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7. Child welfare and the regulation of access to uterus transplantation

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1. INTRODUCTION

Uterus transplantation (UTx) combined with IVF (UTx-IVF) is a novel reproductive-transplant programme of treatment that aims to provide a solution to absolute uterine factor infertility (AUFI). Notably, IVF is required as part of this package due to the current clinical infeasibility of connecting the uterine graft to the recipient's fallopian tubes to enable spontaneous conception. Since the first live birth following a successful UTx in Sweden in 2014,[1] the prospect and practice of gestation in a transplanted uterus has sparked lively ethical and legal discussion in the academic literature, the media and the public sphere. As the chapters in this edited collection demonstrate, the issues raised by UTx are broad, impacting not only the immediate key stakeholders involved, but also wider society. Given that the purpose of UTx-IVF treatment is to enable recipients to have children, a further significant issue that must be addressed is that of child welfare. By this I mean that we must examine the role that considerations about the welfare of a hypothetical child who may be born to the recipient of a donor uterus (and their partner) do and should have in our ethical and legal reasoning about UTx.

In the context of assisted reproductive technologies (ARTs), many countries either legally mandate, or recommend through professional guidance, that clinics consider the welfare of a to-be-conceived child prior to providing fertility treatment.[2] In essence, this is a pre-conception welfare principle

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[1] M. Brännström and others, 'Livebirth after Uterus Transplantation' (2015) 385 The Lancet 607

[2] See L. O'Donovan, 'Why UTx Requires Us to Rethink the Role of the Pre-conception Welfare Principle' (2022) 9 JLB 1; J. Lind, 'Child Welfare Assessments and the Regulation of Access to Publicly Funded Fertility Treatment' (2020) 10 Reproductive Biomedicine & Society Online 19; S.L. de Lacey, K. Peterson and J. McMillan, 'Child Interests in Assisted Reproductive Technology:

(PCWP) – a threshold requirement to determine whether or not any concerns about a future child's welfare exist such that treatment should not be provided. While the aim of the PCWP is the protection of potential future stakeholders (hypothetical children), it is enacted through the scrutiny of existing stakeholders (the prospective parent(s)). Despite comprehensive academic criticism of the principle,[3] not only does it endure in its various forms around the world as a condition of access to assisted conception services, but it has been further suggested that child welfare considerations could be used to assist with the allocation of donor uteri in the context of UTx.[4] This would transform the PCWP from a threshold tool determining treatment provision into a prioritisation and optimisation tool – something far beyond its original purpose.

In this chapter, I seek to critically analyse the role of the PCWP in the regulation of UTx. The structure is as follows. In section 2, the origins of the principle and how it operates in practice are explored. In section 3, I set out a brief exposition of some of the key criticisms levelled against the PCWP providing key context for the critique that follows in section 4. The final section examines the relevance of the PCWP in the context of UTx. It first considers the role and scope of the principle as a threshold tool to determine patient access to assisted conception services as part of the UTx programme of treatment. Thereafter, it challenges recommendations that pre-conception welfare considerations should inform transplant listing and allocation policy on the basis that the inclusion of social criteria in transplant policy is both ethically problematic and unjustly burdensome for patients. This analysis will primarily focus on the PCWP as it exists in United Kingdom (UK) legislation. However, given that the principle exists (in different forms, though materially the same) in multiple jurisdictions, the general critique advanced here also has direct relevance for other countries where UTx is being pursued.

How Is the Welfare Principle Applied in Practice?' (2015) 30 Human Reproduction 616; T. Egeland, T.K. Rudd, H.I. Hanevik et al, 'A Study of the Experience of Norwegian IVF Physicians in Evaluating the Parenting Capacity of Patients' (2023) Reproductive Biomedicine Online 103368.

[3] E. Jackson, 'Conception and the Irrelevance of the Welfare Principle' (2002) 65 Mod L Rev 176; E. Blyth and others, 'Welfare of the Child Assessments in Assisted Conception: A Social Constructionist Perspective' (2008) 26 J Reprod Infant Psychol 31; S. Waxman, 'Applying the Pre-conception Welfare Principle and the Harm Threshold: Doing More Harm than Good?' (2017) 17 Med Law Int 134

[4] M. Bayefsky and B.E. Berkman, 'The Ethics of Allocating Uterine Transplants' (2016) 25 Camb Q Healthc Ethics 350; B. Bruno and K.S. Arora, 'Uterus Transplantation: The Ethics of Using Deceased versus Living Donors' (2018) 18 AJOB 6

2. WHAT IS THE PRE-CONCEPTION WELFARE PRINCIPLE?

Prior to interrogating the role of the PCWP in the context of UTx, it is necessary to unpick and explore its origins and substance, to foreground the critical analysis that follows.

2.1 The Origins of the Principle in the United Kingdom

In the UK, the PCWP was placed on statutory footing with the enactment of the Human Fertilisation and Embryology Act 1990 (the 1990 Act). This followed the earlier 1984 publication of the Report of the Committee of Inquiry into Human Fertilisation and Embryology led by Mary Warnock.[5] Notably, the Report acknowledged that there may be occasions where clinicians 'may, after discussion with professional health and social work colleagues, consider that there are valid reasons why infertility treatment would not be in the best interests of the patient, *the child that may be born following treatment, or the patient's immediate family*'.[6] It further recommended that all of the services considered by the Committee (including IVF, intrauterine insemination and embryo research) should only be provided under licence.[7]

Indeed, to go back to its origins in UK legislation, the inclusion of a child welfare principle in assisted reproductive technology (ART) regulation was, perhaps, inevitable given the longstanding focus of English law on the paramountcy of child welfare in disputes about children.[8] To those members of the Commons and the Lords (the UK Parliament) debating what was then a proposed bill to regulate developments in human reproduction, it was axiomatic that a principle focused on child welfare should be included.[9] For instance, as Jackson points out, its addition to the bill was neither questioned nor defended.[10] The rationale for this appears to be the fact that the purpose of fertility treatment is the creation of children, and, given the interests of children are fundamental in child law, so too should those interests be a key consideration in the regulation governing their creation via third-party assistance. This can

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[5] Report of the Committee of Inquiry into Human Fertilisation and Embryology (1984) Cmnd 9314 (Warnock Report)

[6] ibid, 12 (emphasis added)

[7] ibid, 77

[8] See Guardianship of Infants Act 1925; Guardianship of Minors Act 1971; Children Act 1989

[9] Jackson (n3), 180

[10] ibid

be seen in the multiple references to the paramountcy of child welfare in the parliamentary debates in 1990.[11] Thus, at least in the UK, the PCWP appears to have been derived from convention.

In the absence of any regulatory framework at the time, the 1990 Act was an ambitious piece of legislation. Paragraph 1 of Schedule 2 to the Act lists the activities that may be authorised by a licence. This includes the creation, procuring, keeping, testing, processing and distribution of embryos and gametes.[12] Section 13 makes it clear that every licence under Paragraph 1 of Schedule 2 is subject to the conditions contained therein. This applies to all cases of fertility treatment including the provision of IVF services (with or without intracytoplasmic sperm injection), intrauterine insemination, pre-implantation genetic testing and proscribed processes designed to prevent the transmission of serious mitochondrial disease. In its original form, s13(5) provided that a 'woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of the treatment (including the need of that child for a father), and of any other child who may be affected by the birth'.

Almost 20 years after its passing, the 1990 Act was amended by the Human Fertilisation and Embryology Act 2008 (hereafter the 2008 Act). Indeed, in order to keep up with scientific and social developments, reform of this major piece of legislation was inevitable. While the 1990 Act continues to remain in force, the 2008 Act brought with it several important legislative changes, one of the most controversial of which was the small but significant change to the welfare principle contained in s13(5). Section 14(2)(b) of the 2008 Act amended s13(5) of the 1990 Act by replacing the child's need 'for a father' with a need 'for supportive parenting'. The principle contained in s13(5) otherwise remained intact.

Amendment of the requirement directing clinics to consider the child's need for a father was welcomed as a measure to remove discrimination against single women and lesbian couples seeking fertility treatment.[13] However, it was, and remains, disappointing that in the four years of reviews, consultations

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[11] For example, see HL Deb 06 March 1990 vol 516 cc1053-115 and HC Deb 02 April 1990 vol 170 cc914–85

[12] Schedule 2, para 1(1)(a)–(g) of the Human Fertilisation and Embryology Act (as amended)

[13] J. McCandless and S. Sheldon, 'The Human Fertilisation and Embryology Act 2008 and the Tenacity of the Sexual Family Form' (2010) 73 Modern Law Review 175; E. Lee, S. Sheldon and J. Macvarish, 'After the "Need for… a Father": "The Welfare of the Child" and "Supportive Parenting" in Assistive Conception Clinics in the UK' (2017) 6 Families, Relationships and Societies 71

and debates culminating in the 2008 Act, the premise of the required welfare assessment prior to the provision of treatment was never questioned.

2.2 Child Welfare and the International Context

Multiple jurisdictions utilise some form of child welfare principle as a threshold tool to determine access to treatment provision. This is either enshrined in legislation or contained within industry guidance to the fertility sector from professional organisations. For example, in Australia,[14] Canada,[15] New Zealand[16] and Sweden,[17] the future child's welfare is expressly protected by statute. In terms of the wording of any legislative provisions, child welfare is either of paramount importance,[18] to be given priority[19] or an important consideration,[20] or treatment can only be carried out if it is 'assumed that the child will grow up in good circumstances'.[21]

In the United States, on the other hand, the child welfare principle is not contained within any federal statute. Rather, it is the Ethics Committee of the American Society for Reproductive Medicine (ECASRM, a non-governmental professional organisation) that advises clinics that assessing child welfare is a 'valid consideration'.[22] The Committee is clear that '[f]ertility programs may withhold services from prospective patients on the basis of well-grounded reasons that those patients will be unable to provide minimally adequate or safe care for offspring'.[23] It suggests further that '[f]ertility programs may

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[14] South Australia Reproductive Technology Act 1988; Victoria Infertility Treatment Act 1995; Western Australia Human Reproductive Technology Amendment Act 2004; New South Wales Assisted Reproductive Technology Act 2007

[15] Assisted Human Reproduction Act 2004

[16] Human Assisted Reproductive Technology Act 2004

[17] SFS (The Swedish Statute Book), 2006. 351 Lagen om genetisk integritet [Act on genetic integrity].

[18] As seen in section 4A of the Assistive Reproductive Treatment Act 1988 (South Australia)

[19] Section 2 of the Assisted Human Reproduction Act 2004 (Canada)

[20] Section 4(1) Human Assisted Reproductive Technology Act 2004 (New Zealand)

[21] Section 3 of the Genetic Integrity Act 2006 (Sweden)

[22] Ethics Committee of the American Society for Reproductive Medicine, 'Child-rearing Ability and the Provision of Fertility Services: An Ethics Committee Opinion' (2017) 108 Fertil Steril 944, 944

[23] ibid, 944

provide services to prospective patients who would benefit from medical treatment except when significant harm to a future child is likely'.[24]

While the form of this principle may differ across jurisdictions, its substance is largely the same – consideration of a hypothetical child's welfare *prior* to the provision of that treatment is either legally mandated or viewed as part of professional good practice standards. As such it is clear that assessments of child welfare are likely to be relevant to a significant number of patients pursuing UTx-IVF treatment.

2.3 The Operation of the Principle in Practice

In practice, in the UK, the Human Fertilisation and Embryology Authority (the HFEA, the regulatory body that oversees fertility treatment and embryo research), frames the PCWP as a risk assessment exercise. For example, Guidance Note 8 in its current Code of Practice (CoP) sets out a list of different factors to consider during the assessment process.[25] This includes, but is not limited to, information about: convictions; familial violence or discord; mental or physical conditions; substance abuse; and circumstances that the centre considers likely to cause serious harm to any child.[26] This requires treatment providers to weigh up any information disclosed in relation to these factors to determine if they indicate a risk of serious harm or neglect to any child who may be born from treatment, or to an existing child of the family.[27]

Regarding the child's need for supportive parenting, the CoP advises centres that 'it is presumed that that all prospective parents will be supportive parents, in the absence of any reasonable cause for concern'.[28] While such a presumption may frame the assessment of welfare more positively for patients, it lacks legal force. A further shortcoming of section 13(5) of the 1990 Act as amended is the fact that the term 'supportive parenting' is not defined in the legislation. As will be explored further below, this necessarily creates scope for fertility centres to impose their own value-laden judgements and subjective bias when discharging their statutory responsibility.

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[24] ibid

[25] Human Fertilisation and Embryology Authority, Code of Practice, Version 9.4 (London, Redman Place, 2023), 92 https://portal.hfea.gov.uk/media/za0j5qqr/2023-10-26-code-of-practice-v9-4.pdf accessed 1 December 2023, 90–3

[26] ibid, 92

[27] ibid, 92

[28] ibid, 93

3. A BRIEF CRITIQUE OF THE PRE-CONCEPTION WELFARE PRINCIPLE

Though the PCWP has been enshrined in legislation in the UK for the past 34 years, it nevertheless remains a contestable requirement. It is not the purpose of this chapter to provide a full rehearsal of all of the objections to the PCWP.[29] However, a brief overview of some of the key objections is warranted so that the role of the principle in our ethical and legal reasoning about UTx may be fully interrogated.

Perhaps one of the main objections to the principle is the subjective nature of the assessment it requires centres to undertake, and the ground for discrimination to which this gives rise. Indeed, not only does section 13(5) of the HFE Act 1990 (as amended) fail to define the term ‘supportive parenting’, but ‘welfare’ itself is not defined or elaborated upon. The HFEA’s CoP does offer a definition of ‘supportive parenting’ that centres may consider, but the statute nevertheless remains silent. It has been suggested that moral reasoning is ‘in no way alien to the operation of the law’,[30] and this is clearly evidenced by the PCWP in that it necessarily invites moral judgement in the exercise of its interpretation and application precisely because the terms are vague and undefined. Indeed, as Brassington argues, section 13(5) ‘was plainly taking a moral (or moralising) position, since “need” cannot be understood as relating to anything other than something to do with [a] child’s best interests’.[31]

While, as noted above, the HFEA does provide guidance listing relevant factors for centres to consider when assessing the risk prospective patient(s) may pose to any future child, neither the CoP nor the Act offer any guidance to assessors regarding how this information should be translated into a predictive assessment of the future family environment.[32] What this means is that welfare assessments will be typically informed by the subjective views of assessors themselves regarding the family unit and the familial circumstances most conducive to child welfare. Such considerations of child welfare have also been

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[29] For a more detailed critique of the PCWP see Jackson (n3); Blyth (n3); Waxman (n3); I. Glenn Cohen, ‘Regulating Reproduction: The Problem with Best Interests’ (2012) 96 Minnesota Law Review 423; R. Tonkens, ‘Infertilism: Unjustified Discrimination of Assisted Reproduction Patients’ (2018) 35 Monash Bioethics Review 26; N.J. Williams and J. Harris, ‘What is the Harm in Harmful Conception? On Threshold Harms in Non-identity Cases’ (2014) 35 Theoretical Medicine and Bioethics 337

[30] I. Brassington, ‘On the Relationship Between Medical Ethics and the Law’ (2018) 26 Med Law Rev 225, 242

[31] ibid

[32] O’Donovan (n2), 10

seen to impact decisions taken by those responsible for local NHS budgets when it comes to determining access to fertility treatment. For example, in the UK, this can be seen in the problematic policies previously adopted by what were then called Clinical Commissioning Groups (CCGs)[33] in South-East London. Indeed, in 2019, it was reported that these CCGs had adopted a blanket policy to refuse fertility treatment to single women 'because of the known disadvantage that providing assisted conception to a single woman would cause both the child and the mother'.[34] Justifying the refusal, the fertility funding policies went on to cite an internal NHS document[35] which stated that 'a sole woman is unable to bring about the best outcomes for children'[36] and that they 'exert less control on their children'[37] and are a 'burden to society'.[38] While the CCG policy refusal to fund treatment was not explicitly set out in terms of child welfare or the language of section 13(5), it is clear that those responsible for the policy at the time were making value-laden judgements about welfare and the *ideal* family form.[39] Indeed, discussion of disadvantage, best outcomes for children, control of children and burden to society are all factors that clearly link to child welfare and supportive parenting.

In general terms, it is also argued that the PCWP is discriminatory precisely because it requires that infertile individuals who seek assistance to pursue their parenting projects be subject to scrutiny to which individuals who are able to

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[33] Clinical Commissioning Groups were clinically led NHS bodies responsible for the planning and commissioning of healthcare in specific geographically defined areas. They were dissolved in July 2022 and their functions were subsumed into new organizational bodies termed Integrated Care Systems.

[34] Gabriel Pogrund, 'NHS Trust Denies Single Women IVF Treatment', *The Times* (London, 18 August 2019) www.thetimes.co.uk/article/nhs-trusts-deny-single-women-ivf-treatment-gs9b7qxbt (accessed 5 July 2022).

[35] Note that this newspaper article (see Pogrund (n34)) reproduced excerpts of the report in question, which was removed from the NHS host website shortly after the publication of the news article.

[36] Pogrund (n34)

[37] ibid

[38] ibid

[39] It should be noted that in response to public complaints about the language used in the funding policies and media coverage of the issue, a rapid review of the policy in relation to IVF access criteria was conducted which resulted in a reversal of the decision to refuse fertility treatment to single women in 2020. See K. Johnston, 'IVF Postcode Lottery: Single Women Now Eligible after South-East London NHS Review' *Southwark News* (London, 25 January 2020) https://southwarknews.co.uk/area/southwark/ivf-postcode-lottery-single-women-now-eligible-after-south-east-london-nhs-review/

conceive without ART assistance are not.[40] Jackson, for instance, posits that this parental scrutiny transforms what would otherwise be a self-regarding decision (an exercise of reproductive autonomy) afforded appropriate decisional privacy into an other-regarding decision – a choice judged on the basis of the impact it may have on a hypothetical other.[41]

A further objection to the PCWP centres on the incoherence of the requirement. In the ART context, it is the welfare needs of a child who does not yet exist that are central to the decision as to whether treatment leading to the birth of that child should proceed. Such arguments are inherently incoherent because unless being brought into existence itself is considered to be a harm, a child born following ARTs cannot be said to be harmed if they would not otherwise have been born, unless they have a life so poor as to be 'not worth living'.[42] This is the result of a problem in philosophy often attributed to Derek Parfit, known as the 'non-identity problem'.[43]

4. THE RELEVANCE OF THE PRE-CONCEPTION WELFARE PRINCIPLE IN THE CONTEXT OF UTERUS TRANSPLANTATION

Having set out above what the PCWP is, how it is interpreted in practice and why, in general terms, it is problematic, I turn now to consider the role that child welfare considerations do, and should, have in relation to UTx.

4.1 Child Welfare and the Regulation of Fertility Treatment

In the context of UTx, as patients require IVF treatment to produce embryos prior to transplant surgery (and possibly again afterwards if embryo supply is low or has been exhausted), all patients pursuing UTx-IVF (and their partners) in the UK will be subject to an assessment of child welfare. As will be further explored in the following section, this is an important point to note because it means that at the IVF stage, potentially *before* any transplant listing or allocation decisions have been made, or indeed before patients might have even approached UTx programmes, they will have been through the welfare assessment process.

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[40] Jackson (n3); Blyth (n3); Waxman (n3); O'Donovan (n2)

[41] Jackson (n3), 182

[42] D. Parfit, *Reasons and Persons* (Clarendon Press, 1984)

[43] ibid

Indeed, it would be illegal for clinics to provide a recipient with treatment to create embryos without a welfare assessment taking place.[44] As most UTx programmes around the world and in the UK require that recipients have a minimum number of embryos available as a condition of eligibility for UTx, it seems even more likely that recipients will have already passed the threshold welfare requirement within the ART setting. As an aside, it should be noted that if, in the future, it becomes possible to connect the uterine graft to the patient's own fallopian tubes facilitating natural conception without the need for IVF, then UTx would fall outside the regulatory schema of the 1990 Act entirely. While there is not sufficient space in this chapter to explore this potential regulatory gap, I have considered this possibility elsewhere,[45] and maintain that it is an important issue which forces us to reconsider the legal distinction made between treatments to which the licence conditions of the Act apply and those to which they do not.[46]

A particular welfare concern that may be raised in relation to UTx concerns the medical risk posed by the procedure and any existing children the recipient may already have. On this issue, Hammond-Browning suggests that 'if account is taken of existing children of the family, the medical risks of this procedure further justify excluding women who are already mothers'.[47] It is important to point out that she does not posit this claim on the basis of section 13(5) of the 1990 Act. Rather, Hammond-Browning's claim is a response to the eligibility criteria for clinical trials set out by the UK UTx team which listed previous children as a recipient exclusion criterion. That said, the language of section 13(5), that is, the taking into account of any existing children (these being 'any other child who may be affected by the birth'[48]), is precisely what the PCWP requires that centres providing assisted conception services do. As such, expressed in these terms, the claim is fundamentally a welfare one.

While there may be just reason to exclude those who already have children (whether through adoption, surrogacy or previous pregnancy) on resource grounds, in my view it is problematic to suggest that a recipient's status as a parent and their responsibility for existing children justifies withholding access to a medical procedure. As I have suggested elsewhere, if we take this

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[44] See sections 3, 4, 13(5) and 41 of the Human Fertilisation and Embryology Act 1990 (as amended)

[45] See O'Donovan (n2)

[46] ibid, 16–20

[47] N. Hammond-Browning, 'UK Criteria for Uterus Transplantation: A Review' (2019) 126 BJOG 1320, 4

[48] Section 13(5) of the Human Fertilisation and Embryology Act 1990 (as amended)

seriously, it ‘would not only preclude all recipients with existing children from treatment, but may also lead to the conclusion that the birth of a second child should not be pursued due to the potential impact associated risk factors […] may have on the health of the patient and consequently the first born child’.[49] The welfare of existing children does not, for example, constitute reason to prohibit patients from seeking and consenting to other quality-of-life enhancing surgeries such as elective cosmetic surgery. Like UTx, this kind of surgery also poses physical and psychological risks to the patient, and thus singling UTx out in this way is inconsistent with the law’s approach to treatment provision and consent in other medical contexts.

4.2 Should Considerations of Child Welfare Guide Transplant Listing and Allocation Policy?

Organ transplantation is a medical treatment with two distinct stages. The first of these is the listing (threshold) stage, where a decision is made based on clinical factors about the patient’s condition and their suitability for transplantation to add them to the transplant waiting list. The second stage is the ranking (prioritisation and optimisation) stage, where a variety of different factors are used to distinguish between prospective patients on the waiting list to determine who should receive a particular organ when it becomes available. Regarding UTx, it is commonly accepted in the literature that demand for donor uteri is likely to far outweigh the available supply of donor organs.[50] This is due to the limited number of living non-directed altruistic donors, the limited number of people who die in circumstances where donation is possible, the fact that the uterus of a multiparous (someone who has given birth before) and pre-menopausal donor is generally preferred, and due to difficulties associated with obtaining familial consent to the donation of what is a non-vital organ which may be viewed as particularly sensitive for some.[51]

Thus, faced with a demand that is likely to exceed supply, careful listing and prioritisation decisions will need to be made when it comes to determining who should be able to access UTx and how uteri that become available should be allocated. However, unlike other medical conditions which may affect patients’ health to different degrees of severity, providing some way to (par-

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[49] O’Donovan (n2) 11

[50] Bayefsky and Berkman (n4); L. O’Donovan, N.J. Williams and S. Wilkinson, ‘Ethical and Policy Issues Raised by Uterus Transplants’ (2019) 131 BMB 19

[51] O’Donovan, Williams and Wilkinson (n50); N.J. Williams, L. O’Donovan and S. Wilkinson, ‘Presumed Dissent: Opt Out Organ Donation and the Exclusion of Organs and Tissues’ (2022) 30 Med Law Rev 268

tially) distinguish between patients, AUFI – the condition that UTx is being pursued to overcome – does not come in degrees. Rather, all patients 'have an equal chance i.e. no chance of reproducing "naturally"',[52] as all patients either lack the primary organ required for pregnancy and gestation, or this organ is dysfunctional, meaning pregnancy and gestation is not possible. Moreover, the 'patient benefit'[53] of transplantation is the same for all patients with AUFI seeking UTx – the possibility of having a child resulting from the patient's own pregnancy. To this end, and bearing in mind that the purpose of the transplant is reproduction, factors additional to blood group and tissue type matching will need to be considered to distinguish between prospective recipients.

A number of proposals for such additional criteria have been put forward in the literature.[54] This includes suggestions relating to: childlessness; age-related reproductive opportunity; motivation for seeking treatment; the amount of ART treatment required; factors explored by Tonkens in the previous chapter of this collection; and the primary focus of this chapter – assessments of child-rearing capacity (in other words, a child welfare assessment). In the final part of this analysis, I examine and reject the case for the inclusion of child welfare considerations in both the listing and the ranking stages of UTx.

4.2.1 Child welfare and patient listing

Bayefsky and Berkman argue that 'we should only give uteruses to people who meet certain standards for child-rearing ability'.[55] This, they suggest, comes down to the purpose of UTx – to create opportunities for parenthood. Thus, an appeal to precedent is made which seeks to draw similarities between UTx and adoption on the ground that the state already intervenes to limit the reproductive opportunity of those who are not deemed suitable in the latter example, providing justification to do so in the former given both practices concern the creation of parents.[56] However, such an appeal is unconvincing. Certainly, the state has a legal and ethical responsibility to assess the child-rearing ability of prospective adopters given that it is the state that is legally responsible for the welfare of *existing* children who are placed in the care system in the absence of someone with parental authority. In the context of UTx (and other ARTs), however, the PCWP is concerned with the welfare of a *hypothetical* child

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[52] O'Donovan, Williams and Wilkinson (50), 24

[53] NHS Blood and Transplant, 'Pol 187/4.1 Assessment of Allocation Policies for Organs from Deceased Donors' (2023) https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/30867/pol187.pdf accessed 1 December 2023

[54] Bayefsky and Berkman (n4); Bruno and Arora (n4)

[55] Bayefsky and Berkman (n4), 359

[56] ibid, 359–60

whose very existence depends on the treatment in question being provided.[57] Appealing to adoption to justify welfare assessments as a UTx listing criterion is thus a non sequitur.

Building upon their case for equivalence, Bayefsky and Berkman turn to draw a comparison between UTx and IVF, as opposed to recognising that IVF is an integral *part* of the programme of treatment and that, in many countries, child welfare is required to be assessed before assisted conception services can be provided. Further, they posit that

> certain minimum criteria are necessary in the cases of adoption and fertility treatment for three interrelated reasons: (1) because it is better to promote the best interests of some future children, even if we cannot do so for all future children; (2) so that governments and physicians are not complicit in the mistreatment of future children; and (3) because of the social responsibility to act as sound stewards of a scarce resource, which requires that the state (or the OPTN, which has been empowered by the state) should promote (1) and avoid (2).[58]

It may be thought that UTx and IVF are morally equivalent, given they have the same goal of enabling patients (and their partners) to have children. However, it is not clear, at least on Bayefsky and Berkman's account, why UTx (specifically, the transplant part of the programme of treatment) should be distinguished from other fertility-related treatments, such as surgery to unblock the fallopian tubes, for example, which do not require an assessment of child welfare prior to being provided.

Regarding the authors' tripartite rationale for screening parenting ability at the transplant listing stage, in other work I have argued that all three of these justifications can be dismantled.[59] In brief, this is because reason (1) inevitably falls foul of Parfit's non-identity problem,[60] and, as noted above, assuming existence is preferable to non-existence (absent a life so poor as to be not worth living), it is not clear that the best interests of some children *are* promoted in this way.[61] Reason (2) essentially stretches 'the boundaries of moral responsibility for all actions to the limit',[62] which seems unjustified where others (the parents) are directly responsible for bringing about adverse consequences (the mistreatment of children) and for the prevention of those consequences

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[57] Cohen (n29)

[58] Bayefsky and Berkman (n4), 360

[59] O'Donovan (n2)

[60] Parfit (n42)

[61] O'Donovan (n2), 24–5

[62] ibid, 25

materialising in the first place.[63] Finally, premise (3) is again undermined by issues of non-identity. Furthermore, it is also not clear why concerns about the scarcity of resources apply uniquely to UTx. Even if one were to argue that concerns about resource waste on welfare grounds do apply to other fertility-related treatments (such as the provision of drugs to boost ovulation, surgery to unblock the fallopian tubes, and the like), for reasons of consistency and fairness, unless and until welfare assessments are introduced to filter out patients for other such medical treatments on this ground, they ought not to be introduced at the point of transplant listing in UTx.

This leads me on to a further problem with accounts that promote the use of the PCWP at this threshold stage. Because authors including Bayefsky and Berkman,[64] and later Bruno and Arora,[65] view UTx as a transplant procedure in isolation, as opposed to a programme of treatment also requiring IVF, they each neglect to consider the fact that patients pursuing UTx will also be subject to assessments of child welfare when they seek to create embryos through IVF. This point is noted by Wall and Testa, two surgeons involved in the UTx trial – now clinical programme – at Baylor Medical Center.[66] They point out that existing listing requirements – '(1) phone screening; (2) objective medical and psychological evaluation; (3) selection committee presentation; (4) in vitro fertilisation; and (5) final selection committee review' – already fulfil welfare criteria in this regard.[67] Presumably here they are referring to the ECASRM's recommendation explored in section 2 advising that assessing child welfare is a 'valid consideration' in IVF provision.[68] Neglecting this and taking seriously these authors' proposals potentially means that UTx patients may be subject to 'double assessment', an arguably unduly burdensome prospect for them. Furthermore, if this were to occur it is not clear that the standards against which child welfare (child-rearing ability) is assessed as a condition of IVF provision, and later as a condition of transplant listing, will be the same, nor that the assessment process itself will be the same. This seems likely given the substance of the proposals advanced by Bayefsky and Berkman and Bruno and Arora.

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[63] R. Tonkens, 'Misusing Uteruses? Childrearing Capacity and Access to Transplantable Wombs' (2020) 29 Bioethics 389, 111

[64] Bayefsky and Berkman (n4)

[65] Bruno and Arora (n4)

[66] A. Wall and G. Testa, 'Living Donation, Listing and Prioritization in Uterus Transplantation' (2018) 18 AJOB 7

[67] ibid

[68] Ethics Committee of the American Society for Reproductive Medicine (n22)

Indeed, the first set of authors suggest that 'we should develop minimum standards for child-rearing capacity before offering a uterus to a potential recipient',[69] but that this does not mean 'that we should rank each woman or couple based on the likelihood of being good parents'.[70] This minimum standard or 'low-bar for parenting capacity', they argue, should include a criminal background check and require UTx candidates to meet a minimum level of financial stability.[71] While this suggestion appears to mirror the minimum standard or 'risk assessment'-style framing of the PCWP as it exists in the UK,[72] and as recommended by the ECASRM in the US, Bruno and Arora go further. They suggest that a comprehensive assessment of child-rearing capacity similar to assessments undertaken by prospective adopters should be introduced.[73] In the UK, prospective adopters are required to undergo criminal record checks, health checks and interviews, to name three referees for the agency to interview and to undertake some form of adoption preparation.[74] This would clearly go well beyond what is currently required of patients and appears, without more, to be a significantly more intrusive undertaking.

Finally, perhaps the strongest reason to reject the proposals advanced above lies in the fact that they appear to be contrary to established ethical and policy guidance on patient selection and allocation policies. For example, in the UK, NHS Blood and Transplant's (NHSBT) guidance document on patient selection and organ allocation policies states that the 'criteria for selection and allocation of a donated organ must be *objective* and the reasons evidence-based where possible'.[75] Even preferring one group over another on the basis of something like age 'has to be proportionate and justified on clinical grounds',[76] given that age is a protected characteristic under the Equality Act 2010, which prohibits discrimination on this basis.[77] Moreover, as Horvat and Iltis have noted in the US setting, the Organ Procurement and Transplantation

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[69] Bayefsky and Berkman (n4), 359

[70] ibid

[71] ibid, 360

[72] Human Fertilisation and Embryology Authority (n25), Guidance Note 8

[73] Bruno and Arora (n4), 12

[74] Department for Education, 'Statutory Guidance on Adoption' (2013) https://assets.publishing.service.gov.uk/media/5a7badc640f0b645ba3c5dff/adoption_statutory_guidance_2013.pdf accessed 5 January 2024

[75] NHS Blood and Transplant, 'Pol200/5.1 – Introduction to Patient Selection and Organ Allocation Policies' (2022), 4 https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/26764/pol200.pdf accessed 1 December 2023 (emphasis added)

[76] ibid, 13

[77] Section 5, 13 and 14 of the Equality Act 2010

Network (OPTN) prohibits the inclusion of non-medical factors in policies on allocation and patient selection.[78] Indeed, current OPTN guidance states that 'there is widespread consensus that certain social aspects of utility should not be taken into account. In particular, the social worth or value of individuals should not be considered, including social status, occupation, and so forth.'[79] Assessments of child welfare may well be viewed as making a judgement about the social worth of patients and the purported value they have to offer as parents.[80] For these reasons, it may be difficult if not impossible to justify the inclusion of the PCWP as a valid criterion.

4.2.2 Child welfare and patient ranking

Taking further the proposal of Bayefsky and Berkman discussed in the previous section, Bruno and Arora have previously suggested that child-rearing capacity should be utilised to assist with patient ranking *in addition* to patient listing.[81] Like the previous authors, they were mindful to explain that 'imposing one's own view on what a "good mother" is should be avoided'.[82] Instead, they claimed that 'the best interest and safety of the future child should be paramount'[83] – language seen here in this jurisdiction in the context of child law (concerning disputes about existing as opposed to hypothetical children).[84] Notably, taking seriously their suggestion for a more comprehensive assessment at either the listing or prioritisation stage would have the effect of elevating child welfare to be the primary concern in decisions about uterus transplantation. This is particularly problematic where welfare is not considered to be paramount in other iterations of the PCWP, when welfare is assessed by patients seeking IVF in the UK and the US, for example.[85] In this context a child is yet to exist, and so the reproductive autonomy of prospective patients must also be given sufficient weight; hence the framing of these considerations as considerations of risk assessment.

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[78] M. Horvat and A. Iltis, 'What Are Good Guidelines for Evaluating Uterus Transplantation?' (2019) 21 Ama J Ethics E988, 992

[79] Organ Procurement and Transplantation Network, 'Ethical Principles in the Allocation of Human Organs' (2015) https://optn.transplant.hrsa.gov/professionals/by-topic/ethical-considerations/ethical-principles-in-the-allocation-of-human-organs/ accessed 1 December 2023

[80] Horvat and Iltis (n78)

[81] Bruno and Arora (n4)

[82] ibid

[83] ibid

[84] For example, see section 1(1) of the Children Act 1989

[85] See section 13(5) of the Human Fertilisation and Embryology Act; Ethics Committee of the American Society for Reproductive Medicine (n22)

Bayefsky and Berkman reject outright the use of welfare assessments to rank patients on transplant waiting lists, describing this as 'burdensome and morally questionable'.[86] In later work, Bruno and Arora later acquiesce to the view that separating listing and prioritisation by allowing patients who pass such an assessment to be listed but not later using this information to prioritise recipients would address concerns about incorporating child-rearing capacity into existing regulation (in the US).[87] Though they may no longer be advocating for the inclusion of child welfare in patient prioritisation policies, I suggest that any such proposal should be categorically rejected in stronger terms.

Indeed, as a tool to assist with prioritisation, employing this criterion to rank patients would require assessors both to identify the parenting characteristics most likely to lead to a good life for a hypothetical child and to score prospective recipients according to their ability to meet this standard. This is precisely because prioritisation is not a yes/no decision but, rather, a tool to distinguish between patients on a given list. As previously noted, in the context of UTx, 'clinical need' does not offer a way of determining which patient between those with the same blood and tissue type should receive a particular uterus. Thus, using child welfare at this decisional stage would presumably imply that patients receive more or fewer points depending on their child welfare score, and move up or down the waiting list accordingly. Such an assessment would inevitably be a much more difficult task with a greater risk of the imposition of value judgements and inconsistency in decision making. It also necessarily involves a deeper level of scrutiny and the prioritisation of patients according to imagined social futures.[88] This, as I have previously argued, is deeply problematic as it 'could result in the marginalisation of particular patients or patient groups due to biased listing procedures'.[89] Further, it leaves open a greater possibility for discrimination and should thus be avoided.

Finally, as with the use of welfare assessments to determine whether a patient should be added to the transplant waiting list, using such assessments to inform prioritisation frameworks would similarly conflict with ethical and policy guidance. In the UK, for example, specific guidance from NHSBT on the assessment of allocation policies states that 'allocation must not be on, for example, the basis of ethnicity, age, gender, disability, *lifestyle, and perceived*

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[86] Bayefsky and Berkman (n4), 359

[87] B. Bruno and K.S. Arora, 'Uterus Transplantation: Response to Open Peer Commentaries on the Ethics of Using Deceased vs. Living Donors' (2018) 18 AJOB W6; see also Wall and Testa (n66); A. Rogers, 'Allocating Uterus Transplants – Who Gets to Be a Gestational Mother?' (2018) 18 AJOB 38

[88] O'Donovan (n2), 30

[89] ibid

value to society or ability to pay'.[90] Again, for this reason, the inclusion of such a criterion to assist with organ allocation seems hard, if not impossible, to justify.

5. CONCLUSION

This chapter has critically analysed the role of the PCWP in ethical and legal reasoning about UTx. It set out to challenge recommendations that pre-conception welfare considerations should inform patient selection and organ allocation criteria. To build this case cautioning against the use of the PCWP in listing and prioritisation decisions, I first presented an overview of the principle and how it operates in practice, before considering some of the key objections to it discussed in the literature. Later, I moved on to critically examine the relevance of the principle in the context of UTx. It was noted that as UTx is a hybrid reproductive-transplant treatment, patients seeking it will already be subject to a welfare assessment by IVF providers. The chapter then continued to explore whether child welfare assessments should be used to guide transplant listing and allocation policies. In summary, I categorically rejected any such proposals on the following grounds: that the PCWP leaves open too much room for the imposition of value judgements and inconsistency in decision making that may lead to patients being unjustly discriminated against and marginalised; that the prospect of double assessment (by IVF providers and transplant clinicians) would be unduly burdensome for patients; and that using such criteria in this way would arguably be contrary to ethical and policy guidance advocating for fair and equitable systems of organ allocation.

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[90] NHS Blood and Transplant (n53), 3