin M Macleod (eds), *The Moral and Political Status of Children* (Oxford University Press 2002), 2.

This chapter is broadly structured in three parts. The first part serves as an introduction. Here, I set out the concepts and legal principles that apply to decisions regarding children. I introduce the social constructs of the child and childhood and frame the role of parents with respect to their children by reference to the ethics of parenthood and parental authority and the statutory concept of parental responsibility under the Children Act 1989 (hereafter CA 1989) in force in England and Wales, and the Children (Scotland) Act 1995 (hereafter C(Scotland)A 1995). I note the relevance of children's rights to the principle of respect for the autonomy of the child although I do not pursue a rights-based line of enquiry because the purpose of this thesis is to examine the concept of autonomy within the current legal framework and I do not to seek to reconcile domestic law with international children's rights law. I conclude by examining autonomy from the broader perspective of the future autonomy of the child.

The remainder of this chapter is structured according to legal jurisdiction as there are fundamental differences between the law in England and Wales, where the child is defined as a person under the age of 18 years and organ donation by a child may be lawful subject to court approval, and the law in Scotland, which prohibits organ donation from persons under the age of 16 years, while older teenagers are regarded as adults and the legal requirements for authorisation to donation set out in Chapter 3 apply.

Accordingly, the second part of this chapter examines the law in England and Wales and is divided into three sections. I begin by setting out the principles of medical decision-making involving children under English law and discuss the legal test for competence and the principle of the best interests of the child. I then examine the legal and regulatory framework for organ donation involving children in England and Wales. In the final section, I examine how autonomy fits in with the determination of the best interests of the child. The focus is on how the concept of autonomy applies to decision-making when the organ donor is a child. My analysis will address the following question: whose autonomy is relevant when decisions about the transplantation of an organ from a living child are made; and to what extent do the legal and regulatory frameworks for living organ donation in the England and Wales uphold the developing autonomy of children and teenagers, in terms of protecting the wellbeing and future autonomy of the younger child with limited understanding of donation, engaging the child in the decision-making process and respecting the views and choices of the mature child, while taking into account the interests of family members.

The third part of this chapter examines the law in Scotland and begins by setting out the principles of medical decision-making involving children under Scots law with reference to legal capacity. I then examine the legal and regulatory framework in Scotland and consider how autonomy can be conceptualised in the context of the absolute prohibition of the use of organs from children.

5.1.1 The concept of the child

It is generally accepted that childhood is a socially constructed concept[711] and our understanding of childhood relates to a particular set of experiences which society identifies and labels as childhood.[712] In the Western world, the predominant view is of the child as a person who is not yet complete and focuses focussing on the shortcomings of childhood as a state of non-adulthood.[713] Children are dependent, immature, and lack autonomy of thought or action.[714] They are regarded as having limited decision-making capacity because they have unstable, transient values, no real concept of ‘the good’, of death, of their future, or their likely future goals, values, and interests.[715] This view can be traced to Locke’s idea of the child as a blank slate requiring experience in order to develop as persons and to acquire knowledge.[716] For the philosopher, the child lacks the rationality, freedom, and moral responsibility of a fully grown human.[717] The justification for treating children differently to adults centres on the idea that children have limited understanding and reasoning skills which impairs their ability to make decisions affecting long and short-term interests and rational moral choices.[718] Developing goals and a life-plan and taking responsibility for one’s choices is regarded as an essential feature of achieving adult

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[711] Sultana Norozi and Torill Moen, ‘Childhood as a Social Construction’ (2016) 6 Journal of Educational and Social Research 75.

[712] Jonathan Herring, ‘Are Children More Vulnerable Than Adults?’ in Jonathan Herring, *Vulnerability, Childhood and the Law* (Springer International Publishing 2018), 42.

[713] Priscilla Alderson, ‘Children’s Consent and the Zone of Parental Discretion’ (2017) 12 Clinical Ethics 55; Priscilla Alderson and Jonathan Montgomery, *Health Care Choices: Making Decisions with Children* (Institute for Public Policy Research 1996), 4.

[714] Jonathan Todres, ‘Independent Children and the Legal Construction of Childhood’ (2014) 23 Southern California Interdisciplinary Law Journal, 261-304.

[715] Buchanan and Brock *Deciding for others: the Ethics of Surrogate Decision Making* (Cambridge University Press 1987), 221-222.

[716] Robert Duschinsky, ‘Tabula Rasa and Human Nature’ (2012) 87 Philosophy 509.

[717] David Archard Philosophical Perspectives on Childhood Robert Bagshaw Children Through Tort in Julia Fionda, *Legal Concepts of Childhood* (2001), 46-52.

[718] RB Redmon, ‘How Children Can Be Respected as “ends” yet Still Be Used as Subjects in Non-Therapeutic Research’ (1986) 12 Journal of Medical Ethics 77, 77.

status.[719] Under UK law, childhood commences at birth and the attainment of 18 years, the age of full majority,[720] marks adulthood. However, different age thresholds apply to discrete branches of the law and in the medical context, as will be discussed below, children under 16 years of age may consent to medical procedures, in England and Wales if they are Gillick competent, and in Scotland, based on the medical practitioner's assessment of capacity, while 16- and 17-year-olds are regarded as adults with respect to giving consent to medical procedures in Scotland, although they do not have exclusive decisional authority in England and Wales. Children are treated differently because they are considered, at least to some degree, irrational or unable to understand or process complex information and because their values and views are not yet developed or are regarded as transient. Their views carry different moral authority, and their consent or dissent does not have same significance in law as that of the adult.[721]

Arguably, an age threshold is not a meaningful marker for the definition of childhood because it does not accurately capture the characteristics of the specific child, as growing up is a process and children develop and evolve at different stages.[722] Changes in cognitive and psychosocial capacities and emotional maturity do not exactly mirror physiological growth and may not occur at clearly identifiable stages. Classic Piagetian theory postulates that there are four stages in the cognitive development of the child.[723] At the age of 11 children develop their ability to think in abstract terms about themes such as morality and justice and the age of 14 is widely regarded as the threshold for maturity in making decisions that will help others.[724] This is corroborated by research on complex medical decision-making involving children concluding that the decision-making processes of 14-year-olds was not markedly different from that of adults.[725] While these thresholds are not absolute, the evidence that many children reach a stage of cognitive development such that

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[719] Robert Goodin and Philip Pettit (eds), *Contemporary Political Philosophy: An Anthology* (Blackwell Publishers 1997); Archard and Macleod (n 653).

[720] s.1(1) Family Law Reform Act 1969 (England and Wales); s1(1) Age of Majority (Scotland) Act 1969; s.1(1) Age of Majority Act (Northern Ireland) 1969.

[721] Tamar Shapiro, 'What Is a Child?' (2015) 15 Thinking: The Journal of Philosophy for Children, 716.

[722] Herring, 'Are Children More Vulnerable Than Adults?' (n 19), 43

[723] Anthony Malerstein and Mary M Ahern, 'Piaget's Stages of Cognitive Development and Adult Character Structure' (1979) 33 American Journal of Psychotherapy 107.

[724] Ibid; Thomas Grisso and Linda Vierling, 'Minors' Consent to Treatment: A Developmental Perspective.' (1978) 9 Professional Psychology 412; S Leikin, 'A Proposal Concerning Decisions to Forgo Life-Sustaining Treatment for Young People' (1989) 115 The Journal of Pediatrics 17.

[725] Lois Weithorn, 'A Constitutional Jurisprudence of Children's Vulnerability' 69 Hastings Law Journal.

their decision-making skills are comparable to those of competent adults should alert decision makers to pay attention to the views of young teenagers.

Psychosocial maturity is achieved later and this may justify oversight of medical decisions involving a strong psychosocial component:[726] the child may have the cognitive ability to analyse and solve a problem within a specified context or under certain conditions yet their ability to plan and consider the consequences of living organ donation may be limited. A defective perception of danger is also regarded as a characteristic of childhood[727] and this has important ramifications for the understanding of the risks involved in surgery. It is also recognised that life circumstances of a young prospective donor, for example, living with a chronically ill sibling, will affect the assessment of medical decisions and these children often have a more mature understanding of the situation.[728] In some cases, the child will plainly be too young to understand the organ donation process and will be unable to form a view or make a meaningful choice for themselves and any decision to donate will be made for the child. In others, the child will have reached a degree of maturity to be able to understand the donation process and its ramifications to some extent.[729]

This thesis does not seek to establish whether and at what stage of development children should be allowed to make their own decisions about organ donation. The focus is on how the concept of autonomy applies to decision-making when the organ donor is a child and specifically, whose autonomy is relevant when decisions about the transplantation of an organ from a living child are made. I seek to determine to what extent the legal and regulatory frameworks for living organ donation in the UK uphold the developing autonomy of children and teenagers in terms of protecting the wellbeing and future autonomy of the younger child with limited understanding of donation, engaging the child in the decision-making process and respecting the views and choices of the mature child, and taking into account the interests of family members. The point I wish to highlight here is that whatever we understand autonomy to be, its conceptualisation with respect to the child donor must consider that its present status is transient. In this sense, it is an evolving

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[726] Laura Capitaine and others Should Minors Be Considered as Potential Living Liver Donors? Liver Transplantation 2013, 19:649, 652.

[727] Samia A Hurst, 'Vulnerability in Research and Health Care; Describing the Elephant in the Room?' (2008) 22 Bioethics 191.

[728] Campbell M et al. How Young Is Too Young to Be a Living Donor? American Journal of Transplantation 2013; 13: 1643, 1646.

[729] Campbell and others (n 638).

concept and respect for the autonomy of the child whose organs may be used for transplantation account for both present limitations and anticipated future autonomy.

5.1.2 Accounts of parental authority

Society seeks to protect children by controlling permissible activities, defining the social environment which children inhabit, and limiting their access to resources.[730] Raising children is perceived by society as a requirement, 'whether they like it or not',[731] and it is generally accepted that the most appropriate persons to make decisions regarding children are those who care for them.[732] The law confers authority upon parents to control, discipline, and organise their children.[733] Herring has written extensively on the concept of vulnerability of the child and questions its use to justify unfettered parental control.[734] Children need the support and care of adults, yet it is important that they have the chance to use their developing decision-making abilities without putting themselves at undue risk.[735] Meyer also expresses unease with the 'moral rhetoric' of vulnerability in which the mere status of childhood is used to legitimise any practice as a right over children with no need for justification.[736] The dynamics of parental authority within the parent-child relationship are complex, with conflicting views surrounding the moral authority of parents and the claims of children, the power relationships between family members, and the understanding of human flourishing within the family unit.[737] Ultimately, there is no universally accepted view of what the family ought to be.[738] The traditional account of parental authority, historically rooted in the Roman doctrine of patria potestas,[739] conceives

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[730] James, Curtis, and Birch, 'Care and Control in the Construction of Children's Citizenship' in (eds.) A Invernizzi, *Children and Citizenship* (SAGE Publications Ltd 2007).

[731] Shapiro (n 665). p 735.

[732] Jonathan Montgomery, 'Children as Property?' (1988) 51 The Modern Law Review 323, 328.

[733] Jonathan Herring, 'Children and Vulnerability' in Jonathan Herring, *Vulnerability, Childhood and the Law* (Springer International Publishing 2018), 247-257; Julia Fionda, *Legal Concepts of Childhood* (Hart 2001), 127-150.

[734] Herring, 'Children and Vulnerability' (n 677) 243.

[735] Sarah Elliston, *Best Interests of the Child in Healthcare* (1st ed, Routledge-Cavendish 2007), 8.

[736] Anneke Meyer, 'The Moral Rhetoric of Childhood' (2007) 14 Childhood 85.

[737] Tristram Engelhardt, 'Beyond the Best Interests of Children: Four Views of the Family and of Foundational Disagreements Regarding Pediatric Decision Making' (2010) 35 Journal of Medicine and Philosophy 499, 510.

[738] Ibid.

[739] For useful discussions of the doctrine of patria potestas see: Barry Nicholas, *An Introduction to Roman Law* (Reprint, Clarendon Press 1995); Beryl Rawson, *The Family in Ancient Rome: New Perspectives* (Cornell University Press 1992), 120-144; John Boswell, *The Kindness of Strangers: The Abandonment of Children in Western Europe from Late Antiquity to the Renaissance* (The Penguin Press 1989), 58-75.

of natural parents acquiring quasi-property rights over their children by virtue of the fact that the children are their own.[740] In philosophy, this idea is reflected in the Hobbesian view that children are subject to the 'natural dominion' of their parents[741] and the idea of the family as a "mini-state" in which parents are vested with extensive powers of control over their children.[742] While contemporary western bioethics rejects the literal interpretation of the child as property, it is generally accepted that parents are entitled to impart values to their children as part of their child-rearing responsibilities, which society accords to the family.[743] Parents' interest in directing the development of their child is an important element of the moral theory of parenthood.[744]

On a different view, parental authority is derived from and constrained by the duty to uphold the interests of children.[745] Dickens identifies basic duties to provide essential health care, food, shelter and clothing, and education in order to protect the child from physical, psychological, social, and moral harm.[746] Dworkin maintains that society imposes legal and moral duties on parents to act as proxies for their children because they are the most likely persons to have their interests at heart.[747] Erskine refers to the natural obligations of parents towards their children.[748] Accordingly, parental powers are necessary for the proper discharge of the obligation to protect and nurture their children.[749] Justified[750] or liberal[751] paternalism recognises that parental authority is vested in parents as trustees on behalf of their children and is not indefinite, as children will normally acquire, in time, the

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[740] David Archard, 'Do Parents Own Their Children?' (1993) 1 The International Journal of Children's Rights 293.

[741] Leviathan (1651), Chapter XX, 'Of Dominion Paternall, and Despotical' in Deborah Baumgold (ed), 'Chapter 20 of The Elements of Law / Chapter 6 of De Cive / Chapter 18 of Leviathan', Three-Text Edition of Thomas Hobbes's Political Theory (1st edn, Cambridge University Press 2017).

[742] Jonathan Montgomery, 'Children as property?' (1988) 51 The Modern Law Review 323.

[743] Gilmour (n 167), 234.

[744] David Archard, *Children, Family, and the State* (Ashgate 2003), 97.

[745] See also the exchange theory based on the idea that parents are holders of rights because they have responsibilities and that they have responsibilities because they are holders of rights. KT Bartlett Re-expressing Parenthood 1998 98 Yale Law Journal 293, 297; P Montague the myth of parental rights (1981) KT Bartlett Re-expressing Parenthood 1998 98 Yale Law Journal 293, 297.

[746] BM Dickens The Modern Function and Limits of Parental Rights (1981) 97 LQR 462.

[747] Gerald Dworkin Consent , Representation and Proxy Consent in Willard Gay, 'Who Speaks for the Child: The Problems of Proxy Consent' Michigan Law Review 5, 204.

[748] 'John Erskine, An Institute of the Law of Scotland, 1824, Vol I, VI', 53

[749] Norrie [6.02].

[750] Gay (n 691), 293-294.

[751] Michael Freeman, *Law and Childhood Studies Current Legal Issues Volume 14* (Oxford University Press 2012) 57.

skills to make decisions for themselves. In defence of paternalism, Brock and Buchanan argue that a child's well-being is more fully determined by the developmental needs of children of that age generally, rather than by their current preferences, which are typically transient.[752] While adults have a strong interest in making important decisions according to their values, life plans, and their conception of the self, children's self-identity is developing and 'it is not their interest *qua* children in making decisions for themselves, but their interest in developing the capacities to be self-determining adults'.[753] This perspective recognises that merely acting in the interests of children, as defined by those who are responsible for them, is not sufficient: involving children in decisions which concern them is fundamental because participation allows children to develop the skills to make decisions independently. Some commentators have expressed this more forcefully as a parental duty to foster the development of the child's capacity to make decisions for themselves.[754]

There are conflicting views regarding parental discretion in the exercise of parental authority and whether this is limited to what is best for the child or whether parents are entitled to take into account their own interests as well as the interests of the child.[755] Independent parental rights and the creation of the family may be conceived as part of a parent's own life plan,[756] an extension of the adult's right to self-determination. Bainham's independence theory recognises the freestanding rights of parents as rights which are not entirely derivative and reducible to their parental duties.[757] Acknowledging the existence of parental rights that are independent of the child's welfare, McCall Smith pragmatically distinguishes child-centred parental rights, which further the interests of the child, from parent-centred parental rights, which define an area of parental control within which parents have discretion to decide the sort of child they wish to raise and pursue goals which

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[752] Gilmour (n 167), 227-232.

[753] Ibid.

[754] Archard, 'Do Parents Own Their Children?' (n 684), 293.

[755] Andrew Bainham, Is there Anything Now Left of Parental Rights? in Rebecca Probert, Stephen Gilmore and Jonathan Herring (eds), *Responsible Parents and Parental Responsibility* (Hart Pub 2009), 26.

[756] Charles Fried, *Right and Wrong* (Harvard University Press 1978), 152.

[757] Bainham (n 779), 28-31. For example, decisions relating to matters such as where and how family time is spent or whom a child befriends are decisions taken by parents which are clearly about the kind of life parents wish to live and are not generally contested by the law, regardless of the objections of the children.

society will tolerate.[758] Parents may be bound to uphold the child's basic interests but beyond that, they have a discretion to act and choose how to rear their child.[759]

This broadly accords with the liberal minimum intervention perspective, based on society's commitment to accepting diverse lifestyles and family situations coupled with a lack of consensus about proper methods of raising children.[760] This account of an exclusive remit within which parents bring up their children is articulated by Goldstein, Freud and Solnit in their influential work 'The Best Interests of the Child: The Least Detrimental Alternative'. This is based on the premises that the state does not have the resources or the sensitivity to assume a parenting role and that the child's need for security and the ability of parents to meet the physical and emotional needs of their children, rest upon the integrity of family life. Upholding family integrity requires the recognition in law of parental autonomy rights and privacy rights.[761] Schoeman encapsulates family rights as a right to privacy that entitles the adults of the family to exclude external interference in family matters and decisions and a right to autonomy, which is not absolute, that entitles the adults, therefore parents, to make important decisions about their children.[762]

From the perspective of the autonomy of the child donor, this conceptualisation of parental rights and authority raises two important questions. Firstly, about the role of the child in decisions to donate and secondly, how the idea of parents making important decisions about their family can be reconciled with the legal framework in England and Wales that requires court approval for living donation to proceed and the absolute prohibition of organ donation from the living child in Scotland, irrespective of the views of the parents. I will examine these below.

5.1.3 The statutory concept of parental responsibility

The CA 1989 and the C(Scotland)A 1995 regulate decision-making processes involving children and establish the rights and responsibilities of parents in respect of children and

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[758] Alexander McCall Smith Is Anything Left of parental rights? In Elaine Sutherland, Alexander McCall Smith and JK Mason (eds), *Family Rights: Family Law and Medical Advance* (Edinburgh University Press; Distributed in North America by Columbia University Press 1990), 9-10.

[759] Colin M Macleod, 'Conceptions of Parental Autonomy' (1997) 25 Politics & Society 117.

[760] Michael Wald, 'State Intervention on Behalf of "Neglected" Children: A Search for Realistic Standards' (1975) 27 Stanford Law Review 985.

[761] Joseph Goldstein, Anna Freud and Albert J Solnit, *Beyond the Best Interests of the Child* (New ed with Epilogue, Free Pr 1979), 90-91.

[762] Ferdinand Schoeman, 'Protecting Intimate Relationships: Children's Competence and Children's Rights' (1982) 4 IRB: Ethics and Human Research.

the duties of the court. Widely regarded as the 'core' of child law,[763] these statutes support, to varying degrees, the participation of children in decisions concerning them, although they do not accord power to the child to make or control these decisions nor do they guarantee protection of the choices that the child is able to make.[764] Instead, concepts such as competence and capacity, which are central to the child's ability to perform a juridical act are governed by the common law on consent, the Family Law Reform Act (FLRA) 1969 in England and Wales, and the Age of Legal Capacity (Scotland) Act 1991 in Scotland.

The authority of parents to make decisions regarding their children is recognised in law as 'parental responsibility' under the CA 1989, which applies to persons under the age of 18 years in England and Wales. In Scotland, this authority is recognised both as 'parental responsibilities' under section 1 and as 'parental rights' under section 2 of the C(Scotland)A 1995. Section 3.1 of the CA 1989 defines parental responsibility as 'all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property'.

This brings sharply into focus the key role of the legal duties and powers conferred to parents which allow them to take care of and act on behalf of their child.[765] Except for the administration of a child's estate, the CA 1989 does not set out the specific rights and duties associated with parental responsibility, conferring wide discretion upon parents.[766] In its review of the law on guardianship and custody, which preceded the introduction of the CA 1989, the Law Commission avoided defining the specific duties of parenthood deeming the requirement for regular updates impractical.[767] Crucially, despite the paramountcy of the welfare concept, the CA 1989 does not expressly state concern for the welfare of the child as an element of parental responsibility. In contrast, s.1(1) of the C(Scotland)A 1995 clearly sets out the responsibilities of parents in relation to their child to safeguard and promote the child's health, development, and welfare and provide direction and guidance according to the child's stage of development.

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[763] Fionda (n 753), 196.

[764] Andrew Bainham and others, *Children, the Modern Law* (Fourth edition, Family Law 2013), 52.

[765] Ibid.

[766] Jane Fortin, *Children's Rights and the Developing Law* (Cambridge University Press 2009), 275.

[767] Law Comm Report No 172 Review of Child Law: Guardianship and Custody (1988) [2.6]

It is claimed that the concept of parental responsibility marks the departure from traditional parental rights as the dominant legal concept in the parent-child relationship to the idea of parental duties, distinct from parental powers,[768] with an emphasis on the centrality of care,[769] adopting an adult-trustees and children-beneficiaries model.[770] In England, this transition was strongly supported by the Law Commission which declared the term 'parental rights' to be 'not only inaccurate as a matter of juristic analysis but also a misleading use of ordinary language'.[771] The introduction of parental responsibility provides parents with a remit within which they can make choices in respect of their child's upbringing, at the same time requiring them to behave dutifully towards their children.[772] In Scots law, the trustee-beneficiary model of parental rights is rooted in the common law relationship of obligation between parent and child[773] and is set out explicitly in the C(Scotland)A 1995, in which the Scottish Law Commission reformulated the rights of parents in terms of rights held for the specific purpose of enabling them to discharge their duties towards their children.[774] These include the right to control, direct or guide, in a manner appropriate to the stage of development of the child, the child's upbringing[775] and the right to act as the child's legal representative.[776] An important facet of parental responsibility is the recognition that it confers entitlement to rear the child with a degree of freedom from the scrutiny and intervention of the state.[777] This idea was articulated by the House of Lords in *Re KD*, affirming that state interference is not warranted unless there is a risk to the child's moral or physical health.[778]

In England, parental responsibilities under the CA 1989 continue up to the age of 18 years. Below this threshold, young persons can make medical decisions for themselves, under the FLRA and common law, although this authority is not exclusive. Under the C(Scotland)A

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[768] Fionda (n 753).

[769] Jonathan Herring, *Family Law* (3rd edn. Harlow Pearson Education 2007), 376.

[770] M Fineman In the Child's best interests? Reading the Children Act critically 1992 45 Current Legal problems 173, 185.

[771] Report on Illegitimacy. Law Commission, 1982, para. 4.18, 4.19 and Law Commission "Custody' Law Com Working Paper No96, 1986 para 7.16; Law Comm 118, HC98, 1982 [4.18].

[772] Lord Mackay L.C., when introducing the Bill, said as much (Hansard, H.L. Debs. 502, col. 490). See also Department of Health, Introduction to the Children Act 1989 (HMSO 1989) [1.4].

[773] Stair, I, v, 1.

[774] Lilian Edwards and Anne MO Griffiths, *Family Law* (1. publ, Green [u.a] 1997); 'Scottish Law Commission - 1987 - Report on the Legal Capacity and Responsibility of Parents. [2.1]

[775] Section 2(1)(b)

[776] Section 2(1)(d)

[777] See paragraph 1.1 Law Commission paper 1985. Develop this point further.

[778] [1988] A.C. 806 at 812. The case concerned a mother's right of access to her child.

1995, the parental duty to provide direction to the child terminates at the age of 16 years. This coincides with the cut-off under the Age of Legal Capacity (Scotland) Act 1991 allowing 16- and 17-year-olds to give consent to medical treatment.[779] Beyond the age of 16, parents retain a duty to provide guidance until the child is 18 and to 'have regard so far as practicable to the views (if he wishes to express them) of the child concerned, taking account of the child's age and maturity'.[780]

I will examine below whether the statutory duties and responsibilities that parents have in respect of their children are relevant to the conceptualisation of the autonomy of the child donor within the legal framework in England and Wales based on best interests. I will then consider the legal framework that applies in Scotland and approach this question from the perspective of the absolute prohibition of donation from children and the adult requirements for consent to donation that apply to 16- and 17-year-olds.

5.1.4 The statutory concept of welfare

The central role of child welfare in decisions made by the courts under the CA 1989 and the C(Scotland)A 1995 reflects the emerging concern for the wellbeing of children[781] and the recognition that their wellbeing may be compromised by parents and that parenting is not entirely a private matter beyond the scrutiny of the state.[782] The view that protective measures are required to safeguard the child is endorsed by the judiciary on grounds that the child lacks the maturity to 'weigh the longer term against the shorter' and the experience to 'measure the probable against the possible'.[783]

The concept of welfare in relation to children was introduced in English law under section 1 of the Guardianship of Infants Act 1925 (later consolidated in section 1 of the Guardianship of Minors Act 1971) which imposed a duty upon the courts to 'regard the welfare of the infant as the first and paramount consideration' in proceedings in respect of matters regarding the custody or upbringing of an infant. In the House of Lords case of *J v C,* Lord MacDermott explained this approach as:

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[779] Although this is not authoritatively settled for cases of refusal of treatment, as discussed below.

[780] Age of Legal Capacity (Scotland) Act 1991 s.6(1).

[781] Montgomery (n 676), 325.

[782] Alderson and Montgomery (n 656), 24.

[783] *Re S* [1993] 2 FLR 437, 448.

> […] a process whereby, when all the relevant facts, relationships, claims and wishes of parents, risks, choices and other circumstances are taken into account and weighed, the course to be followed will be that which is most in the interests of the child's welfare as that term has now to be understood. That is the first consideration because it is of first importance and the paramount consideration because it rules upon or determines the course to be followed.[784]

Section 1(1)(a) of the CA 1989 applies this interpretation, stating that when a court determines any question with respect to the upbringing of a child, the child’s welfare is the court’s paramount consideration. The expression ‘paramount consideration’ is taken to mean ‘only consideration’. The High Court's jurisdiction is derived from the right and duty of the Crown as *parens patriae* to protect the welfare, maintenance, and education of children who are the subjects of the Crown.[785] Medical interventions involving a child may be authorised under the court’s inherent jurisdiction, or in proceedings for a specific order under s.8(1) of the CA 1989. Section 1(5) adopts a non-interventionist approach, with orders made only if the court is satisfied that making an order is better for the child than not making an order.[786]

In considering the child’s welfare, the court has wide discretion to consider any factor which it considers relevant and, specifically, the court is guided by the wishes and feelings of the child, his physical and emotional needs, and any harm he is suffering or is at risk of suffering.[787] The court has a duty to ‘have regard’ for the child’s views, taking into account his understanding of the specific circumstances. However, there is no duty for the court to establish the child’s wishes and to this extent, the CA 1989 supports a limited form of participatory decision making.[788] The court retains considerable discretion in balancing individual factors and the views of children could quite legitimately be set aside if the risk of harm is deemed unacceptable by the courts. The fact that the courts are not bound to abide by the child’s views which are subordinate to his welfare and that welfare is determined by the court’s views of what is best for the child, has not escaped criticism.[789] Importantly, while the relevance of the child’s views is dependent on his maturity and

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[784] [1970] AC 668 [710], [711].

[785] Hope v Hope (1854) 4 De GM & G 328, at 344–345. See also Re Spence (1847) 2 Ph 247, at 251 and Re A (Children) [2013] UKSC 60, [2013] 3 WLR 761; Re M (Wardship: Jurisdiction and Powers) [2015] EWHC 1433 (Fam), Re M (Wardship: Jurisdiction and Powers [2016] 1 FLR 1055.

[786] See Lord President Rodger in *White v White 2001 S.C. 698* at [21].

[787] CA 1989 s. 1(3).

[788] Bainham and others (n 708), 49.

[789] Tom Campbell, ‘The rights of the minor: as person, as child, as juvenile, as future adult’ (1992) 6 International Journal of Law, Policy and the Family 1.

understanding, the CA 1989 remains silent on the association between understanding and the acquisition of competence and the relationship between competence and welfare considerations.

In Scotland, the Court of Session or the sheriff court may issue a specific issue order in relation to a specific question arising in connection with parental rights or responsibilities.[790] The court shall regard the welfare of the child as its paramount consideration, understood as of overriding importance against any consideration inconsistent with it or unrelated to the child's welfare.[791] The C(Scotland)A 1995 does not include a welfare checklist, following the recommendations of the Scottish Law Commission that this would encourage a perfunctory approach to the consideration of welfare.[792] However, it is likely that considerations comparable to those under the CA 1989 would also apply in Scotland.[793] The participatory rights of the child are explicitly recognised.[794] Under s.11(7)(b) the Scottish courts must ascertain if the child wishes to express his views and, if so, give him the opportunity to express these and have regard for them, taking into account the child's age and maturity.[795] The courts are not bound by the child's views and welfare concerns may prevail but failure to allow the child to express his view or to have due regard to these views will give a ground of appeal against the court's decision on the basis of procedural irregularity or error of law.[796] Section 11(1) creates a presumption that a child of or over the age of 12 is of sufficient age and maturity to form a view.[797] While the courts in Scotland have the power to issue a specific issue order up until the child attains the age of 18 years, justification for overriding the views of children aged over 12 years is required under s.11(1).[798] The duty to have regard for the child's

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[790] Section11(2)(e) C(Scotland)A 1995

[791] Kenneth McK Norrie and AB Wilkinson, *The Law Relating to Parent and Child in Scotland* (Third edition, W Green 2013). para 9.08

[792] *Report on Family Law: Laid before Parliament by the Lord Advocate under Section 3(2) of the Law Commissions Act 1965* (HMSO 1992). para 5.20-23

[793] Elliston (n 759), 16.

[794] Unlike the position under the CA 1989.

[795] The use of both terms "age" and "maturity" (following the wording of the UN CRC) has been questioned, as age per se is arguably less relevant once maturity is established, see Kay Tisdall and Kathleen Marshall; The Children (Scotland) Act 1995: Developing Policy and Law for Scotland's Children. (The Stationary Office Limited, Edinburgh 1997) 88.

[796] Norrie [9.43]. See also *H v H* , 2000 Fam. L.R. 73; *Shields v Shields*, 2002 S.C. 246.

[797] This was seen by the Scottish Law Commission to reflect actual practice in Scotland with regards to the views of the minor child and the presumption was not regarded as precluding the courts from having regard to the views of children younger than 12 years see Scottish Law Commission (No 135) Report on Family Law 1992 [5.25].

[798] Norrie [9.48].

perspective applies even where the child is under 12 because this is relevant to his welfare [799] although where the child is clearly too young to understand the options available, the court is entitled to decide on the basis of the welfare and minimum intervention principles.[800]

5.1.5 Decision making and the rights of children under the European Convention of Human Rights and the United Nations Convention on the Rights of the Child

Before examining the understanding of autonomy in medical law, it is important to recognise the impact of human rights law on the treatment of children and the claims that children may as persons entitled to equal concern and respect of their autonomy, understood as the capacity to live as separate human beings and make independent decisions regarding life choices.[801] By recognising the child as a rights holder, the ECHR and the United Nations Convention on the Rights of the Child (UNCRC) have provided the impetus towards a changing legal conception of the child.[802]

The ECHR focuses on the prevention of state interference with civil and political rights and while not specifically designed for the protection of children as a group, children can claim rights under the ECHR. Article 8, the right to respect of the individual's private and family life, is central to medical decision-making because it concerns the right to make choices regarding one's life. Article 8 engages the rights of the prospective child donor and requires that the child's best interests are balanced with the interests of parents who may have conflicting interests where the recipient is also their child.[803] As a qualified right, interference is legitimate only if it is necessary, achieves a fair balance, and is proportionate to its legitimate aim.[804] The UK courts must act in a way reconciles the

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[799] Ibid.

[800] *Stewart v Stewart* , 2007 S.C. 451 [12].

[801] Michael Freeman, *The Moral Status of Children: Essays on the Rights of the Child* (Martinus Nijhoff Publishers; distributed in the USA and Canada by Kluwer Law International 1997), 37.

[802] Edwards and Griffiths (n 718), 6.

[803] The courts have generally adopted a broad interpretation of Article 8 which has been engaged in relation to physical integrity in *Pretty v UK* [2002] 2 FCR 97, privacy regarding medical information *Campbell v MGN Ltd* [2006] EWHC 1668 and the upbringing of children *Mabon v Mabon and Others* [2005] EWCA Civ 634.

[804] Article 8(2) ECHR. Fortin, *Children's Rights and the Developing Law* (n 710), 58.

paramount role of the child's welfare under domestic legislation with the rights of parents or other children under the ECHR.[805]

The UNCRC is a comprehensive UN human rights instrument specifically assigning civil, political, economic, social, and cultural rights to children as a distinct group.[806] The UNCRC was ratified by the UK in 1991 and while it has not been directly incorporated into UK law, these rights have been recognised by the judiciary as commanding respect[807] and are frequently used as an international template against which to measure domestic standards.[808] While it will be incorporated into Scots law by means of the UNCRC (Incorporation) (Scotland) Bill, this has been delayed as a result of a recent UK Supreme Court decision.[809] While acknowledging that the incorporation of these rights will raise important questions regarding the current restrictions on living organ donation, a more detailed analysis of the implications of the incorporation of the UNCRC cannot be pursued here. Notably, the provisions for participatory rights of children in legal proceedings under the C(Scotland)A 1995 were included by the Scottish Parliament in compliance with the UNCRC.[810] The UNCRC recognises the best interests test as the standard to govern decision-making on behalf of children. The courts and public authorities are under a duty to regard the child's best interests as *a primary* consideration and ensure the protection and care necessary for the child's well-being taking into account the rights and duties of persons with parental responsibility for the child.[811] In this respect, there is a fundamental difference with domestic legislation where the child's welfare must be determined by the child's best interests (the paramount consideration).[812] Article 12 allows independent

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[805] Jonathan Herring, 'The Welfare Principle and the Children Act: Presumably It's about Welfare?' (2014) 36 Journal of Social Welfare and Family Law 14, 230.

[806] Fionda (n 753), 10.

[807] Bainham and others (n 708).

[808] Fortin, *Children's Rights and the Developing Law* (n 710).

[809] Reference by the Attorney General and the Advocate General for Scotland – United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Bill, [2021] (UKSC 42).

[810] 'United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Bill'.

[811] Articles 3.1 and 3.2 of the United Nations Convention on the Rights of the Child.

[812] Jane Fortin, 'Children's Rights: Are the Courts Now Taking Them More Seriously?'(2004)15 The Kings College Law Journal 253, 268. For a critique of the inconsistency between the paramountcy and primacy principles see Jonathan Herring, 'The HRA and the Welfare Principle in Family Law—Conflicting or Complementary?' (1999) 11 Child and Family Law Quarterly 237, 233. See also Reece's argument that the paramountcy principle should be replaced with a framework that recognises the child as merely one participant in a process in which the interest of all participants matter Helen Reece, 'The Paramountcy Principle: Consensus or Construct?' (1996) 49 Current Legal Problems 267, at 303. Similarly, Bainham argues that it is unrealistic to claim that children's interest should predominate and advocates an approach based on hierarchical primary and secondary duties of children and parents Andrew Bainham 'Non-Intervention and Judicial Paternalism' in Birks (ed) *The Frontiers of Liability* (Oxford University Press 1994).

representation of the child's views and participation in family proceedings[813] and imposes a duty on the State to consider these procedural rights in its application of domestic laws on consent to treatment involving children.[814] Under Article 12(1) the child who is capable of forming his own views is accorded the right to express his views freely in all matters affecting him and these views are given "due weight" according to the age and maturity of the child.[815] In judicial hearings concerning the child, Article 12(2) creates a right to be heard, either directly or through a legal representative. Articles 12 and 3 encapsulate the tension between participatory rights of the child and the duty to protect the best interests of the child.[816] Alderson and Montgomery highlight the important distinction between granting children the right to express their opinion, which Article 12 purports to do, and the right to influence a decision.[817] The UNCRC does not implement decisional rights; nevertheless, the recognition of participatory rights requires that the courts respect the child's right to have his views heard and give these views due consideration in their determination of the child's best interests.[818] The UNCRC focuses on the rights of the child within the family and in relation to the state, recognising, in its preamble, the family as the 'fundamental group of society and the natural environment for the growth and well-being of all its members and particularly children'.[819] Article 18 recognises that parents have the primary responsibility for the upbringing and development of the child and that the best interests of the child will be their 'basic concern'. Article 5 imposes upon the State the duty to respect parental responsibilities and rights to provide 'appropriate direction and guidance' in the exercise by the child of their rights under the UNCRC, taking into account their developing capacities.

Supporters of children's rights argue that it is important to confer the status of 'right' to claims where children are concerned, even where children are too young to form or express a view. Firstly, because the language of rights recognises that the child is an individual of moral worth entitled to make claims and exercise choices and, secondly, because it

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[813] Bainham and others (n 708).

[814] Alison Cleland and Elaine Sutherland (eds), *Children's Rights in Scotland* (2nd edn, W Green/Sweet & Maxwell 2001).

[815] Article 12(1) of the United Nations Convention on the Rights of the Child.

[816] Freeman (n 745), 56-57.

[817] Alderson and Montgomery (n 656), 19-21.

[818] Redmon (n 661); David Archard and Skivenes Marit, 'Balancing a Child's Best Interests and a Child's Views' (2009) 17 International Journal of Children's Rights 1.

[819] Bainham and others (n 708); 'United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Bill' (n 754).

imposes a duty upon the decision maker to seriously consider what is important for that child and justify how an action can plausibly be one which the child could want.[820] The HRA 1998 and the UNCRC do not provide a comprehensive account of the relationship between the commitment to the autonomy rights of the child and the promotion of the child's best interests.[821] This is particularly problematic in decisions resulting in harm to the child [822] and where the interests of the child and his carers do not coincide. The UK judiciary has exerted its powers to override decisions made by children where it considers that these compromise welfare. Fortin takes a different approach rejecting the view that children's rights can include the entitlement to pursue a course of action which will cause harm to the child[823] and is sceptical of the use of the welfare principle by the courts to trump these rights, arguing instead that in these cases the child does not have that right.[824] In the UK, the judiciary has largely dismissed the idea of inconsistency between the welfare and rights approaches,[825] although this view is disputed in academic circles.[826] Fortin argues that the reluctance of the domestic courts to incorporate the rights of children in their decisions is based on the assumption that s.1 of the CA 1989 requires that all cases are decided by reference to children's welfare.[827] Nevertheless, in *Mabon*, Thorpe LJ acknowledged that the law must 'reflect the extent to which, in the 21st century, there is a keener appreciation of the autonomy of the child'.[828]

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[820] John Eekelaar, 'The Eclipse of Parental Rights'(1986) 102 Law Quarterly Review 4. This is based upon the assumption that claims can only be rights where the fully informed person would plausibly wish to exercise those rights.

[821] Engelhardt, (n 761).

[822] John Eekelaar, 'Parental Responsibility: State of Nature or Nature of the State?' (1991) 13 Journal of Social Welfare and Family Law 37; Jonathan Herring, 'Farewell Welfare?' (2005) 27 Journal of Social Welfare and Family Law 159.

[823] Jane Fortin, 'Children's Rights - Substance or Spin?' (2006) 36 Family Law 759.

[824] Jane Fortin, 'Accommodating Children's Rights in a Post Human Rights Act Era.' (2006) 69 The Modern Law Review 299, 310-312. See Fortin's analysis of *Mabon v Mabon and Ors* [2005] EWCA Civ 634 [26] -[28], concerning the participatory rights of three brothers in court proceedings. The rights were recognised in the case although Thorpe LJ implied that he could have overridden the wishes of the young men under the welfare principle if he had concluded that independent representation would cause them harm.

[825] See Court of Appeal in *Re S (Adoption Order or Special Guardianship Order)* [2007] EWCA Civ 54 in which the CoA stated that it was unlikely that in most cases Art 8 would add anything to the court's central task of applying the welfare principle. See also *Payne v Payne* (2001) EWCA Civ 166 [2011] 1 FLR 1052, [35]-[37] per Thorpe LJ and [82] per Butler Sloss LJ.

[826] Shazia Choudhry, 'Taking the Rights of Parents and Children Seriously: Confronting the Welfare Principle under the Human Rights Act' (2005) 25 Oxford Journal of Legal Studies 453; Herring, 'Farewell Welfare?' (n 765).

[827] Fortin, (n 767), 306.

[828] *Mabon v Mabon* [2005] EWCA Civ 634 [26].

It is increasingly recognised that the concept of children's rights is more nuanced than mere self-determination and incorporates elements of paternalism or welfarism.[829] While the language of rights may support the decision-making autonomy of the child, the right to be protected from harm, emphasised by academics, such as Eekelaar, Freeman, and Fortin, may curb this autonomy, aligning the rights approach more closely with the welfarist approach.[830] Philosophically, the interest theory of rights[831] allows conceptions of the child's welfare to be accommodated within conceptions of the child's interests or rights.[832] On this view, children may have some rights to self-determination based on their interest in choice, without having the absolute right to make all fundamental decisions regarding their future the required level of maturity is reached.

The question of whether the recognition of children as rights holders has fundamentally changed the balance between the child's welfare and autonomy is beyond the remit of this thesis. Children's rights are relevant here to the extent that the interests that they uphold clarify how the principle of respect for individual autonomy applies to the potential child donor and how the regulation of living donation upholds the developing autonomy of the child within the limits of the duty of the courts to protect the welfare of the child and within the boundaries of parental rights and responsibilities.

5.1.6 Future autonomy

The conceptualisation of autonomy must take into account a distinction, unique to children, between actual autonomy, which is the autonomy they have acquired, and potential autonomy, which is their capacity for future autonomy and must be safeguarded.[833] Accordingly, limited paternalism is seen as morally justified where it protects children from irrational actions, understood as actions which causes immediate harm or irreversibly undermines the development of future capacities of rational choice. This is what Gerald Dworkin refers to as 'future-oriented' consent or restrictions on present autonomy, justified

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[829] Bainham and others (n 708), 80.

[830] Shazia Choudry, Jonathan Herring, and Julie Wallbank, 'Welfare, rights, care and gender in family law' in Julie Wallbank, Shazia Choudhry, and Jonathan Herring (eds), *Rights, Gender and Family Law* (Routledge 2010); John Eekelaar 'The interests of the child and the child's wishes: the role of dynamic self-determinism' in Ursula Kilkelly and Laura Lundy (eds) *Children's Rights* (Routledge 2017).

[831] *Cf.* the will or choice theory of rights according to which only children with a capacity for choice can exercise the rights available to adults.

[832] Jane Fortin, 'Accommodating Children's Rights in a Post Human Rights Act Era.' (n 767), 318.

[833] Michael Freeman; The Moral Status of Children Essays on the Rights of the Child Kluwer Law International 1997, 36-37.

as restrictions which the child will later understand and come to accept.[834] If we recognise its role in protecting the child's potential for future choices and long-term autonomy, paternalism is not necessarily inconsistent with self-determination.[835]

This idea resonates with Feinberg's concept of the child's 'right to an open future'[836] developed in response to the controversial 1972 case *Wisconsin vs. Yoder*[837] in which the Supreme Court ruled in favour of Amish parents challenging Wisconsin's school attendance law on grounds that compulsory higher education was of limited benefit to the practical skills required as part of their traditional way of life and exposure of their children to the influence of wider society threatened to alienate them from their community. Feinberg's critique of the verdict was aimed at the court's exclusive focus on the parents' rights to religious liberty, failing to account for the rights of the children.

Feinberg distinguished between two types of rights relevant to the child: rights derived from their present state of dependency demanding that their basic needs are met until they are capable of taking care of themselves; and rights derived from their future autonomy, that is, from their development into a person capable of making decisions for himself. [838] These rights are 'rights in trust' that are saved until he is an adult but which can be violated in advance, even when the child is too young to exercise them. If this occurs, certain options will no longer be open to the child when he grows up and would otherwise be in a position to exercise his rights. The right to an open future refers to the entitlement that future opportunities are not unduly restricted but does not negate the value of paternalism which Feinberg recognises as an intrinsic part of raising children.[839] Respect for the child's future autonomy as an adult requires protecting the child, including adolescents, from immature, instinctive or uninformed decisions.

Feinberg's theory ignited a philosophical debate over the limits of state intervention in the upbringing of children in pluralistic societies where parents hold conflicting religious views and have different moral conceptions of the good life. The goal is to maximise the

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[834] Tom Wilkinson, 'Dworkin on Paternalism and Well-Being' (1996) 16 Oxford Journal of Legal Studies 433; Dworkin (n 71); Richard Wasserstrom, *Morality and the Law* (Wadsworth 1971).

[835] Fortin, *Children's Rights and the Developing Law* (n 710).

[836] Joel Feinberg, *Rights, Justice, and the Bounds of Liberty - Essays in Social Philosophy* (Princeton Univeristy Press 2016).

[837] See *Wisconsin v. Yoder*, 406 U.S. 205 (1972).

[838] Joel Feinberg. The child's right to an open future., in Joel Feinberg, *Freedom and Fulfilment: Philosophical Essays* (Princeton University Press 1994), 76-7.

[839] Ibid., 88-89.

opportunities available to children so that they have a range of options and life paths open to them in the future.[840] Decisions to donate an organ in childhood engage the future autonomy rights of the adults the child is expected to become. For example, important considerations apply to the child facing many years living with a single kidney, such as the increased risk of future disease or injury affecting the kidney, the impact on future career or lifestyle choices, and increased health risks during pregnancy. Furthermore, donation as a child precludes the opportunity to act as a donor to future offspring or a partner later in life. There are clearly limitations to this theory, in the sense that any choice will inevitably limit some future options so even the decision not to donate an organ to a sibling may limit the child's future autonomy and potentially to a greater extent, according to the consequences of not proceeding with transplantation on the recipient's health.[841]

The protection of the child's future autonomy must be viewed in the context of a genuine commitment to foster the development of decision-making skills as the child matures. Schapiro conceives progression from the heteronomy of childhood to the autonomy of adulthood as the gradual acquisition of self-determination by the child in selected domains of their lives to the extent that this is possible, listening to what children have to say about matters that affect them, and expanding the domains of discretion.[842] Eekelaar has written extensively on children's rights and argues that the aim of the law on children is:

> To bring children to the threshold of adulthood with the maximum opportunities to form and pursue life-goals which reflect as closely as possible an autonomous choice.[843]

His theory of dynamic self-determinism synthesizes the welfare and rights approach because it supports children in the acquisition of decision-making skills by allowing them to make their own choices, unless doing so infringes their basic or developmental interests, as this would limit the available range of options once they reach full autonomy in adulthood.[844] Children are encouraged to make an increasing number of decisions as they grow up, but not allowed to make a decision which would unduly restrict their future life choices. Within this framework, the prospective donor child is accorded a genuine participatory role in decision making and his wishes are treated as a significant, albeit not

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[840] Gilmour (n 167), 231.

[841] Campbell et al. How Young Is Too Young to Be a Living Donor? 2013 13 American Journal of Transplantation 1643, 1648.

[842] Shapiro (n 665), 737-736.

[843] Eekelaar in Kilkelly (ed.) (n 774), 53.

[844] Ibid.

deciding, factor. The approach recognises the difference between the interest in choice and the right to self-determination so that, even where children lack rights of self-determination, their views should not be altogether disregarded.[845]

Proper regard for future autonomy of the child presents robust arguments that justify overriding the autonomy of the child where an intervention may prevent them from developing into functionally autonomous agents.[846] Applied to the context of living donation it is arguable that overriding the present autonomy of the child who chooses to donate an organ may be justifiable on grounds that surgery inevitably results in serious injury and may have future repercussions in terms of long-term complications and restrictions on future quality of life, as well as precluding the child from donating as an adult. I will examine below how these considerations apply when decisions are made by the courts on the basis of the best interests of the prospective donor child.

5.2 Principles of medical decision-making involving children in England and Wales

5.2.1 Gillick competence

A key aspect of what autonomy means with respect to the living child donor is the extent to which the child is able and encouraged to engage with the decision-making process and the respect accorded to the child's wishes where he is mature enough to understand and express a view. A full analysis of the law on consent to medical intervention by minors is beyond the remit of this thesis. Here, I will examine the meaning of capacity under statutory and common law and the judicial interpretation of the best interests of the child insofar as these concepts clarify the restrictions placed on the child's decisional authority over the use of his organs for transplantation.

The landmark case of *Gillick v West Norfolk & Wisbech Area Health Authority*[847] establishes that children under the age of 16 years can give valid consent to treatment if

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[845] Eekelaar, 'Parental Responsibility' (n 765); Archard and Macleod (n 653).

[846] Emma Cave, 'Goodbye *Gillick*? Identifying and Resolving Problems with the Concept of Child Competence' (2014) 34 Legal Studies 103, 111.

[847] [1985] UKHL 7, [1986] AC 112.

competence is demonstrated.[848] *Gillick* concerned a challenge by a mother to the legality of guidance issued by the Department of Health and Social Security to doctors regarding the provision of contraceptive advice to a girl under 16 years without the consent or knowledge of her parents. The majority in the House of Lords, with the leading judgments delivered by Lord Scarman and Lord Fraser, held that a doctor could give such advice provided that certain conditions were satisfied. Lord Scarman set out the requirement for 'sufficient understanding and intelligence to enable him or her to understand fully what is proposed',[849] with the caveat that understanding the nature of the advice given was not enough and that the child must also have 'sufficient maturity' to understand the moral, family, emotional, and long-term health implications of her decision.[850] Lord Fraser's approach was more prescriptive, setting out a checklist of five factors for doctors to consider in the assessment of competence. These hinge on the child's comprehension of the medical advice and require that the proposed treatment is in his best interests.[851]

These approaches to the determination of legal capacity are fundamentally different.[852] The threshold for competence set by Lord Scarman is higher because it requires not only intellectual understanding but also the emotional maturity to grasp the wider issues involved.[853] Lord Fraser's requirement that treatment is in the best interests of the child is consistent with the welfare principle, and limits the remit within which the child is allowed to make decisions to protect him from consequences adversely affecting his well-being.

While *Gillick* specifically concerned the provision of contraceptive advice, the underlying principles have been applied to a wide range of medical interventions. The issue of competence was revisited in the 2006 case of *Axon,*[854] involving a challenge by Mrs Axon to the Department of Health advice on the provision of information about sexually transmitted diseases and services for contraception and abortion to girls aged under 16 years without parental knowledge on grounds that this interfered with the parental right to private and family life under Article 8 of the ECHR. Silber J, in a detailed judgment,

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[848] Robert Wheeler, 'Gillick or Fraser? A Plea for Consistency over Competence in Children' (2006) 332 British Medical Journal 807.

[849] [1985] UKHL 7, [1986] AC 112.

[850] Ibid., at [189 A–E].

[851] Wheeler (n 790).

[852] Elliston (n 759), 80.

[853] John Eekelaar, 'The emergence of human rights' (1986) 6 Oxford Journal of Legal Studies 161-182, 181.

[854] The Queen on the application of *Sue Axon v The Secretary of State for Health (The Family Planning Association: intervening)* [2006] EWHC 37 (Admin)

confirmed the validity of both the competence and best interests criteria set out by Lord Scarman and Lord Fraser. The effect of combining these competence requirements is a further restriction of the remit within which the mature child is allowed to make medical decisions[855] as children must demonstrate broader decision-making skills than adults yet, unlike adults, they may only give their consent to procedures that deemed in their best interests by the courts.

The courts have generally been unwilling to find that a child is competent if their decision conflicts with the court's view of their welfare.[856] In *An NHS Trust v ABC & A Local Authority*,[857] the only reported case in which the courts allowed disputed treatment to proceed on the basis of a Gillick competent child's wishes, the court was asked to determine whether a 13-year-old girl had the appropriate capacity to consent to the termination of pregnancy, which she had requested. Mostyn J noted that the primary question was whether the girl had the required capacity and that if she did, it was implicit in Gillick that she was entitled to take steps which were contrary to her best interests.[858] The judgment, which did not refer to *Axon,* separated the content of the medical decision from the assessment of decision-making capacity, in alignment with the view that competent children should be treated as competent adults.

Gillick also concerned the issue of continued parental involvement in medical decisions. The court's traditional view was that parental rights 'dwindle' to an advisory role as the child approaches majority.[859] Unfortunately, *Gillick* does not conclusively establish what happens to parental rights once the child acquires competence and whether these cease altogether.[860] *Re W (A Minor) (Medical treatment: Court's jurisdiction)* concerned refusal by a 16-year-old girl with severe anorexia to undergo recommended treatment.[861] The complete cessation of parental rights was rejected in favour of concurrent powers of consent, captured by the legal 'flak jacket' analogy: parents can give consent on behalf of

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[855] Elliston (n 759), 83.

[856] Rachel Taylor, 'Reversing the Retreat from Gillick? R (Axon) v Secretary of State for Health' (2007) 19 17.

[857] *Re A (A child)* [2014] EWHC 1445 (Fam).

[858] Ibid., at [10].

[859] *Hewer v Bryant* [1970] 1 QB 357 at 369 per Lord Denning.

[860] Stephen Gilmore, 'The Limits of Parental Responsibility' in Probert, Gilmore and Herring (n 699), 64

[861] [1993] 1 FLR.

the Gillick competent child, irrespective of their wishes, but cannot override their consent.[862]

Re W also supported the court's jurisdiction and confirmed that the child's welfare or best interests were the first and paramount concern. The 'theoretically limitless' inherent jurisdiction of the court, exceeding both parental powers and the child's wishes, was also recognised in *Re R (A Minor) (Wardship: Consent to Treatment,*[863] involving a 15-year-old ward of the court with mental health problems refusing recommended psychiatric treatment. The right of a competent child to refuse treatment remains controversial.[864] The treatment refusal cases typically involve situations where an older child makes a decision that will have serious health consequences and the courts have generally overridden their wishes on the basis of their best medical interests[865] or by setting a higher competence threshold and making a finding of incompetence.[866] These cases raise important questions on the courts' recognition of the evolving autonomy of the child and the respect accorded to the self-determination of the mature child. Space does not permit an exploration of the critique of the asymmetry between the legal authority of the child to consent and to refuse consent to treatment. However, the preponderance of judicial authority suggests a right to refuse treatment is not recognised, at least where the untreated condition is life threatening,[867] and this has been justified by the need to protect the child's welfare or best interests.[868]

The applicability of the Gillick criteria for competence to potential organ donors under the age of 16 remains controversial.[869] Lord Donaldson's view in *Re W (A Minor) (Consent to Medical Treatment)* was that, as a matter of law, the Gillick principles apply to living organ donation although his lordship expressed doubt that a court would find a minor

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[862] *Re W (A Minor) (Consent to Medical Treatment)* [1993] 1 FLR per Lord Donaldson [8], [9].

[863] [1992] Fam 11 [25B,] [28G]; [1992] 1 FLR 190 at [199C], [203B].

[864] David Archard, 'Children, Adults, Best Interests and Rights' (2013) 13 Medical Law International 55.

[865] *Re P (Medical Treatment: Best Interests)* [2004] 2 FLR 1117; *Re P (A Child* [2014] EWHC 1650 (Fam).

[866] *Re E*; *Re L* (n 3). See also Emily Jackson, *Medical Law Text, Cases and Materials* (2nd edn. Oxford University Press), 268; *Re W (a minor) (medical treatment)* [1992] 4 All ER 627, CA; and *Re R (a minor) (wardship: medical treatment)* [1991] ER 177, CA.

[867] Norrie [5.10]. See the judgments of Lord Donaldson, MR, in *Re R (A Minor) (Medical Treatment)* [1991] 4 All E.R. 177 and *Re W (A Minor) (Medical Treatment)* [1992] 4 All E.R. 627, discussed below, para.7.31. See also *Re P (Medical Treatment: Best Interests)* [2004] 2 F.L.R. 1117.

[868] Nigel Lowe and Satvinder Juss, 'Medical Treatment - Pragmatism and the Search for Principle' (1993) 56 The Modern Law Review 865; Charles Bridge, 'Religious Beliefs and Teenage Refusal of Medical Treatment' (1999) 62 The Modern Law Review 585.

[869] Lisa Cherkassky, '*Gillick* , Bone Marrow and Teenagers' (2015) 83 Medico-Legal Journal, 154-158.

competent to consent to donation[870] and indicated that the seriousness of the issues involved warranted recourse to the courts for approval.[871] While these obiter dicta must be interpreted with caution, to date, there is no authority for the proposition that the principles of Gillick competence *do not apply* to decisions to become a live organ donor. However, in practice, whether Gillick competence confers upon the older child the decisional authority to agree to organ donation is a moot point because court approval is required in all cases involving children. It is notable that there is a limited body of case law concerning treatment decisions involving older children.[872] In *Re M (A Child) (Refusal of Medical Treatment)* in which Johnston J ordered a life-preserving heart transplant for a 15-year-old girl with heart failure who refused the procedure, which was supported by her parents.[873] The court's decision, considering the certainty of imminent death without the transplant, in this case represents a prima facie decision based on the best interests of the child.[874] However, treatment refusal cases, particularly where refusal is life-threatening are of limited guidance in living organ donation. The resection of a healthy organ from a healthy child presents unique circumstances as the surgical procedure is not a therapeutic procedure from the perspective of the donor and in this sense is it is not treatment recommended by doctors. Taking into account the courts duty to uphold the welfare of the child, the lack of medical benefit and the risk of harm to the child donor, and the possibility of viable alternatives (either an alternative donor for the recipient or renal dialysis), it is hard to see how the courts would focus on the narrow question of whether

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[870] [1993] 1 FLR at [10].

[871] Nolan LJ also held that the jurisdiction of the court should always be involved in the case of a child, of whatever age, consenting to organ donation at […]. This view endorses the approach of Lord Templeman in *Re B (A minor) (Wardship: Sterilisation)* [1988] AC 199 at pp 205-206 in the context of a sterilisation procedure on a patient with incapacity for the purpose of preventing pregnancy.

[872] Due to space constraints, I do not propose to rehearse the facts of these cases, which involve refusal of treatment, here. For further analysis, see Jo Bridgeman 'The Legal Duties of Doctors to Children in Their Care' in Jo Bridgeman (ed.) *Medical Treatment of Children and the Law* (Routledge 2021), 80. Of note, Bridgeman observes that the paucity of cases involving older children may be due to greater respect afforded to the decisions of older children or good medical practice allowing a satisfactory course of treatment to be agreed upon by the child and the responsible medical practitioner(s).

[873] *Re M (medical treatment: consent)* [1999] 2 FLR 1097.

[874] A similar case arose in 2008 in which a 12-year-old girl chose, with the support of her parents, to refuse a potentially life-saving heart transplant after suffering many years of chronic ill health. The case generated considerable debate about whether a chid of 12 years could be competent to make a decision that would lead to her death. For commentary see Sheila McClean, 'Hannah's Choice' *The Guardian* (11 November 2008); Jenny Percival and Paul Lewis, 'Teenager who Won Right to Die: 'I have had too much Trauma' *The Guardian* (11 November 2008)*;* Patrick Barkham 'Hannah's Choice' *The Guardian* (12 November 2008). The case was not referred to the courts and Hannah eventually changed her mind and underwent a successful transplant procedure. However, it is important to consider the ramifications of imposing an unwanted transplant and lifelong immunosuppressive therapy upon an unconsenting recipient whose parents support her refusal of treatment see Emma Cave, 'Adolescent Consent and Confidentiality in the UK' (2009) 16 European Journal of Health Law, 318.

the child is competent to make a decision to donate and then eschew the assessment of best interests if a finding of competence is made. On balance, it seems likely that decisions about organ donation from young teenagers and older children will be made by the courts in their best interests. Nonetheless, the views of the child regarding the proposed donation should carry more weight where they demonstrate a fuller understanding of the relevant issues.

5.2.2 Young persons and capacity to consent to treatment

While the age of full majority in the UK is 18 years,[875] in certain circumstances, minors may have full legal capacity to enter into binding transactions. In the healthcare context, s.8(1) FLRA 1969, which applies to England and Wales, allows 16- and 17-year-olds to consent to medical treatment.[876] The effect is that young persons[877] are presumed to have, like adults,[878] the legal capacity to consent to medical treatment, which can be lawfully administered without parental consent. Whether this provision creates an entitlement to self-determination depends on whether this capacity confers exclusive decision-making powers, in relation to the specific treatment. This point was considered in *Re W (A Minor) (Consent to Medical Treatment).*[879] In the leading judgment, Lord Donaldson recognised adolescence as 'progressive transition' to adulthood, acknowledging that the scope of decision-making left to the young person should increase with maturity and experience to enable him, by bearing the consequences of his decisions, to acquire decision-making skills.[880] Exclusive decision-making powers were not recognised and the case sets tight boundaries around medical decision-making by adolescents. Further, *Re W* confirmed that court's powers were not restricted by s.8 of the FLRA 1969 and that the court retained ample discretion in medical decision-making over adolescents on the cusp of adulthood, justified under the welfare principle. The court has a duty to consider any physical or mental harm the child has suffered or is likely to suffer,[881] not avoiding all risks, but

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[875] s.1(1) Family Law Reform Act 1969 (England and Wales); s1(1) Age of Majority (Scotland) Act 1969; s.1(1) Age of Majority Act (Northern Ireland) 1969.

[876] In Scotland, the principle of competency of children under 16 years to consent to procedures is incorporated into the Age of Legal Capacity Act (Scotland) 1991, which requires that the child is capable of understanding the nature and possible consequences of the procedure or treatment. The Children (Scotland) Act 1995 endorses this principle.

[877] The term "young persons" is used throughout this thesis to indicate persons aged 16 and 17.

[878] The presumption of capacity in adults is set out in section1(2) MCA 2005

[879] [1993] 1 FLR.

[880] [1993] 1 FLR at [12].

[881] [1993] 1 FLR per Nolan LJ at [24]

avoiding those which may have irreparable consequences or which are disproportionate to the benefits.[882]

The obiter remarks of Lord Donaldson in *Re W*, that the statutory presumption of capacity only applies to treatment and diagnostic procedures and not to the removal of an organ for transplantation, provide some guidance on the definition of treatment for the purposes of the FLRA 1969 and limit the scope of what young persons can consent to.[883] This interpretation has been incorporated into the MCA 2005 and paragraph 12.12 of the MCA 2005 Code of Practice states that the s.8 FLRA 1969 presumption of decision-making capacity in the medical context does not apply to organ donation, non-therapeutic procedures, and research.[884] Accordingly, as with children under the age of 16, legal capacity of young persons to consent to live donation must be established. There is an overlap between the jurisdiction of the Family Division of the High Court[885] and the Court of Protection in respect of the assessment of capacity to consent to medical treatment of young persons and there are no specific rules for deciding which court should be involved.[886] The Court of Protection assesses capacity under the MCA 2005[887] and can make a declaration regarding the capacity of a person to make a decision under s.15(1)(a) and (b). As discussed in Chapter 3, lack of capacity to make a decision under the MCA 2005 is understood as the inability to understand the information relevant to the decision, retain that information, use or weigh that information as part of the decision-making process, or communicate the decision.[888] Importantly, incapacity must be caused by an ‘impairment of, or a disturbance in the functioning of, the mind or the brain’ (s.2(1)) so a young person who does not demonstrate a flawed reasoning process but wishes to take a calculated risk by donating an organ to a family member would not be considered as lacking capacity under the MCA 2005. Lack of capacity cannot be attributed merely to age (s.2(3)) and the medical professional is under a duty to take practical steps to maximise the capacity of the person and give them every opportunity to develop and demonstrate

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[882] [1993] 1 FLR at [12].

[883] [1993] 1 FLR per Lord Donaldson at [10].

[884] John Harris and Søren Holm, ‘Should We Presume Moral Turpitude in Our Children?--Small Children and Consent to Medical Research’ (2003) 24 Theoretical Medicine and Bioethics 121.

[885] Under its inherent jurisdiction.

[886] ‘Mental Capacity Act 2005’ (n 222). Code of Practice [12.7].

[887] Ibid. Code of Practice [1.2].

[888] Section 3(1) MCA 2005.

capacity.[889] Crucially, where capacity is established, the Court of Protection does not have the power to make an order overriding the young person's wishes on the basis of what their best interests are seen to be. Such cases are dealt with in the High Courts.[890] A finding of capacity, as with adults, means that the authority to make the decision rests exclusively with the young person. This is consistent with the principle underpinning the MCA 2005 that decisions made by a person with capacity are to be respected. Section 8 of the FLRA 1969, by conferring upon 16- and 17-year-olds the presumption of capacity that applies to adults, distinguishes young persons from children. Accordingly, the more coherent approach for the assessment of capacity of young persons would be under the MCA, as with adults.[891] However, the MCA Code of Practice states that in non-therapeutic medical interventions where the s.8 presumption of capacity does not apply, as in organ donation, legal capacity, must be demonstrated using the test for 'Gillick competence'.[892] This approach was followed in the case of a 17-year-old refusing life-saving treatment for a drug overdose in which capacity was discussed both in terms of the MCA 2005 and Gillick competence.[893] Therefore, compared to adults, more onerous criteria[894] apply to the assessment of competence of young persons wishing to donate.

On balance, the assessment of the best interests of the prospective donor appears unavoidable either as part of the Gillick test or under the duties of the court to protect the welfare of all children under the age of 18 years. The young person may fulfil the criteria for understanding the nature of the organ retrieval procedure, its risks and future

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[889] See Emma Cave, 'Maximisation of Minors' Capacity' (2011) 23 Child and Family Law Quarterly 431, 448.

[890] 'MCA 2005 Code of Practice' (n 222) [12.14]. However, in the context of research, guidance by the NHS Health Research Authority and the MRC (updated in 2021) sets out a presumption that children over the age of 16 years in England and Wales are capable of giving consent on their behalf to participate in Clinical Trials of Investigational Medicinal Products, see https://www.hra-decisiontools.org.uk/consent/principles-children-Scotland.html accessed 10 January 2023. However, this guidance also refers to research more generally stating that 'in the absence of law relating specifically to research, it is commonly assumed that the principle of "Gillick competence" can be applied not only to consent to treatment, but also to consent for research'. Overall, the guidance provides minimal analysis of the legal justification for this approach and the applicability of this presumption to living organ donation cannot be adequately analysed within the remit of this thesis. I maintain that there is considerable ambiguity in legislation, limited case law on medical decision making involving older children, and inconsistent approaches by the courts with respect to refusal of life-saving treatment. On this basis, I agree with the view that there is no certainty that the older child's competent decisions will be respected even when the autonomy rights of the child are engaged (see Emma Cave 'Competence and authority: adolescent treatment refusals for physical and mental health conditions' 2013 8 Contemporary Social Science 92).

[891] Pattinson, *Medical Law and Ethics* (Sweet & Maxwell (UK) 2020), 161.

[892] MCA 2005 Code of Practice (n 222) [12.12].

[893] *An NHS Foundation Hospital v P* [2014] EWHC 1650 (Fam) Case No: ZC14P00123.

[894] David Archard, *Children: Rights and Childhood* (Third edition, Routledge, Taylor & Francis Group 2015). p 66

implications, as well as the odds of success transplantation and the consequences for the recipient of a failed transplant, yet they do not have the de facto authority to decide whether or not to proceed with donation and cannot act on their choice to donate unless the court is satisfied that donation is in their best interests.

5.2.3 Incompetent children and best interests

For children under the age of 16 years who do not meet the threshold for competence, consent to medical treatment can be given by a person with parental responsibility for the child. Generally, the courts are involved only where there is disagreement among parents and/or medical professionals over treatment and decisions are made under the court's inherent jurisdiction or the CA 1989.[895] In exercising their powers under the inherent jurisdiction, the judiciary follow the well-established principle that 'the court's prime and paramount consideration must be the best interests of the child'.[896]

Munby LJ, writing extra-judicially, captures the difficulty with the concept of best interests:

> What exactly is meant by a patient's best interests is neither self-evident nor altogether clear. There are two reasons for this uncertainty. First, the question has been given surprisingly little consideration by the courts. Secondly, and notwithstanding strong criticism, the courts have traditionally failed, and even on occasions refused, to articulate any principles or values to be applied in operating the best interests test.[897]

The welfare principle under the CA 1989 has been interpreted as synonymous with best interests[898] and in the Court of Appeal case of *Wyatt,* LJ Wall stated that in deciding what is in the child's best interests 'the welfare of the child is paramount, and the judge must look at the question from the assumed point of view of the child'.[899] In the academic literature, the term best interests is often used interchangeably with welfare, benefit, and wellbeing,[900]

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[895] *R v Portsmouth Hospital NHS Trust, ex p Glass* [1999] 2 FLR 905 at 910 per Lord Woolf MR.

[896] *Re J* (a minor) (wardship: medical treatment) [1990] 3 All ER 145, CA, per Taylor LJ.

[897] Sir James Munby Consent to treatment in Andrew Grubb, Judith Lain, Jean McHale (eds.), *Principles of Medical Law* (4th edn. Oxford University Press 2017), 548.

[898] In *re B (A Minor) (Wardship: Sterilisation)* [1988] AC 199 at 202 a case decided under the CA 1989

[899] *Wyatt v Portsmouth NHS Trust (No 3)* [2005] EWHC 693 (Fam) para.87.

[900] Stephen Darwall, *Welfare and Rational Care* (Princeton University Press 2004); Buchanan and Brock (n 13); Bart Schultz, 'L. W. Sumner, Welfare, Happiness, and Ethics (Clarendon Press 1996), Pp. Xii + 239.' (2002) 14 Utilitas 403; Richard Kraut, *What Is Good and Why: The Ethics of Well-Being* (Harvard University Press 2009).

although this overlooks important distinctions between the two concepts.[901] The application of the welfare principle may identify a range of options which may reasonably be chosen, while the best interests approach is based on the idea that there is a single preferable option from a range of interventions which the court is under a duty to identify and apply.[902] Beauchamp and Childress state that the term 'best' refers to the obligation to 'maximize benefit through a comparative assessment that locates the highest net benefit'.[903] On this view, the best interests approach imposes a more onerous requirement than the welfare principle.

When determining the course of action which is in the best interests of the child, the courts have widely endorsed the balance-sheet approach, which seeks to establish the intervention with the greatest overall benefit by weighing against each other the actual and potential benefits and burdens of the proposed courses of action and the alternatives.[904] The courts take a broad approach to best interests, interpreting these not simply as medical interests but also as the emotional, psychological, and social benefits to the child.[905] The inclusion of non-medical considerations in the best interests calculus is central to the ethical and legal justification for organ removal for transplantation which necessarily exposes the donor to the physical harm of surgery and is not for the medical treatment of the donor. At the same time, the inclusion of a *social* dimension to the child's interests raises important questions regarding our understanding of the best interests principle as strictly individualistic and to what extent the interests of other family members, such as the parents and the recipient sibling, are taken into account in the determination of the child's best interests.

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[901] Elliston (n 759), 17.

[902] In *re S (Adult Patient: Sterilisation)* [2001] Fam 15 per Dame Elizabeth-Butler Sloss P at [27].

[903] Beauchamp and Childress (n 73), 138.

[904] *Re A (Male Sterilisation* [2000] 1 FLR 549. The approach of Thorpe LJ in this case was endorsed in *Wyatt & Another v Portsmouth Hospital NHS & Another* [2005] EWCA Civ 1181 para 56; Beauchamp and Childress Principles of Biomedical Ethics (5th edn. Oxford University Press 2001) 99-103.

[905] *Re A (Male Sterilisation)* [2000] 1 FLR 549 at 555 (Butler-Sloss P); Re Y [1997] 2 WLR 556 at 562.

5.3 The legal and regulatory framework for living donation involving children in England and Wales

Under the HTA Regulations 2006 living organ donation is lawful if the HTA is satisfied that there is and will be no reward for the organ[906] and that consent has been given or removal of the organ is otherwise lawful.[907] In making this decision, the HTA must consider a report by the IA.[908] Further details of procedures and requirements for HTA approval are provided in the HTA Code of Practice F part 1: Living Organ Donation (hereafter Code F part 1),[909] the HTA Guidance for Transplant Teams and Independent Assessors (hereafter "HTA Guidance Document")[910] and the HTA Guidance for living organ donors on the Human Tissue Authority's independent assessment process (hereafter "HTA donor Guidance Document").[911]

As court approval is required in all cases involving donation by the living child, the lawfulness of the procedure is determined by the courts so consent of the child is not a legal requirement. Regulation 11(6) requires the IA to conduct separate interviews with the prospective donor, the person giving consent, and the recipient, unless organ removal for transplantation was authorised by a court order.[912] Court approval is always required for organ donation from the living child and this means that there is no third-party providing consent on behalf of the child donor and this includes parents. This point is significant because it means that organ donation is considered to be an activity which falls beyond the decision-making remit of parents and the statutory duties and the responsibilities of parents under the CA 1989 do not allow them to make the decision about organ donation on behalf of their child. Regulation 11(9) states that the IA must cover the information given to the donor about the nature of the transplant and the risks involved, the capacity to understand the nature of the medical procedure and the risk involved, and that consent may be withdrawn at any time before removal.

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[906] Section 11(3)(a) HTA Regulations 2006.

[907] Section 11(3)(b) HTA Regulations 2006.

[908] Sections 11(4) and 11(6)-(9) HTA Regulations 2006.

[909] Human Tissue Authority Code of Practice F Part 2 Donation of solid organs and tissue for transplantation, (2017).

[910] HTA Guidance for Transplant Teams and Independent Assessors (2017).

[911] Guidance for living organ donors on the Human Tissue Authority's Independent assessment process, HTA (2018)

[912] Human Tissue Act 2004 Regulations (Persons who Lack Consent and Transplants) 2006. Of note, the reference to the "person giving consent" applies to the donation of bone marrow and stem cells, which are also covered by the Regulations, as persons with parental responsibility can give consent to donation of these materials on behalf of their child.

The HTA Standard Operating Procedures, obtained by request from the HTA, state: '[t]he need for an IA interview with the donor is dispensed with in situations where the removal of organs for transplantation is authorised by a court order'.[913] This statement contradicts the HTA Guidance Document, as shown below.

Code F Part 1 provides limited guidance on donation by children, generally, and on the interviews, specifically. In relation to the donor child, it simply states that donation may occur 'only in extremely rare circumstances' and requires both the approval of the courts and of the HTA.[914] Court approval is justified as being '[i]n accordance with common law and the Children Act 1989'[915] with no further explanation. Unlike the section on living donation from adults with incapacity[916] which sets out the definition of capacity and the assessment of capacity, there is no mention of the assessment of the capacity or best interests of the prospective donor child. Code F Part 1 does not specifically refer to interviews with the child donor, although the statement that an interview is still required even if the donor is not able to give consent [917] should apply to children. In relation to adults lacking capacity, Code F Part 1 states that 'as the court is authorising the removal, there is no-one else providing consent on the donor's behalf, and therefore only interviews with the donor and recipient can be undertaken'.[918] While parents are not consenting on the child's behalf, some level of parental involvement with the IA would be reasonably expected, particularly when the child is young and their presence at the donor interview is desirable or necessary. Furthermore, at the very least, interviews with the parents are necessary for the HTA to ensure that no reward for the organ is being promised, as the HTA must reject applications in these circumstances.

The HTA Guidance Document[919] sets out the process of assessment and referral of prospective living donors to the HTA and provides guidance to IAs, clinicians and transplant teams about the HTA regulatory requirements applicable in England and Wales.[920] Clinicians considering a child as a living organ donor are advised 'to discuss the

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[913] HTA-POL-102. HTA Policy for the assessment of living organ donation cases [41].

[914] HTA Code of Practice F Part 2 Donation of solid organs and tissue for transplantation (Human Tissue Authority, 2017) [45], [46].

[915] Ibid.

[916] Ibid.

[917] Ibid., para 35.

[918] Ibid., para 57.

[919] Guidance for Transplant Teams and Independent Assessors, HTA, (2017) para 2.

[920] Guidance for Transplant Teams and Independent Assessors, HTA, (2017).

case with the HTA at the earliest opportunity'[921] and seek advice from the Hospital Trust's legal team.[922] Only cases that have been approved by the court can be referred to the HTA by the registered medical practitioner with clinical responsibility for the donor.[923] An HTA panel consisting of at least three members is required in all cases where the prospective donor is a child[924] and decisions to approve transplantation may be made by a majority if a unanimous decision cannot be reached.[925] Paragraph 194 of the HTA Guidance Document sets out the individual sections of the IA report. Section D is entitled "About the Donor" and here, the IA is required to confirm whether the donor is a child and state whether there is any concern regarding donor capacity to understand the organ retrieval procedure and the risks involved.[926] Concerns regarding capacity should be discussed with the HTA after the interview.[927] Interestingly, under the same section in the earlier, 2015 version, the IA was required to confirm whether the donor was a child *who is competent to understand the donation process in order to consent* [emphasis added].[928] This suggests that under earlier guidance, the IA was required to make an assessment of the competence of the child and this implies, in principle at least, that a child could have been regarded as competent to consent to organ donation. However, the assessment is problematic because a finding of competence to consent is at odds with the best interests approach of the courts. The current guidance appears to resolve this inconsistency by removing the requirement for a determination of competence and limiting the IA's enquiry to exploring concerns about the child's understanding of the organ retrieval procedure and it risks.

The lack of clarity and detail regarding the assessment process for prospective child donors contrasts with the approach towards child recipients. A specific section of the HTA Guidance Document covers interviewing techniques and assessment of capacity in the child recipient.[929] For example, if it appears to the IA that the recipient lacks capacity to be interviewed, the IA is advised to seek guidance from the HTA on whether to attempt the

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[921] Human Tissue Authority, Code of Practice F on Donation of Organs, Tissues and Cells for Transplantation, 2006 para 44.

[922] Guidance for Transplant Teams and Independent Assessors, HTA, 2015 (reviewed 2017) para 86

[923] Human Tissue Authority, Code of Practice F Part 2 Donation of Organs, Tissues and Cells for Transplantation, 2020 para 57

[924] Regulation 12(2)(a) of The HTA Regulations 2006

[925] Guidance for Transplant Teams and Independent Assessors, HTA, 2015 (reviewed 2017) para 204.

[926] Ibid., para 194.

[927] Guidance for Transplant Teams and Independent Assessors, HTA, 2015 (reviewed 2017) para 162

[928] Ibid., 185

[929] Ibid., paras 155-158. See also para 92 HTA Code of Practice F Part 1 Donation of Solid Organs for Transplantation which covers recipient interviews by the IA.

interview or whether adjustments are required to conduct the interview and overcome difficulties with communication.[930] The IA is required to note the information elicited during interview regarding the understanding of the procedure and its risks and the voluntariness of the decision to undergo transplantation or state that no relevant information was elicited.[931] Overall, the HTA Guidance Document provides minimal guidance on how the donor child's views and understanding of the process are explored and what steps are taken where the IA forms the view that the child has limited understanding of donation and raises these concerns with the HTA. Furthermore, while the HTA Guidance Document refers to the MCA 2005 in the context of persons with incapacity, there is no reference to the welfare principle, the assessment of competence, or the best interests of the child.

In addition to the guidance for medical professionals and IAs, the HTA published guidance for living organ donors. The 2012 version of the HTA donor Guidance stated that, where the donor is a child who is not competent to consent, a suitable person can consent on their behalf and that the IA was required to interview the person giving consent on behalf of the donor, rather than the donor, as well as the recipient, both separately and together.[932] This appears consistent with the earlier version of the HTA Guidance document aimed at professionals. A subsequent revision of these guidelines was published in November 2018.[933] The paragraph explaining proxy consent on behalf of the non-competent child was removed from the guidance. The terms "child" or "minor" do not appear in the document at all. Confusingly, the 2018 version of the donor Guidance still states that the IA will need to interview the donor (*or the person giving consent on the donor's behalf*) [emphasis added] and the recipient, both separately and together, to ask them a range of questions about the proposed donation.[934] As discussed above, this statement is incorrect as the role of the courts in approving living donation from a child is inconsistent with there being a person giving consent on the donor's behalf. It is regrettable that the donor Guidance document introduces further confusion and uncertainty to what is already an area of practice in which clear guidance is lacking.

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[930] Guidance for Transplant Teams and Independent Assessors, HTA, 2015 (reviewed 2017) para 182.

[931] Guidance for Transplant Teams and Independent Assessors, HTA, 2015 (reviewed 2017) paras. 181, 183, 184

[932] HTA Guidance for living organ donors on the Human Tissue Authority's independent assessment process, September 2012, 3.

[933] Ibid.

[934] Ibid., 4.

It is not clear how the HTA's role fits in with the court's approval process of donation by children. While the duty to assess whether a reward has been promised in exchange of an organ falls clearly within the remit of the HTA's activities, there is potential for duplication of work in the assessment of the donor. It is reasonable to assume that the HTA's role in the evaluation of the capacity of the child will be limited, as approval has already been granted by the courts by the time the application for living donation is made to the HTA. Another possibility is that the IA does not in fact conduct donor interviews, as noted above in relation to the HTA Standard Operating Procedures. However, this would severely limit the remit of enquiry of the HTA. The documentation provided by the HTA does not address the questions I posed in respect of the assessment of the potential donor child by the HTA following court approval and the potential for divergence of views between the HTA and the courts.[935]

Despite the lack of detail on the process for child donor assessment by the IA in the HTA guidance documents, it is clear that court approval of applications for living donation involving a donor under the age of 18 years is required in all cases. To date, the question of the lawfulness of organ transplantation involving a living child donor has not been argued before the courts in the England and Wales. The approaches of the courts in reported cases involving inter-sibling organ and bone marrow donation in US and Australian jurisprudence and the limited UK case law on bone marrow donation are likely to be relevant. In the following sections I will consider how the concept of autonomy applies to the donor child based on key themes emerging from judicial and academic analysis of the justification for the removal of an organ from a child: the relationships of the donor with the recipient, altruism, and moral obligations towards family members. I will then consider whether the interpretation and determination of the interests of the child in relation to organ donation allow for meaningful engagement of the child in the decision-making process and whether decisions made in their best interests respect the developing maturity and decision-making skills of the older child, as acknowledged by Lord Donaldson in *Re W (A Minor) (Consent to Medical Treatment)*,[936] and offer protection for the future autonomy of the child.

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[935] Contact made by email directly to the HTA and a request for information was made under the Freedom of Information Act 2000.

[936] [1993] 1 FLR at [12].

5.4 Court approval and the interests of the child donor

5.4.1 The psychosocial benefit of donation

The law is concerned with the welfare of the child who is the subject of the proceedings, and the claims of other family members are only relevant to the extent they directly affect the child's welfare.[937] The claim that the removal of an organ from a child for transplantation can be in the interests of that child is broadly based on the idea that the treatment of the recipient will benefit the donor. This section will examine the arguments used in medical jurisprudence and in the broader bioethics literature to define the best interests of the child and justify donation of tissue and organs.

The first kidney transplants from a child to a sibling were performed in the US in the late 1950s with the approval of the courts. Although the justification for authorising surgery has not always been clearly set out, this is broadly based on the finding of a benefit to the donor child in the context of a close pre-existing relationship with the recipient. In three unreported cases [938] the Supreme Judicial Court of Massachusetts authorized kidney transplants from minors,[939] identical twins aged 19, 14, and 14 years old, respectively. The expert psychiatric evidence of a psychological benefit to the donor was accepted - in one case surgery was found to be necessary for the 'continued good health and future well-being' of the donor[940] - although the courts relied heavily on the assent of the minors and, importantly, the consent of their parents.[941]

Hart v Brown[942] represents the first published opinion of a case involving organ donation from a child. Here, both parents and two appointed guardians ad litem agreed to kidney transplantation from a 7-year-old girl to her identical twin sister. Although both parents had offered their own kidneys, transplantation from the identical twin had the greatest

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[937] *Re P (Contact: Supervision)* [1996] 2 FLR314, at p.328. See Jonathan Herring, 'The Human Rights Act and the Welfare Principle in Family Law – Conflicting or Complementary?' (1999) 11 CFLQ 223; Jonathan Herring The Human Rights Act and the Welfare Principle in Family Law - Conflicting or Complementary (1999) 11 Child & Fam. Law Quarterly 223, 225.

[938] Madsen v. Harrison, No 68651 Eq. (Mass. Sup. Jud. Ct.1957); Huskey v. Harrison, No. 68666 Eq. (Mass. Sup. Jud. Ct.1957); Foster v. Harrison, No. 68674 Eq. (Mass. Sup. Jud. Ct.1957).

[939] The age of majority being 21 years at the time.

[940] Quoted in Curran WJ. A problem of consent: kidney transplantation in minors in Thomas H Murphy Jr, 'Minor Donor Consent to Transplant Surgery: A Review of the Law' 62 Marquette Law Review 23.

[941] Charles H Baron, Margot Botsford and Garrick F Cole, 'Live Organ and Tissue Transplants from Minor Donors in Massachusetts' (1975) 55 Boston University Law Review. Boston University. School of Law 159.

[942] (1972) 289 A 2d 386.

chance of success. The Superior Court of Connecticut approved transplantation, taking into account parental consent, the 'strong identification' between the donor and her sister, and the expert psychiatrist's view that 'the donor would be better off in a family that was happy than in a family that was distressed'. In a case that has been criticised as an example of acquiescence to the wishes of the family,[943] the court never specifically referred to the interests of the donor and held that this was a decision within the remit of parental authority and that it was reasonable for parents to balance the interests of one child against the other. The requirement for a benefit to the donor is also evident in judicial decisions not to authorise transplantation. In *re Roy Allen Richardson,*[944] the Court of Appeal of Louisiana refused to approve donation of a kidney from a 17-year-old with Down's syndrome to his 32-year-old sister, rejecting as speculative the arguments that the sister would take care of her brother in future. While there was limited discussion in the judgment on the underlying principles, the court took into account the fact that the sister could survive on dialysis and that there were other siblings who could donate, albeit with a greater chance of organ rejection. In *Little v Little,*[945] the Texas Court of Appeals approved kidney donation from a 14-year-old girl with Down's Syndrome to her brother, despite the disagreement for the guardian ad litem. The court applied the best interests test, noting the close relationship between the siblings and stating that the donor would receive 'substantial psychological benefits' from donating a kidney to her brother and experience 'an increase in personal welfare'.[946]

The leading authority in the US on the lawfulness of inter-sibling donation where the donor is a child is *Curran v Bosze,*[947] in which the Supreme Court of Illinois was asked by a father to authorise testing of his twin 3-year-old children for compatibility for bone marrow donation to their 12-year-old half-brother, their father's child born out of a previous relationship, who suffered from leukaemia. The twins lived with their mother who had a 'parentage order' granting her sole care, custody, control and educational responsibility for the children although consultation with the father was required for all matters of importance relating to health and welfare. The mother refused to consent to the procedure. While the case concerns bone marrow donation, the detailed judgment provides

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[943] Morley M. (2002) 111 Yale Law Journal, 1215-49.

[944] (1973) 284 So.2d 185

[945] (1979) 576 SW 2d 493

[946] James Dwyer and Elizabeth Vig, 'Rethinking Transplantation between Siblings' (1995) 25 The Hastings Center Report 7.

[947] (1990) 566 N.E.2d 1319 per Calvo J at 1343-4.

an important benchmark for the analysis of the lawfulness solid organ donation involving minors. The court explicitly accepted the best interests standard as the relevant test and identified three requirements: informed consent of the parent regarding the risks and benefits of the bone harvesting procedure, emotional support available to the donor following the procedure, and a close relationship between prospective donor and recipient. The court refused to authorise the procedure, concluding that in the absence of a close relationship between the twins and their half-sibling and without the emotional support of the mother, who opposed donation, the procedure was not in their best interests. The boy had died of leukaemia by the time the written judgment was issued.

The approach in *Curran v Bosze* regards the proximity of the relationship between the donor child and the sibling as the essential pre-requisite for a psychological benefit of donation upon which the determination of the best interests of the donor is based. Donation may benefit the child donor by enabling him to enjoy a relationship with a healthy sibling. Benefit may also be calculated as the avoidance of the negative impact of non-donation, for example the child's emotional suffering due to the death of the sibling.

There is limited jurisprudence in the UK on the use of bodily material removed from a person with no capacity to give consent for the benefit of a third party. *Re Y (Mental Patient: Bone Marrow Donation)*, is the first reported case in English law in which the courts considered this question.[948] The case involved an adult rather than a child. Nonetheless, the judgment merits discussion here as it is evidence of how the best interests standard has been interpreted by the English courts to justify an invasive procedure on a non-competent person for the treatment of a family member.[949] A woman with deteriorating non-Hodgkin's lymphoma sought a declaration from the courts authorising bone marrow harvesting from her 25-year-old sister for tissue compatibility testing. Y suffered from severe mental and physical disability and could not give her consent to testing. Connell J was clear that the appropriate test to establish the lawfulness of the procedure was that this was in the best interests of the incompetent prospective donor. It was accepted that the relationship between the sisters was limited and could not be used as the basis for the best interests test. However, Y, who lived in community care, was regularly visited by her mother and these visits were deemed valuable. It was accepted that the death of the ill daughter would have a profound effect on the health of the mother and her future ability to

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[948] *Re Y (Mental Incapacity) (Bone Marrow: Transplant)* [1996] 2 FLR 787 [1997] Fam 110.

[949] Shih-Ning Then, 'Best Interests: The "Best" Way for Courts to Decide If Young Children Should Act as Bone Marrow Donors?' (2017) 17 Medical Law International 3-42.

visit Y. The judgment in *Re Y* included an extensive analysis of *Curran v Bosze,*[950] although it did not explicitly set out which factors of this case it considered relevant. Testing was authorised on grounds that the physical discomfort and risks of anaesthesia were outweighed by indirect benefits to Y's welfare, namely the emotional, psychological and social benefits of maintaining contact with her mother.

The case of *Re Y* raises serious concerns regarding the understanding of a psychological benefit of donation and the evaluation of such a benefit that are equally applicable to donation by children. If psychological benefits to a particular child are claimed, it is imperative that these are clear and based on a proper assessment of the child and of family dynamics by a professionally trained person. However, in this case, the court relied on evidence of the psychological benefits of donation to Y presented by the Official Solicitor's representative. It has also been noted that a medical professional qualified in assessing learning difficulties would have provided a more thorough account of the likely effect on Y of her mother being unable to visit, particularly as the emotional bond between them was unusual, Y being unaware that the person visiting was her mother.[951] The outcome in cases involving children and donation of solid organs remains speculative[952] and the case only concerned testing for tissue compatibility with a separate ruling required to authorise retrieval of bone marrow, although no further applications are reported.

More recently, the Court of Protection again considered the matter of tissue donation from an incompetent person in *A NHS Foundation Trust v MC*.[953] It is notable that this is the first case to come before the courts since the HTA was created. The case concerned a proposed peripheral blood stem cell donation from an MC, an 18-year-old woman with a learning disability, to her mother who had been diagnosed with leukaemia. There were no other suitable donors and the mother's prospects of survival were very poor. There was no dispute regarding the lack of capacity of MC to consent to the procedure. In addition to the risks of stem cell harvesting the procedure involved admission to hospital during the COVID-19 pandemic. Cohen J considered the loving relationship between MC and her mother and found that MC's best interests were inextricably linked to her mother's survival and that there were clear psychological, emotional, social, and financial benefits to

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[950] (1990) 566 NE 2d 1319.

[951] Feenan. A Good Harvest? 309.

[952] Cherkassky (n 897) 154.

[953] [2020] EWCOP 33.

MC in prolonging her mother's life.[954] On this basis the court provided the required consent to allow the HTA to authorise the proposed procedure.

An important aspect of this case is that Cohen J considered wider concerns arising from the fact that MC had recently turned 18 but the assessments for the proposed stem cell harvesting had begun when she was still a minor with the consent of her father. Cohen J recognised the 'vacuum' in the legislation applied to minors which required parental consent for the procedure with HTA oversight limited to merely ensuring valid consent, specifically the absence of payment to the donor, pressure or coercion.[955] Cohen J commented that that there was no legal requirement that the best interests of the donor be considered[956] and expressed a clear view that a 'considered risk benefit analysis' should be performed by the HTA accredited assessor based on the requirements for the best interests assessment under s.4 of the MCA 2005.[957] These comments on the importance of the best interests assessment in all cases involving donation from a child lacking capacity are important because they recognise that the interests of the child need to be properly assessed by the HTA rather than leaving this matter to the discretion of the child's parents.

Cohen J also noted that there is a lack of data on the numbers of donations from minors with incapacity approved by the HTA.[958] Bone marrow is routinely harvested from children across the UK with the consent of parents and these cases do not routinely reach the courts as there is no requirement for court approval unless there is disagreement between parents or between parents and the medical professionals involved.[959] The psychosocial benefit to the donor child came under scrutiny following an article by Delany[960] on the case of *R v Cambridge Health Authority, ex parte B.*[961] This was a judicial review of a Health Authority's decision, driven party by resource allocation issues, to refuse a 10-year-old girl further treatment for acute myeloid leukaemia. While the details of the judicial review are beyond the scope of this discussion, it is important to note that the evidence indicated that

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[954] Ibid. [15].

[955] Ibid. [20].

[956] Ibid. [21].

[957] Ibid. [22]. Of note, the case of Re Y predated the MCA 2005 and the creation of the HTA under the HT Act 2004.

[958] Ibid. [19].

[959] HTA Code G Donation of Allogeneic Bone Marrow and Peripheral Blood Stem Cells for Transplantation 2017 [70], [77].

[960] Linda Delany 'Protecting Children from Forced Altruism: the Legal Approach' in Altruism By Proxy: Volunteering Children For Bone Marrow Donation (1996) 312 British Medical Journal 240, 240.

[961] *R v Cambridge Health Authority, ex parte B* [1995] 2 All ER 129.

the girl had been previously treated with bone marrow extracted from her younger sister and that a second bone marrow harvest, if approved, would have also involved the younger sister, although this was not commented on by the judge. Delany, focused on this aspect of the case, supporting the application of the best interests test to determine the lawfulness of donation but cautioning that the use of bone marrow in the absence of a clear emotional bond between the child donor and the recipient could infringe the donor's interests. The issue became a question about the legitimacy of parental authority in these circumstances as many commentators criticised Delany's overestimation of the risks to the donor, supporting a more holistic approach, which takes into account the interests and needs of the family as a whole, leaving the assessment of these interests to parents.[962]

I will examine the remit of parental authority in the context of family interests later; however, for the purposes of this discussion it is important to highlight that as there are different views on what constitutes a psychosocial benefit to the donor and that while the idea of benefit may be plausible, the extrapolation that organ donation is in the *best* interests of the child donor appears contrived,[963] particularly where the child's understanding of donation is limited.[964] Kagan distinguishes between a person's subjective perception of their life and the assessment of the person's life made by others.[965] However as autonomy is conceptualised in relation to the child donor, my central argument is that, as with adults, it is the perspective of the child donor that matters. This distinction is crucial because what is seen by the parent or the courts as being in the interests of the child does not necessarily coincide with what the child perceives and, importantly, with what the child may perceive once transplantation goes ahead. There is broad consensus that interests are subjective in the sense of being endorsed by the individual as an authentic experience.[966] If we accept that the individual's interests concern what matters to that particular individual, the determination of these non-medical benefits is challenging where

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[962] J Savulescu, 'Substantial Harm but Substantial Benefit' (1996) 312 British Medical Journal 241; Larry Palmer, 'Should Liability Play a Role in Social Control of Biobanks?' (2005) 33 Journal of Law, Medicine & Ethics 70.

[963] Robert Griner, 'Live Organ Donations between Siblings and the Best Interest Standard: Time for Stricter Judicial Intervention' [1995] Specialty Law Digest. Health Care Law 9; Leonard Fleck, 'Children and Organ Donation: Some Cautionary Remarks' (2004) 13 Cambridge Quarterly of Healthcare Ethics; Lynn Jansen, 'Child Organ Donation, Family Autonomy, and Intimate Attachments' (2004) 13 Cambridge Quarterly of Healthcare Ethics Jennifer C Kesselheim and others, 'Is Blood Thicker Than Water?: Ethics of Hematopoietic Stem Cell Donation by Biological Siblings of Adopted Children' (2009) 163 Archives of Pediatrics & Adolescent Medicine 413; Barry Lyons, 'The Good That Is Interred in Their Bones: Are There Property Rights in the Child?' (2011) 19 Medical Law Review 372.

[964] Fleck (n 895) 162.

[965] Shelly Kagan, 'XIV—Me and My Life' (1994) 94 Proceedings of the Aristotelian Society 309.

[966] Buchanan and Brock (n 13); Schultz (n 840).

the potential donor is too young to properly recognise and understand their own interests in the survival of the recipient.

Crouch and Elliott claim that one of the necessary preconditions of the psychological benefit of donation is that the donor grasps the social dimension of donation: understanding that their organ will be transplanted into their sibling is not sufficient; what is needed is a genuine appreciation that donation is a sacrifice that they are in a unique position to make in order to help his sibling.[967] If the donor is too young to appreciate the significance of donation at the time of surgery, this realisation may occur at a later stage.[968] However, it should be properly recognised that these are projections of a future benefit of the relationship between siblings and remain speculative, at best.[969] It may be that the child donor is better off growing up in a family which has not been affected by the death of a child yet it is by no means certain that donation will allow the donor to be raised within a stable, nurturing family, and enjoy a close relationship with their now healthy sibling. The validity of the assumption that psychological benefit, rather than harm, will flow to those in established relationships is, in itself, controversial.[970] Research in the wider health context shows there are benefits to persons in maintaining their relationships with their siblings[971] and that a sibling's death can have negative repercussions on the surviving child with anxiety, depression and aggression.[972] However, the lack of empirical evidence on the effects of successful and failed transplantation following inter-sibling donation is problematic.

While intuitively it is assumed that benefits derive from saving a family member, a better understanding is required of the circumstances and the relationships within which the purported benefit is likely to materialize to justify overriding the child's present and identifiable interest in bodily integrity by less certain interests. The fact that many adults who are emotionally invested in an ill recipient do not consider donation in the first place, decide not to pursue donation following initial contact with the transplant team, and

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[967] Crouch and Elliott (n 338), 275-287.

[968] Ibid., 282.

[969] Then (n 975), 34.

[970] Compelled Body Part Donations From Children', in Michele Goodwin, *The Global Body Market: Altruism's Limits* (Cambridge University Press 2013); Cheyette (n 387).

[971] Gene Brody, 'Siblings' Direct and Indirect Contributions to Child Development' (2004) 13 Current Directions in Psychological Science 124; Michael Lamb and Brian Sutton-Smith, *Sibling Relationships: Their Nature and Significance across the Lifespan* (Psychology Press 2014) .

[972] Aradhana Bela Sood and others, 'Children's Reactions to Parental and Sibling Death' (2006) 8 Current Psychiatry Reports 115-116.

withdraw during the transplant workup shows how assumptions about any benefits of donation to the donor are unfounded. This also highlights that caution must be exercised when drawing conclusions about how the repercussions of not donating affect potential donors and how harm caused by not donating is used to substantiate the idea of the overall benefit of donation. If we accept that the harm-benefit calculation is a deeply personal matter and that different people will come to different conclusions, the expectation that the courts, as third parties, should make this assessment for the child is difficult to defend. Morley is sceptical about placing the burden of helping a family member upon a child through uninformed, non-consensual, and invasive surgery and notes that while the circumstances may be such that children are in a position to help in 'extraordinary ways' this alone does not provide the justification for allowing children to donate and serious judicial analysis is lacking.[973]

5.4.2 Altruism as an interest

In the context of non-therapeutic medical research involving children, the idea that participating in research enables the child to act altruistically, contributing to the child's moral development,[974] has been propounded. A similar argument has been applied to organ donation with some commentators interpreting the psychological benefit to the child donor as the opportunity to instil the 'virtue of altruism'.[975] Morley takes a less controversial standpoint focusing on the recognition of the humanity of incompetents and claims that the best interests test, by restricting the incompetent person to being 'always a receiver, a taker, never a giver' of benefits and resources,[976] prevents them from following the morally right course of action and helping a family member in need.[977]

This is consistent with the views of the British Medical Association that while the wish of incompetent children to participate in interventions for the medical benefit of others should not be assumed, it would also be wrong to assume that they would not wish to help

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[973] Michael Morley, 'Proxy Consent to Organ Donation by Incompetents' (2002) 111 The Yale Law Journal 1215, 1240-1243.

[974] Nancy King, 'Defining and Describing Benefit Appropriately in Clinical Trials' (2000) 28 The Journal of Law, Medicine & Ethics 332; Redmon (n 661); Harris and Holm (n 824) 333, 81 and 121.

[975] Lainie Friedman Ross, 'Moral Grounding for the Participation of Children as Organ Donors' (1993) 21 Journal of Law, Medicine & Ethics 251.

[976] Pescinski 226N.W.2d at 184 per Day, J. This argument is based on the dissenting judgment in which the court did not authorise a kidney donation from an incompetent to his sister.

[977] Morley, (n 1000).

others.[978] However, the use of altruism to justify living donation by a child raises serious ethical concerns.[979] Taking Nagel's definition of altruism as 'willingness to act in consideration of the interests of persons, without the need of ulterior motives', altruism is understood as an exclusively or predominantly others-regarding moral concern, requires a deliberate and voluntary choice and the reflective capacity to appreciate the importance of transplantation to the recipient. Where the prospective donor is a young child with limited understanding of the process, the promotion of altruism as an intrinsic good may result in the imposition of this value. This is relevant to the case of *A NHS Foundation v MC* as Cohen J stated that he gave 'some weight' to the fact that MC 'may be seen by others positively by acting altruistically'.[980] I consider that reliance upon altruism as part of the ethical justification of donation is potentially problematic because the concept is poorly defined in policy[981], its moral relevance is questionable when the individual does not have the ability to appreciate the selfless act and, in any event, it is unclear whether the concept can apply to situations where the decision to act is made by a third party on behalf of a person lacking capacity.

Goodwin rightly calls for greater scrutiny of the '*language of the gift*' which has become an established rhetoric in transplantation because depicting children as givers and receivers, may overlook the conflicts of interests and imbalance of power within the family and the potential for manipulation and parental pressure of the child donor.[982] Altruism cannot be forced[983] and without voluntariness and reflective capacity, donation is merely an obligation imposed on children by virtue of their age, which is otherwise unacceptable in the case of adult donors.

This point was made clear in US case of *McFall v Shimp*[984] where Shimp refused to donate bone marrow to his cousin who suffered from aplastic anaemia, citing immediate family responsibilities that outweighed his obligation to assist his cousin. The court was asked to

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[978] Carol Dyer, 'Guide to Ethics of Treating Children Published' (2000) 321 British Medical Journal 1491 .

[979] Linus Broström and Mats Johansson, 'Involving Children in Non-Therapeutic Research: On the Development Argument' (2014) 17 Medicine, Health Care, and Philosophy 53.

[980] Ibid. [17].

[981] Moorlock, Ives and Draper (n 391).

[982] Goodwin, Michele, Compelled Body Part Donations from Children in *'The Global Body Market: Altruism's Limits'*, (Cambridge University Press 2013), 82-83. Michele Goodwin, 'My Sister's Keeper: Law, Children, and Compelled Donation' (2007) 29 Western New England Law Review 357, 377-78.

[983] Sheldon Zink and Stacey L Wertlieb, 'Forced Altruism Is Not Altruism' (2004) 4 The American Journal of Bioethics 29.

[984] 10 Pa D&C (3d) 90 (1978).

consider whether it could compel a competent adult to undergo the potentially life-saving procedure without his consent and held that it could not. While Mr Shimp's refusal was condemned by the judge as morally indefensible, the choice was his to make and Mr McFall died of his disease. Cases in which the individual refuses to donate pose significant challenges to the ethical acceptability of making decisions regarding organ donation on the behalf of children because these expose the fact that different individuals, for a variety of reasons that are personal to them, are not willing to donate in similar circumstances.

In my view, the ethical relevance of altruism lies in its explanatory power as the motivation for the child's wish to proceed with donation. Altruism is often overlooked by the best interests requirement for a tangible benefit and an altruistic wish to help the recipient is considered relevant only where this translates into specific positive outcomes for the donor. I maintain the position set out in my analysis of living organ donation by adults that altruistic motives and self-interest are not necessarily mutually exclusive. The ethical concern, as I see it, is that the focus on the self-serving benefit may cause us to disregard altruism as the moral value underpinning the child's choice to donate. This distorts the motivation to donate and interferes with an evaluation of the authenticity of the decision. If authenticity is ethically relevant to the conceptualisation of autonomy, and I claim that it is, other-regarding interests should be properly considered and accounted for. At the same time, I endorse the view that altruism requires sufficient maturity and self-reflection to understand the sacrifice involved and the difference that a transplanted organ will make to the recipient's life.

5.4.3 A relational approach to the donor child's interests

The law is concerned with the welfare of the child who is the subject of the proceedings, and the claims of other family members are only relevant to the extent they directly affect the child's welfare.[985] The critique of the best interests principle for its unreserved focus on the individual child and its disregard for how the interests of different family members affect decision-making in real life is well rehearsed.[986] Ekman claims that this traditional welfare approach is based on the premises that the interests of parents and those of their children can be separated and that the wellbeing of the individual child is the only

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[985] *Re P (Contact: Supervision)* [1996] 2 FLR314, at [328]. See Herring, 'The Human Rights Act and the Welfare Principle in Family Law - Conflicting or Complementary?' (n 877), 225.

[986] Lainie Friedman Ross, 'Health Care Decision-making by Children Is It in Their Best Interest?' (1997) 27 The Hastings Center Report 41, 41-45; Erica Salter, 'Deciding for a Child: A Comprehensive Analysis of the Best Interest Standard' (2012) 33 Theoretical Medicine and Bioethics 179.

consideration, prevailing over the interests of other family members.[987] A relational perspective challenges this assumption, recognising that the interests of parents and their children cannot be neatly compartmentalised[988] and that healthcare decisions do not only affect the welfare of the child involved but have significant consequences for the rest of the family.[989] On this view, the child is merely one participant in a process where the interests of all participants matter and are taken into account.[990] It is claimed that this represents a more realistic view of the family, which recognises the 'conflict, confluence, and confusion of interests characteristic of life within a family'.[991]

Herring, who has written extensively on relational ethics in the healthcare context, developed the idea of 'relationship-based welfare', based on the premises that children are best raised in the context of healthy relationships and that their welfare is promoted by supporting the interests of parents and of the family. This view accepts just and fair relationships as requiring a degree of 'give and take' between family members[992] because the decisions of the individual affect family members by virtue of the relationship between them.[993] Families are a communal enterprise and responsibilities flow from meaningful relationships.[994] In the course of everyday family life, sacrifices made and benefits gained are not perceived as independent interests or rights, although the law treats them as such by balancing each against the other.[995] What is in the interests of the child, as the person who is being cared for, is to be in a relationship with his parent which promotes the interests and well-being of them both.[996] This may involve making decisions which, in a narrow

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[987] Rosalind Ekman Ladd, 'The Child as Living Donor: Parental Consent and Child Assent' (2004) 13 Cambridge Quarterly of Healthcare Ethics 143.

[988] Herring (n 877).

[989] Salter (n 1013).

[990] Helen Reece, 'The Paramountcy Principle: Consensus or Construct?' (1996) 49 Current Legal Problems 267.

[991] Crouch and Elliott (n 338).

[992] Charles Foster and Jonathan Herring, 'Rethinking the Welfare and Best Interest Principles' in Charles Foster and Jonathan Herring, *Altruism, Welfare and the Law* (Springer International Publishing 2015) 34.

[993] Jonathan Herring, 'Relational Autonomy' in Jonathan Herring, *Relational Autonomy and Family Law* (Springer International Publishing 2014), 267.

[994] Foster and Herring (n 922) 37.

[995] Wallbank, Choudhry and Herring (n 773), 266.

[996] Jonathan Herring, Caregivers in Medical Law and Ethics' (2008) 25 The Journal of Contemporary Health Law and Policy 38.

sense, do not explicitly promote the child's welfare or may even result in some harm, if that is a fair aspect of a caring relationship upon which the child's wellbeing depends.[997]

The emphasis on the relational component of the interests of a person would seem to provide a more authentic explanation of how a non-therapeutic procedure which involves physical harm may be justified on the basis of the child's interests, circumventing the difficulties with the more contrived claim that organ removal is in the *best* interests of the donor child. However, Herring maintains that, in practice, the courts already balance the welfare of the child against the interests of others and that the concept of relationship-based welfare is an open and honest recognition of the plurality of relevant interests that are in fact already regarded as relevant by the courts when considering the best interests of the child[998] rather than a contending principle. Similarly, Kopelman argues that properly understood in the medical decision-making context, the best interests standard is used as a standard of reasonableness to identify the choice that 'most informed, rational people of good will would regard as maximising next benefits and minimising net harms for children, given the legitimate interests and rights of others and the available options' rather than as an ideal standard to do what is the absolute best for the specific child, ignoring the conflicting interests and needs of other children and family members.[999] On this view, the relational approach to the best interests principles does not seek to dislodge the child donor's best interests as the paramount consideration of the courts, rather, it seeks to analyse the interests of the child, who is part of a family and include the effect of decisions on relationships that are important to the child in the best interests assessment. The outcome, it is argued, is in the overall interests of the child, taking into account the benefits to the child of being in the family.[1000]

This approach was followed in *Re Y,* regarded by some commentators as a significant shift towards the recognition of the importance of emotional connection and acceptance that the wellbeing of the prospective donor is intertwined with the wellbeing of other family members.[1001] The court's decision circumvents the difficulties with the requirement for an existing emotional bond between donor and recipient, identified in *Curran*, by looking at

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[997] Herring (n 877), 233; Herring (n 765), 159.

[998] Jonathan Herring and Charles Foster, 'Welfare Means Relationality, Virtue and Altruism' (2012) 32 Legal Studies 480, 483.

[999] Lottie Kopelman, 'The Best-Interests Standard as Threshold, Ideal, and Standard of Reasonableness' (1997) 22 Journal of Medicine and Philosophy 271, 281.

[1000] Paul Baines, 'Family Interests and Medical Decisions for Children' (2017) 31 Bioethics 599, 605.

[1001] Herring and Foster (n 928).

the impact of successful transplantation on family relationships that are meaningful to the donor. The decision creates a precedent for very young children to whom the principles in *Curran* cannot apply because they haven't had the chance to develop a bond with the ill sibling[1002] and are significantly dependent upon parental care.[1003] This broader conceptualisation of best interests in *Re Y* has been criticised for allowing the court to take into account the interests of Y's sister and her mother.[1004] However, the court was careful to frame the relevant interests in terms of the self-regarding interests of Y, consistent with the application of the welfare principle under which any benefits and losses are assessed with respect to the *donor* child. It is regrettable that the evidence supporting the purported detrimental effects on Y of diminished contact with her mother is tenuous and that the case does not convincingly show that Y's relational interests in maintaining this connection were genuinely regarded as paramount vis-à-vis the interests of her sister and mother that the transplant take place. My central contention is that if we are serious about donor's wellbeing viewed from the perspective of the child, it is imperative that any purported relational interests are set out transparently and carefully scrutinised so that it is clear how these affect the donor in a meaningful way.

While formally the best interests principle has not been re-defined, the courts have been prepared to consider interests from a relational perspective, albeit in different disparate contexts. The Court of Appeal in the case of *Re J*[1005] concerning an application by a Muslim father for a specific order for the circumcision of his son who lived with his mother, a non-Muslim, who did not agree with the procedure, recognised that circumcision is an irreversible surgical procedure that carries physical risks to the child and accepted that the proper justification lies in maintaining the child's place within his network of relationships.[1006] The fact that the child was not being raised as a practising Muslim, coupled with the objections of the child's primary carer, led to a finding that circumcision was not in his best interests. In the case of *ABC v St George's Healthcare NHS Trust*[1007]

[1002] Delany (n 982).

[1003] Dermot Feenan 'A good harvest? Re Y (Mental Incapacity: Bone Marrow Transplant) (1997) 9 Child & Family Law Quarterly 305.

[1004] Lisa Cherkassky, 'Children and the Doctrine of Substituted Judgement' (2014) 14 Medical Law International 213, 229; Lisa Cherkassky, 'The Wrong Harvest: The Law on Saviour Siblings' (2015) 29 International Journal of Law, Policy and the Family 36, 48–49; S Mumford, Bone marrow donation – the law in context (1998) 10 Child and Family Law Quarterly 135. See also Jonathan Herring, *Caring and the Law* (Hart Publishing 2013), 162.

[1005] *Re J (Specific issue orders: child's religious upbringing and circumcision)* [2000] 1 FLR 571.

[1006] *Re J (Specific Issue Orders: Muslim upbringing and circumcision)* [1999] 2 FLR 678; affirmed at [2000] 1 FLR 571.

[1007] *ABC v St George's Healthcare NHS Trust & Others* [2020] EWHC 455.

concerning a claim in negligence by a mother against her father's doctor for his failure to warn her during the pregnancy of her risk of having or being a carrier of an untreatable and fatal genetic disease. Following birth, the claimant was found to have the disease and brought a claim for damages for the loss of opportunity to terminate the pregnancy. A relational view was tentatively articulated by the High Court in its recognition of a clinician's duty of care to balance the personal interests of significant others against the interests of the patient and in so doing, this approach appears to endorse, where appropriate, actions taken in accordance with the interests of others (here, the relative of a patient with a familial genetic condition) although ultimately, the claim failed with respect to breach of duty and causation.[1008] The case of *Barts Health NHS Trust v Raqeeb* [1009] represents a case in which relational interests were considered as part of the determination of best interests of the patient. The case concerned an application for a determination of the best interests of four-year-old Tafida Raqueeb who had suffered a catastrophic brain injury resulting from a rare arteriovenous malformation. The view of the medical team was that she had no prospect of recovery and treatment was foolish and not in her best interests. However, Tafida's parents who were devout Muslims wished to take her, against the advice of the doctors in the UK, to the Gaslini Paediatric Hospital in Genoa, Italy, where she could be assessed for weaning from mechanical ventilation. If successful, weaning would have allowed Tafida's parents to care for her at home doing everything to sustain her life, according to the tenets of their Islamic faith. It was accepted by the court that Tafida was unlikely to feel pain in her present state and while her condition could not be improved, life sustaining treatment would allow Tafida to live for a number of years. MacDonald J found that transfer to the Italian hospital was in her best interests. The case raised concerns about the fact that the determination of best interests separated medical interests from overall best interests allowing the court to rely heavily upon the evidence of the family Tafida, despite her young age, had begun to show appreciation for the principles underpinning her parents' religious beliefs, so that ultimately her best interests were framed in terms of what in future she may have come to believe had she followed her parents' religious beliefs.[1010]

[1008] Charles Foster, Roy Gilbar, Is There A New Duty To Warn Family Members In English Medical Law? ABC v St George's Healthcare NHS Trust and Others [2020] EWHC 455 (2021) 29 Medical Law Review 359, 360.

[1009] [2019] EWHC 2530 (Fam); [2019] EWHC 253.

[1010] See Emma Cave , Joe Brierley, and David Archard 'Making Decisions for Children – Accommodating Parental Choice in Best Interests Determinations: *Barts Health NHS Trust v Raqee*b [2019] EWHC 2530 (Fam); *Raqeeb and Barts Health NHS Trust [2019]* EWHC 253' (2019) 28 Medical Law Review

These cases may represent a shift in the conceptualisation of best interests and increased support for pluralism of values although the courts have not explicitly acknowledged relational interests.[1011]

From a practical perspective, it is not obvious how the recognition of relational interests resolves the problem of how to determine an outcome when the child's interests conflict with those of other family members.[1012] In cases involving organ donation, a recognition of the value of preserving the life of a family member does not remove or diminish the donor's interest in bodily integrity yet the consequences for the recipient of not receiving a transplant justify, at least in principle, significant sacrifices by the donor child.[1013] However, there is an important point to be made and that is that even if we recognise the existence of relational interests within a family, there remain certain interests that are individual-specific and the interest in bodily integrity is one of these: the healthy child has a fundamental interest in the preservation of his physical integrity and this can and must be separated from the child's other relational interests and from the interests of the parents and recipient.

5.4.4 A relational approach to the moral duty to donate

The connection between the moral duty to donate to family members and relational autonomy was explored in Chapter 3. Some considerations apply to children specifically and these are discussed here. The core argument of relational duties is that we should be expected to do things for family members we would not do for others.[1014] On this view, parents and children living under their care owe responsibilities toward each other that do not exist among members of society at large.[1015] However, critics note that different relationships within the family give rise to different obligations and interests and while a parent may feel a moral duty to donate an organ to a child, a sibling may feel differently: a

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183. See also Cressida Auckland and Imogen Goold Re-Evaluating 'Best Interests' in the Wake of *Raqeeb* v *Barts NHS Foundation Trust & Anors* 2020 83 The Modern Law Review 1328.

[1011] Aukland (n 1010).

[1012] Eekelaar Children beyond cultures (2004) 18 International Journal of Law Policy and Family 178.

[1013] Elliston (n 759).

[1014] Crouch and Elliott (n 338), 275-287

[1015] Morley (n 905),1244.

very young sibling may only have a basic understanding of family relationships, or an older sibling may have a different set of priorities and responsibilities.[1016]

The attribution of moral obligations to young children is questionable because even if they may be moral agents in other areas of day-to-day living, it is not clear how agency can be attributed for the purpose of donation when the choice to donate is not theirs to make and when they are too young to make the decision by themselves in the first place.[1017] Dwyer and Vig claim that the best interests standard ignores donor responsibilities to family members which are important aspects of various relationships.[1018] They develop the idea of a 'proper fit between risk and relationship' based on the premises that the strength of the family relationship may justify imposing risks, which may be significant in the case of parents towards their children although they accept only 'some risk' may be justified in the case of siblings.[1019] It is argued that the court's objective is to reach an outcome that allows the child to live as good a life as possible and, crucially, good life is taken to include the notions of altruism, meeting one's obligations, and relationality.[1020]

The underlying idea is that the child's interests remain paramount but the child's relationships with others are seen to be fundamental to the best interests assessment and these relationships are based on obligations.[1021] It is claimed that the best interests should take into account moral interests, as well as physical and psychological interests, and this means considering 'the injunction to do the right thing, all things considered' and taking into account the responsibilities to family members, which are an important aspect of relationships within the family and may justify imposing the risks of organ removal to the donor.[1022] Lyons argues that the language of moral obligations owed by children to their families is merely 'justificatory gloss' for what is essentially a consequentialist decision-

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[1016] Griner (n 275), 603; Cheyette (n 289).

[1017] Barry Lyons, 'Obliging children' (2011) 19 Medical Law Review 55, 71.

[1018] Dwyer and Vig (n 886), 11.

[1019] James Dwyer and Elizabeth Vig, ''Rethinking Transplantation Between Siblings,'' (1995) 25 The Hastings Center Report 7, 11.

[1020] Herring and Foster (n 928), 484.

[1021] Jonathan Herring and Charles Foster, 'Welfare Means Relationality, Virtue and Altruism' (2012) 32 Legal Studies 480, 498.

[1022] Lyons (n 944).

making process, with any justification being secondary to the recipient's need for a transplant.[1023]

Crucially, the obligations model does not explain why children, and not adults, should be obliged to donate. If we accept the claim that the natural duty to help others is grounded in the relationship with the other person[1024] and that this provides the justification for living donation, this should also apply to adults. The starting point, according to Lyons, is that 'all persons should be treated in a similar fashion unless there is a compelling reason to behave differently towards one group when compared with others'.[1025] The law regulating adult living donation does not presuppose a moral duty to donate. Donation is regarded as a personal decision and, as discussed in Chapter 3, the primary function of the legal and regulatory frameworks for living donation is to ensure the voluntariness of consent or authorization by excluding undue pressure and coercion. Of course, adults can and do feel bound by a moral duty to help a loved one, particularly if the recipient is their child. It is the role of the medical assessment team and the IA to explore perceived moral obligations and assess whether it compromises the voluntariness of the decision to donate. The separation of donor and recipient transplant team is required to ensure impartiality. The IA, on behalf of the HTA, assesses whether the legal requirements for transplantation are met and are under the duty to explore the donor candidate's understanding of donation and their motivations. The idea of moral obligations between family members is not used by the transplant team or the IA to encourage the donor towards donation and any assumptions made by the IA about a moral duty to donate would compromise their position as an objective and impartial actor.

Within the legal framework that applies to children, the position is different because if a moral obligation to donate is incorporated into the determination of the child's best interests, as Herring and Foster demand, there is a real risk that donation is considered to be in the interests of the donor *because* fulfilling their obligations towards a sibling is in their interests. We are effectively setting a moral standard that we do not require of others.[1026] We may accept that acting morally is an important part of human thriving and flourishing but it does not necessarily follow that the courts should approve donation

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[1023] Ibid., 89.

[1024] Dwyer and Vig (n 886).,11

[1025] Lyons (n 944), 84

[1026] Rebecca Pentz and others, 'Designing an Ethical Policy for Bone Marrow Donation by Minors and Others Lacking Capacity' (2004) 13 Cambridge Quarterly of Healthcare Ethics 149.

because allowing the child to do the right thing is in their best interests. Lyons aptly points out that the confusion lies in the crucial difference between ‘being under an obligation to do something’ and ‘being obliged to do something’: a moral obligation involves choice and requires agency to exercise that preference and the sanction for refusal of the obligation may be society’s disapproval, while being obliged to do something is premised on the notion that that thing will be done.[1027] It could be argued that the older child may have sufficient grasp of the circumstances to genuinely feel a sense of duty to donate. However, the point remains that a third party makes the assessment of whether a moral duty applies and how it is perceived by the child and the third party evaluates the relative weight of the obligation on behalf of the child.

Importantly, while it may be ethically desirable that the child who donates come to accept this obligation in time, this cannot be known with any degree of certainty at the time the decision is made by the courts. Retroactive approval by the adult-that-the-child-has-become of a decision made by his parents when he was a child has been used to provide retrospective justification for the decision.[1028] However, this amounts to self-justifying paternalism because the conditions within which the original choice was made are materially different to those available now to the grown adult and the effects of the decision itself are likely to have significant bearing on the adult's approval of the original choice.[1029] The child who donates a kidney to a sibling with good outcomes for the recipient and who resumes normal life will have a very different view about his participation in the transplant procedure from the child who suffers psychological or physical harm following surgery or the donor child who experiences a failed transplant procedure. Retroactive approval does not displace the fact that there is a fundamental difference between giving first person consent to donation and authorisation of organ removal by the courts with the agreement of parents.[1030] Risks may or may not materialise and their severity and impact upon the child donor vary from case to case. However, first person consent involves understanding that those risks may materialise and accepting sub-optimal outcomes such that even regret does not displace the initial assumption of responsibility for the consequences of the decision.

[1027] Lyons (n 944), 59 referring to HLA Hart, The Concept of Law (Clarendon Press, Oxford 1961) 77 and 80.

[1028] The idea of retroactive consent as justifying the unequal treatment of children is described in Samantha Brennan and Robert Noggle, ‘The Moral Status of Children: Children’s Rights, Parents’ Rights, and Family Justice’ (1997) 23 Social Theory and Practice 4.

[1029] Michael Austin, *Conceptions of Parenthood: Ethics and the Family* (Ashgate 2007), 67.

[1030] Ibid., 67.

5.4.5 Family interests and the donor child

The critique of the individualistic approach of the best interests formulation has generated increasing academic interest in the collective interests of the family.[1031] This approach concedes that children have separate interests as individuals but focuses on their interests as members of a family and in this sense, there is some common ground with relational interests.[1032] The balancing and reconciling of interests is seen as an intrinsic part of parenting and decisions about donation are taken to be the prerogative of parents, although not of third parties.[1033] Savulescu refers to this parental prerogative as 'distributing benefits and burdens within a family'.[1034]

The concept of family interests resonates with the decision of the Court of Appeal in *Re T (Wardship: Medical Treatment)*[1035] to allow an appeal by the mother of a severely ill baby against the direction of the trial court under its inherent jurisdiction that her refusal to consent to a liver transplant for her child was unreasonable and contrary to medical advice and to the welfare of the child. The Court of Appeal held that the best interests of the baby were the primary consideration but that prolongation of life was not the sole objective of the court and that the impact of forcing the mother to deal with the consequences of major surgery on her child would not be in the best interests of the baby. The court articulated the unconventional interpretation that '[t]his mother and this child are one for the purpose of this unusual case'. Some commentators have expressed reservations over the intrafamilial principle[1036] in which the interests of several family members are 'poured into one pot'.[1037] Elliston is critical of this broad construction of the best interests on grounds that the child donor is being used as a means to an end.[1038] The potential for commodification and harm to the child also arises in the context of pre-implantation tissue typing used to conceive saviour siblings who, as direct tissue matches, are potential stem cell and bone marrow

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[1031] 'Scottish Law Commission, Report on the Legal Capacity and Responsibility' (1987); Lilian Edwards and Anne Griffiths, *Family Law* (1. publ, Green [u.a] 1997); Andrew Bainham, Honour thy Father and the Mother: Children's Rights and Children's Duties in Gillian Douglas and Leslie Sebba (eds), *Children's Rights and Traditional Values* (Ashgate/Dartmouth 1998).

[1032] Morley (n 905), 1243.

[1033] James Dwyer and Vig (n 886), 10.

[1034] Savulescu (n 894).

[1035] *Re T (A Minor) (Wardship: Medical Treatment)* [1997] 1 WLR 242.

[1036] See K Devolder, 'Preimplantation HLA Typing: Having Children to Save Our Loved Ones' (2005) 31 Journal of Medical Ethics 582.

[1037] Lisa Cherkassky, 'Children and the Doctrine of Substituted Judgement' (2014) 14 Medical Law International 213, 214.

[1038] Elliston (n 759).

donors for an existing sibling suffering from a life-threatening disease. In *Quintavalle* the House of Lords unanimously ruled that the practice of tissue typing could be authorised by the Human and Fertilisation and Embryology Authority.[1039] However, Taylor-Sands, defending the decision, argues that a framework in which the interests of the saviour children are pitted against those of their parents and existing siblings does not represent a complete or realistic picture of the interests at stake within the family unit.[1040] Collective family interests are at the core of inter-sibling donation because this is a 'shared enterprise' and these should be viewed 'in connection with, rather than in opposition to, the collective interests the child shares with his/her family'.[1041]

The family interests model has been used to support inter-sibling bone marrow donation in the Australian case of *Re Inaya*[1042] to allow a bone marrow harvest from a 13-month-old infant to her 7-month-old cousin. This appears to have been the rationale for the decision The judgment included statements from evidence presented by a clinical psychologist on the impact of the procedure on the child referring to the 'closely knit family'[1043] and alluding to a familial benefit that is difficult to reconcile with the traditional legal interpretation of best interests of the child, focused on the child's interests. The underlying principle seems to be that donation benefits the family as a whole and this, in turn, promotes the child's present and future wellbeing, allowing the child donor to serve his *own* ends so that the child is not treated simply as a means to advance the health interests of a sibling.[1044] While this case is not binding on the English courts, it represents an insight into the potential effects of judicial recognition of family relationships in the context of non-therapeutic interventions involving children.

Ross has developed an influential theory of decision-making in bone marrow and organ donation from children based on a model of 'Constrained Parental Authority and non-state interference'. This is part of a broader critique of the recognition of decisional rights of children and adolescents in medical decision-making[1045] and a rejection of the best interests

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[1039] *Quintavalle v Human Fertilisation and Embryology Authority* [2005] UKHL 28.

[1040] Michelle Taylor-Sands, 'Saviour Siblings and Collective Family Interests' (2010) 20 Monash Bioethics Review 12.1.

[1041] Ibid., 12.8.

[1042] *Re Inaya* (2007) 38 Fam LR 546.

[1043] Ibid., per J Cronin at [88]

[1044] Lainie Friedman Ross, 'Moral Grounding for the Participation of Children as Organ Donors' (1993) 21 Journal of Law, Medicine & Ethics 251.

[1045] Ibid.

principle. Broadly, the intimate relationship within the family is the legitimate basis for deference to parental rights[1046] and this justifies wide parental discretion in determining and implementing family goals and in pursuing their conception of the good life and promoting the child's well-being.[1047] On this view, the ethical permissibility of inter-sibling donation is not based on the risk/benefit calculation of the best interests of the child donor, rejected because it is indeterminate and does not allow parents to balance the interests of different family members, but is properly justified by parental authorization for the procedure on behalf of the child because 'it is in the interest of the family as a whole, of which the donor is a member, to prevent the sick child's death when help is available at a minor increase over minimal risk' and this does not presuppose any direct personal benefit to the child donor.[1048] Ross accepts that family interests may not be reducible to the interests of individual family members and these may be in conflict with each other; nevertheless parents must be allowed to make 'inter-familial trade-offs' and a set-back of interests of the child donor is acceptable.[1049] Nevertheless, parental discretion is constrained by the principle of respect for the person which prohibits actions which cause serious harm to the interests of children and places a duty upon parents to treat their children as an end-in-themselves, or at least the ends-they-will-become.[1050] Critics have rejected this approach claiming that there is an ethically significant difference between morally innocuous trade-offs, such as using family resources to promote the interests of one child, which inevitably limits the resources available to another child, and the trade-off involved in donation, which is clearly more radical as it involves promoting the interests of one child by pursuing an action which harms the other.[1051] In defence, Ross acknowledges that the right of parents to trade-off interests is not absolute, drawing the line at the 'basic needs' of the child and broadly distinguishing between two levels of risk to the child donor: (1) donation involving a minimal to minor increase over the minimal everyday risk to which children are inevitably exposed, which includes blood and bone marrow donation; and (2) donation which involves more than a minor increase over minimal risk, which includes organ donation.[1052] The distinction, by Ross's own admission is 'somewhat arbitrary'.[1053]

[1046] Ibid., 43.

[1047] Ibid., 107.

[1048] Ross, 'Health Care Decision making by Children Is It in Their Best Interest?' (n 355), 30, 31, and 41-45.

[1049] Lainie Friedman Ross, *Children, Families, and Health Care Decision Making* (Clarendon Press 1998) 43.

[1050] Lainie Friedman Ross, 'Justice for children: the child as an organ donor' (1994) 8 Bioethics 105, 110.

[1051] Robert Noggle, 'For the Benefit of Another: Children, Moral Decency, and Non-Therapeutic Medical Procedures' (2013) 25 HEC Forum 289, 295.

[1052] Ross, *Children, Families, and Health Care Decision Making* (n 976), 112.

Nonetheless, the fundamental elements of her theory that parents can authorise bone marrow donation even over the child's dissent[1054] are reflected in the current policy in England and Wales, at least as far as incompetent children are concerned. Instead, permission from the child is required for solid organ donation because surgery carries significant risk of irreversible harm, which may interfere with the child's long-term autonomy and ability to fulfil their own life plans, and does not fully respect the person that the child will become.[1055] The difficulty with assessments based on harm is that there is no consensus on thresholds for acceptable and unacceptable harm and the increased risk of kidney donation over bone marrow donation may be interpreted as negligible.[1056] It is important to examine what 'permission' means in this context: how this relates to the true wishes of the child who is able to form a preference and how a lack of objection, in the absence of assent is interpreted.

A fundamental element of the theory proposed by Ross is the critique that conferring decisional authority to children places too much emphasis on 'present-day-autonomy', which, because of the child's limited experience of the world, is not part of a 'well-conceived life plan' and does not allow them to make meaningful decisions.[1057] On this view, children should not be allowed to make decisive choices that could adversely affect their future options. The distinction between present-day autonomy and life-time autonomy becomes the basis for according wide discretion to parents in the pursuit of family goals which, it is accepted, may conflict with the interests of individual family members. However, while this distinction may hold true in more trivial cases, such as the child afraid of needles who refuses medication, caution should be exercised when using this to ground an unfettered right of parents to make decisions on behalf of their children. Campbell et al.,[1058] considering donation from a child to a parent, focus on how saving the life of the parent allows them to continue to provide 'critical guidance' to the young donor as they transition into adulthood and note that probable harm resulting from the death of a parent is far worse than the probable harm caused by organ removal.

[1053] Ibid., 112.

[1054] Ibid., 115, 117.

[1055] Ibid.

[1056] Robert Noggle, 'For the Benefit of Another: Children, Moral Decency, and Non-Therapeutic Medical Procedures' (2013) 25 HEC Forum 289.

[1057] Ross, 'Health Care Decision making by Children Is It in Their Best Interest?' (n 355), 42.

[1058] Campbell and others (n 638), 1647-1648.

The impact of healthcare decisions on the welfare of the whole family is important, nonetheless there remains a lack of consensus regarding what family interests are taken to mean. Baines identifies a weak and a strong conception of family interests. The weak or collective conception is based on an understanding of family interests as the combined individual interests of family members. On this view, the interests of different family members are taken into consideration when assessing the interests of a particular family member and sacrifice of the individual's interests may be permissible. According to a strong conception of family interests these go above and beyond the interests of individual members of the family.[1059] The family is conceived as 'an intimate arrangement with its own goals and purposes' that is inherently valuable and not merely of instrumental benefit to individual family members.[1060] A critique of the concept of family interests is beyond the remit of this discussion. However, decisions made for the child raise questions regarding the extent to which sacrifice is justifiable in the name of preserving or promoting family interests and how the benefit to the child of the sacrifice of his interests is calculated. It is not immediately obvious how family interests can be separated from the authority of parents to make decisions for their children. There is a natural imbalance of power within families due to the dependency of children upon their families for their psychological, emotional, and financial support. During this time, children live under the de facto authority of the family of which they are part.[1061] Schoeman distinguishes family interests from the interests of parents, although parents represent both, with no further elaboration.[1062] In practice, parents determine the content of family interests because they make decisions for their children, particularly young children, and also have a final say in many decisions involving older children, so a claim that decisions should be based on family interests can become a claim for strong parental authority over children, where parents see themselves as entitled to proceed with a course of action according to their own conception of good.[1063] Ross argues that parents, as representatives of the family's interests, may detach themselves from their own interests and parental decisions is influenced by the needs and interests of children.[1064] However, Baines rightly notes that this does not

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[1059] Ross, *Children, Families, and Health Care Decision Making* (n 976); F Schoeman, 'Parental Discretion and Children's Rights: Background and Implications for Medical Decision-Making' (1985) 10 Journal of Medicine and Philosophy 45; Julie Nelson, 'Taking Families Seriously' (1992) 22 The Hastings Center Report 6; Taylor-Sands (n 967).

[1060] Schoeman (n 986), 48-50. See also Nelson (n 986), 44.

[1061] Engelhardt (n 681), 500.

[1062] Ferdinand Schoeman, 'Rights of Children, Rights of Parents, and the Moral Basis of the Family' (1980) 91 Ethics 6, 19.

[1063] Baines (n 930), 168.

[1064] Ross, *Children, Families, and Health Care Decision Making* (n 976), 32-33.

guarantee that parents will act objectively or that they will properly consider the interests of a particular child.[1065]

In the absence of a court precedent on interfamilial donation of solid organs in English law, there is considerable uncertainty regarding the approach of the courts to the incorporation of family interests or interests of family members into the determination of the best interests of the child donor. What is clear is that respect for the developing autonomy of the child demands that the child's understanding of what donation entails and what transplantation is expected to achieve is thoroughly explored and that their wishes are established to the extent that they are able to express their views.

5.5 Persons under the age of 18 and medical decision-making in Scotland

5.5.1 Legal capacity in young adults of 16 and 17 years

I now turn to examine framework in Scotland for living donation involving children and start by briefly examining legal capacity. Scots law, following the Roman law, adopted a gradualist approach to the acquisition of legal capacity, reflecting the development of physical and mental capacities with increasing age and experience.[1066] Broadly, pupils (boys below 14 years and girls below 12 years) had no legal capacity and minors (children above pupillarity but below majority)[1067] were accorded full legal capacity subject, for most acts, to the requirement of the agreement of their curators.[1068] These rules were reformed by the Age of Legal Capacity (Scotland) Act 1991 and under s.1(1)(b) a person of or over the age of 16 years has legal capacity to enter into any transaction. These transactions are valid and binding.[1069] The cut-off was intended to create a two-tiered system establishing that persons under the age of 16 years generally have no legal capacity, except for specific

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[1065] Baines (n 930).

[1066] Norrie and Wilkinson (n 735) [5.02].

[1067] Originally 21 years, then 18 years following the enactment of the Age of Majority (Scotland) Act 1969 s.1.

[1068] Norrie and Wilkinson (n 735) [5.02].

[1069] Ibid., [5.12].

circumstances,[1070] while young persons aged 16 and 17 have full legal capacity to enter into binding transactions.[1071] The Scottish Law Commission deemed the age of 16 to be a threshold reflecting social reality and differentiating those who needed special protection because of immaturity and those who did not.[1072] The 'lifespan' of parental rights and responsibilities under the C(Scotland)A 1995 is consistent with this threshold, as all parental rights cease when the child reaches 16 years of age and parents retain only a responsibility to provide guidance[1073] until the age of 18. This means that they do not have a right to make choices for their child beyond the age of 16 years.

Limited protection against relative immaturity is offered under s.3(1) which allows persons under the age of 21 years to apply for an order to set aside a prejudicial transaction in which the person entered at 16 or 17 years of age. However, s.3(3) states that this does not apply to the giving of consent to any surgical, medical or dental procedure or treatment. It follows, that in the healthcare context in Scotland, adulthood is effectively reached at the age of 16 when young persons may give consent to treatment or interventions and parents do not have the power to consent for them or override their wishes.[1074] With regards to the position of the Scottish courts, it seems highly unlikely that the court could exercise authority over a person of 16 or 17 years, even via the *nobile officium*, as the basis of modern law is that the person over 16 is *sui juris.*[1075] Where capacity is disputed in persons of 16 years or over, this is assessed under the AWI(Scotland) Act 2000 and decisional authority is removed from the young person where incapacity is established.

5.5.2 Legal capacity in children under 16 years

In Scotland, the concept of Gillick competence is captured by s.2(4) of the Age of Legal Capacity (Scotland) Act 1991, which provides that a person under the age of 16 years may give valid consent to any medical, surgical or dental procedures or treatment:

[1070] These include the legal capacity to make testaments (s.2(2)) or to consent to the making of an adoption order in relation to the child himself (s.2(3)), where the child has attained the age of 12. At this age, there is also a presumption of capacity to instruct solicitors in relation to civil matters (s.4A).

[1071] Age of Legal Capacity (Scotland) Bill HL Deb 01 July 1991 vol 530 cc866 per Lord Macaulay of Bragar.

[1072] Report on the Legal Capacity and Responsibility of Minors and Pupils, Scot. Law Com. No.110 (1987) [3.5] and [3.19].

[1073] s.1(1)(b)(ii).

[1074] Norrie and Wilkinson (n 735) [5.16].

[1075] Anne Griffiths, Frankie McCarthy, and John M Fotheringham, *Family Law* (4th edn. W Green, Thomson Reuters 2015), 4-40 .

> where, in the opinion of a qualified medical practitioner attending him, he is capable of understanding the nature and possible consequences of the procedure or treatment.[1076]

The 1987 Report of the Scottish Law Commission,[1077] which in the area of consent to healthcare interventions was accepted and enacted with no changes,[1078] clarifies that the expression 'any medical, surgical or dental procedures or treatment' was deliberately chosen to cover non-therapeutic procedures, including blood donation, non-essential surgery, and preventive medical procedures, taking the approach that the nature of these procedures does not affect the validity of the child's consent, although ethical considerations may preclude their use.[1079] Importantly, the assessment of capacity is a matter of professional judgment for the medical practitioner. The use of an objective legal test (that the child understands the proposed intervention rather than is believed to understand) was rejected by the Scottish Law Commission on grounds that it imposed too great an onus on the doctor assessing the child's understanding, leaving medical professionals open to liability where a court subsequently came to a different view regarding the maturity of the child and that treatment would be reluctantly provided except for the uncontroversial cases.[1080]

Nevertheless, the requisite under s.2(4) that the child understands the 'possible consequences' of the procedure, and, as Elliston[1081] notes, the Scottish Law Commission's explicit approval of the judgment of Lord Scarman in *Gillick*, supports a requirement for an understanding of the broader implications of the medical procedure, beyond the technicalities of the procedure itself. In this sense, *Gillick* is recognised as highly influential in Scots law. Nevertheless, following extensive consultation the Scottish Law Commission explicitly rejected Lord Fraser's requirement for the intervention to be in the best interests of the child on the basis that this has 'no bearing' on the question of consent

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[1076] Age of Legal Capacity (Scotland) Act 1991 s.2(4).

[1077] Scottish Law Commission, *Report on the Legal Capacity and Responsibility of Minors and Pupils* (HMSO 1987).

[1078] Para 3.83 sets out the Scottish Law Commission's recommendation:

> 'Without prejudice to the existing law and practice regarding the provision of treatment without consent, a person below the age of 16 should have capacity to consent to any surgical, medical or dental procedure or treatment if, in the opinion of a qualified medical practitioner attending that person, he is capable of understanding the nature and consequences of the treatment proposed'.

See also Sarah Elliston (n 759), 83.

[1079] Scottish Law Commission (n 1003).

[1080] Ibid., [3.72]-[3.73].

[1081] Elliston (n 759), 83.

and if a child was deemed to have sufficient maturity then it did not matter whether the treatment was for his benefit or not.[1082] Norrie notes that 'once the child has satisfied the maturity condition, there is nothing more that can be demanded of the child'[1083] and that the absence of any requirement that the procedure be in the child's best interests or promote in any way the child's welfare is coherent because the law should allow the child who understands the procedure and the risks involved to determine for himself whether to take the risk.[1084]

The matter of treatment refusal has not been authoritatively decided by the Scottish courts and cases decided in the English courts are not automatically binding upon the Scottish courts and must be interpreted according to the principles of Scots law. In the healthcare context, any right which a parent may claim to exercise in relation to his child must be covered by s.2 of the C(Scotland) Act 1995 and must be directed towards the achievement of parental responsibilities.[1085] In Norrie's view, this right does not comfortably fall within the right to control, direct or guide the child's upbringing[1086] but is more accurately a parental right of legal representation under s.1(1)(d), the legal representative having the power to give consent to any legal transaction.[1087] The effect of s.2(4) of the Age of Legal Capacity (Scotland) Act 1991 on parental rights and responsibilities, specifically as part of the overall responsibility to safeguard and promote the child's health, development and welfare, must be interpreted in light of the C(Scotland) Act 1995.[1088] Accordingly, once a child acquires capacity to consent under s.2(4), the child can make their own decisions regarding treatment, including the right to refuse, even when this treatment is, objectively, in the interests of the child.[1089] The child acquires the right to override parental wishes once they have sufficient capacity to perform a legal transaction on their own behalf under s.2(4) because at this point parents have no right under the C(Scotland) A 1995 to act as the child's legal representative and consent to treatment.[1090] This interpretation is consistent with the Scottish case of *Houston,*[1091] which concerned an application for compulsory

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[1082] Scottish Law Commission (n 1003).

[1083] Elliston (n 759), 83.

[1084] Norrie and Wilkinson (n 735) [5.10].

[1085] Set out in s.1 C(S)A 1991. Norrie and Wilkinson (n 735) [7.23].

[1086] Children (Scotland) Act 1995 s.2(1)(c).

[1087] Children (Scotland) Act 1995 s.15(5).

[1088] Norrie and Wilkinson (n 735) [7.31].

[1089] Ibid. ,[7.31].

[1090] Ibid., [7.1].

[1091] *Houston, Applicant* 1996 SCLR 943, Sh Ct.

detention in hospital of a 15-year old mentally ill patient who was capable of understanding the nature and possible consequences of treatment but refused treatment. The court did not rule on the mother's authority to give consent and override the refusal of the competent child. However, both parties were in agreement that the right of a capable child to refuse treatment was intrinsic in the right to consent and Sheriff McGowan noted that the minor's decision is paramount, accepting this point of law as the logical conclusion, unfortunately, with no further discussion.[1092] It is difficult to make any definitive conclusion on the position in Scots law on the authority of parents to override a competent child's decision to refuse treatment, as this point is obiter in *Houston* and the case itself was at first instance. The case of *V v F,*[1093] in which the court authorised treatment against the wishes of a 15-year-old girl with depression, on the basis of parental consent, has little value as precedent as it was decided before s.2(4) of the Age of Legal Capacity(Scotland) Act 1991 came into force and it was not clear from the report whether the girl was competent. Although the question of persisting parental rights has not been definitively settled by the courts, there is no justification under s.2(4) for these rights once the child reaches capacity.

The question of whether the Scottish courts have the power to override a competent child's refusal of treatment remains controversial.[1094] There is currently no court authority in Scotland on this point, as *Houston*[1095] concerned the question of whether the treatment should be given under a s.18 order of the Mental Health (Scotland) Act 1984, in which the consent of the person is irrelevant. There is support for the proposition that the position in Scots law is different to that in English law and that the right to consent subsumes a right to refuse treatment because this is the logical implication of consent being recognised as an important aspect of individual autonomy.[1096] There are of course valid arguments in support of court intervention on grounds that the paramount consideration for the courts is the welfare of the child,[1097] particularly where refusal is life-threatening.[1098] However,

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[1092] Ibid., at [945].

[1093] 1991 SCLR 225.

[1094] Elliston (n 759), 114-115.

[1095] *Houston, Applicant* 1996 SCLR 943, Sh Ct.

[1096] James Dalrymple Stair and Law Society of Scotland (eds), *The Laws of Scotland: Stair Memorial Encyclopaedia* (Reissue [ed], Law Society of Scotland: Butterworths 1999) [278].

[1097] Graheme Laurie and Emily Postan, 'Rhetoric or Reality: What is the legal status of the consent form in hralth related research?' (2013) 21 Medical Law Review 371, 142; John Kenyon Mason and Graheme Laurie, 'Consent or Property? Dealing with the Body and Its Parts in the Shadow of Bristol and Alder Hey' (2001) 64 Modern Law Review 710; Lilian Edwards and Anne Griffiths, *Family Law* (1. publ, Green [u.a] 1997) [2.33].

Elliston notes that the application of the inherent jurisdiction to children remains uncertain and, in any event, is unlikely to be used.[1099] It is likely that Scottish courts retain jurisdiction to decide on a course of action where the views of the parent and the child are in conflict, on the basis of the right to make an order in relation to parental responsibilities and parental rights under s.11(1) of the C(Scotland)A 1995 until the child reaches 16 years.[1100] At the same time, there is a strong argument against the overriding of the child's wishes on grounds that the Scottish Law Commission explicitly rejected the best interests approach to capacity[1101] and that, where a child is considered to have capacity to consent, a welfare approach not only is not warranted but cannot be justified, as it entails the application of an age-based principle (welfare) which does not equally apply to adults.[1102]

5.5.3 Incapacity and the child

Where the child does not have the required capacity to consent,[1103] medical treatment can proceed on the basis of the consent of the person with parental responsibility for the child.[1104] Parents are under a duty to promote the child's health, development and welfare under s.1(1)(a) of the C(Scotland)A 1995. Unlike the flourishing jurisprudence in England and Wales, there is limited Scottish case law to guide the exercise of parental authority over a child who lacks capacity to make his own healthcare decisions.[1105] The issue of the powers of the court to override parental wishes where parents do not fulfil their responsibilities arose obliquely in *Docherty v McGlynn,*[1106] involving the question of consent to blood tests of the child in an action to establish paternity. In *Finlayson, Applicant,*[1107] the parents of a 9-year-old child with severe haemophilia refused a blood transfusion, due to fear of HIV infection, preferring homeopathic remedies. The parents were found not to be acting in the best interests of their child, despite their genuine concern for his well-being, and compulsory measures were ordered to treat the child. In all major

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[1098] Jane Blackie, *Mental Health: The Law in Scotland.* (Butterworths Law 2005) [11.20].

[1099] Elliston (n 759), 12.

[1100] Griffiths, McCarthy and Fotheringham (n 1002). p 28-29

[1101] _'Scottish Law Commission - 1987 - Report on the Legal Capacity and Responsibility'; Lilian Edwards and Anne MO Griffiths, *Family Law* (1. publ, Green [u.a] 1997).

[1102] Elliston (n 759)., 91.

[1103] Under the Age of Legal Capacity (Scotland) Act 1991 s.2(4).

[1104] Norrie and Wilkinson (n 735) [7.29].

[1105] Ibid., [7.29].

[1106] 1983 S.L.T. 645.

[1107] Finlayson Petr 1989 SCLR 601.

healthcare decisions, parents have a duty under s.6(1) of the C(Scotland)A 1995 to consider, as far as practicable, the child's views, taking into account the child's age and maturity. While this provision is not legally enforceable, if the matter became the subject of legal proceedings, the courts have a duty under s.11(7)(b) to accord the child the entitlement to express their views and take these views into account. There is no reported Scottish case law on decisions where treatment will result in the shortening of the child's life. Norrie[1108] maintains that the Scottish courts would follow the welfare approach of the English courts. As discussed above, the Scottish courts are under a duty to allow the child to express their view, have due regard for their wishes, and justify overriding the wishes of the child aged over 12 years.

5.6 The legal and regulatory framework in Scotland:

5.6.1 The prohibition on living donation from children

Paragraph 17 of the Policy Memorandum on the Human Tissue (Scotland) Bill states that the prohibition on the removal of an organ or non-regenerative tissue from a living child for the purpose of transplantation is in force for the 'protection of the position of children'.[1109] Different age thresholds for the prohibition of living donation have been proposed and amply discussed in the ethico-legal literature.[1110] These broadly correlate with a particular view of the cognitive and emotional development of the child. The threshold of 16 years under the HT(Scotland)A 2006 and the Live Transplants (Scotland) Regulations 2006 corresponds to the achievement of adulthood in Scots law in the context of health decisions, the underlying principle being that the state should not intervene to shield adults with capacity from bad decisions.

The vulnerability of children and the need to protect them emerged as the underlying concern in the Scottish Parliament debates on the Human Tissue (Scotland) Bill. Broadly, there are three strands to the opposition to the use of organs of a child for transplantation: that the child's long-term health interests could be compromised by a decision that is made

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[1108] Norrie and Wilkinson (n 735). para 7.30. See also Earle and Whitty, Stair and Law Society of Scotland (n 1022) [368].

[1109] Human Tissue (Scotland) Bill Policy Memorandum [17].

[1110] See 'My sister's keeper?: Law, Children and Compelled Donation' (n 303); Nicole Hebert, 'Creating a life to save a life: an issue inadequately addressed by the current legal framework under which minors are permitted to donate tissue and organs' 17 Southern California Interdisciplinary Law Journal 44, 375.

while their body is still developing";[1111] that the child could be coerced or pressured too easily in a 'closed and emotional family situation';[1112] and the concern over the pressure that children would be put through if they decided not to proceed with donation, particularly if the recipient died.[1113] Interestingly, none of the views expressed in the course of the debates in the Scottish Parliament explicitly negates the child's capacity to consent to donation.

On the first view, subjecting a child to physical harm and unknown long-term health risks for no direct therapeutic benefit is regarded as ethically unacceptable, irrespective of the child's capacity to understand the process of donation and its consequences or of the child's willingness to donate an organ. This position does not allow for any consideration of non-medical benefits which may be important to the child and may make the risk-benefit balance of the procedure acceptable to a particular child. The focus appears to be on the certain physical harm of organ removal rather than on any psychological harm to the child which may result from the loss of a close family member. Serious physical harm is an intrinsic and inevitable part of the procedure and the long-term effects of surgery remain undetermined as even with kidney donation, where kidney resection is a technically straightforward procedure, there is a paucity of long-term studies on the risk of developing renal failure among donors.[1114] The evidence on the long-term risks for young donors is even more limited. Partial liver resection is associated with higher peri-operative morbidity and mortality.[1115] The view that, in the absence of solid long-term data, exposing children to an unquantifiable but serious physical risk is not ethically acceptable cannot be set aside easily. This is a compelling argument, although it should be noted that the risk is not solely applicable to persons under the age of 16 years: the young adult of 16, 18 or 21 years is equally exposed to physical harm and the long-term risks are equally uncertain, as discussed in Chapter 3. Here, I do not seek to establish whether the age threshold of 16 years is justifiable or whether another threshold is preferable. My remit is limited to the

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[1111] Lewis Macdonald (Deputy Minister for Health and Community Care), Human Tissue (Scotland) Bill Health Committee 25 October 2005.

[1112] Roseanna Cunningham Plenary Session 30 November 2005; Nanette Milne, Plenary Session 30 November 2005; Lewis MacDonald (The Deputy Minister for Health and Community Care) Plenary Session 30 November 2005.

[1113] Human Tissue (Scotland) Bill Health Committee 3 October 2005, Kate Maclean

[1114] Geir Mjøen and others, 'Long-Term Risks for Kidney Donors' (2014) 86 Kidney International 162; Abimereki Muzaale and others, 'Risk of End-Stage Renal Disease Following Live Kidney Donation' (2014) 311 Journal of the American Medical Association 579.

[1115] Singer and others (n 170).

question of whether the absolute prohibition of donation from children reflects a particular account of autonomy.

On the second view, the prohibition is justified by concerns about the voluntariness of decisions made by children, which is also independent of the child's capacity to understand the procedure and its risks. The voluntariness of decisions made by children, particularly young children who are heavily dependent on their parents, is a legitimate concern. While feelings of guilt may affect any person who feels they do not want to proceed with donation, the fear that refusing to donate to a family member will jeopardise parental love and affection is a real concern among children. This may drive children, more than adults, to comply with the wishes of their parents because of the dependency on their parents and on their parent's approval. However, again, undue pressure from family members affects 14-year-olds, 15-year-olds who are approaching adulthood and 16-year-olds who are classed as adults,[1116] many of whom are still living with and are economically dependent on their parents. It could be argued that concerns regarding the voluntariness of a decision to donate are more properly addressed by optimising the effectiveness of the scrutiny of the young donor's personal circumstances to ensure that transplantation proceeds only in cases where consent is freely given. Even if it were accepted that undue pressure cannot be adequately identified and that, on balance, the harm caused by allowing donation where the choice is not truly voluntary is greater than the harm resulting from an indiscriminate and absolute restriction of the decision-making rights of children, the policy inadequately responds to the problem. The prohibition up to the age of 16 offers no protection to young adults who may display the rational and cognitive capacities of an older adult but are nonetheless vulnerable to pressure from their families because of their psychological, emotional, and financial dependence on their parents. Resilience to pressure and feelings of guilt may be more difficult to achieve than where individuals are more self-sufficient and have lives out with the immediate family nucleus.

The third view endorses the prohibition on grounds that adequate procedural safeguards cannot prevent the psychological impact on children who choose not to donate, and the state should protect them from having to make the decision to donate in the first place.[1117] This view appears to be the key reason for the Health Committee's support for the

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[1116] Sheila McLean and Sarah Elliston; Written Evidence Submission from Independent Review Group On The Retention Of Organs At Post-Mortem to the Health Committee, 8 September 2005.

[1117] Human Tissue (Scotland) Bill Health Committee 3 October 2005, see Kate Maclean.

prohibition of living donation involving child donors.[1118] It reflects a concern for the well-being of all children drawn into this complex decision-making process and seeks to prevent any psychological harm to those who do not wish to donate: the prohibition removes altogether the element of personal responsibility for the failure to help. However, it could be argued that young children may be less vulnerable to feelings of guilt for failing to donate because of limited grasp of the circumstances while the age threshold of 16 fails to protect older teenagers who are likely to be fully aware of the repercussions of refusing to donate and, because of this insight, are particularly vulnerable to feelings of blame and guilt.

What appears clear is that in Scotland, the law is based on the presumption that welfare concerns necessarily override any interest that a particular child may have in donating an organ, including to an ill sibling, irrespective of whether the child has the required capacity to make the decision.[1119] The prohibition on organ donation raises the question of how a limitation on the type of risk to which children are permitted to agree can be consistent with the view that competence confers upon the child the right to make any healthcare choice, even one which may be seen as detrimental to their interests. Denying competent children the legal rights enjoyed by adults may be excessively restrictive[1120] and the fact that any absolute prohibition would mean that the capacity of the child is not interpreted or regarded in a way that is consistent with the Age of Legal Capacity (Scotland) Act 1991 was raised in the parliamentary debates.[1121] However, there was no reference to any autonomy interests of the child or explanation for why organ donation specifically, justifies a different approach when, in the broader medical context, the law grants minors, who can demonstrate maturity, a high degree of self-determination in making decisions for themselves even when these are not in their interests. If, in the opinion of a medical professional, the child is capable of understanding the transplant procedure and the

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[1118] Health Committee 19th Report, 2005 (Session 2) Stage 1 Report of the Human Tissue (Scotland) Bill [118].

[1119] Jennifer Robbennolt, Victoria Weisz, and Craig M Lawson, 'Advancing the rights of children and adolescents to be altruistic: bone marrow donation by minors' 9 Journal of Law and Health 35, 213.

[1120] Sheila McLean and Sarah Elliston; Written Evidence Submission from Independent Review Group On The Retention Of Organs At Post-Mortem to the Health Committee, 8 September 2005. The prohibition was also challenged by Alison Whiting on behalf of the General Medical Council in 27 September 2005 – Supplementary Written Evidence. The British Medical Association changed its position on live donation by children in the course of the passage of the Bill: following a BMA Ethics Committee review in September 2005, the BMA endorsed live donation from competent children under 16 years of age (it had previously supported an absolute prohibition on donation from all persons under 16 years).

[1121] Sheila McLean, Human Tissue (Scotland) Bill Health Committee, 8 September 2005.

possible consequences of organ donation, the normal application of s.2(4) would allow the child to give valid consent to organ removal.[1122]

Furthermore, despite the fact that legislation was brought in force in 2006, there was no discussion about how an absolute prohibition would affect the participatory rights of the child under the UNCRC that are directly incorporated into the C(Scotland)A 1995, specifically the right of the child to have their views taken into account on matters of importance which affect them. Genuine respect for the developing autonomy of the child means engaging the child in these decisions and allowing them to make choices according to their ability. These are issues which will become even more pressing in Scotland when full incorporation of the UNCRC has been accomplished.

It is important to consider whether, from a procedural perspective, the Scottish courts would have the power to regulate decisions to donate if the procedure were allowed on an ad hoc basis as under English law. The assessment of competence is a matter of opinion of the medical professional with little remit for intervention by the courts unless the grounds for the opinion of the medical professional are challenged. As discussed above, the use of the court's inherent jurisdiction to override the decision of a competent child to donate under Scots law is less certain than under English law[1123] and where parents support the child's decision to donate and the child willingly agrees to donate, this route appears doubtful. However, in the event of disagreement between parents and their child regarding the decision of the child to donate, the Scottish courts would have jurisdiction to make an order under s.11(1) of the C(Scotland)A 1995.[1124]

The only basis for overriding the decision of the child to donate is that the welfare of the child would be compromised by donation yet this goes against the clear rejection of the best interests approach to the determination of capacity in Scots Law and the understanding that capacity confers decisional authority to the child which is due the same respect as with adults. The incoherence is not easily resolved in the absence of a review of the definition of competence under the Age of Legal Capacity (Scotland) Act 1991. Mclean argues that if the legal community genuinely regards a child as legally competent,

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[1122] Kristof Van Assche and others, 'Living Tissue and Organ Donation by Minors: Suggestions to Improve the Regulatory Framework in Europe' (2016) 16 Medical Law International 58; Mason and Laurie (n 1023).

[1123] Elliston (n 679), 12.

[1124] Griffiths, McCarthy and Fotheringham (n 1002).

it is difficult to justify 'second guessing' their decision.[1125] The Scottish Law Commission, in its *Report on Legal Capacity and Responsibility of Minors and Pupils* stated that 'moral and ethical considerations may rule out a particular medical procedure', citing experimental surgery as an example, but that this would not affect the validity of the patient's consent.[1126] The difficulty with this position is that declaring consent valid, while imposing a statutory prohibition on living donation, is inconsistent with the understanding of what capacity to consent actually means. I maintain that if capacity entails taking responsibility for the consequences and the risks of a decision, a statutory prohibition to protect the child from harm embraces the paternalism of the best interests rationale rejected by the Scottish legal system in the first place.

It is not clear that the statutory prohibition on living donation from children incorporates the concerns about the welfare of the child, the UNCR participatory rights of the child recognised under the C(Scotland)A 1995, and the rejection of a best interests approach to consent to medical treatment into a cohesive and justifiable policy. What is clear, in my view, is that the prohibition in Scotland on living donation of organs from children rejects all arguments for a relational interpretation of the donor's well-being to justify the removal of a solid organ: the healthy child is detached from the needs and well-being of the recipient and their interests are not merged with the interests of different family members or conceived as part of family interests.

With regards to the immature child, the prohibition responds to the ethical concern of those who argue that incompetent persons can only be sources of organs and not donors and who regard the use of organs from children as a decision driven by the interests of the recipient in violation of bodily integrity rights which are unequivocally granted to competent adults irrespective of the needs of other persons or of the psychosocial bond with the recipient.[1127] On this view, case-by-case adjudication by the courts, as in England and Wales, are inherently flawed because they substitute the views and consent of a third-party decision maker for the views and consent of the child whose organ will be removed.[1128] The fact that the decision maker is an impartial member of the judiciary is ethically irrelevant: the harm is done when substitute decision makers make the kind of intensely private decision on

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[1125] McLean (1146).

[1126] Scottish Law Commission (n 1003). No 110, [3.78].

[1127] Cheyette (n 387), 495.

[1128] Ibid., 510.

behalf of an incompetent party that few would suggest ought to be made on behalf of a competent individual.[1129]

The reasons for which individuals do not come forward to donate an organ to a significant other are complex and personal and cannot be explored fully here. What is clear is that a genuine wish to donate to a loved one and a resolve to be a living donor cannot be assumed from a strong emotional or biological relationship with the person in need of a transplant. Substitute decision making on behalf of the child is necessarily based on assumptions and these may be mistaken. I argue that the prohibition on living organ donation from incompetent children should be properly understood as paternalism directed towards the preservation of the child’s right to an open future, protecting the child from choices made by third parties which could compromise their future choices and future autonomy. It is important to recognise that a decision by the courts and the HTA not to approve donation is not a neutral preservation of the status quo but a decision in itself which has consequences because prolonged illness or death of the person in need of an organ will affect the future choices and future autonomy of the developing child in some way, at least when they become aware that donation was an option. However, a prohibition on donation from all children removes the personal responsibility attached to the decision by taking away the possibility of a choice altogether. In my view, the prohibition does not necessarily deny the existence of relational interests of the child within the family unit but it circumvents the use of relational interests – specifically, the assumption that transplantation will benefit the donor child and/or the imposition of a moral obligation to help a family member – as grounds for justifying donation where the child does not have sufficient understanding of the process to be able to make a decision by themselves.

5.6.2 Decision-making powers of 16- and 17-year-olds

The threshold for the definition of a child in Scotland establishes a key difference with the living donation regulatory framework in England and Wales because in Scotland, 16- and 17-year-old prospective organ donors are considered adults. This has important consequences in terms of the restrictions which can legitimately be imposed on the decision of older teenagers to donate. Firstly, all parental rights cease when the child reaches 16 years of age and parents retain only a responsibility to provide direction until the age of 18.[1130] While parents would legitimately be expected to express their views and

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[1129] Griner (n 895).

[1130] Children (Scotland) Act 1995 s.1(1)(b)(i) and s.1(2)(a).

discuss the donation process, they do not have the authority to make a decision regarding organ donation on behalf of their 16- or 17- year-old child. Their role in a young person's decision to donate would be scrutinised as part of the assessment process to identify any undue influence, as with adult donors; conversely, parents objecting to donation would not have the legal authority to override their child's decision to donate. Secondly, while there is no legal precedent in Scotland, it seems unlikely that the courts could override the decision to donate of a 16- or 17-year-old who has capacity under the AWI(Scotland)A 2000, in the absence of undue influence, coercion or reward. Adopting a similar approach to the MCA 2005, a finding of capacity does not require the depth of understanding set out by Lord Scarman or that the intervention is in the person's best interests.

The AWI(Scotland)A 2000 provides greater scope to separate the assessment of capacity from the content of the decision. Importantly, there are no requirements regarding how information, once understood, should be balanced to reach a decision. Therefore, the young person, as the adult, is entitled to accept or even disregard the risks of organ removal and prioritise other factors, such as saving the life of a family member. Furthermore, as discussed above, there is a statutory duty to facilitate independent decision making as far as possible and under s.1(6) all reasonable efforts to communicate with the person in an appropriate way should be made before arriving at a decision on incapacity. If the young person lacks capacity, living donation may not proceed as the donor would be classified as an adult with incapacity and transplantation would be unlawful under the HT(Scotland)A 2006. Once capacity is demonstrated the young person has the statutory right to make the decision and like an adult may donate to an emotionally or biologically related person or to a stranger. In this sense, the decisional authority of young persons is significantly greater than that of their counterparts in England and Wales as they are granted full rights of self-determination with no requirement for court approval.

The procedural requirements for HTA approval of applications for living donation in Scotland are set out by the HTA in the document entitled 'Guidance for transplant teams, Independent Assessors and Accredited Assessors in Scotland'[1131] (hereafter HTA Guidance document for Scotland). These have been discussed in Chapter 3 and involve an interview and a report by the IA. The referring clinician is required to confirm that the donor has capacity to authorise the donation under s.1(6) of the AWI(Scotland) A 2000 and this is a matter of opinion. The IA's report for the HTA must include the information provided to

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[1131] HTA 2017 Guidance for Transplant Teams and Independent Assessors' (n 182).

the prospective donor regarding donation and confirmation that the young person has the capacity to understand the nature of the surgical procedure and the risks involved in organ removal and any 'wider relevant implications arising from the intended donation'.[1132] The HTA interprets this to mean that the prospective donor has taken into account the effect on any children or dependent relatives. Whether these 'wider implications' may be interpreted more broadly to include a more onerous threshold for capacity remains to be seen. However, when a finding of capacity is made by the relevant medical professional, according to the statutory definition of incapacity, there appears to be limited scope for the HTA, which does not routinely interview the prospective donor, to reach a different conclusion using a more onerous definition of capacity than that defined by statute.

Organ resection causes serious physical harm to the healthy donor and there remains considerable uncertainty surrounding the long-term health risks of donation on young persons who are normally expected to live a full and long life. This raises important questions about whether granting 16- and 17-year-olds absolute self-determination in decisions to become living donors offers adequate protection to young persons. Of course, a limitation of the use of an age threshold for capacity in law is that age groups with comparable characteristics and circumstances at either side of the age threshold are treated differently. This thesis does not seek to determine whether the current age thresholds in different UK jurisdictions are ethically defensible. A young person may have the legal capacity to consent to donation because they can demonstrate the cognitive ability to understand the procedure and the risks and consequences of surgery. Nonetheless, their reliance on their parents for support combined with their developing psychosocial skills[1133] and limited life experience raise important ethical concerns. Firstly, concerns about the ability of the young person to make a normative judgment about the situation they face and come to a decision that is authentic, well-reflected, and based on settled values and moral principles they genuinely endorse. Second, concerns about the young person's ability to deal with the expectation to donate.

I will now discuss the vulnerability of the young person in the context of donation to a family member, a friend, a stranger, and a connection made through social media. Where a family member needs an organ transplant and there is a clear emotional connection with the recipient, it remains imperative to scrutinise the application to ensure that the young

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[1132] 'HTA 2017 Guidance for Transplant Teams and Independent Assessors' (n 182).

[1133] Laura Capitaine and others, 'Should Minors Be Considered as Potential Living Liver Donors?: Ethics of Living Liver Donation by Minors' (2013) 19 Liver Transplantation 649, 652.

person is making the decision freely and not as a result of undue pressure or coercion from the family. A crucial role of the HTA, through the IA interview, is to 'make a judgement on whether the will of the donor has been overborne such that they can no longer make an independent decision'[1134] while recognising that young persons will have achieved sufficient maturity to be aware of moral obligations towards family members. Rigorous donor assessment processes, including psychosocial assessment of the donor, are in place and their role includes identifying and exploring uncertainty and reluctance to donate. The law treats 16- and 17-year-olds as adults yet in many cases they will be living with their parents and be financially dependent on them, potentially for a number of years, with limited alternatives. While financial dependence and similar home circumstances may also apply to a mature adult partner, younger donors with more limited life experience may lack resilience as they are less likely to have the skills to respond to the pressure to donate and deal with the psychological consequences of not donating to a sibling or another family member.

The use of a solid organ from a young person for transplantation to a friend is also potentially controversial. On one hand, it is argued that it is the strength of the connection between donor and recipient that is ethically relevant and that a biological relationship is not a pre-requisite for a close emotional bond and provides no assurances that the bond will endure in the future.[1135] However, adolescence is a phase of emotional and psycho-social development, characterised by significant shifts in opinions and feelings and critics highlight that while adolescents may display cognitive capacity comparable to adults, psychosocial maturity is attained later.[1136] Important elements of psychosocial maturity are risk evaluation and future orientation, with young persons being more tolerant of the unknown and more focused on the short-term consequences of their actions than adults.[1137] This means that there is a real possibility that a young donor will, in time, reconsider the motivation for donation and view matters differently. Change is an intrinsic and inevitable part of life, including adult life, and donation policies cannot account for the transience of relationships and the fluctuating boundaries of personhood and individual morality. Nevertheless, when considering commitment to help a loved one, it is fair to say that the premises for donation to a partner with whom one shares a home and perhaps a family are more likely to endure in time, even where the relationship breaks down, than those where

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[1134] 'HTA Guidance for Transplant Teams and IAs and AAs in Scotland' (n 184) [80].

[1135] Capitaine and others (n 1062).

[1136] Ibid.

[1137] Ibid.

the donor is a 16-year-old donating to a best friend from school. There will always be exceptions, although the greater degree of uncertainty with young persons generally, coupled with the physical harm and unknown long-term risks of the procedure for a person who is expected to have a full life ahead, single out young donors as a potentially vulnerable group.

The ethical acceptability of living organ donation from a young person where the recipient is a stranger or where there is no pre-existing relationship with the recipient is controversial. As adults, 16- and 17-year-olds in Scotland may donate a kidney organ to a stranger on the waiting list. Donation is made in the knowledge that the parties will remain anonymous, and that the donor may have no or limited information on the outcome of donation. Anonymity removes the relational and self-interest elements which, in the majority of cases, drive the donor to put themselves at risk. If the young person genuinely understands and accepts these conditions, the curtailment of altruistic behaviour appears unfounded. Young persons may also donate a kidney to a previously unknown individual where the personal connection is made through social media. The need to explore the premises for these relationships is rendered more urgent by the greater availability today of social media platforms as a means for making an appeal for an organ and connecting directly with prospective donors. Henderson et al. highlight the need for guidance on the types of donor-recipient relationships that are ethically acceptable where deeply felt connections are made between individuals who have never met face-to-face.[1138] In a world in which social networking has become a normal means of communicating and interacting with others, the increased susceptibility of adolescents to social pressure raises concerns regarding the impact on young persons of appeals for an organ through carefully redacted social media profiles and compelling personal stories that may distort reality. A carefully vetted application involving interviews with the prospective donor and recipient should reveal any deception and pressure by the recipient, although not proceeding with transplantation does not altogether remove the harm caused to the young person involved.[1139]

If we recognise that young donors are exposed to greater harm than adults in view of the uncertain long-term risks, their increased life expectancy, and the volatility of their convictions, it may be acceptable to require a clear benefit of donation and a clear need for

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[1138] ML Henderson and others, ‘Social Media and Organ Donation: Ethically Navigating the next Frontier’ (2017) 17 American Journal of Transplantation 2803.

[1139] Ibid., 2805.

donating at a young age. From this perspective it is important to properly acknowledge the difference between saving the life of a stranger and saving the life of a person with whom the donor has a genuine relationship which has flourished independently of the recipient's medical needs. The broader question of whether the nature of the relationship justifies a curtailment of self-determination in order to protect the young person goes beyond the remit of this thesis. The point made here is that a restriction on donation to strangers is finite and still allows the young person to donate altruistically to a stranger later in life, should they choose to. Yet in Scotland no legal restrictions were deemed necessary and, in stark contrast with the paternalistic approach to children up to and including the age of 15 who are not allowed to donate an organ irrespective of capacity, 16- and 17-year-olds can consent to organ donation to known and unknown recipients with no requirement for court approval and their parents do not have the legal authority to override their consent.

5.7 Conclusions

In this chapter I have explored the meaning of autonomy in decisions about living organ donation from the perspective of the child whose organs are to be used for transplantation. Living donation by children is rarely performed and has been mainly confined to inter-sibling donation. The analysis in this chapter is largely based on donation within this particular relationship although I maintain that the conclusions reached here are applicable to different relationships, such as donation from a child to a parent. The objective of this chapter is not to take a view about the ethical acceptability of living donation from children. I have explored the ethical concerns surrounding this practice for the purpose of understanding how autonomy is conceptualised when the donor is a child and whose autonomy is relevant in the determination of the best interests of the child by the courts in England and Wales. In relation to donation in Scotland, I have examined how these ethical concerns fit in with the absolute prohibition of donation by children and the full decisional rights accorded to 16- and 17-year-olds.

Lyons claims that transplantation using organs from the living child is a 'social fabrication' driven by our emotional desire to do something to help the recipient.[1140] This assessment encapsulates a fundamental difference between the conceptualisations of adult donation and donation from children: with children, the starting point appears to be acceptance that

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[1140] Lyons (n 895), 376.

the child may be the solution to restoring the health of the ill sibling and the question becomes whether this can be done within ethical and legal boundaries. The pursuit of donation as an option generally does not stem from the wish of the child to help and sacrifice themselves, it is initiated by the parent. It seems to me that this approach loses sight of the fact that the mere option of transplantation does not mean that this course of action is justified.

I maintain that the conceptualisation of autonomy in relation to the child must take into account two dimensions: the present and the future. Present autonomy is linked to the interests that the child has at the time organ donation is contemplated, although it is important to note that unlike adults, children may have limited, negligible or no awareness about what these interests are according to their stage of development. Future autonomy refers to the autonomy of the adult that the child is expected to become. I have examined Feinberg's claim that the future autonomy of the child requires us to consider how a present decision and course of action affects future options and opportunities. The long-term risks of donation are also relevant to future autonomy and I have discussed in Chapter 3 how the these are largely unknown because donor follow-up in clinical studies is typically too short to evaluate the lifetime outcomes of living with one kidney. I have discussed how this argument has been used both to defeat the justification for donation and as a justification for proceeding with donation because transplanting an organ and not transplanting an organ are both actions that entail consequences.[1141] I am not concerned with whether one perspective is preferable to the other. The point made here is that future autonomy demands respect and should be properly taken into account in decisions about donation involving the organs of children. The ethical impasse indicates that, at the very least, there are serious concerns about the future autonomy of the donor child and that there is a real risk that this may be compromised either because the initial assessment of the child's interests is flawed or because life simply takes its course and unpredictable situations arise. I will return to the point of whether the mere existence of the potential for error may warrant a conservative position with respect to living donation from children as is currently in place in Scotland.

In England and Wales transplantation may proceed using the organs of a living child if authorised by the courts. The use of the child's organs is lawful if the courts determine that it is in the best interests of the child. Transplantation represents a unique situation because

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[1141] Campbell et al. 'How Young Is Too Young to Be a Living Donor?' (2013) 13 American Journal of Transplantation 1643, 1648.

unlike other medical interventions, parents who support this course of action have no legal authority to consent on behalf of their child. Living organ donation clearly falls out with the remit of statutory duties and responsibilities under the CA 1989. There are many different interests at stake in inter-sibling donation and once the idea of donation is entertained, serious harm is inevitable either to the donor child who undergoes surgery for the removal of a kidney or to the recipient if donation does not proceed. Parents are equally vulnerable as they will be negatively affected by any adverse consequence to their children arising out of the donation or a failure to transplant.

My analysis has shown that there are polarising views amongst academic scholars about the proper equilibrium between the interests of family members and the interests of the child when decisions about healthcare are to be made. At the beginning of this chapter, I examined parental discretion in choices concerning the family and the proper boundaries of the exercise of parental authority. Establishing conclusions on these points is of limited practical value to the conceptualisation of the autonomy of the child donor because the question for the courts is not whether parents are justified in taking the decision that they have but whether donation is in the interests of the child. In essence, it is more constructive to consider the *interests* of parents in the health and wellbeing of their children rather than their legal duties and responsibilities under the CA 1989 as the decision is made by the courts.

I have explored the concept of the interests of the family from a relational perspective and distinguished between the collective and independent interests of the family as a ‘unit’ from the interests of individual family members. I am not concerned with establishing whether either of these types of interests is a more appropriate legal construct nor with seeking to reconcile the idea of parents making important decisions about their family with the legal requirement that all decisions about living organ donation are made by the courts: the focus of my enquiry is on whether the determination of the best interests of a child can accommodate a relational interpretation of their interests and what this means in terms of the autonomy of the child.

I find the arguments that the determination of the child’s best interests incorporates elements of relational theory persuasive. Relational ethics theory is broad and at a basic level it may be taken as a recognition that the interests of significant others can be relevant to decision-making. One does not have to accept the model of obligations proposed by Ross to conclude that donation to a sibling is in the interests of the child. Nonetheless, in my view, the incorporation of a social dimension into the best interests tests raises particular concerns with regards to child donor because of the nature of transplantation as a lifesaving or life-changing treatment. The balance sheet approach compares the risks and benefits of donation to the child and does not explicitly weigh the benefits of successful transplantation to the recipient because the magnitude of the unquestionable good that transplantation can achieve may, in principle, justify extensive sacrifice by the donor. Nonetheless, the benefit to the recipient makes its way into the equation under the guise of the benefit to the child in saving their sibling.

I have shown that this benefit is ethically problematic. Firstly, the assessment of the benefit remains fundamentally an assessment made by a third party about present interests of which the child may have limited awareness. Furthermore, the child may not recognise the benefit when they reach maturity and, in any event, as discussed earlier, retrospective approval is hardly a sound ethical basis for allowing the removal of an organ to proceed. The benefit relies on a projection of what the child's future wellbeing and this is speculative at best. One of the central arguments throughout this thesis is that a decision to donate an organ is a deeply personal matter and it is important that the choice is authentic in the sense that it is recognised by the individual as a the choice they wish to make. As discussed in Chapter 3, there are many motivations driving an individual to donate an organ and equally, we should not ignore the fact that there are many reasons individuals choose not to donate. These reasons are complicated and personal because they are based on matters that are important to the individual, be these moral principles and obligations, religious values, relational duties or more mundane and practical considerations. Respect for autonomy means that these views should be taken at face value. From this perspective, it is hard to see how a decision made by a third party on behalf of a child who has minimal understanding of donation and appreciation of their role in saving their sibling can ever *ensure* that both present and future autonomy are respected.

I have discussed how these concerns were articulated in the passage of the Human Tissue (Scotland) Bill. Prima facie, the absolute prohibition on donation from children may be most obviously reconciled with denial of autonomy because it removes the choice altogether until legal adulthood is reached and fails to discern between different stages of development of the child. However, it could also be plausibly argued that the prohibition of living donation from children respects the autonomy of the child despite its paternalism because it allows the child to continue their trajectory through life without assumptions that they can or should be part of the treatment of their sibling. Removing the option of donation, displaces the burden of the guilt of not donating because if donation is an impossibility there cannot be a failure to donate. Importantly, the prohibition ensures that children are treated as adults because it rejects the imposition of a moral duty to donate.

The second element of my enquiry relates to the autonomy of young persons. I have discussed how the fundamentally paternalistic approach of the best interests determination can be reconciled with an approach that promotes the participation of the older child or young person in the decision in a way that respects their developing autonomy. Eekelaar's theory of dynamic self-determinism is compelling although arguably, this should be properly regarded as an overarching approach to progressively engage children in decision-making and build up their competencies and skills throughout childhood and adolescence. However, its application to a once-in-a-lifetime irreversible decision involving certain and serious physical harm to the child does not advance our understanding of what autonomy means for the child whose organs will be used. The participation of 16- and 17-year-olds in legal proceedings is essential for the courts to explore motivations and determine whether a wish to donate is authentic. I also contend that if we are serious about young person's welfare, it is imperative that any purported relational interests are set out transparently and carefully scrutinised so that it is clear how these affect the prospective donor.

The position of 16- and 17-year-olds in Scotland is that, as adults, they are legally able to give their authorisation to donation for themselves. In these cases, there are significant concerns about the authenticity of the decision to donate in view of the (likely) emotional and financial dependence of the prospective donor on their parents and the potential for transience in moral values and motivations that are part of the normal development.

6 Conclusions

This thesis has explored the understanding of autonomy in relation to decisions to donate an organ for transplantation from the perspective of the person whose organs are used. I have argued that donor autonomy is central to organ donation because choosing to allow one's organs to be removed and used for the benefit of another is a deeply personal decision based on motivations that matter to the individual.

The requirement for consent or authorization for the use of an organ for transplantation is consistent with an approach that recognises donor autonomy as a fundamental ethical principle underpinning living and deceased organ donation. I have drawn attention to the conspicuousness of the idea of autonomy in the ethical discourse surrounding donor decision making in organ transplantation. Legislation regulating organ procurement focuses exclusively on the requirements for valid consent to donation yet my analysis has revealed how the concept of donor autonomy and authenticity in making choices about donation remains poorly articulated within the HTA regulatory framework and guidance documents for medical professionals involved in transplantation.

My central claim is that consent or authorization to organ donation that are valid in law do not ensure that the individual makes an authentic decision. I have examined the legal and regulatory frameworks governing organ donation in England, Wales, and Scotland to determine whether these are consistent with a particular understanding of autonomy. This analysis considered whether consent or authorization that is lawful from a procedural perspective ensures that the choices of the person whose organs are used for transplantation are respected and requires that these choices are based on a decision-making process that engages with personal autonomy in a meaningful way. The conceptualisation of autonomy in children requires some qualification as a broader construct is required that takes into account both their present, limited, autonomy and their future autonomy, in the sense of the autonomy of the adult that the child is expected to become. I have shown how respect for autonomy demands that their welfare and interests are properly accounted for. I will review the main arguments made throughout this thesis.

Chapter 2 explored the understanding of autonomy as a philosophical construct and as a core principle in biomedical ethics providing a frame of reference for the analysis of the concept of donor autonomy in transplantation. I identified three core perspectives of autonomy: the traditional construct of autonomy in liberal political theory, relational theories of autonomy, and communitarian theory. I highlighted the limitations of the use of a liberal construct of autonomy based on the independent and rational agent because the decision to donate an organ, whether posthumously or in life, almost invariably affects the donor's significant others. This is true even for deceased donation where the procedural ease of registering a preference for donation obscures the harrowing discussions with medical professionals that family members have to endure when the person, now a patient, is at the end of life and organ donation is being considered.

I have argued for a more nuanced understanding of donor autonomy that can accommodate vulnerability and meaningful relationships within the decision-making process and accord the proper weight and respect for moral values and commitments. I have discussed how relational autonomy and communitarian theory offer useful insights into the relevance of the value system of the perspective donor in choices based on moral obligations and responsibilities towards family members.

Having highlighted the key features of these accounts of autonomy, Chapters 3, 4, and 5 analysed donor autonomy in specific donation contexts. Chapter 3 examined the understanding of autonomy in living organ donation from the perspective of the adult donor. I have proposed altruism, authenticity, self-reflection, and a sense of moral duty as the key concepts underpinning the conceptualisation of autonomy from the perspective of the person who willingly accepts the serious and inevitable harm of a surgical procedure carrying no medical benefit to themselves in order to help another person. I argued that the statutory requirements for valid consent and authorisation demand that decisions are informed, voluntary, and not driven by recompense but overlook how the decision is made. I contend that the main focus is on voluntariness rather than authenticity and have shown how the concern of the law is to exclude external sources of pressure and coercion.

I then examined the assessment process of prospective donors by medical professionals and by the IA on behalf of the HTA and concluded that while motivations are explored as part of the psychosocial evaluation of the donor candidate, their evaluation is primarily aimed at identifying incapacity or mental health illness precluding donation.

I have argued how the individualistic notion of the rational autonomous agent fails to account for the decision to donate in circumstances where there is a meaningful relationship between the donor and recipient because the evaluation of the risks and benefits of donation is not based on a rational calculation. I have considered the dynamics of donation from parents to their children as the prime example of a relationship in which donation is driven by affective rather than rational reasoning. I have discussed how a relational approach to autonomy offers useful insights into decisions that may appear instinctive and poorly informed. The central argument that I make is that moral commitments and a parent's sense of responsibility for the welfare of their child should be properly acknowledged as strong motivating factors for donation. I have discussed how internal pressure to donate and to conform to expectations of family members and reluctance to donate are not necessarily incompatible with autonomy where the donor accepts the decision to donate as theirs. Respect for donor autonomy means accepting these reasons as valid and genuine yet as discussed, the legal and regulatory requirements demand informed consent and the HTA and BTS guidelines for medical professionals acknowledge affective reasoning but do not explicitly accept anything short of informed consent.

Chapter 4 examined the understanding of autonomy in deceased organ donation by reference to the broad range of interests that a living person may have in relation to posthumous donation. I argued that an individualistic account of autonomy directed towards the interests in the control and use of our bodies after death does not fully account for the reasons why it is important to respect the wishes of the previously living person regarding donation.

I have discussed how under the current opt-out system a relational approach operates to the extent that family members have de facto powers, albeit not the legal authority, to override the wish to donate of the previously living person. This 'soft' approach to deceased organ procurement is not as innocuous as the term may suggest because the fundamental fact is that an objection to donation expressed by the next of kin will always override the wishes of the person to donate. Furthermore, the 'relational element' of discussions about the possibility of posthumous donation involve family members and transplant professionals yet exclude the dying patient. This point highlights the fundamental discrepancy between the process of first-person consent or authorisation by the person whose organs will be used and the discussions about organ donation taking place between family members and the transplant team. In the first case, giving consent or authorisation to donation is a perfunctory registration of a preference to donate which requires no understanding of the donation process or its implications for the dying process or any commitment to donation. A lack of objection suffices for donation. On the other hand, direct discussions of the family with transplant professionals about the possibility of organ donation provide the opportunity for meaningful engagement of family members and essentially fulfil the requirements for informed consent that is not required because family members no longer have the legal power to consent to donation on behalf of the deceased person.

While communitarian theory may be used to ground a ‘hard’ approach to opt-out legislation, I claim that the ‘soft’ opt-out model in place in all three jurisdictions in the UK reflects a relational approach to decision-making. Firstly, it explicitly rejects a right of the next of kin to make a decision about donation (in the absence of valid delegation of the authority to make the decision on behalf of the deceased person) in their own right. At the same time, it respects the feelings and views of the families and loved ones and attempts to resolve differences in preferences about donation through dialogue. This is important, not simply because the practicalities of donation require the support and collaboration of the family but also because it is important to recognise that even committed donors may not wish donation to cause excessive distress to grieving family members after their death and the imposition of their wish to donate may not necessarily be what they wanted. Finally, the family’s role in the consent or authorization process recognises the fallibility of the opt-out system and the importance of allowing those who knew the previously living person to voice any concerns regarding their preferences about donation that may invalidate deemed consent or authorisation.

With respect to the relationship between deemed consent or authorisation and autonomy, the pursuit of registration on the ODR as the preferable means for registering a preference and the use of informational campaigns encouraging discussion about end-of-life care and preferences regarding donation with significant others support an understanding of donation as a choice that is meaningful to the individual. However, this is contradicted by the purported justification for deemed consent legislation which is based on the idea that this facilitates the realisation of the wishes of the majority of the public.

I have discussed how arguments based on the predisposition of the public towards donation should be approached with caution and that the primary aim of deemed consent is to channel apathy into a preference for donation. I accept that many individuals may not feel strongly about what happens to their organs after death and my view is that there is a need for serious ethical analysis to establish whether transplantation in such cases causes harm and how it can be justified without making assumptions about preferences. However, this does not change the fact that from the perspective of the autonomy of the donor, deemed consent does not take authenticity and motivations seriously. I maintain that if the interests that individuals have in how their bodies are used after death genuinely matter, the way in which we accept consent or authorisation for posthumous donation needs to reflect this. Having dismissed the empirically dubious claim that most individuals wish to donate an organ after death as the legitimate basis for introducing the opt-out system, I have argued that this framework cannot be divorced from the recognition that posthumous donation is the morally right thing to do and that this offers a more coherent account of why we should accept donation as the default position. I have argued that this position is not incompatible with individual autonomy and that this depends on whether and how individuals internalise the moral duty and accept this as their own view.

Chapter 5 examined how the autonomy of the child donor requires us to consider both the present and limited autonomy of the child and their future autonomy, understood as the autonomy that the child is expected to achieve as an adult. I have argued that however autonomy is conceptualised, the starting point must be that obligations are not imposed on children that are not imposed upon adults and that the availability of transplantation as a treatment option for an ill sibling does not mean that refusal of donation requires a justification framed in terms of the harm caused to the donor by the continued ill health or demise of the sibling.

I have highlighted the conflict of interests within the family that inevitably and tragically surrounds inter-sibling donation and I have discussed the determination of the best interests of the child from a relational autonomy perspective. I maintain that while relational interests are incorporated into the best interests assessment, this does not extend to a relational duty to donate. Nonetheless, I argue that the inclusion of considerations about the benefits of donation to the child donor indirectly introduce the benefits of transplantation to the recipient into the balance sheet drawn up by the courts. At the very least, this approach raises concerns about losing sight of the fact that the decision should be made from the perspective of the donor child.

I have suggested that the prohibition of organ donation from children in Scotland may be reconciled with an approach that respects both present and future autonomy despite its obviously paternalistic stance. In any event, what is clear is that the legal framework prioritises the physical welfare of child over any relational considerations. This is in sharp contrast with the position of 16- and 17-year-old persons who, as adults, are legally able to give their authorisation to donation for themselves. I have discussed the concerns that arise with respect to the authenticity of the decision to donate and specifically, regarding their (likely) emotional and financial dependence on their parents, the stability of their values and motivations for donating, and the uncertainty over the lifelong risks of donation.

Throughout this thesis I have endorsed the view that a substantive account of autonomy is required to make sense of how individuals make the choice to donate an organ and that autonomy relates to the ways in which individuals make authentic choices, in the sense of decisions based on values and principles that they accept as their own. While different considerations apply to decisions to donate in life or after death, I maintain that the choice to donate an organ is fundamentally a personal decision based on motivations that matter to the donor. I have argued that a substantive understanding of autonomy goes beyond mere decisional authority of an individual over the use of their organs and engages elements of relational theory such as self-reflection, personal values and relationships, and moral responsibilities and commitments towards other persons. I claim that a relational autonomy approach is sensitive to the interests and responsibilities that are ethically relevant to the prospective donor and can offer a comprehensive and coherent account of autonomy from the perspective of the person whose organs are used for transplantation.

Table of Legislation

Age of Legal Capacity (Scotland) Act 1991

Adults with Incapacity (Scotland) Act 2000

Children Act 1989

Children (Scotland) Act 1995

Convention on Human Rights and Biomedicine

European Convention of Human Rights

Family Law Reform Act 1969

Human Organ and Tissue Live Transplants (Scotland) Regulations 2006

Human Rights Act 1998

Human Tissue Act 1961

Human Tissue Act 2004

Human Tissue Act 2004 (Persons who Lack Capacity to Consent and Transplants) Regulations 2006

Human Organ and Tissue Live Transplants (Scotland) Regulations 2006

Human Tissue (Authorisation) (Scotland) Act 2019

Human Tissue (Scotland) Act 2006

Human Transplantation (Wales) Act 2013

Mental Capacity Act 2005

Organ Donation (Deemed Consent) Act 2019

United Nations Convention of the Rights of Children 1989

Table of Cases

England and Wales

Re B (A Minor) (Wardship: Sterilisation) [1988] AC 199

Re J (a minor) (wardship: medical treatment) [1990] 3 All ER 145

Re J (Specific Issue Orders: child's religious upbringing and circumcision) [2000] 1 FLR 571

Re P (Medical Treatment: Best Interests) [2004] 2 FLR 1117

Re P (Contact: Supervision) [1996] 2 FLR314

Re R (A Minor) (Wardship: Consent to Treatment [1992] Fam 11

Re T (A Minor) (Wardship: Medical Treatment) [1997] 1 WLR 242

Re W (A Minor)(Medical Treatment) [1993] 1 FLR

Re Y (adult patient)(bone marrow transplant) [1997] 2 WLR 556

Wyatt v Portsmouth NHS Trust (No 3) [2005] EWHC 693 (Fam)

Scotland

Docherty v McGlynn 1983 S.L.T. 645

Finlayson Petr 1989 SCLR 601

Houston Applicant 1996 SCLR 943

Montgomery v Lanarkshire Health Board [2015] UKSC 11

Re S [1993] 2 FLR 437

V v F 1991 SCLR 225

United States of America

Curran v Bosze (1990) 566 N.E.2d 1319

Foster v. Harrison, No. 68674 Eq. (Mass. Sup. Jud. Ct.1957).

Hart v Brown (1972) 289 A 2d 386

Huskey v. Harrison, No. 68666 Eq. (Mass. Sup. Jud. Ct.1957)

Little v Little (1979) 576 SW 2d 493 (Tex Ct of App)

McFall and Shimp 10 Pa. D. & C. 3d 90 (July 26, 1978)

Madsen v. Harrison, No 68651 Eq. (Mass. Sup. Jud. Ct.1957)

Nathan v Flanagan Civil No J74-109 (Mass, Oct 4, 1974)

re Roy Allen Richardson (1973) 284 So.2d 185

Wisconsin v. Jonas Yoder, 406 U.S. 205 (1972)

Australian

Re Inaya (2007) 38 Fam LR 546.

Abbreviations

BTS British Transplantation Society

GMC General Medical Council

HTA Human Tissue Authority

IA Independent Assessor

NHS National Health Service

NHSBT NHS Blood and Transplant

ODR Organ Donation Register

Bibliography

Abecassis M and others, ‘Consensus Statement on the Live Organ Donor’ (2000) 284 Journal of the American Medical Association 2919

Albertsen A, ‘Deemed Consent: Assessing the New Opt-out Approach to Organ Procurement in Wales’ (2018) 44 Journal of Medical Ethics 314

Albertsen Andreas, ‘Assessing Deemed Consent in Wales - the Advantages of a Broad Difference-in-Difference Design’ (2019) 45 Journal of Medical Ethics 211

Alderson P, ‘Children’s Consent and the Zone of Parental Discretion’ (2017) 12 Clinical Ethics 55

Alderson P and Montgomery J, *Health Care Choices: Making Decisions with Children* (London, Institute for Public Policy Research 1996)

Ali Norozi S and Moen T, ‘Childhood as a Social Construction’ (2016) 6 Journal of Educational and Social Research 75

Appelbaum PS, ‘Ought We to Require Emotional Capacity as Part of Decisional Competence?’ (1998) 8 Kennedy Institute of Ethics Journal 377

Appelbaum PS, ‘Assessment of Patients’ Competence to Consent to Treatment’ (2007) 357 New England Journal of Medicine 1834

Archard D, ‘Do Parents Own Their Children?’ (1993) 1 The International Journal of Children’s Rights 293

Archard D, *Children, Family, and the State* (Ashgate 2003)

Archard D, ‘Children, Adults, Best Interests and Rights’ (2013) 13 Medical Law International 55

Archard D, *Children: Rights and Childhood* (3rd edn. Routledge, Taylor & Francis Group 2015)

Archard D and Macleod CM (eds), *The Moral and Political Status of Children* (Oxford University Press 2002)

Archard D and Marit S, ‘Balancing a Child’s Best Interests and a Child’s Views’ (2009) 17 International Journal of Children’s Rights 1

Atkins K, ‘Autonomy and Autonomy Competencies: A Practical and Relational Approach’ (2006) 7 Nursing Philosophy: An International Journal for Healthcare Professionals 205

Auckland C and Goold I, Re-Evaluating ‘Best Interests’ in the Wake of *Raqeeb* v *Barts NHS Foundation Trust & Anors* 2020 83 The Modern Law Review 1328

Aulakh R, ‘Too Young to Save His Mother’s Life? Hospital Changes Policy for Teen’ *Toronto Star* (Toronto, ON, 2011)

Austin MW, *Conceptions of Parenthood: Ethics and the Family* (Ashgate 2007)

Baines P, ‘Family Interests and Medical Decisions for Children’ (2017) 31 Bioethics 599

Bailey P and Huxtable R, ‘When Opportunity Knocks Twice: Dual Living Kidney Donation, Autonomy and the Public Interest’ (2016) 30 Bioethics 119

Bainham A and Gilmore S, *Children, the Modern Law* (4th edn. Family Law 2013)

Banner NF, ‘Can Procedural and Substantive Elements of Decision-Making Be Reconciled in Assessments of Mental Capacity?’ (2013) 9 International Journal of Law in Context 71

Barclay L, ‘Autonomy and the Social Self’ in Catriona Mackenzie and Natalie Stoljar (eds), *Relational autonomy. Feminist perspectives on autonomy, agency, and the social self* (Oxford University Press 2000)

Baron CH, Botsford M and Cole GF, ‘Live Organ and Tissue Transplants from Minor Donors in Massachusetts’ (1975) 55 Boston University Law Review 159

Baumgold D (ed), ‘Chapter 20 of *The Elements of Law* / Chapter 6 of *De Cive* / Chapter 18 of *Leviathan*’, *Three-Text Edition of Thomas Hobbes’s Political Theory* (1st edn. Cambridge University Press 2017)

Beauchamp T and Childress J, *Principles of Biomedical Ethics* (Oxford University Press 2009)

Beauchamp T and Kahn J, ‘Ethical Theory and Bioethics’ in Tom Beauchamp and others (eds), *Contemporary issues in bioethics* (8th edn. Wadsworth Cengage 2014).

Beauchamp TL and Childress JF, *Principles of Biomedical Ethics / Tom L. Beauchamp, James F. Childress* (4th edn. Oxford University Press 1994)

Becker M, ‘Patriarchy and Inequality: Towards a Substantive Feminism’ 69

Bell DA, ‘A Communitarian Critique of Authoritarianism: The Case of Singapore’ (1997) 25 Political Theory 6

Belliotti R, ‘Do Dead Human Beings Have Rights?’ (1979) 60 The Personalist 201

Ben-David O, *Organ Donation and Transplantation: Body Organs as an Exchangeable Socio-Cultural Resource* (First, Westport; Praeger 2005)

Bennett AH and Harrison JH, ‘Experience with Living Familial Renal Donors’ (1974) 139 Surgery, Gynecology & Obstetrics 894.

Berlin I, ‘Two Concepts of Liberty’ in Isaiah Berlin and Henry Hardy (eds), *Liberty: Incorporating ‘Four Essays on Liberty’* (Oxford University Press 2003)

Beyleveld D and Brownsword R, ‘My Body, My Body Parts, My Property?’ (2000) 8 Health Care Analysis 87.

Beyleveld D and Brownsword R, *Consent in the Law* (Oxford, Hart 2007)

Biller-Andorno N and others, ‘Who Should Be Allowed to Give?’ (2001) 22 Theoretical Medicine and Bioethics 351.

Biller-Andorno, ‘Who Shall Be Allowed to Give? Living Organ Donors and the Concept of Autonomy’ 18

Blackie J, *Mental Health: The Law in Scotland* (Butterworths Law 2005)

Blum LA, *Friendship, Altruism and Morality* (2010)

Blumenthal-Barby JS and Burroughs H, 'Seeking Better Health Care Outcomes: The Ethics of Using the "Nudge"' (2012) 12 The American journal of bioethics: AJOB 1

Boddington P, 'Organ Donation After Death — Should I Decide, or Should My Family?' (1998) 15 Journal of Applied Philosophy 69

Boswell J, *The Kindness of Strangers: The Abandonment of Children in Western Europe from Late Antiquity to the Renaissance* (The Penguin Press 1989)

Brazier M, 'Do No Harm. Do Patients Have Responsibilities Too?' (2006) 65 The Cambridge Law Journal 397

Brecher B, 'Our Obligation to the Dead' (2002) 19 Journal of Applied Philosophy 109

Brennan S, and Noggle R, The Moral Status of Children: Children's Rights, Parents' Rights, and Family Justice' (1997) 23 Social Theory and Practice 1

Bridge C, 'Religious Beliefs and Teenage Refusal of Medical Treatment' (1999) 62 The Modern Law Review 585

Jo Bridgeman *Medical Treatment of Children and the Law: Beyond Parental Responsibilities* (Routledge 2021)

Brock DW, 'Decision-making Competence and Risk' (1991) 5 Bioethics 105

Brody GH, 'Siblings' Direct and Indirect Contributions to Child Development' (2004) 13 Current Directions in Psychological Science 124

Broström L and Johansson M, 'Involving Children in Non-Therapeutic Research: On the Development Argument' (2014) 17 Medicine, Health Care, and Philosophy 53

Brownsword R, 'The Cult of Consent: Fixation and Fallacy' (2004) 15 King's Law Journal 223

Buchanan A and Brock D, *Deciding for Others: The Ethics of Surrogate Decision Making* (Cambridge University Press 1990)

Burnell P, Hulton S-A, and Draper H, 'Coercion and Choice in Parent–Child Live Kidney Donation' (2015) 41 Journal of Medical Ethics 304

Callahan D, 'Individual Good and Common Good: A Communitarian Approach to Bioethics' (2003) 46 Perspectives in Biology and Medicine 496

Callahan JC, 'On Harming the Dead' (1987) 97 Ethics 341

Campbell M and others, 'How Young Is Too Young to Be a Living Donor?: Young Living Donors' (2013) 13 American Journal of Transplantation 1643

Campbell TD, 'The Rights of the Minor: As Person, As Child, As Juvenile, As Future Adult' (1992) 6 International Journal of Law, Policy and the Family 1

Capitaine L and others, ‘Should Minors Be Considered as Potential Living Liver Donors?: Ethics of Living Liver Donation by Minors’ (2013) 19 Liver Transplantation 649

Caplan AL, ‘Am I my Brother's Keeper? Suffolk University Law Review 15

Cave E, ‘Maximisation of Minors’ Capacity’ (2011) 23 Child and Family Law Quarterly 431,

Cave E, ‘Goodbye *Gillick* ? Identifying and Resolving Problems with the Concept of Child Competence’ (2014) 34 Legal Studies 103

Cave E, Brierley J, and Archard D ‘Making Decisions for Children – Accommodating Parental Choice in Best Interests Determinations: Barts Health NHS Trust v Raqeeb [2019] EWHC 2530 (Fam); Raqeeb and Barts Health NHS Trust [2019] EWHC 253’ (2019) 28 Medical Law Review 183

Charland LC, ‘Mental Competence and Value: The Problem of Normativity in the Assessment of Decision-making Capacity’ (2001) 8 Psychiatry, Psychology and Law 135

Charland L, ‘Is Mr Spock Mentally Competent? Competence to Consent and Emotion.’ (1998) 5 Philosophy, Psychiatry, and Psychology 67.

Charland LC, ‘Appreciation and Emotion: Theoretical Reflections on the MacArthur Treatment Competence Study’ (1998) 8 Kennedy Institute of Ethics Journal 359

Cherkassky L, ‘Children and the Doctrine of Substituted Judgement’ (2014) 14 Medical Law International 213

Cherkassky L, ‘*Gillick* , Bone Marrow and Teenagers’ (2015) 83 Medico-Legal Journal 154

Cherkassky L, ‘The Wrong Harvest: The Law on Saviour Siblings’ (2015) 29 International Journal of Law, Policy and the Family 36

Cheyette C, ‘Organ Harvest from the Legally Incompetent: An Argument Against Compelled Altruism’ (2000) 52 Boston College Law Review 465

Childress JF, ‘The Place of Autonomy in Bioethics’ (1990) 20 The Hastings Center Report 12

Childress JF, *Practical Reasoning in Bioethics* (Indiana University Press 1997)

Choudhry S, ‘Taking the Rights of Parents and Children Seriously: Confronting the Welfare Principle under the Human Rights Act’ (2005) 25 Oxford Journal of Legal Studies 453

Christman J, ‘Constructing the Inner Citadel: Recent Work on the Concept of Autonomy’ (1988) 99 Ethics 109

Christman J, ‘Relational Autonomy, Liberal Individualism, and the Social Constitution of Selves’ (2004) 117 Philosophical Studies 143

Clarke A, Mitchell A, and Abraham C, ‘Understanding Donation Experiences of Unspecified (Altruistic) Kidney Donors’ (2014) 19 British Journal of Health Psychology 393

Cleland A and Sutherland E (eds), *Children's Rights in Scotland* (2nd ed, W Green/Sweet & Maxwell 2001)

Coggon J, 'Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?' (2007) 15 Health Care Analysis 235

Coggon J, 'Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?' (2007) 15 Health Care Analysis 235

Coggon J and Miola J, 'Autonomy, Liberty, and Medical Decision-Making' 70 Cambridge Law Journal 523

Cohen S, 'Nudging and Informed Consent' (2013) 13 American Journal of Bioethics 3

Costa-Font J, Rudisill C and Salcher-Konrad M, '"Relative Consent" or "Presumed Consent"? Organ Donation Attitudes and Behaviour' (2021) 22 The European Journal of Health Economics 5

Crouch RA and Elliott C, 'Moral Agency and the Family: The Case of Living Related Organ Transplantation' 13

Crowley-Matoka M, Siegler M and Cronin DC, 'Long-Term Quality of Life Issues Among Adult-to-Pediatric Living Liver Donors: A Qualitative Exploration' (2004) 4 American Journal of Transplantation 744

Darwall SL, *Welfare and Rational Care* (Princeton University Press 2004)

Davidai S, Gilovich T and Ross LD, 'The Meaning of Default Options for Potential Organ Donors' (2012) 109 Proceedings of the National Academy of Sciences of the United States of America 15201

Linda Delany 'Protecting Children from Forced Altruism: the Legal Approach' in Altruism by Proxy: Volunteering Children For Bone Marrow Donation (1996) 312 British Medical Journal 240

Delmonico F and Council of the Transplantation Society, 'A Report of the Amsterdam Forum On the Care of the Live Kidney Donor: Data and Medical Guidelines' (2005) 79 Transplantation S53

Delmonico FL and Harmon WE, 'The Use of a Minor as a Live Kidney Donor' (2002) 2 American Journal of Transplantation 333

Delmonico FL and Surman OS, 'Is This Live-Organ Donor Your Patient?' (2003) 76 Transplantation 1257

Den Hartogh G, 'Can Consent Be Presumed?: Can Consent Be Presumed?' (2011) 28 Journal of Applied Philosophy 295

Derrida J, 'Given Time: I. Counterfeit Money', Peggy Kamuf (translator) (The University of Chicago Press 1992)

Devolder K, 'Preimplantation HLA Typing: Having Children to Save Our Loved Ones' (2005) 31 Journal of Medical Ethics 582

Dew MA and others, ‘Guidelines for the Psychosocial Evaluation of Living Unrelated Kidney Donors in the United States’ (2007) 7 American Journal of Transplantation 1047

Donnelly M, ‘Capacity Assessment under the Mental Capacity Act 2005: Delivering on the Functional Approach?’ (2009) 29 Legal Studies 464

Donnelly, *Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism* (Cambridge University Press 2010)

Dor F and others, ‘New Classification of ELPAT for Living Organ Donation’ (2011) 91 Transplantation 935

Dorflinger LM and others, ‘Assessing Living Donor Priorities Through Nominal Group Technique’ (2018) 28 Progress in Transplantation (Aliso Viejo, Calif.) 29

Douglas G and Sebba L, *Children’s Rights and Traditional Values* (Ashgate/Dartmouth 1998)

Douglas JF and Cronin AJ, ‘The Human Transplantation (Wales) Act 2013: An Act of Encouragement, Not Enforcement: The Human Transplantation (Wales) Act 2013’ (2015) 78 The Modern Law Review 324

Duerinckx N and others, ‘Predonation Psychosocial Evaluation of Living Kidney and Liver Donor Candidates: A Systematic Literature Review’ (2014) 27 Transplant International: Official Journal of the European Society for Organ Transplantation 2

Duschinsky R, ‘*Tabula Rasa* and Human Nature’ (2012) 87 Philosophy 509

Dworkin G, *The Theory and Practice of Autonomy* (Cambridge University Press 1988)

Dworkin G, ‘The Nature of Autonomy’ (2015) 2015 Nordic Journal of Studies in Educational Policy 28479

Dworkin G, ‘Paternalism’(1972) 56 Monist 64

Dworkin R, *Life’s Dominion: An Argument about Abortion and Euthanasia* (HarperCollins 1993)

Dworkin R, *Justice in Robes* (Belknap Press 2021)

Dwyer J and Vig E, ‘Rethinking Transplantation between Siblings’ (1995) 25 The Hastings Center Report 7

Dyer C, ‘Guide to Ethics of Treating Children Published’ (2000) 321 British Medical Journal 1491

Edwards L and Griffiths A, *Family Law* (Green/Sweet & Maxwell 1997)

Eekelaar J, ‘The Emergence of Children's Rights (1986) 6 Oxford Journal of Legal Studies 161

Eekelaar J, ‘Parental Responsibility: State of Nature or Nature of the State?’ (1991) 13 Journal of Social Welfare and Family Law 37

Eekelaar J, ‘The Eclipse of Parental Rights’ (1986) 102 Law Quarterly Review 4

Elliott C, ‘Doing Harm: Living Organ Donors, Clinical Research and The Tenth Man.’ (1995) 21 Journal of Medical Ethics 91

Elliston S, *Best Interests of the Child in Healthcare* (1st edn. Routledge-Cavendish 2007)

Emmett C and others, ‘Homeward Bound or Bound for a Home? Assessing the Capacity of Dementia Patients to Make Decisions about Hospital Discharge: Comparing Practice with Legal Standards’ (2013) 36 International Journal of Law and Psychiatry 73

Engelhardt HT, ‘Beyond the Best Interests of Children: Four Views of the Family and of Foundational Disagreements Regarding Pediatric Decision Making’ (2010) 35 Journal of Medicine and Philosophy 499

Engelhardt HT, ‘Beyond the Best Interests of Children: Four Views of the Family and of Foundational Disagreements Regarding Pediatric Decision Making’ (2010) 35 Journal of Medicine and Philosophy 499

English V and others (eds), *Medical Ethics Today: The BMAs Handbook of Ethics and Law* (3rd edn. Wiley-Blackwell 2012)

Etzioni A, ‘Organ Donation: A Communitarian Approach’ (2003) 13 Kennedy Institute of Ethics Journal 1

Etzioni A, ‘A Neo-Communitarian Approach to International Relations: Rights and the Good’ (2006) 7 Human Rights Review 69

Etzioni A, ‘Communitarianism revisited’ (2014) 19 Journal of Political Ideologies 241

Fabre J, Murphy P and Matesanz R, ‘Presumed Consent: A Distraction in the Quest for Increasing Rates of Organ Donation’ (2010) 341 British Medical Journal c4973

Faden RR, Beauchamp TL and King NMP, *A History and Theory of Informed Consent* (Oxford University Press 1986)

Fan R, ‘Self-Determination vs. Family-Determination: Two Incommensurable Principles of Autonomy’ (1997) 11 Bioethics 309

Farrell AM, ‘Time for Change: The Need for a Pragmatic Approach to Addressing Organ Shortage in the UK’ (2008) 3 Clinical Ethics 149

Farrell A-M, ‘Time for Change: The Need for a Pragmatic Approach to Addressing Organ Shortage in the UK’ (2008) 3 Clinical Ethics 149

Farell A-M, ‘Addressing Organ Shortage : Are Nudges the Way Forward’ (2015) 7 Law, Innovation and Technology 253

Farrell A-M, Price D and Quigley M, *Organ Shortage Ethics, Law and Pragmatism* (Cambridge University Press 2011)

Feinberg J, *Freedom and Fulfilment: Philosophical Essays* (Princeton University Press 1994)

Feinberg, J, *Rights, Justice, and the Bounds of Liberty - Essays in Social Philosophy.* (2016)

Feinberg J and Feinberg J, *The Moral Limits of the Criminal Law. 2: Offense to Others* (Oxford University Press 1987)

Feinberg J, *The Moral Limits of the Criminal Law. 3: Harm to Self* (Oxford University Press 1989)

Feinberg J, *Harm to Others* (Oxford University Press 1990)

Feinberg J, *The Moral Limits of the Criminal Law. 4: Harmless Wrongdoing* (Oxford University Press 1990)

Feinberg J. The Rights of Animals and Unborn Generations in William Blackstone (ed) *Philosophy and Environmental Crisis*, University of Georgia Press 1974)

Feldman F. 'Some Puzzles about the Evil of Death' (1991) 100 Philosophical Review 205227'

Fellner CH and Marshall JR, 'Kidney Donors--the Myth of Informed Consent' (1970) 126 The American Journal of Psychiatry 1245

Fineman M, 'The vulnerable subject: anchoring equality in the human condition' (2008) 20 Yale Journal of Law and Feminism 1

Fionda J, *Legal Concepts of Childhood* (Hart 2001)

Fleck LM, 'Children and Organ Donation: Some Cautionary Remarks' (2004) 13 Cambridge Quarterly of Healthcare Ethics

Forsberg A and others, 'The Essence of Living Parental Liver Donation - Donors' Lived Experiences of Donation to Their Children' (2004) 8 Pediatric Transplantation 372

Fortin J, 'Children's Rights: Are the Courts Now Taking Them More Seriously?'(2004)15 The Kings College Law Journal 253

Fortin J, 'Accommodating Children's Rights in a Post Human Rights Act Era.' (2006) 69 The Modern Law Review 299

Fortin J, 'Children's Rights - Substance or Spin?' (2006) 36 Family Law 759

Fortin J, *Children's Rights and the Developing Law* (Cambridge University Press 2009)

Fortin M-C and others, 'The Enigmatic Nature of Altruism in Organ Transplantation: A Cross-Cultural Study of Transplant Physicians' Views on Altruism' (2010) 3 BMC Research Notes 216

Foster C, 'Autonomy in the Medico-Legal Courtroom: A Principle Fit for Purpose?' (2013) 22 Medical Law Review 48

Foster C and Herring J, 'Rethinking the Welfare and Best Interest Principles' in Charles Foster and Jonathan Herring (eds), *Altruism, Welfare and the Law* (Springer International Publishing 2015)

Fox RA, 'Confucian and Communitarian Responses to Liberal Democracy' (1997) 59 The Review of Politics 561

Frankfurt HG, ‘Freedom of the Will and the Concept of a Person’ (1971) 68 The Journal of Philosophy 5

Frankfurt HG, *The Reasons of Love* (1st edn. Princeton University Press 2019)

Franklin PM and Crombie AK, ‘Live Related Renal Transplantation: Psychological, Social, and Cultural Issues’ (2003) 76 Transplantation 1247

Freeman M, ‘Law and Childhood Studies: Current Legal Issues’ (2013) 14 Children and Society 78

Freeman MD, *The Moral Status of Children: Essays on the Rights of the Child* (Martinus Nijhoff Publishers; sold and distributed in the USA and Canada by Kluwer Law International 1997)

Freyenhagen F and O’Shea T, ‘Hidden Substance: Mental Disorder as a Challenge to Normatively Neutral Accounts of Autonomy’ (2013) 9 International Journal of Law in Context 53

Friedman M, *Autonomy, Gender, Politics* (Oxford University Press 2003)

Friedman M, ‘Relational Autonomy and Individuality' (2013) 63 University of Toronto Law Journal 327

Fuggle SV and others, ‘Factors Affecting Graft and Patient Survival after Live Donor Kidney Transplantation in the UK’ (2010) 89 Transplantation 694

Fujita M and others, ‘A Model of Donors’ Decision-Making in Adult-to-Adult Living Donor Liver Transplantation in Japan: Having No Choice’ (2006) 12 Liver Transplantation 768

Gare R and others, ‘Understanding Barriers and Outcomes of Unspecified (Non-Directed Altruistic) Kidney Donation from Both Professional’s and Patient’s Perspectives: Research Protocol for a National Multicentre Mixed-Methods Prospective Cohort Study’ (2017) 7 British Medical Journal Open e015971

Garwood-Gowers A, *Healthcare Law: The Impact of the Human Rights Act 1998.* (Routledge-Cavendish 2002)

Gauthier CC, ‘Moral Responsibility and Respect for Autonomy: Meeting the Communitarian Challenge’ (2000) 10 Kennedy Institute of Ethics Journal 337

Gauthier DP, *Morals by Agreement* (Reprint [der Ausg] 1986, Oxford University Press 2006)

Gay W, ‘Who Speaks for the Child: The Problems of Proxy Consent’ Michigan Law Review 5

Gerrand N, ‘The Misuse of Kant in the Debate about a Market for Human Body Parts’ (1999) 16 Journal of Applied Philosophy 59

General Medical Council, Decision making and consent: Guidance on professional standards and ethics for doctors (General Medical Council, September 2020)

Gilbar R and Miola J, ‘One Size Fits All? On Patient Autonomy, Medical Decision Making and the Impact of Culture’ (2015) 23 Medical Law Review 375

Gilligan C, *In a Different Voice: Psychological Theory and Women’s Development* (Harvard University Press 2003)

Gillon R, ‘Medical Ethics: Four Principles plus Attention to Scope’ (1994) 309 BMJ 184

Glannon W, ‘Persons, Lives, and Posthumous Harms’ (2001) 32 127

Glannon W, ‘Do the Sick Have a Right to Cadaveric Organs?’ (2003) 29 Journal of Medical Ethics 153

Glannon W and Ross LF, ‘Do Genetic Relationships Create Moral Obligations in Organ Transplantation?’ (2002) 11 Cambridge Quarterly of Healthcare Ethics 153

Gohh RY and others, ‘Controversies in Organ Donation: The Altruistic Living Donor’ (2001) 16 Nephrology, Dialysis, Transplantation 619

Goldman LS, ‘Liver Transplantation Using Living Donors. Preliminary Donor Psychiatric Outcomes’ (1993) 34 Psychosomatics 235

Goldstein J, Freud A and Solnit AJ, *Beyond the Best Interests of the Child* (Free Press 1979)

Goodin R*, Protecting the Vulnerable: A Reanalysis of our Social Responsibilities*, (Chicago Press, 1985).

Goodin R and Pettit P, *Contemporary Political Philosophy: An Anthology* (Blackwell Publishers 1997)

Goodwin M, *The Global Body Market: Altruism’s Limits* (Cambridge University Press 2013)

Goodwin M, ‘My Sister’s Keeper?: Law, Children, and Compelled Donation’ 29 Western New England Law Review 49

Gracia D, ‘The Many Faces of Autonomy’ (2012) 33 Theoretical Medicine and Bioethics 57

Great Britain and others, *Report of a Census of Organs and Tissues Retained by Pathology Services in England* (Stationery Office 2001)

Great Britain and Department of Health, *Learning from Bristol: The Department of Health’s Response to the Report of the Public Inquiry into Children’s Heart Surgery at the Bristol Royal Infirmary 1984-1995* (Stationery Office 2002)

Gregor M, *Kant, Practical Philosophy* (Cambridge University Press 1996)

Griffiths AMO, McCarthy F and Fotheringham JM, *Family Law* (4th edn. W Green, Thomson Reuters 2015)

Griner RW, ‘Live Organ Donations between Siblings and the Best Interest Standard: Time for Stricter Judicial Intervention’ (1995])Specialty Law Digest. Health Care Law 9

Grisso T and Appelbaum PS, *Assessing Competence to Consent to Treatment: A Guide for Physicians and Other Health Professionals* (Oxford University Press 1998)

Grisso T and Vierling L, 'Minors' Consent to Treatment: A Developmental Perspective.' (1978) 9 Professional Psychology 412

Guedj M, Sastre MTM and Mullet E, 'Donating Organs: A Theory-Driven Inventory of Motives' (2011) 16 Psychology, Health & Medicine 418

Gylling HA, 'Autonomy Revisited' (2004) 13 Cambridge Quarterly of Healthcare Ethics

Halpern SD, Ubel PA and Asch DA, 'Harnessing the Power of Default Options to Improve Health Care' (2007) 357 The New England Journal of Medicine 1340

Hamer CL, 'A Stronger Policy of Organ Retrieval from Cadaveric Donors: Some Ethical Considerations' (2003) 29 Journal of Medical Ethics 196

Hamm D and Tizzard J, 'Presumed Consent for Organ Donation' (2008) 336 British Medical Journal 230

Hammond-Browning N and Yao SL, 'Deceased Donation Uterus Transplantation: A Review' (2021) 2 Transplantology 140

Hardcastle R, *Law and the Human Body: Property Rights, Ownership and Control* (Hart Publishing 2009)

Harris J, 'Consent and End of Life Decisions' (2003) 29 Journal of Medical Ethics 10

Harris J and Holm S, 'Should We Presume Moral Turpitude in Our Children?--Small Children and Consent to Medical Research' (2003) 24 Theoretical Medicine and Bioethics 121

Hart HLA and Bulloch PA, *The Concept of Law* (2nd edn. Clarendon Press 1998)

Hart HLA, Hacker PMS and Raz J (eds), *Law, Morality, and Society: Essays in Honour of H. L. A. Hart* (Clarendon Press 1977)

Hartogh GD, 'Is Consent of the Donor Enough to Justify the Removal of Living Organs?' (2013) 22 Cambridge Quarterly of Healthcare Ethics 45

Hebert N, 'Creating A Life To Save A Life: An Issue Inadequately Addressed By The Current Legal Framework Under Which Minors Are Permitted To Donate Tissue And Organs' 17 Southern California Interdisciplinary Law Journal 44

Henderson AJZ and others, 'The Living Anonymous Kidney Donor: Lunatic or Saint?: Living Anonymous Kidney Donor' (2003) 3 American Journal of Transplantation 203

Henderson ML and others, 'Social Media and Organ Donation: Ethically Navigating the next Frontier' (2017) 17 American Journal of Transplantation 2803

Hermann H and others, 'Emotion and Value in the Evaluation of Medical Decision-Making Capacity: A Narrative Review of Arguments' (2016) 7 Frontiers in Psychology

Hermann H, 'Decision-Making Capacity: From Testing to Evaluation' (2020) 23 Medicine, Health Care and Philosophy 253

Herring J, ‘The Human Rights Act and the Welfare Principle in Family Law – Conflicting or Complementary?’ (1999) 11 Child and Family Law Quarterly 223

Herring J, ‘Farewell Welfare?’ (2005) 27 Journal of Social Welfare and Family Law 159

Herring J, ‘Forging a Relational Approach: Best Interests or Human Rights?’ (2013) 13 Medical Law International 32

Herring J, ‘Relational Autonomy’ in Jonathan Herring, *Relational Autonomy and Family Law* (Springer International Publishing 2014)

Herring J, ‘The Welfare Principle and the Children Act: Presumably It’s about Welfare?’ (2014) 36 Journal of Social Welfare and Family Law 14

Herring J, ‘*Saviour Siblings: A Relational Approach to the Welfare of the Child in Selective Reproduction* , Michelle Taylor-Sands’ (2016) 30 International Journal of Law, Policy and the Family 221

Herring J, ‘Are Children More Vulnerable Than Adults?’ in Jonathan Herring, *Vulnerability, Childhood and the Law* (Springer International Publishing 2018)

Herring J, ‘Children and Vulnerability’ in Jonathan Herring, *Vulnerability, Childhood and the Law* (Springer International Publishing 2018)

Herring J and Foster C, ‘Welfare Means Relationality, Virtue and Altruism’ (2012) 32 Legal Studies 480

Herring J and Foster C, ‘Welfare Means Relationality, Virtue and Altruism’ (2012) 32 Legal Studies 480

Herring J and Wall J, ‘Autonomy, Capacity and Vulnerable Adults: Filling the Gaps in the Mental Capacity Act’ (2015) 35 Legal Studies 698

Hilhorst M and others, ‘Can We Turn down Autonomous Wishes to Donate Anonymously?: Turn down Wishes’ (2011) 24 Transplant International 1164

Hilhorst M, ‘Can We Turn down Autonomous Wishes to Donate Anonymously?: Turn down Wishes’ (2011) 24 Transplant International 1164

Hilhorst MT, Kranenburg LW and Busschbach JJV, ‘Should Health Care Professionals Encourage Living Kidney Donation?’ (2007) 10 Medicine, Health Care and Philosophy 81

HTA Code A Guiding Principles and the Fundamental Principle of Consent (Human Tissue Authority, May 2020)

HTA Code of Practice F Donation of Solid Organs and Tissues for Transplantation, Part one: Living organ donation (Human Tissue Authority, May 2020)

HTA Code of Practice F Donation of Solid Organs and Tissues for Transplantation, Part two: Deceased organ and tissue donation (Human Tissue Authority, May 2020)

HTA Code of Practice G Donation of Allogeneic Bone Marrow and Peripheral Blood Stem Cells for Transplantation (Human Tissue Authority, April 2017)

HTA Code of Practice on the Human Transplantation (Wales) Act 2013 (Human Tissue Authority, updated May 2020)

HTA Guidance for living organ donors on the Human Tissue Authority's independent assessment process (Human Tissue Authority, September 2012)

HTA Guidance for living organ donors on the Human Tissue Authority's independent assessment process (Human Tissue Authority, November 2018)

HTA Guidance for Transplant Teams and Independent Assessors (Human Tissue Authority, updated December 2017)

HTA Guidance for Transplant Teams, Independent Assessors, and Accredited Assessors in Scotland (Human Tissue Authority, November 2018)

Human Tissue (Scotland) Act 2006: A Guide to Its Implications for NHS Scotland

Hurst SA, 'Vulnerability in Research and Health Care; Describing the Elephant in the Room?' (2008) 22 Bioethics 191

Independent Review Group on Retention of Organs at Post Mortem: Final Report 2001

Invernizzi, A, *Children and Citizenship* (SAGE Publications Ltd 2007)

Ismail SY and others, 'Toward a Conceptualization of the Content of Psychosocial Screening in Living Organ Donors: An Ethical Legal Psychological Aspects of Transplantation Consensus' (2015) 99 Transplantation

Jackson E, *Medical Law: Text, Cases, and Materials* (5th edn. Oxford University Press 2019)

Jacob MA, 'Another Look at the Presumed-versus-Informed Consent Dichotomy in Postmortem Organ Procurement' (2006) 20 Bioethics 293

Jansen LA, 'Child Organ Donation, Family Autonomy, and Intimate Attachments' (2004) 13 Cambridge Quarterly of Healthcare Ethics

'John Erskine, An Institute of the Law of Scotland, 1824, Vol I, VI'

Kagan S, 'XIV—Me and My Life' (1994) 94 Proceedings of the Aristotelian Society 309

Kamm FM, 'Morality, Mortality Volume I: Death and Whom to Save From It' *Death and Whom to Save from It* (Oxford University Press 1998)

Kane F, Clement G and Kane M, 'Live Kidney Donations and the Ethic of Care' (2008) 29 Journal of Medical Humanities 173

Kant I, *Critique of Practical Reason* (Bobbs-Merrill Company, Inc 1949)

Kant, Immanuel, Mary J. Gregor, Jens Timmermann, et al. *, 'Groundwork of the Metaphysics of Morals'*, (Cambridge University Press 2012)

Kant I, *Foundations of the Metaphysics of Morals* (The Bobbs-Merrill Company, Inc 1959)

Kassirer JP, 'Adding Insult to Injury. Usurping Patients' Prerogatives' (1983) 308 The New England Journal of Medicine 898

Kausikan B, ‘Asia’s Different Standard’ (1993) Foreign Policy 24

Kennedy I, *Treat Me Right: Essays in Medical Law and Ethics* (Clarendon Press 1988)

Kesselheim JC and others, ‘Is Blood Thicker Than Water?: Ethics of Hematopoietic Stem Cell Donation by Biological Siblings of Adopted Children’ (2009) 163 Archives of Pediatrics & Adolescent Medicine 413

Kilkelly U, *Children’s Rights* (Routledge 2017)

King NM, ‘Defining and Describing Benefit Appropriately in Clinical Trials’ (2000) 28 The Journal of Law, Medicine & Ethics: A Journal of the American Society of Law, Medicine & Ethics 332

Kisch AM and others, ‘The Meaning of Being a Living Kidney, Liver, or Stem Cell Donor—A Meta-Ethnography’ (2018) 102 Transplantation 744

Kluge E-HW, ‘Competence, Capacity, and Informed Consent: Beyond the Cognitive-Competence Model’ (2005) 24 Canadian Journal on Aging / La Revue Canadienne du Vieillissement 295

Knibbe ME, Maeckelberghe ELM and Verkerk MA, ‘Confounders in Voluntary Consent about Living Parental Liver Donation: No Choice and Emotions’ (2007) 10 Medicine, Health Care and Philosophy 433

Kopelman LM, ‘The Best-Interests Standard as Threshold, Ideal, and Standard of Reasonableness’ (1997) 22 Journal of Medicine and Philosophy 271

Kramer MH, ‘Do Animals and Dead People Have Legal Rights?’ (2001) 14 Canadian Journal of Law & Jurisprudence 29

Kraut R, *What Is Good and Why: The Ethics of Well-Being* (Harvard University Press 2009)

Kuczewski MG, ‘Reconceiving the Family: The Process of Consent in Medical Decisionmaking’ (1996) 26 The Hastings Center Report 30

Ladd RE, ‘The Child as Living Donor: Parental Consent and Child Assent’ (2004) 13 Cambridge Quarterly of Healthcare Ethics

Ladyman S, ‘House of Commons - Health - Minutes of Evidence’ [2004] Under-Secretary of House of Commons Standing Committee G, col 66 4

Laing JM and others (eds), *Principles of Medical Law* (Fourth edition, Oxford University Press 2017)

Lamb ME and Sutton-Smith B, *Sibling Relationships: Their Nature and Significance across the Lifespan* (Psychology Press 2014)

Laurie G and Postan E, ‘Rhetoric Or Reality: What Is The Legal Status Of The Consent Form In Health-Related Research?’ (2013) 21 Medical Law Review 371

Lederman Z, ‘Communitarianism and Presumed Consent’ (2018) 6 Asian Bioethics Review 302

Leikin S, ‘A Proposal Concerning Decisions to Forgo Life-Sustaining Treatment for Young People’ (1989) 115 The Journal of Pediatrics 17

Lennerling A and others, ‘Living Organ Donation Practices in Europe - Results from an Online Survey’ (2013) 26 Transplant International 145

Lennerling A, Forsberg A and Nyberg G, ‘Becoming a Living Kidney Donor’ (2003) 76 Transplantation 1243

Lentine KL and Patel A, ‘Risks and Outcomes of Living Donation’ (2012) 19 Advances in Chronic Kidney Disease 220

Li J, *Can Death Be a Harm to the Person Who Dies?* (Kluwer 2002)

Lowe N and Juss S, ‘Medical Treatment - Pragmatism and the Search for Principle’ (1993) 56 The Modern Law Review 865

Łuków P, ‘Pure Altruistic Gift and the Ethics of Transplant Medicine’ (2020) 17 Journal of Bioethical Inquiry 95

Lyons B, ‘“The Good That Is Interred in Their Bones”: Are There Property Rights in the Child?’ (2011) 19 Medical Law Review 372

Lyons B, ‘Obliging Children’ (2011) 19 Medical Law Review 55

Machado N, *Using the Bodies of the Dead; Legal, Ethical and Organisational Dimensions of Organ Transplantation.* (Routledge 2019)

Mackay D and Robinson A, ‘The Ethics of Organ Donor Registration Policies : Nudges and Respect for Autonomy’ (2016) 16 The American Journal of Bioethics 3

Mackenzie C, ‘Relational Autonomy, Normative Authority and Perfectionism’ (2008) 39 Journal of Social Philosophy 512

Mackenzie C and Rogers W, ‘Autonomy, Vulnerability and Capacity: A Philosophical Appraisal of the Mental Capacity Act’ (2013) 9 International Journal of Law in Context 37

Mackenzie C and Stoljar N, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self* (Oxford University Press 2000)

Maclean A, ‘Autonomy, Consent and Persuasion’ (2006) 13 European Journal of Health Law 321

Maclean A, *Autonomy, Informed Consent and Medical Law* (Cambridge University Press 2009)

Macleod CM, ‘Conceptions of Parental Autonomy’ (1997) 25 Politics & Society 117

Malerstein AJ and Ahern MM, ‘Piaget’s Stages of Cognitive Development and Adult Character Structure’ (1979) 33 American Journal of Psychotherapy 107

Manara AR and others, ‘Donation and Transplantation Activity in the UK during the COVID-19 Lockdown’ (2020) 396 Lancet 465

Mange KC, Joffe MM and Feldman HI, 'Effect of the Use or Nonuse of Long-Term Dialysis on the Subsequent Survival of Renal Transplants from Living Donors' (2001) 344 The New England Journal of Medicine 726

Manson NC and O'Neill O, *Rethinking Informed Consent in Bioethics* (Cambridge University Press 2007)

Maple H and others, 'Motivations, Outcomes, and Characteristics of Unspecified (Nondirected Altruistic) Kidney Donors in the United Kingdom' (2014) 98 Transplantation 1182

Maple H, 'Donating a Kidney to a Stranger: A Review of the Benefits and Controversies of Unspecified Kidney Donation' (2020) 272 Annals of Surgery 45

Marteau TM and others, 'Judging Nudging: Can Nudging Improve Population Health?' (2011) 342 British Medical Journal (Clinical Research edn.) d228

Mason JK and Laurie GT, 'Consent or Property? Dealing with the Body and Its Parts in the Shadow of Bristol and Alder Hey' (2001) 64 Modern Law Review 710

Massey EK and others, 'Encouraging Psychological Outcomes After Altruistic Donation to a Stranger: Altruistic Donor Follow-Up' (2010) 10 American Journal of Transplantation 1445

Massey EK and others, 'The ELPAT Living Organ Donor Psychosocial Assessment Tool (EPAT): From "What" to "How" of Psychosocial Screening - a Pilot Study' (2018) 31 Transplant International 56

Matas AJ and others, 'Morbidity and Mortality after Living Kidney Donation, 1999-2001: Survey of United States Transplant Centers' (2003) 3 American Journal of Transplantation 830

Matesanz R and others, 'Spanish Experience as a Leading Country: What Kind of Measures Were Taken?' (2011) 24 Transplant International333

Matesanz R, Miranda B and Felipe C, 'Organ Procurement and Renal Transplants in Spain: The Impact of Transplant Coordination. Spanish National Transplant Organization (ONT)' (1994) 9 Nephrology, Dialysis, Transplantation 475

McCarthy JR, 'The Powerful Relational Language of "Family": Togetherness, Belonging and Personhood' (2012) 60 The Sociological Review 68

McGuinness Sheelagh and Brazier Margaret, 'Respecting the Living Means Respecting the Dead Too' (2008) 28 Oxford Journal of Legal Studies 297

McLean S, 'Consent and the Law: Review of the Current Provisions in the Human Fertilisation and Embryology Act 1990 for the UK Health Ministers' (1997) 3 Human Reproduction Update 593

McLean S, *Autonomy, Consent and the Law* (Routledge-Cavendish 2010)

Merle J-C, 'A Kantian Argument for a Duty to Donate One's Own Organs. A Reply to Nicole Gerrand' (2000) 17 Journal of Applied Philosophy 93

Meyer A, 'The Moral Rhetoric of Childhood' (2007) 14 Childhood 85

Meyers DT, *Self, Society, and Personal Choice* (Columbia University Press 1989)

Mill JS, *On Liberty* (Gertrude Himmelfarb ed, Reprinted, Penguin Books 1985)

Mill JS, *Utilitarianism: And, On Liberty: Including Mill's Essay on Bentham' and Selections from the Writings of Jeremy Bentham and John Austin* (2nd edn. Blackwell Pub 2003)

Mill JS and Gray J, *On Liberty and Other Essays* (Oxford University Press 2008)

Mjøen G and others, 'Long-Term Risks for Kidney Donors' (2014) 86 Kidney International 162

Moazam F, 'Families, Patients and Physicians in Medical Decision-making: A Pakistani Perspective (200) 30 Hastings Center Report 28.

Molina-Pérez A and others, 'Public Knowledge and Attitudes towards Consent Policies for Organ Donation in Europe. A Systematic Review' (2019) 33 Transplantation Reviews 1

Montgomery J, 'Children As Property?' (1988) 51 The Modern Law Review 323

Moorlock GJ, Ives J and Draper H, 'Altruism in Organ Donation - An Unnecessary Requirement: 819' (2012) 94 Transplantation Journal 143

Morley MT, 'Proxy Consent to Organ Donation by Incompetents' (2002) 111 The Yale Law Journal 1215

Mumford S, 'Bone marrow donation – the law in context' (1998) 10 Child and Family Law Quarterly 135

Murphy TH, 'Minor Donor Consent to Transplant Surgery: A Review of the Law' (1978) 62 Marquette Law Review 23

Musquera M and others, 'Outcomes after 20 Years of Experience in Minimally Invasive Living-Donor Nephrectomy' (2022) 40 World Journal of Urology 807

Muzaale AD and others, 'Risk of End-Stage Renal Disease Following Live Kidney Donation' (2014) 311 Journal of the American Medical Association 579

Nagel T, 'Death' (1970) 4 Noûs 73

Nagel T, *The Possibility of Altruism* (Princeton University Press 1978)

Nair M and Peate I (eds), *Fundamentals of Applied Pathophysiology: An Essential Guide for Nursing and Healthcare Students* (2nd edn. Wiley-Blackwell 2013)

Nedelsky J, 'Reconceiving Autonomy: Sources, Thoughts and Possibilities' 1 Yale Journal of Law and Feminism 31

Neill OO, 'Paternalism and Partial Autonomy' (1984) 10 173

Nelson JL, 'Taking Families Seriously' (1992) 22 The Hastings Center Report 6

Nelson JL, ‘Internal Organs, Integral Selves, and Good Communities: Opt-out Organ Procurement Policies and the “Separateness of Persons”’ (2011) 32 Theoretical Medical Bioethics 289

‘New Approach to Organ and Tissue Donation in England: Government Response to Public Consultation’ 28

Nicholas B, *An Introduction to Roman Law* (Reprint, Clarendon Press 1995)

Nickels MW and others, ‘A Psychosocial Evaluation Process for Living Liver Donors: The University of Rochester Model’ (2011) 41 International Journal of Psychiatry in Medicine 295

Noggle R, ‘For the Benefit of Another: Children, Moral Decency, and Non-Therapeutic Medical Procedures’ (2013) 25 HEC Forum 289

Norrie K and Wilkinson A, *The Law Relating to Parent and Child in Scotland* (Third edition, W Green 2013)

Noyes J and others, ‘Short-Term Impact of Introducing a Soft Opt-out Organ Donation System in Wales: Before and after Study’ (2019) 9 BMJ Open e025159

Nozick R, *Anarchy, State and Utopia* (Blackwell 1974)

Nuffield Council on Bioethics (ed), *Human Tissue, Ethical and Legal Issues* (KKS Printing 1995)

‘Nuffield Council on Bioethics, *Human Bodies: Donation for Medicine and Research* (London: Nuffield Council on Bioethics 2011)

Nussbaum MC, *Women and Human Development: The Capabilities Approach* (2000)

O’Keeffe L and others, ‘Mid- and Long-Term Health Risks in Living Kidney Donors: A Systematic Review and Meta-Analysis’ (2018) 168 Annals of Internal Medicine 276

O’Neill O, *Constructions of Reason: Explorations of Kant’s Practical Philosophy* (Cambridge University Press 1989)

O'Neill, *Autonomy and Trust in Bioethics* (Cambridge University Press 2002)

O’Neill O, ‘Some Limits of Informed Consent.’ (2003) 29 Journal of Medical Ethics 4

Owen G and others, ‘Mental Capacity and Decisional Autonomy: An Interdisciplinary Challenge’ (2009) 52 Inquiry 79

Palmer L, ‘Should Liability Play a Role in Social Control of Biobanks?’ (2005) 33 Journal of Law, Medicine & Ethics 70

Parsons J, ‘Ensuring Appropriate Assessment of Deemed Consent in Wales’ (2019) 45 Journal of Medical Ethics 210

Parsons J, ‘Deemed Consent for Organ Donation: A Comparison of the English and Scottish Approaches’ (2021) 8 Journal of Law and the Biosciences lsab003

Partridge E, ‘Posthumous Interests and Posthumous Respect’ (1981) 91 Ethics 243

Pattinson, *Medical Law and Ethics* (Sweet & Maxwell (UK) 2020)

Pattinson S, 'Directed Donation and Ownership of Human Organs' (2011) 31 Legal Studies 392

Paul EF, Miller FD and Paul J (eds), *Altruism* (Cambridge University Press 1993)

'Payne, J. Scottish Parliamentary Debate on the Organ Donation Taskforce (2008a) Report, 'Organs for Transplants: A Report', SPICe Briefing, 5th March 2008'

Pellegrino E and Thomasma D, *For the Patient's Good: The Restoration of Beneficence in Health Care* (Oxford University Press 1988)

Pentz R and others, 'Designing an Ethical Policy for Bone Marrow Donation by Minors and Others Lacking Capacity' (2004) 13 Cambridge Quarterly of Healthcare Ethics 149

Pitcher G, 'The Misfortunes of the Dead.' (1984) 21 American Philosophical Quarterly 183

Potts S and others, 'Mental Health Assessment of Altruistic Non-Directed Kidney Donors: An EAPM Consensus Statement' (2018) 107 Journal of Psychosomatic Research 26

Potts S, 'Transplant Psychiatry' (2009) 39 The Journal of the Royal College of Physicians of Edinburgh 331

Price D, 'Living Kidney Donation in Europe: Legal and Ethical Perspectives - the EUROTOLD Project' (1994) 7 Suppl 1 Transplant International S665

Price D, 'From Cosmos and Damian to Van Velzen: The Human Tissue Saga Continues' (2003) 11 Medical Law Review 1

Price D, *Human Tissue in Transplantation and Research: A Model Legal and Ethical Donation Framework* (Cambridge University Press 2010)

Price D, *Legal and Ethical Aspects of Organ Transplantation* (Cambridge University Press 2000)

Probert R, Gilmore S and Herring J (eds), *Responsible Parents and Parental Responsibility* (Hart Pub 2009)

Quigley M, 'Nudging for Health: On Public Policy and Designing Choice Architecture' (2013) 21 Medical Law Review 588

Ralph AF and others, 'Donor and Recipient Views on Their Relationship in Living Kidney Donation: Thematic Synthesis of Qualitative Studies' (2017) 69 American Journal of Kidney Diseases 602

Rawls J, *A Theory of Justice* (Rev edn. Belknap Press of Harvard University Press 1999)

Rawls J and Freeman SR, *Collected Papers* (Harvard University Press 1999)

Rawson B and Australian National University, *The Family in Ancient Rome: New Perspectives* (Cornell University Press 1992)

Raymond B, *Posthumous Harm: Why the Dead Are Still Vulnerable* (Lexington Books 2013)

Raz J, *The Morality of Freedom* (Oxford University Press 1986)

Redmon RB, ‘How Children Can Be Respected as “ends” yet Still Be Used as Subjects in Non-Therapeutic Research’ (1986) 12 Journal of Medical Ethics 77

Reece H, ‘The Paramountcy Principle: Consensus or Construct?’ (1996) 49 Current Legal Problems 267

Reese PP and others, ‘Creating a Medical, Ethical, and Legal Framework for Complex Living Kidney Donors’ (2006) 1 Clinical journal of the American Society of Nephrology: CJASN 1148

Reese PP, Boudville N and Garg AX, ‘Living Kidney Donation: Outcomes, Ethics, and Uncertainty’ (2015) 385 The Lancet 2003

Robbennolt JK, Weisz V and Lawson CM, ‘Advancing The Rights Of Children And Adolescents To Be Altruistic: Bone Marrow Donation By Minors’ (1994) 9 Journal of Law and Health 35

Roberts JTF, ‘Autonomy, Competence and Non-Interference’ (2018) 30 HEC Forum 235

Rodrigue JR and others, ‘Measuring the Expectations of Kidney Donors: Initial Psychometric Properties of the Living Donation Expectancies Questionnaire’ (2008) 85 Transplantation 1230

Rodrigue, ‘Altruistic Kidney Donation to a Stranger: Psychosocial and Functional Outcomes at Two US Transplant Centers’ (2011) 91 Transplantation 772

Ross LF, ‘Moral Grounding for the Participation of Children as Organ Donors’ (1993) 21 Journal of Law, Medicine & Ethics 251

Ross LF, ‘Justice for Children: The Child As Organ Donor’ (1994) 8 Bioethics 105

Ross LF, ‘Health Care Decision making by Children Is It in Their Best Interest?’ (1997) 27 The Hastings Center Report 41

Ross LF, *Children, Families, and Health Care Decision Making* (Clarendon Press 1998)

Ross LF, ‘Should All Living Donors Be Treated Equally?’ (2002) 74 Transplantation 418

Ross LF and Thistlethwaite JR, *The Living Donor as Patient: Theory and Practice* (Oxford University Press 2022)

Rossler B, ‘Problems with Autonomy’ (2002) 17 Hypatia 143

Rostill LD, ‘The Ownership That Wasn’t Meant to Be: Yearworth and Property Rights in Human Tissue’ (2014) 40 Journal of Medical Ethics 14

The Royal College of Surgeons of England, ‘Consent: Supported Decision-Making – A Guide to Good Practice’ (November 2018)

Royal Liverpool Children’s Inquiry and Redfern M (eds), *The Royal Liverpool Children’s Inquiry Report* (Stationery Office 2001)

Russell S and Jacob RG, ‘Living-Related Organ Donation: The Donor’s Dilemma’ (1993) 21 Patient Education and Counseling 89

Salter EK, ‘Deciding for a Child: A Comprehensive Analysis of the Best Interest Standard’ (2012) 33 Theoretical Medicine and Bioethics 179

Sanner MA, ‘The Donation Process of Living Kidney Donors’ (2005) 20 Nephrology Dialysis Transplantation 1707

Sauder R and Parker LS, ‘Autonomy’s Limits: Living Donation and Health-Related Harm’ (2001) 10 Cambridge Quarterly of Healthcare Ethics 399

Saunders B, ‘Opt-out Organ Donation without Presumptions’ (2012) 38 Journal of Medical Ethics 69

Saunders B, ‘Altruism or Solidarity? The Motives for Organ Donation’ (2012) 26 Bioethics 376

Saunders B, ‘How Altruistic Organ Donation May Be (Intrinsically) Bad’ (2018) 44 Journal of Medical Ethics 681

Saunders J, ‘Bodies, Organs and Saving Lives: The Alternatives’ (2010) 10 Clinical Medicine 26

Savulescu J, ‘Substantial Harm but Substantial Benefit’ (1996) 312 BMJ 241

Schoeman F, ‘Rights of Children, Rights of Parents, and the Moral Basis of the Family’ (1980) 91 Ethics 6

Schoeman F, ‘Protecting Intimate Relationships: Children’s Competence and Children’s Rights’ (1982) 4 IRB: Ethics and Human Research 1

Schoeman F, ‘Parental Discretion and Children’s Rights: Background and Implications for Medical Decision-Making’ (1985) 10 Journal of Medicine and Philosophy 45

Schultz B, ‘L. W. Sumner ,Welfare, Happiness, and Ethics, Oxford, Clarendon Press, 1996, Pp. Xii + 239.’ (2002) 14 Utilitas 403

Schweda M and Schicktanz S, ‘The “Spare Parts Person”? Conceptions of the Human Body and Their Implications for Public Attitudes towards Organ Donation and Organ Sale’ (2009) 4 Philosophy, Ethics, and Humanities in Medicine 4

Schweitzer J and others, ‘Psychological Consultation before Living Kidney Donation: Finding out and Handling Problem Cases’ (2003) 76 Transplantation 1464

Scottish Law Commission, *Report on the Legal Capacity and Responsibility of Minors and Pupils* (HMSO 1987)

Secker B, ‘The Appearance of Kant’s Deontology in Contemporary Kantianism: Concepts of Patient Autonomy in Bioethics.’ (1999) 24 The Journal of Medicine and Philosophy 43

Segev DL, ‘Perioperative Mortality and Long-Term Survival Following Live Kidney Donation’ (2010) 303 Journal of the American Medical Association 959

Shampo MA and Kyle RA, ‘Joseph E. Murray—Nobel Prize for Organ Transplantation’ (2001) 76 Mayo Clinic Proceedings 240

Shapiro T, ‘What Is a Child?’ (2015) 15 Thinking: The Journal of Philosophy for Children 4

Sharif A, ‘Presumed Consent Will Not Automatically Lead to Increased Organ Donation’ (2018) 94 Kidney International 249

Sharif A and Moorlock G, ‘Influencing Relatives to Respect Donor Autonomy: Should We Nudge Families to Consent to Organ Donation?’ (2018) 32 Bioethics 155

Sherwin S and Winsby M, ‘A Relational Perspective on Autonomy for Older Adults Residing in Nursing Homes: A Relational Perspective on Autonomy for Older Adults’ (2011) 14 Health Expectations 182

Siegal G and Bonnie RJ, ‘Closing the Organ Gap: A Reciprocity-Based Social Contract Approach’ (2006) 34 The Journal of Law, Medicine & Ethics 415

Silverman H, ‘The Role of Emotions in Decisional Competence, Standards of Competency, and Altruistic Acts’ (1997) 8 The Journal of Clinical Ethics 171

Simmons RG, Marine SK and Simmons RL, *Gift of Life: The Effect of Organ Transplantation on Individual, Family, and Societal Dynamics* (Transaction Books 1987)

Singer PA and others, ‘Ethics of Liver Transplantation with Living Donors’ (1989) 321 The New England Journal of Medicine 620

Sixty-Third World Health Assembly, World Health Organization, ‘WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation’ (2010) 11 Cell and Tissue Banking 413

Sood AB and others, ‘Children’s Reactions to Parental and Sibling Death’ (2006) 8 Current Psychiatry Reports 115

Sperling D, *Posthumous Interests: Legal and Ethical Perspectives* (Cambridge University Press 2008)

Spielman B (ed), *Organ and Tissue Donation: Ethical, Legal, and Policy Issues* (Southern Illinois University Press 1996)

Spital A, ‘Ethical Issues in Living Organ Donation: Donor Autonomy and Beyond’ (2001) 38 American Journal of Kidney Diseases 189

Stair JD and Law Society of Scotland (eds), *The Laws of Scotland: Stair Memorial Encyclopaedia* (Reissue [ed], Law Society of Scotland : Butterworths 1999)

Steel J (ed), *Living Donor Advocacy: An Evolving Role Within Transplantation* (Springer New York 2014)

Steiner R and Matas AJ, ‘First Things First: Laying the Ethical and Factual Groundwork for Living Kidney Donor Selection Standards’ (2008) 8 American Journal of Transplantation 930

Stoljar N, 'Informed Consent and Relational Conceptions of Autonomy' (2011) 36 Journal of Medicine and Philosophy 375

Stothers L, Gourlay WA and Liu L, 'Attitudes and Predictive Factors for Live Kidney Donation: A Comparison of Live Kidney Donors versus Nondonors' (2005) 67 Kidney International 1105

Sunstein CR, 'Deciding by Default' 162 University of Pennsylvania Law Review 58

Sutherland E, McCall Smith A and Mason JK (eds), *Family Rights: Family Law and Medical Advance* (Edinburgh University Press 1990)

Tai MC, 'Developing a Culturally Relevant Bioethics for Asian People' (2001) 27 Journal of Medical Ethics 51

Tauber AI, 'Sick Autonomy' (2003) 46 Perspectives in Biology and Medicine 484

Taylor JS (ed), *Personal Autonomy: New Essays on Personal Autonomy and Its Role in Contemporary Moral Philosophy* (Cambridge University Press 2005)

Taylor R, 'Reversing the Retreat from Gillick? R (Axon) v Secretary of State for Health' (2007) 19 Family Law 17

Taylor RS, 'Kantian Personal Autonomy' (2005) 33 Political Theory 602

Taylor-Sands M, 'Saviour Siblings and Collective Family Interests' (2010) 20 Monash Bioethics Review 12.1

Testa G, 'Ethical Issues Regarding Related and Nonrelated Living Organ Donors' (2014) 38 World Journal of Surgery 1658

Thaler RH and Sunstein CR, *Nudge: Improving Decisions about Health, Wealth, and Happiness* (Yale University Press 2008)

The Authors for the Live Organ Donor Consensus Group, 'Consensus Statement on the Live Organ Donor' (2000) 284 Journal of the Journal of the American Medical Association 2919

Then S-N, 'Best Interests: The "Best" Way for Courts to Decide If Young Children Should Act as Bone Marrow Donors?' (2017) 17 Medical Law International 3

Todres J, 'Independent Children And The Legal Construction Of Childhood' 23 Southern California Interdisciplinary Law Journal 44

Tomasini F, *Remembering and Disremembering the Dead* (Palgrave Macmillan UK 2017)

Tong A and others, '"It Was Just an Unconditional Gift." Self Reflections of Non-Directed Living Kidney Donors: Perspectives of Altruistic Donors' (2012) 26 Clinical Transplantation 589

Truog RD, 'The Ethics of Organ Donation by Living Donors' (2005) 353 New England Journal of Medicine 444

Truog RD, 'When Does a Nudge Become a Shove in Seeking Consent for Organ Donation?' (2012) 12 The American Journal of Bioethics 42

Ursin LØ, 'Personal Autonomy and Informed Consent' (2009) 12 Medicine, Health Care and Philosophy 17

Van Assche K and others, 'Living Tissue and Organ Donation by Minors: Suggestions to Improve the Regulatory Framework in Europe' (2016) 16 Medical Law International 58

Varelius J, 'Decision-Making Competence and Respect for Patient Autonomy' (2011) 8 Res Cogitans 10

Veatch RM, 'Autonomy's Temporary Triumph' (1984) 14 The Hastings Center Report 38

Veatch RM, 'The Foundations of Bioethics' (1999) 13 Bioethics 206

Veatch RM and Ross LF, *Transplantation Ethics* (2nd edn. Georgetown University Press 2015)

Wald M, 'State Intervention on Behalf of "Neglected" Children: A Search for Realistic Standards' (1975) 27 Stanford Law Review 985

Wallbank JA, Choudhry S and Herring J, *Rights, Gender and Family Law* (Routledge 2010)

Waluchow W, 'Feinberg's Theory of "Preposthumous Harm"' (1986) 25 Dialogue 727

Wasserstrom RA, *Morality and the Law* (Wadsworth 1971)

Wellman C, *Real Rights* (Oxford University Press 1995)

Weithorn LA, 'A Constitutional Jurisprudence of Children's Vulnerability' 69 Hastings Law Journal 97

Weyl-Ben-Arush M, 'The Price of the Successful Treatment of Pediatric Malignancies' (2017) 13 Current Pediatric Reviews 4

Wheeler R, 'Gillick or Fraser? A Plea for Consistency over Competence in Children' (2006) 332 British Medical Journal 807

White L, 'The Need for Authenticity-Based Autonomy in Medical Ethics' (2018) 30 HEC Forum 191

Wicclair M, 'Ethics and Research with Deceased Patients' [2008] Cambridge Quarterly of Healthcare Ethics 87

Wicclair MR, 'Patient Decision-Making Capacity and Risk' (1991) 5 Bioethics 91

Wilkinson T, 'Dworkin on Paternalism and Well-Being' (1996) 16 Oxford Journal of Legal Studies 433

Wilkinson T, 'Last Rights: The Ethics of Research on the Dead' (2002) 19 Journal of Applied Philosophy 31

Wilkinson TM, *Ethics and the Acquisition of Organs* (Oxford University Press 2011)

Williams NJ, 'On Harm Thresholds and Living Organ Donation: Must the Living Donor Benefit, on Balance, from His Donation?' (2018) 21 Medicine, Health Care and Philosophy 11

Williams V and others, ‘Best Interests Decisions: Professional Practices in Health and Social Care’ (2014) 22 Health & Social Care in the Community 78

Willis BH and Quigley M, ‘Opt-out Organ Donation: On Evidence and Public Policy’ (2014) 107 Journal of the Royal Society of Medicine 56

Yeung K, ‘Nudge as Fudge: Nudge as Fudge’ (2012) 75 The Modern Law Review 122

Young H, ‘The Right to Posthumous Bodily Integrity and Implications of Whose Right It Is’ (2013) 14 Marquette Elder’s Advisor 72

Young R, *Personal Autonomy: Beyond Negative and Positive Liberty* (Croom Helm 1986)

Zink S and Wertlieb SL, ‘Forced Altruism Is Not Altruism’ (2004) 4 The American Jourl of Bioethics 29