<u>A relational approach to medical decision-making and best interests'</u> <u>assessments; a solution to mitigate the influence of gendered stereotypes on</u> <u>the treatment of female patients</u>

Dani O'Connor

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Summary

Does a person's gender determine the course of their life and are women predisposed to less independence and greater struggle due to their biological construction? This thesis considers the concepts of autonomy, capacity and consent from a feminist perspective. The purpose of which is to assert that a need exists for a shift from an individual approach to autonomy to a relational one. Self-determination concerns a person's ability to choose and control the course of their life. However, this thesis reveals that access to such an ability is often barricaded by genderimposed constraints. Despite achievements in the last 100 years, which have included the right to vote and the right to equal pay, this research will indicate that women are still considered the lesser sex. For example, the chapter on feminism illustrates that women are likely to be poorer than men, with limited access to health resources and be the recipients of a lower standard of medical treatment. The result of these factors is that a woman's right to autonomy is often damaged and consequently weakened. This broken sense of autonomy leads to a loss of independence which can have major ramifications for rulings of capacity and subsequent qualifications to consent. This weakened conception of a woman is situated within an extremely masculine environment. The courts and medical profession have traditionally been dominated by upper class males which has resulted in an unequal balance of power. Feminist theories seek to understand how power operates in society and the limits that are placed on our personal freedoms. Thus, a feminist perspective will be employed when reviewing literature and judicial decisions in order to analyse the effects of traditional masculinity on gender equality. The result of this analysis will prove that gender stereotypes impede on both the diagnosis and treatment of women's health and that a move to a relational approach to autonomy is required to minimise the damage of gender stereotypes in terms of patient treatment and care.

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1 Introduction

"Stereotypes and assumptions about women's lives can lead to unlawful discrimination."¹

1.1 Setting the Scene

Undoubtedly, levels of patient participation in medical decision-making can vary from case to case. Whilst subjectivity is inevitable as humans are not a homogenous group, at times, a patient's participation is impacted by factors which supersede their diagnosis. How a patient is perceived by the relevant healthcare professionals can have ramifications on their autonomous choices regarding medical decision-making. One of the major issues within both medical and judicial dialogues is the existence (and continuance) of gender stereotypes.² Such stereotypes are situated within unconscious biases which result from social constructionism.³ This, coupled with an inherent vagueness in both mental capacity legislation and the adjoining medical guidance,⁴ results in an environment which fails to offer a level playing field to patients. The common denominator between these two counterparts is the role of a patient's emotions. Gender stereotypes can cause a patient's emotions to be

¹ Judiciary UK, 'Equal Treatment Bench Book' (November 2013) available at <u>https://www.judiciary.uk/wp-content/uploads/JCO/Documents/judicial-</u>

college/ETBB Gender finalised .pdf [Accessed 28/08/2023].

² Saima Ali, Gwen Adshead, 'Just Like a Woman: Gender Role Stereotypes in Forensic Psychiatry' 13 (2022) *Frontiers in Psychiatry* 1; Rebecca Stewart, Breanna Wright, Liam Smith et al, 'Gendered stereotypes and norms: A systematic review of interventions designed to shift attitudes and behaviour' 7(4) (2021) *Heliyon*.

³ Jasmine R Marcelin, David S. Siraj, Robert Victor et al, 'The Impact of Unconscious Bias in Healthcare; How to Recognize and Mitigate It' 220 (2019) *The Journal of Infectious Diseases* 1; Ursula Meidert, Godela Donnges, Thomas Bucher et al, 'Unconscious Bias among Health Professionals: A Scoping Review' 20 (16) (2023) *International Journal Environmental Research in Public Health*, 1.

⁴ Peter Bartlett, 'Re-thinking the Mental Capacity Act 2005: Towards the Next Generation of Law' 86(3) (2022) *Modern Law Review* 659; Scott Y H Kim, Nuala B Kane, Alexander Ruck Keene et al, 'Broad concepts and messy realities: optimising the application of mental capacity criteria' 48(8) (2022) *Journal of Medical Ethics* 838.

overlooked in medical decision-making.⁵ This issue is further exacerbated as emotions are not explicitly accounted for within best interests' assessments (which are often the deciding factor for treatment options). The result is that emotional responses are often dismissed as a patient's inability to communicate a will or preference, rather than being accounted for as a legitimate attempt to express an autonomous choice. The roots of this issue can be traced back to the divide between emotional and rational thinking.⁶ Rationality has traditionally been dominant within the medical and judicial sectors and has long been considered a masculine trait.⁷ These combining factors formulate the basis of this thesis, the purpose of which is to highlight the gap of how the rhetoric concerning the promotion of patient participation is failing to effectively translate into practice. Legislation and guidance will be reviewed alongside a selection of cases from the Court of Protection to demonstrate (a) the gap that exists between theory and practice and (b) how such cases could have provided further opportunities for patient participation, had the guidance been adhered to, resulting in an enhancement of patient autonomy.

Furthermore, a trend emerges through the review of cases which posits a worrying revelation. By analysing cases such as *Guys and St Thomas' NHS Foundation Trust* v X, *Re Z* and the pre-MCA 2005 case of *Re S*, it appears that a woman's capacity is only questioned when they refuse consent and disagree with the leading medical advice. This pattern evidences the prevalence of doctor knows best and serves to illustrate how a woman's autonomy is constrained within medical dialogues. Theory suggests that such claims of incapacity often arise during the decision-making process as physicians seek to "protect" patients from what they believe to be bad decisions. Such a process results in the exclusion of the patient from the decision-making process; a relational approach to decision-making seeks to mitigate such

 ⁵ Anke Samulowitz, Ida Gremyr, Erik Eriksson et al, 'Brave Men and Emotional Women: A Theory-Guided Literature Review on Gender Bias in Health Care and Gendered Norms towards Patients with Chronic Pain' (2018) *Pain Research and Management* 1.
 ⁶ Amanda M. Gengler, 'Emotions and Medical Decision-Making' 83(2) (2020) *Social Psychology* 174.

⁷ R. W. Connell and James. W. Messerschmidt, 'Hegemonic Masculinity: Rethinking the Concept' 19(6) (2005) *Gender & Society* 829; Jennifer L. Berdahl, Marianne Cooper, Peter Glick, 'Work as a Masculinity Contest' 74(3) (2018) *Journal of Social Issues* 4229; Karla Elliott, Steven Roberts, Brittany Ralph, 'Understanding autonomy and relationality in men's lives' 73(3) (2022) *The British Journal of Sociology* 571.

issues through the promotion of meaningful dialogue and the inclusion of third-party support. It is important to note that relational autonomy should be used as a mechanism to help navigate issues such as the constraints placed on a woman's autonomy, it should be seen as an all-in-one solution.

This thesis will utilise a combination of feminist theory, doctrinal and content analysis to illustrate how judgments could be "re-imagined" in light of a relational approach to best interests. Whilst it cannot be guaranteed that the alternative outcomes would necessarily accord with the patient's wishes; the process would offer further opportunities for participation by offering a full consideration of the patient's life, acknowledging the stereotypes that exist both in and out of clinical practice. This introduction sets out the background of this research, its aims and questions, and an outline of the thesis.

1.2 Background to research

This section serves to provide brief overviews of the key concepts and principles featured within the thesis to act as a guide to understanding the forthcoming discussions. The explanations will begin by outlining best interests, before moving to review relational autonomy and the subsequent process of supported decision-making, before closing with an insight into the narratives concerning gender stereotypes and the adjoining gender inequities.

1.2.1 Best interests

Best interests is a key concept of policies concerned with decision-making in medical practice.⁸ It is related to the principle of informed consent, in which it is inferred that persons of sound mind should be able to make decisions they deem to be "best" for

⁸ Helen Taylor, 'What are 'best interests? A critical evaluation of 'best interests' decisionmaking in clinical practice' 24 (2) (2016) *Medical Law Review* 176.

themselves.⁹ However, as explained by Birchley, this element of choice can be limited by what is considered to be in the person's best interests.¹⁰ Many barriers to autonomy exist; they can range from barriers to communication, fluctuating capacity, loss of consciousness and so on.¹¹ Ultimately, best interests can be regarded as a fundamental concept that determines medical treatment in the common law.¹² However, critics argue that best interests undermine patient's liberties.¹³ One of the major critiques is that best interests is so vague that it allows any set of factors to be determinate.¹⁴ Further, The United Nations Committee on the Rights of Persons with Disabilities argues that the best interests principle is incompatible with Article 12 of the UNCRPD.¹⁵ Article 12 asserts the superiority of a "rights, will and preferences" standard in upholding the right of disabled persons to have equal recognition before the law.¹⁶

The standard clinical procedure is to obtain a patient's consent before any intervention.¹⁷ Best interests is the statutory framework introduced by the MCA 2005 which is designed to guide decision-making on behalf of patients for whom that is not

⁹ John Coggon, Camilla Kong, 'From best interests to better interests? Values, Unwisdom and Objectivity in Mental Capacity Law' 80 (2) (2021) *The Cambridge Law Journal* 245. ¹⁰ Giles Birchley, 'The theorisation of 'best interests' in bioethical accounts of decision-making' 22 (68) (2021) *BMC Medical Ethics* 1.

¹¹ ibid.

¹² *Tavistock v Bell* [2020] EWHC 3275, *NHS v Raqueeb* [2019] EWHC 2351; Mental Capacity Act 2005.

¹³ Bernard Gert, Charles Culber, K Danner Clouser, *Bioethics: a return to fundamentals* (OUP 1997); Robert Veatch, *Patient heal thyself: how the 'new medicine' puts the patient in charge* (OUP 2009).

¹⁴ Seema Shah, Abby Rosenberg, Douglas Diekema, 'Charlie Gard and the limits of best interests' 171(10) (2017) *JAMA Pediatrics* 937; Elisha Waldman, Joel Frader, 'Charlie Gard: how did things go wrong?' 6(2) (2018) *Current Paediatrics Report* 173; Renu Barton-Hanson, 'Reforming best interests: the road towards supported decision-making' 40(3) *Journal of Social Welfare and Family Law* (2018) 277.

¹⁵ Lucy Series, Anna Nilsson, 'Article 12 CRPD: Equal Recognition before the Law' in Ilias Bantekas, Michael Stein, Dimitris Anastasiou, *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (OUP 2018).

¹⁶ Convention on the Rights of Persons with Disabilities (CRPD), Article 12, Equal Recognition before the law, available at

https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-withdisabilities/article-12-equal-recognition-before-the-law.html [Accessed 12/08/2023].

¹⁷ NHS, 'Consent to Treatment' available at <u>https://www.nhs.uk/conditions/consent-to-</u> <u>treatment/#:~:text=Consent%20to%20treatment%20means%20a,an%20explanation%20by</u> <u>%20a%20clinician</u> [Accessed 01/08/2023].

possible because they lack capacity.¹⁸ However, there is a degree of ambiguity surrounding the application of the best interests standard. Such ambiguity can have a detrimental impact on clinical practice and as such, compromise the rights and interests of those cognitively impaired. Evidence suggests that "best interests" are often equated with the clinician's evaluation of "best medical interests".¹⁹

The historical context of best interests can be traced to *Re F* (Mental Patient: Sterilisation),²⁰ A legal dilemma had existed regarding the care of incapacitated patients; neither the patient, court or any other third party could provide consent to treatment.²¹ Thus, doctors were faced with a double-edged sword - a duty to provide care and the potential liability in trespass for treating without consent. In *Re F*, the Court ruled that the dilemma was "nonsense"; an extensive review of jurisprudence followed which concluded with the decision that treatment in such circumstances could be justified by the principle of necessity.²² Prior to the introduction of the MCA, the duty of necessity was the basis from which powers could be granted to take steps deemed "reasonably necessary and proportionate" to protect others from the immediate risk of harm. Further, it afforded doctors the authority and duty to provide medical treatment to adult patients lacking decision-making capacity. These powers have now been codified by ss5 and 6 of the MCA.²³

Lord Griffiths in *Re F* stated that treatment would be lawful if the doctor considered it "to be in the best interests of his patient",²⁴ and it met the standard set out in *Bolam v Friern Hospital Management Committee*.²⁵ Ultimately, the determination of "best

¹⁸ British Medical Association, 'Best Interests decision-making for adults who lack capacity; A toolkit for doctors working in England and Wales' (2019) *Medical Ethics and Human Rights Department*, available at <u>https://www.bma.org.uk/media/1850/bma-best-interests-toolkit-2019.pdf</u> [Accessed 09/09/2023].
¹⁹ Helen Taylor, 'What are 'best interests? A critical evaluation of 'best interests' decision-

¹⁹ Helen Taylor, 'What are 'best interests? A critical evaluation of 'best interests' decisionmaking in clinical practice 24 (2) (2016) *Medical Law Review* 176.

²⁰ Re F (Mental Patient: Sterilisation) 2 WLR 1025 (HL).

²¹ Helen Taylor, 'What are 'best interests? A critical evaluation of 'best interests' decisionmaking in clinical practice 24 (2) (2016) *Medical Law Review* 176.

 ²² Lord Bridge, Lord Griffiths, Lord Goff, and Lord Jauncey of Tulichettle agreed on this point;
 Lord Brandon dissented and agreed with the position adopted by the Court of Appeal, n14.
 ²³ Nick Brindle, 'When and how to treat patients who refuse treatment' 348 (2014) *British Medical Journal*, 348.

²⁴ Re F (Mental Patient: Sterilisation) 2 WLR 1025 (HL).

²⁵ Bolam v Friern Hospital Management Committee [1957] 1 WLR 583 in which the jury instructions of the High Court formulated "the Bolam test" which dictated: "a medical

interests" lay with the medical profession.²⁶ As explained, in 2005, the Mental Capacity Act was introduced, the purpose, is to uphold an individual's right to autonomy, balanced with a commitment to protect the interests of those unable to do it for themselves.²⁷ The MCA operates from a standpoint that individuals "must be assumed to have capacity unless it is established that he lacks capacity".²⁸ Further if a patient were to be cognitively impaired, "reasonably practicable" steps must be taken to "permit and encourage the person to participate, as fully as possible in any act done for him and any decision affecting him".²⁹ Individual's should be (as much as possible) supported to make their decisions. For others acting on their behalf, it is imperative that they "act in their best interests".³⁰ Within healthcare, it is the treating clinician who will decide whether the patient has capacity to consent to the proposed treatment.³¹ If it is decided that the patient lacks the requisite capacity; treatment usually proceeds under the general defence provided in section 5 of the MCA providing it maintains the patient's best interests.

At face value, the process of best interests decision-making seems "relatively uncontroversial".³² However, best interests are ill-defined and existing guidance is insufficient. Therefore, "far from the empowering legislation that it set out to be, the MCA may instead be used as a risk management tool".³³ Owing to the ambiguity

professional is not guilty of negligence if he has acted in accordance with a practice accepted as proper by a responsible body of medical men skilled in that particular art . . . Putting it the other way round, a man is not negligent, if he is acting in accordance with such a practice, merely because there is a body of opinion who would take a contrary view." ²⁶ Mary Donnelly, 'Best interests, Patient Participation and the Mental Capacity Act' (2009) 17 *Medical Law Review* 29 3.

²⁷ The Law Commission, *Mental Incapacity* (Law Comm. No. 231, 1995) <<u>http://www.bailii.org/ew/other/EWLC/1995/231.html</u>> [Accessed 10/07/2023] [26, para. 2.46]; The Law Commission, *Mentally Incapacitated Adults and Decision-Making: An Overview* (Law Comm. No. 119, 1991) <<u>http://www.bailii.org/cgi-</u>

bin/markup.cgi?doc=/ew/other/EWLC/1991/c119.html&query=title+%28+consultation+%29+ and+title+%28+paper+%29&method=boolean> [Accessed 15/07/2023 [102, para. 4.18]. ²⁸ Mental Capacity Act (2005) s1(2).

²⁹ ibid, s4(4).

³⁰ ibid.

³¹ More complex decisions may require a formal assessment of capacity (Department for Constitutional Affairs, *The Mental Capacity Act 2005: Code of Practice* (The Stationery Office: London, 2007) [54–4.42]), where the matter remains uncertain, an application can be made to the Court of Protection for a declaration under MCA s 15 (1).

³² Helen Taylor, 'What are 'best interests? A critical evaluation of 'best interests' decisionmaking in clinical practice 24 (2) (2016) *Medical Law Review* 176.

³³ ibid.

surrounding best interests and its deference to medical opinion, risks emerge of unconscious bias, permeation of gender stereotypes and an overreliance on individual autonomy which fails to take account of a wider consideration of the patient's wishes and preferences. A solution to such problems can be found in the form of relational autonomy, which provides for greater opportunities to navigate and thus encompass the wider context of patient's lives to mitigate the over-reliance on medical opinion.

1.2.2 Relational autonomy

Autonomy has regularly been defined as a concept of self-rule.³⁴ However, it was originally used to describe Greek cities that operated independently of the State,³⁵ thus inferring there was a collective origin to its nature. Despite this, in recent decades, autonomy has been largely associated with concepts of "hyper-individualism",³⁶ which are seen to disregard, "the fundamentally relational nature of our motivations and the overall social character of our being".³⁷ In contrast, relational autonomy examines, "what it means to be a free, self-governing agent who is also socially constituted and who possibly defines her basic value commitments in terms of interpersonal relationships and mutual dependencies".³⁸ Thus, relational autonomy encompasses, "the social components of our self-concepts as well as emphasising the role that backgrounds social dynamics and power structures play in the enjoyment and development of autonomy".³⁹ In other words, relational autonomy takes account of people's social contexts within which decisions are made and therefore provides greater opportunities to account for the impact gender

³⁴ John Christman, "Autonomy in Moral and Political Philosophy", *The Stanford Encyclopaedia of Philosophy* (Fall 2020 Edition), Edward N. Zalta (ed. Available at: https://plato.stanford.edu/archives/fall2020/entries/autonomy-moral/. [Accessed 10/08/2023].

 ³⁵ Gerald Dworkin, 'Autonomy and Behaviour Control' (1976) 6 *Hastings Center Report* 23.
 ³⁶ John Christman, 'Relational Autonomy, Liberal Individualism and the Social Construction of Selves' (2004) 117 (112) *Philosophy Studies* 143.

³⁷ ibid.

³⁸ ibid.

³⁹ ibid.

stereotyping can have on medical care and treatment. Relational autonomy can be practically realised through a model of supported decision-making, whereby the patient works with a third party to increase their abilities to participate in medical decision-making, hence working as a tool to traverse any barriers facing the patient.

1.2.3 Supported decision-making

Supported decision-making is when an adult with impaired capacity works alongside a trusted person, or persons who assist the adult in exercising and enhancing their self-determination.⁴⁰ Supported decision-making has been reviewed in both the philosophical and disability rights literature as an alternative to guardianship or surrogate decision-making frameworks.⁴¹ A guardianship order operates under the Mental Health Act 1983 and enables a third party to make decisions on behalf of an adult who has been deemed to lack capacity.⁴² Surrogate decision-making similarly involves a third party taking action on behalf of the patient. The Mental Capacity Act allows for surrogate decision makers to be nominated (Lasting Power of Attorney for Health and Welfare) in situations concerning either chronic illness or as an anticipatory measure for future illness.⁴³ The ethos of supported decision-making is to strike a balance between enabling a person to exercise their autonomy while simultaneously protecting the person in light of their vulnerability.⁴⁴ It is a doublefaceted situation; a person with a capacity impairment is vulnerable to (potentially) their own harmful decisions, but also vulnerable to having their autonomy violated. Supported decision-making helps strike a balance between the two. As explained

2018-19-2019-20--2020-21 (20/09/2014) [Accessed 30/10/2023].

⁴⁰ Andrew Peterson, Jason Karlawish, Emily Largent, 'Supported Decision Making With People at the Margins of Autonomy' 21 (11) (2020) *The American Journal of Bioethics* 4.
⁴¹ Leslie Pickering Francis, 'Understanding autonomy in light of intellectual disability' 200 in Kimberley Brownlee and Adam Cureton, *Disability and disadvantage* (OUP 2011); Leslie Pickering Francis and Anita Silvers, 'Liberalism and individually scripted ideas of the good: Meeting the challenge of dependent agency' 33 (2) (2007) *Social Theory and Practice* 311.
⁴² NHS Digital, 'Guardianship under the Mental Health Act 1983, England – 2018-19, 2019-20, 2020-21' (21/10/2021) Available at https://digital.nhs.uk/data-andinformation/publications/statistical/guardianship-under-the-mental-health-act-1983/1983-

⁴³ Mental Capacity Act, 'How to make decisions under the Mental Capacity Act 2005' available at <u>https://www.gov.uk/government/collections/mental-capacity-act-making-decisions</u> [Accessed 20/09/2023].

⁴⁴ Anne Felton, Nicola Wright, Gemma Stacey, 'Therapeutic risk-taking: A justifiable choice' 23(2) (2017) *BJ Psych Advances* 81.

under the critique of individual autonomy,⁴⁵ people with cognitive impairments are often marginalised in the decision-making process because they are alleged to lack the requisite capacities to make independent decisions. Supported decision-making embodies relational principles by facilitating the person lacking the capacity to participate in the decision-making process through third-party support.⁴⁶ Increasing the role of patient participation is vital to combat unfair assumptions that might have been formed of the patient owing to pre-existing gender stereotypes. By affording greater consideration to the patient as an individual, it is likely to reduce the extent to which assumptions can be formed on their behalf. Examples of such assumptions are discussed below about the impact gender stereotypes can have on attitudes.

1.2.4 Gender stereotypes/ gender inequities

Stereotypes are usually described as a set of specific beliefs about a group and are cognitive representations of how members of a group are similar to one another and different from members of other groups.⁴⁷ The stereotype that is frequently employed against women is that they are ruled by their emotions, that they are weak and that they are unstable. For example, Bell et al state, "Symbolically, gendered identities may be constructed and maintained through the diminution and restrictions of women linguistically as 'emotional' or 'sensitive', while the male and masculine identities are enlarged or extended through authoritative terms such as 'order' or 'management.'⁴⁸

Women's propensity to economic and material disadvantage, coupled with the dominance and possible oppression of the medical profession, can result in health inequities. Gender equity connects issues in feminist theory and issues within public health care. The concept of gender equity refers to "fairness of treatment for women and men, according to their respective needs. This may include equal treatment or

 ⁴⁶ Rosie Harding, Ezgi Tascioglu, 'Supported Decision-Making from Theory to Practice: Implementing the Right to Enjoy Legal Capacity' 8 (2) (2018) *Societies* 25.
 ⁴⁷ Theresa Vescio, Kevin Weaver, 'Prejudice and Stereotyping' (Oxford Bibliographies,

2013) available at <u>https://www.oxfordbibliographies.com/view/document/obo-</u>9780199828340/ob<u>o-9780199828340-0097.xml</u> [Last accessed 10/09/21].

⁴⁵ See Chapter 6, "Autonomy: self-rule and the role of social context".

 ⁴⁸ Emma Bell, Susan Merilainen, Scott Taylor, Janne Tienan, 'Time's up! Feminist theory and activism meets organisation studies' 72 (1) (2019) *Human Relations* 4.

treatment that is different, but which is considered equivalent in terms of rights, benefits, obligations and opportunities".⁴⁹ The reason why it is not appropriate to simply state equal treatment is sufficient to ensure gender equity, is because of the biological differences between men and women. Doyal believes that to equate the two to achieve gender equity would be "doomed to failure".⁵⁰ Instead, Doyal believes that "policies in pursuit of gender equity must focus not on health outcomes themselves but on the inputs that provide the basis for human flourishing".⁵¹ The resolution to this would be for both sexes to have equal access to the resources required to satisfy their health requirements and it is imperative to account for the cultural and societal influences that have powerful impacts on gender inequity.⁵²

Sims and Butler argue that women are more likely than men to be poor, from lowincome households equipped with non-negotiable responsibilities in addition to limited access to healthcare resources.⁵³ Family decisions are made collectively, and perhaps reflect power imbalances or gender norms, which undermines the idea of individual freedom of choice. Decisions taken in the unified family can affect the relative abilities of individual family members to support themselves on separation, undermining the norms of individual responsibility, financial independence, and freedom of choice.⁵⁴ Research suggests that society expects mothers to be primary carers⁵⁵ and such beliefs influence the division of paid work and caring responsibilities in unified families.⁵⁶ For example, a mother forgoing dinner so that her children have food. Or a mother agreeing to stay home with the children while

⁴⁹ Letizia Mencarini, 'Gender Equity' in Alex Michalos, *Encyclopaedia of Quality of Life and Well-Being Research* (1st edition, Springer 2014).

⁵⁰ Lesley Doyal, 'Gender equity in health: debates and dilemma' (2000) 51 *Social Science Medicine* 931.

⁵¹ ibid.

⁵² Len Doyal, Ian Gough, A Theory of Human Need (Macmillan, 1991); Martha Nussbaum, Jonathan Glover, *Women, Culture and Development: A Study of Human Capabilities* (OUP 1995).

⁵³ Jaqueline Sims, Maureen Butler, 'Health and environment: moving beyond conventional paradigms' in Piroska Ostlin, *Engendering international health: the challenge of equity* (MIT 2002) 195.

⁵⁴ Anne Heenan, "Neoliberalism, family law, and the devaluation of care." 48 (3) (2021) *Journal of Law and Society* 386.

⁵⁵ British Social Attitudes, Women and Work (2019),

athttps://bsa.natcen.ac.uk/media/39297/4_bsa36_women-and-work.pdf

⁵⁶ ONS, 'Women Shoulder the Responsibility of "Unpaid Work" ONS, 10 November 2016 <u>http://visual.ons.gov.uk/the-value-of-your-unpaid-work/</u> [Accessed 12/07/2023].

dad goes out to work because he believes he has better job prospects. As a result, this has gendered financial consequences on separation. It is proven that women fare worse than men in income, whether they are former spouses or cohabitants.⁵⁷ Poorer financial resources and limited access to medical treatments can impact a woman's ability to thrive with individual autonomy. As a result of the impact of socio-economic status, women are often predisposed to rely on others around them to a greater extent than men. This is in contradiction to neoliberal norms which assume individual responsibility, financial independence, and freedom of choice. As such, it is asserted that owing to how gender has been socially constructed, individual autonomy is an incompatible basis for assessing a woman's agency.

1.3 Research aims, questions and limitations

This thesis argues that judicial constructions of women in the context of cases dealing with capacity and consent to treatment, engage with gender stereotypes to the detriment of women's autonomy. This is because the law in such cases is underpinned by notions of individual autonomy. Adopting a relational autonomy approach, however, would help manoeuvre the negative consequences of such stereotypes by maximising, rather than minimising, women's autonomy.

My research aims to:

(a) Identify what gender stereotypes exist in relation to women;

(b) Illustrate through an analysis of case law that (i) judicial constructions of women engage with such stereotypes, and (ii) that this is to the detriment of women's autonomy;

⁵⁷Mike Brewer and Alita Nandi, Partnership Dissolution: How Does It Affect Income, Employment and Well-Being? (2014),

https://www.iser.essex.ac.uk/research/publications/working-papers/iser/2014-30.pdf [Accessed 12/07/2023]; Hayley Fisher and Hamish Low, 'Recovery from Divorce: Comparing High- and Low-Income Couples' (2016) 30 *International Journal of Law, Policy and the Family* 338.

(c) Offer an explanation of relational autonomy and an analysis of how its use could circumvent the negative consequences of such stereotypes by counteracting the detrimental effect the use of such stereotypes has on women's autonomy

Original contribution:

Relational autonomy will be framed as supported decision-making, aiming to illustrate that supported decision-making is relational autonomy in action. Relational autonomy provides a firmer grounding for supported decision-making than that relied upon by the CRPD and the bodies which interpret it. This thesis does not advocate for an abolition or replacement of the Mental Capacity Act. Rather, it asserts that the best way forward is to maintain the MCA but re-frame it from a viewpoint of relational autonomy.

The crux of the issues within the MCA (as it currently stands) relates to its inherent ambiguity. Whilst its flexibility was intentional, so that it could meet the needs of individual patients, it has resulted in unfair disparities within practice. The caveats of "reasonably practicable" and "reasonably ascertainable" are too open to interpretation and as a result, both the patient's wishes and third-party support are often redacted from medical dialogues. A gap exists from theory to practice; whereby the principles the Act was designed to safeguard are not being implemented effectively. Consequently, the concept of doctor knows best and paternalism remain and despite cases such as *Aintree⁵⁸* which called for best interests to be interpreted holistically, they frequently translate to medical best interests. As such, genderbased assumptions continue to permeate decisions. Through increasing recognition of emotions as a means of communication, which can then be further articulated through third-party support, consistency of opportunity can ensue, and the gap can begin to close.

⁵⁸ Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67.

Scope of analysis

Regarding the scope of analysis, pregnancy cases are used to highlight the extent of the impact of implicit biases impeding upon medical and judicial dialogues. As established in the chapter, "A patriarchal world' the under-representation of women', gender stereotypes are still incredibly prevalent owing to social constructionism. However, it is also demonstrated that stereotypes are more likely to affect a woman to her detriment, owing to connotations of women being emotional, unstable, irrational and unable to make fully formed "rational" decisions. There are many obstacles female patients encounter when attempting to express their autonomy and activate their right to self-determination. These are demonstrated throughout the thesis and are related to issues such as a woman's socio-economic background, her mental health, and her relationship status. Relational autonomy does not seek to eradicate these issues, it must be accepted that such issues exist and will continue to do so, instead, relational autonomy helps us navigate these roadblocks by considering the woman's life outside of the hospital and encompass her within her whole surroundings. Such an approach is not limited to female patients, relational autonomy can serve to help patients of any gender. However, pregnancy cases highlight the extent of this issue and further illustrate how current legislation and guidance concerning decision making is failing to effectively translate into practice. The current approach to medical decision making is too narrow in terms of reviewing someone's capacity. Therefore, relational autonomy should be viewed as a tool to navigate the myriad of relations in terms of deciding upon medical treatment. It seeks to move away from the didactic nature of patient practitioner dialogues, whereby much of the power and as such, the loudest voice, is given to the doctor and rests upon medical expertise. Instead, there should be a holistic view regarding treatment options, whereby multiple parties are able to engage within meaningful dialogues when deciding upon treatment. For example, this could be extended to additional health care professionals, where an occupational therapist or a social worker can also share their views and experiences of the patient in relation to the proposed treatment and adjoining care plan.

Limitations

As this thesis is purely theoretical in nature, there are certain limitations to its scope. These will be addressed and highlighted prior to any substantive discussion. Further, it is important to note that the majority of the case discussions concern pregnancy and owing to biological construction it is impossible to provide a "like for like" comparison with a male patient. A significant component of the thesis focuses on the re-writing of cases, again, it is important to emphasise that this has been done in a theoretical manner. As such, to an extent, the re-writing is slightly speculative. This is owing to a lack of access to particular information, for example, court transcripts including details of capacity assessments or conversations between the healthcare professionals and the patient. Therefore, there is the possibility that things might have been said to the judge outside what is referred to in their judgment, however, this information was not public. Additionally, some cases are further limited by the number of facts made available and as a result, there has been a need to "fill in the gaps" to offer a full picture of the context surrounding the patient. Part of this could be explained by the fact that judgments are confined to the issues and arguments raised by the parties in the case and whether it be owing to time constraints or a lack of information, certain areas concerning relational approaches to treatment options are left unexplored. An obvious caveat to the re-writing of judgments is to note that there are differences between academic and judicial modes of writing, academics are more likely to adopt a tentative approach, whereas judges are bound to make truth claims. Furthermore, it must be recognised that courts are not democratic institutions and judges are not bound to the public they serve, more so, it is unusual for judges to second guess medical opinions. The final limitation to be noted again relates to the theoretical nature of the research, as of yet, there is no empirical evidence to support my recommended changes and ideas, however, I believe that the notable gaps between theory and practice provide a solid foundation for the arguments advocating for a move to a relational approach to medical decision making.

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1.4 Outline of thesis

The Methodology chapter will provide the rationale for the upcoming analysis and explain how qualitative studies in social epidemiology will be used including doctrinal analysis, content analysis and feminist theory. The structure of this chapter is as follows; initially, it will set out the surrounding context which will illustrate a web of interactions proving that as a sex, women, are at a pre-disposed disadvantage to socio-economic opportunities. The research will then narrow down to explain that within the female gender, there are vulnerable groups who are more harshly exposed to unfair biases. This thesis will focus on the vulnerable group of pregnant women. From this point, feminist analysis will be explained and the research methods to be used in the content analysis will be explored. All of this is designed to "set the scene" for the major discourse of the thesis, which will ultimately illustrate that in its current form, the individualistic mode of both judicial and medical analysis leads to outcomes which contravene female patients' autonomy.

The following chapter focuses on feminism and seeks to explain the justification for its inclusion. The feminist viewpoint is suited to this thesis as it focuses on power and its relation to gender. Feminist scholars cover a vast range of topics, but at the centre of each is the idea that in most societies, women have been oppressed, in comparison to men who have had a dominant role.⁵⁹ This chapter deals with the idea of patriarchy and how it relates to the idea of a male-orientated society.⁶⁰ The chapter asserts that patriarchy is embedded within institutional structures that assert men and women are dichotomous and unequal categories. ⁶¹ Related to such dichotomies is that of dominant gender ideology.⁶² This is the belief that physiological sex differences between men and women impact their character. This relates to claims that women are overtly emotional in their thinking, whereas men adopt an approach more grounded in reason. The chapter will focus on such limitations posed on women in the context of healthcare.

 ⁵⁹ Toni- Ann Roberts, Nicola Curtin, Lauren E Duncan et al, *Feminist Perspectives on Building a Better Psychological Science of Gender* (1st edition, Springer 2016).
 ⁶⁰ ibid.

⁶¹ ibid.

⁶² Amy Kroska, 'Conceptualizing and measuring gender ideology as an identity' (2000) 14 *Gender & Society* 368.

The thesis will then move on to consider autonomy. This chapter alleges that despite progressive case law which has appeared to favour the patient, the medical system continues to follow an "in-control" individualistic conception of autonomy.⁶³ The consequences of an individualistic approach render women a weaker version of autonomy, in terms of both accessing healthcare and the quality of medical treatment received. The weaker version of autonomy relates to the idea that there are barriers to women accessing their right to self-determination. The chapter will argue that the individualistic conception of autonomy should be abandoned, asserting the relational approach eases the medical bias which negatively impacts women's access to their autonomy.

In the final substantive chapter, the focus then turns to capacity, which seeks to establish two findings concerning the concept. First, a relational approach is required during capacity assessments to ensure that a person is supported to maximise their ability, either to make decisions themselves or to increase their participation in the decision-making process. Assessments must focus on and encourage supported decision-making. Secondly, this chapter demonstrates that a person's gender can be an influential factor regarding the outcome of capacity assessments owing to genderrelated assumptions and stereotypes. Importantly, this chapter shows how the courts' approach to capacity assessments disproportionately affects women because of unconscious bias problems. This unconscious bias is revealed through an analysis of the language used in judgments and through the comparison of analogous cases where men's capacity and subsequent autonomy appear to be treated with greater respect. Finally, this chapter will also illustrate how adopting a relational approach could address the problems identified.

The thesis will close with a recap of how the research aims have been answered and a summary of the substantive chapters.

⁶³ Jennifer K Walker, Laine Friedman, 'Relational Autonomy: Moving Beyond the Limits of Isolated Individualism' (2014) *American Academy of Paediatrics* available at <u>https://pediatrics.aappublications.org/content/pediatrics/133/Supplement_1/S16.full.pdf</u> [Accessed 29/07/2020].

2 Methodology

2.1 Introduction

This thesis aims to illustrate the impact the use of stereotypes in judicial and medical dialogues can have on a woman's autonomy and to evidence that a gap exists between current theory and practice which could be mitigated by adopting a relational approach to the determination of best interests. It will be asserted that gender-enforced stereotypes result in a weaker notion of autonomy for women. The research will include doctrinal analysis, content analysis and feminist theory. Qualitative research is defined as, 'the interpretative study of a specified issue or problem in which the researcher is central to the sense that is made'⁶⁴ and such methods are used to understand people's beliefs, experiences, attitudes, behaviour, and interactions. As this thesis is based on people, their lives and how attitudes can impact and shape decisions, it is an appropriate mode of study.⁶⁵ Doctrinal' or 'black letter law' methodology means that some of the research is based on analysing the legal rules and cases as well as existing literature.⁶⁶ A doctrinal approach can provide a sound structural basis from which the thesis can proceed.⁶⁷ Specifically, it provides continuity and coherence on the subject matter. ⁶⁸ Content analysis will be employed because it is one that Hall and Wright propose 'resembles the classic scholarly exercise of reading a collection of cases, finding common threads that link

⁶⁴ Alice H Eagly, Sex Differences in social behaviour: A Social-role interpretation (1st edition, Lawrence Erlbaum 1987); Ian Parker, 'Qualitative Research' in Peter Banister, Erica Burman, Ian Parker, Maye Taylor, Carol Tindall (eds), Qualitative Methods in Psychology: A Research Guide (OUP 1994) Alice H Eagly, 'Sex differences in social behaviour: comparing social role theory and evolutionary psychology' (1997) 52 American Psychologist Journal 1380; Amy Kroska, 'Conceptualizing and measuring gender ideology as an identity' (2000) 14 Gender & Society 368; Anne M Koenig and Alice H Eagly, 'Evidence for the social role theory of stereotype consent: observations of groups' roles shape stereotypes' (2014) 107 Journal of Personality and Social Psychology 371; Richard A Lippa, Kathleen Preston, John Penner et al, 'Women's Representation in 60 Occupations from 1972 to 2010: More women in high status jobs, few women in things orientated jobs' (2014) Plos one 9(5).

⁶⁵ Viba Pathak, Bijayini, Sanjay Karla, 'Qualitative research' (2013) 4 (3) *Perspectives in Clinical Research* 192.

⁶⁶ Mike McConville, Wing Hong Chiu, *Research Methods for Law* (EUP 2017) 3, 4.

⁶⁷ ibid.

⁶⁸ ibid.

the opinions, and commenting on their significance'.⁶⁹ This method, they argue, 'is more than a better way to read cases'. It 'meets both the rigorous standards of social science', enriching 'our understanding of case law [and] creating a distinctively legal form of empiricism'.⁷⁰ Finally, a feminist viewpoint studies power and its gender relations. Feminist theory is of vital importance in terms of understanding the doctor-patient relationship and the subsequent implications caused by gendered differences and power relations.

The structure of this chapter is as follows; the first section considers a sample of research methods. To begin, I explain that social epidemiology will form the basis for the analysis owing to its intrinsic relevance to the role of stereotypes in society. The chapter progresses to consider doctrinal analysis where it is determined that whilst it is of certain merit through the review of the relevant statutes and case law, the main thrust of the analysis presides on "law in action". The discourse then develops to consider the dominant methodology, feminist analysis. Initially, a contextual awareness is provided where said methods are reviewed more broadly, before narrowing to consider its application to this thesis. From this, common stereotypes related to reproduction are explored and then explained through relevant case discussion. The chapter continues to review a comparative section of cases concerning male patients to witness the differences in both patient perception and the adjoining dialogues. This is where content analysis features through examining judgments and reviewing the use of language with the previously identified stereotypes. The final method to be included is alternate case theory, inspired by The Feminist Judgments Project.⁷¹ The aim is to re-imagine judgments from a relational perspective to evidence that a shift from individualism and reasonableness secure a holistic view of the patient; resulting in greater patient participation. Finally, (in relation to this section), the limits of such methods are considered. The second part of this chapter explores more of the practicalities of the methodology. It explains the rationale for case selection and the relevance of The Court of Protection. Further, it provides both the justifications and limitations for focusing (largely) on cases

⁶⁹ Mark A. Hall and Ronald F Wright, 'Systematic Content Analysis of Judicial Opinions' (2008) *California Law Review*, 64.

⁷⁰ ibid, [64]-[66].

⁷¹ Rosemary Hunter, Clare McGlynn, Erika Rackley, *Feminist Judgments From Theory to Pract*ice (Bloomsbury Publishing 2010).

concerning reproduction, before concluding that a relational approach to best interests would help level the current gender imbalance within medical and judicial dialogues.

2.2 Research Methods

2.2.1 Social epidemiology

Reviewing the structures in society and how stereotypes can factor into a person's health is a form of social epidemiology. Social epidemiology is "that branch of epidemiology concerned with the way that social structures, institutions, and relationships influence health."⁷² In other words, social epidemiology reveals a problem central to the thesis: that social factors play a crucial role in determining health outcomes. Berkman and Kawachi report that institutions and relationships can have a serious impact on health.⁷³ Buris reports that "consistent correlations across populations between health and forms of social and economic inequality leave little room for doubt that social arrangements account for an important fraction of population's health".⁷⁴ Social epidemiology invites health law scholars to join ongoing efforts to examine how these diverse areas of law are intertwined with health law, how they support existing social injustices and how they reflect biases against the people they purport to serve.⁷⁵ Therefore, social epidemiology is a good basis for the debates that will be explored throughout this thesis and complements the feminist lens that will be employed when conducting doctrinal evaluation and research.

⁷² Kaori Honjo, 'Social epidemiology: Definition, history and research examples' (2004) 9 *Environ Health Preventative Medicine* 193.

⁷³ Lisa Berkman and Ichiro Kawachi, 'A Historical Framework for social Epidemiology: Social Determinants of Population Health' in Lisa Berkman, Ichiro Kawachi and Maria Glymour *Social Epidemiology* (OUP 2014).

 ⁷⁴ Scott Burris, 'From Health Care Law to the Social Determinants of Health: A Public Health Law Research Perspective' *University of Pennsylvania Law Review* 159, NO.6 (2011) 1653.
 ⁷⁵ Nina B Wallerstein, Irene H. Yen, S. Leonard Syme, 'Integration of Social Epidemiology and Community-Engaged Interventions to Improve Health Equity' 101 (5) (2011) *American Journal Public Health* 822; Seema Mohapatra, Lindsay F. Wiley, 'Feminist Perspectives in Health Law' 47 (2019) *The Journal of Law, Medicine and Ethics* 103.

2.2.2 Doctrinal analysis

"Propositions of law are not simply descriptive of legal history in a straightforward way, nor are they evaluative in some way divorced from history. Propositions of law are interpretive of legal history, which combines elements of both description and evaluation, but it is different from both".⁷⁶

Doctrinal or "black letter" methodology is based on analysing the legal rules within common law and legislation and their connections or disjunctions via an examination of cases, the wording of statutes, as well as existing literature. The purpose of which, is to enable a critical analysis of the meanings and implications of these rules and the principles which underpin them. This approach is relevant in the thesis when examining statutes such as The Mental Capacity Act ⁷⁷ and the adjoining Code of Practice⁷⁸ and NICE guidelines.⁷⁹ These instruments feature throughout the thesis, however, they are of notable use in the chapters concerning autonomy and capacity. To a certain extent, black letter analysis will also be employed when reviewing cases and legal precedents, however, the reason why this approach is limited is because of its focus on the letter of the law, rather than the law in action. Whilst it is necessary to a degree to compose a descriptive and detailed analysis of legal rules found in primary sources, to further the analysis and to understand the practical consequences of such instruments on female patients, an amalgamation is required with a feminist viewpoint.

Feminists claim that the theory and practice of law (including doctrinal legal reasoning) fails to offer neutrality as it has been moulded by male-centric values and

⁷⁶ Shane Kilcommins, '*Doctrinal legal method (Black Letterism): assumptions, commitments and shortcomings*' (2016) available at <u>https://core.ac.uk/download/pdf/84112166.pdf</u> [Accessed 12/08/2023].

⁷⁷ The Mental Capacity Act 2005.

⁷⁸ Mental Capacity Act Code of Practice 2013.

⁷⁹ NICE Guides available at <u>https://www.nice.org.uk/guidance</u> [Accessed 01/08/2023].

concerns.⁸⁰ Further, relating to ideas of "gender order",⁸¹ they claim that the law has set "maleness" as the standard for the regulation of human relations.⁸² Additionally claiming that the discourse is so entrenched in the male sex that it denies the voice of women.⁸³ In particular, feminists seek to showcase the patriarchal ideas that pervade the law (often through standpoint epistemology) and raise the "woman question" by reviewing the variety of different ways in which the law fails to acknowledge the values of women and how it might disadvantage them.⁸⁴ Therefore, it is asserted that law, as a mode of social regulation, maybe "deeply antithetical to the myriad concerns and interests of women".⁸⁵

2.2.3 Feminist Analysis

"While there is diversity of experience in everyday life for both women and men, the dominant gender regime that exists today in virtually all societies is sexist in ways that result in the systematic marginalization, oppression and exploitation of women".⁸⁶

⁸⁰ Catharine Mackinnon, 'Feminist Jurisprudence: A Critical Appraisal' 19 (2) (1992) *Journal of Law and Society* 195; Joanne Conaghan, 'Reassessing the Feminist Theoretical Project in Law' 27 (3) (2000) *Journal of Law and Society* 351; Joanne Conaghan, 'Gender, Law and Jurisprudence' in Rosemary Auchmuty, *Great Debates in Gender and Law* (Palgrave Macmillan 2018); Antonio Alvarez Del Cuvillo, Fabio Macioce, Sofia Strid, 'Feminist Political and Legal Theories' in Dragicia Vujadinovic, Mareike Frolich, Thomas Giegerich, *Gender-Competent Legal Education* (Springer 2023).

⁸¹ "Gender order" will be explained in the Chapter 3: "A patriarchal world; the underrepresentation of women".

⁸² Katherine Hay, Lotus McDougal, Valerie Percival et al, 'Disrupting gender norms in health systems: making the case for change' 393 (10190) (2019) *Lancet* 2535; Beniamo Cislaghi, Lori Heise, 'Gender norms and social norms: differences, similarities and why they matter in prevention science' 42(2) (2020) *Sociology of Health & Illness* 407.

⁸³ Siobhan Mullally, 'Feminist Jurisprudence' in Tim Murphy, *Western Jurisprudence* (Thomas Round Hall, 2004) 351.

⁸⁴ Susan Leahy,' Bad Laws or Bad Attitudes? Assessing the Impact of Societal attitudes upon the conviction rates for Rape in Ireland' (2014) 14 (1) *Irish Journal of Applied Social Studies* 18.

⁸⁵ Carol Smart, *Feminism and the Power of Law* (Routledge, 1989) 164.

⁸⁶ Emma Bell, Susan Merilainen, Scott Taylor, Janne Tienan, 'Time's up! Feminist theory and activism meets organisation studies' 72 (2019) *Human Relations* 22.

2.2.3.1 Context

Bell et al suggest that feminist analysis provides opportunities for distinctive practices of knowledge production that challenge the patriarchal social formations which characterise academic work.⁸⁷ Feminist research asks questions that offer a unique and distinctive way of understanding social life, by 'seeing through what is already crazy about the world, notably, the cruelty and injustice with which it tends to go about organizing itself'.⁸⁸ A feminist viewpoint studies power and its gender relations.⁸⁹ Feminist scholars cover a range of topics which include nationality, race, economic status and sexual orientation.⁹⁰ At the centre of all these topics is the notion that in most societies, women have been systematically oppressed, whereas men have traditionally enjoyed a dominant role.⁹¹ West reveals that feminist legal theorists "proffer explanations of law's complicity in the ongoing subordination of women and sexual minorities, while also pursuing the possibilities within the law for achieving lasting gender and sex equality"⁹² Bartlett articulates this conundrum through the development of "the woman question", explaining that it seeks to consider the gendered disparities regarding social conventions, ultimately, aiming to determine if women have been left out of consideration. She writes:

"The woman question asks about the gender implications of a social practice or rule: have women been left out of consideration? If so, in what way; how might that omission be corrected? What difference would it make to do so? In law, asking the woman question means examining how the law fails to consider the experiences and values that seem more typical of women than of men, for whatever reason, or how existing legal standards and concepts might disadvantage women. The question assumes that some features of the law may be not only nonneutral in a general sense but also 'male' in a specific sense. The purpose of the woman question is to

⁸⁷ ibid.

⁸⁸ Jacqueline Rose, *Women in Dark Times* (Bloomsbury 2014).

⁸⁹ Graciela Hierro, Ivan Marquez, 'Gender + Power' (1994) 9 Hypatia 173.

 ⁹⁰ Toni- Ann Roberts, Nicola Curtin, Lauren E Duncan et al, *Feminist Perspectives on Building a Better Psychological Science of Gender* (1st edition, Springer 2016).
 ⁹¹ Mary Becker, 'Patriarchy and Inequality: Towards a Substantive Feminism' (1999) *University of Chicago Legal Forum*, Article 3.

⁹² Robin West, Introduction to Research Handbook on Feminist Jurisprudence" in Robin West, Frederick Haas, Cynthia Grant Bowman *Research Handbook on Feminist Jurisprudence* (Edward Elagar 2019).

expose those features and how they operate, and to suggest how they might be corrected."93

Therefore, a feminist framework can help unpack how a male-centred view of law's role in our social world is harmful.⁹⁴ Examples of how health laws and policies have reflected, and reinforced white male patriarchy abound, and include how the law fails to protect reproductive health decisions and instead treats it as an exception to accepted principles of bodily and decisional autonomy.⁹⁵

Many different types of frameworks exist under feminist theory, for this thesis, the focus will be on relational autonomy. Relationships are important as they help establish who we are and how we are treated in society. Nedelsky champions the relational model of feminist theory. The feminist theory of relational autonomy situates the legal subject within the context of social relationships, allowing "both law and rights [to] be understood in terms of the relations they structure — and how those relations can structure core values, such as autonomy."⁹⁶ This framework will be crucial when reviewing the different models of care employed by healthcare professionals and the judiciary, particularly so when reviewing whether women would retain greater autonomy through a relational approach. Nedlesky purports that feminism is incompatible with an individualistic notion of autonomy.⁹⁷ Individualism embodies the idea of self-rule, which is ultimately what feminists contend for, the right of women to be able to live their lives on equal terms to men. However, as individual autonomy is currently constructed, rather than supporting this feminist intention, it serves to undermine it through the dominance of masculine ideology. Feminism demands respect for women's selfhood and rejects the language and assumptions of individual rights that have dominated the idea of self-hood. Nedlesky

 ⁹³ Katharine Bartlett, "Feminist Legal Methods," 103 (4) (1990) *Harvard Law Review* 837.
 ⁹⁴ Margaret Little, "Why a Feminist Approach to Bioethics?" *Ken- nedy Institute of Ethics Journal* 6, no. 1 (1996): 1, 3 ("Under androcentrism ... we tend to anchor man as the reference point and view woman's nature as a departure from his.").

⁹⁵ Diane E Hoffmann, Anita J Tarzian, 'The Girl Who Cried Pain: A Bias Against Women in the Treatment of Pain' (2003) *Journal of Law, Medicine and Ethics* (29) 13, British Heart Foundation, *Bias and biology: how the gender gap in heart disease is costing women's live* (2019), Gabrielle Jackson, *Pain and Prejudice: A call to arms for women and their bodies* (1st edition, Piatkus 2019).

⁹⁶ Jennifer Nedelsky, *Law's Relations: A Relational Theory of Self, Autonomy, and Law* (OUP 2011) 5.

⁹⁷ ibid.

explains that feminists need a "language of freedom" which takes into account that "there are no human beings in the absence of relations with others".⁹⁸

To expand upon the idea that we are interrelated beings and that we live about one another. Dove et al investigate this idea further, by exploring the concepts of boundaries and what it means for a condition to be external. External conditions are of particular relevance when considering the implementation of relational autonomy, through the inclusion of third-party support. Therefore, it is necessary to consider the following:

"What are the boundaries of a person? Should or must there be any external conditions set around these boundaries? What is 'external' to a person if all her relations are somehow part of her? Should we consider only the patient's family, friends and others as the 'relations' relevant to relational autonomy, or does her healthcare professional (e.g., doctor, nurse) – or the researcher – count as well? If so, what would this look like in practice? And what about close relationships that seem abusive or exploitative? Moreover, can relational autonomy be operationalised in law, which at least in the West has been shaped by methodological individualism – one body, one mind, one person? More simply, what work can relational autonomy do for us as participants, patients, clinicians, researchers, policymakers and as citizens?"⁹⁹

In short, this thesis seeks to assert that a relational approach to supported decisionmaking, embodying the ethos of the CRPD alongside the Mental Capacity Act can work to form collective action; designed to aid those who are marginalised by the consequences of individualistic autonomy to enhance patient participation in dialogues.

Nevertheless, such questions provide some interesting considerations when determining the purpose of feminist methodology. Dove et al debate the meaning of an external influence when the external is inextricably linked to the individual's

⁹⁸ ibid.

⁹⁹ Edward Dove, Susan Kelly, Federica Lucivero et al, 'Beyond individualism: is there a place for relational autonomy in clinical practice and research?' (2017) *Clinical Ethics* 12(3) 154.

selfhood. This observation is particularly important when this thesis advances to consider the issue of pregnancy. Pregnancy quite literally personifies the idea of one being relying on another for their existence and means of support. In agreement with Dove et al, Entwistle et al argue that a relational concept of autonomy within a clinical context could be extremely beneficial in helping clinicians recognise how their interactions and relationships with their patients can either enable or impair patients' autonomy.¹⁰⁰

Ultimately, as Cohen states, the main purpose for utilising feminist theory in terms of a method is because the theory is seeking, the "elimination of the duality of reason and emotion, public and private, political and personal," which "have been the justification for the devaluation of the traditionally female domain, and the equation of power with the traditionally male domain" and arguing that feminist theory "can contribute new perspectives by "offer[ing] a perspective that approaches the issue of responsibility from a unitary, rather than a fragmented, perspective."¹⁰¹

2.2.3.2 Application to research

I will draw on judgments to establish whether gender stereotypes infiltrate decisions from the Court of Protection. In the same vein as the work of Rosemary Hunter et al, the only requirement is that cases chosen could have been decided differently, further, they need not be recent cases, so long as they are important decisions that would benefit from a feminist analysis.¹⁰² I will look for and identify stereotypes applied to female patients in Court of Protection judgments through the review of language and dialogue. In other words, when gender or gendered activities are used during discussions of both medical and judicial communication. The aim is to increase awareness of how gender stereotypes are reproduced in such settings to the detriment of women's autonomy. As part of the feminist methodology, judgments will be analysed to ascertain how frequently gender stereotypes are implied when

¹⁰⁰ Vikki A Entwistle, Stacy M Carter, Alan Cribb and Kirsten McCaffery, 'Supporting Patient Autonomy: The Importance of Clinician-Patient Relationships' (2010) 25 (7) *Journal General International Medicine* 741.

¹⁰¹ Ronnie Cohen, "Feminist Thought and Corporate Law: It's Time to Find Our Way Up from the Bottom (Line)," *American University Journal of Gender and the Law* 2 (1994): 1, 20, 22. ¹⁰² Rosemary Hunter, Clare McGlynn and Erika Rackley, *Feminist Judgments: An Introduction* (Hart Publishing 2010).

discussing female patients. As outlined during the introduction, gender stereotypes are characteristics that are socially and culturally assigned to men and women, and which arise out of sex-based physical differences. Whilst it is stereotypes can impact men as well as women, their impact on women is worse.¹⁰³

This is believed to be a result of the historical roles that have been assigned to women which serve to minimise their relevance and contributions, which have been and still are considered inferior to the roles assigned to men.¹⁰⁴ Thus, it can be ascertained that the social construction of gender has serious implications on how different genders both view and form health-related decisions.¹⁰⁵ Health is, inextricably, socially bound.¹⁰⁶ It is argued that our opinions regarding who is susceptible to problems and who should take action are collectively shaped as a result of health campaigns.¹⁰⁷ When social constructions, such as these, become integrated within human minds, further stereotypes result.¹⁰⁸ Further, the effects of such stereotypes are compounded by social constructions of gender itself, in other words, how men and women are expected to act. The combination of these factors results in a serious impact on medical decision-making. Under the test proposed by

¹⁰³ Bernhard Ertl, Silke Lutternberger, Manuela Paechter, 'The Impact of Gender Stereotypes on the Self-concept of Female Students in STEM Subjects with an Under-Representation of Females' 8 (2017) *Frontiers Psychology* 1; Rebecca Stewart, Breanna Wright, Liam Smith et al, 'Gendered stereotypes and norms: A systematic review of interventions designed to shift attitudes and behaviour' 7 (4) (2021) *Heliyon*, 2; Naznin Tabassum, Bhabani Shankar Nayak, 'Gender Stereotypes and Their Impact on Women's Career Progressions from a Managerial Perspective' 10 (2) (2021) *IIM Kozhikode Society & Management Review* 192.

¹⁰⁴ Naznin Tabassum, Bhabani Shankar Nayak, 'Gender Stereotypes and Their Impact on Women's Career Progressions from a Managerial Perspective' 10 (2) (2021) *IIM Kozhikode Society & Management Review* 192.

¹⁰⁵ Chia-Heng Chang, Fan Yang, 'How Gender Stereotypes Impact Health Information Seeking Intention: Insights from an Implicit Association Team' 7 (2021) *Cogent Social Sciences* 2.

¹⁰⁶ Local Government Association, 'Social determinants of health and the role of local government' available at

https://www.local.gov.uk/sites/default/files/documents/22.52%20Social%20Determinants%2 0of%20Health_05_0.pdf [Accessed 11/08/2023].

¹⁰⁷ Mariusz Duplaga, 'Perception of the Effectiveness of Health-Related Campaigns among the Adult Population: an Analysis of Determinants' 16(5) (2019) *International Journal Environmental Research Public Health*, 791; Paula Braveman, Laura Gottlieb, 'The Social Determinants of Health: It's Time to Consider the Causes of the Causes' 129(2) (2014) *Public Health Rep* 19.

¹⁰⁸ Chia-Heng Chang, Fan Yang, 'How Gender Stereotypes Impact Health Information Seeking Intention: Insights from an Implicit Association Team' 7 (2021) *Cogent Social Sciences* 2.

Cook and Cusack, a stereotype does any of the following: 1. Denies a right or a benefit 2. Imposes a burden 3. Marginalises a person or compromises her dignity.¹⁰⁹ CEDAW has recognised that "gender stereotypes may impact women's capacity to make free and informed decisions and choices about their health care, sexuality and reproduction and, in turn, also impact on their autonomy to determine their own roles in society."¹¹⁰

One area of female health which is particularly susceptible to gender stereotypes is reproduction. Sexual and reproductive health is related to numerous human rights including; the right to life, the right to be free from torture, the right to bodily integrity and to be free from violence, the right to health, the right to privacy, the right to decide freely the number, spacing and timing of children, the right to education, freedom of expression, and, crucially, the prohibition of discrimination.¹¹¹ Stereotypes relating to reproductivity are especially harmful to women exercising their right to make decisions regarding their bodies. Below a table will feature recurring stereotypes and how they are inferred within medical practice.

2.2.3.3 Common stereotypes related to reproduction

Stereotypes related to reproduction can arise in cases concerning; contraception, third party consent to sexual and reproductive health services, termination of pregnancy and pregnancy and childbirth. Such stereotypes serve to obstruct the full enjoyment of women's reproductive health and rights and results in women being marginalised and subordinated to medical control.

¹¹⁰ CEDAW Committee, Summary of the inquiry concerning the Philippines under article 8 of the Optional Protocol to the Convention on the Elimination of All Forms of Discrimination against Women CEDAW/C/OP.8/PHL/1 (2014) para.42.

¹⁰⁹ Rebecca Cook and Simone Cusack, Gender Stereotyping: Transnational Legal Perspectives 21 (2) (2013) *Feminist Legal Studies* 59.

¹¹¹ Human Rights Act 1998, Schedule 1.

Stereotype	Inference Example
Women and adolescent girls are	Doctors and other medical
emotionally volatile and incapable of	professions are justified in making
making rational decisions about their	decisions for women without their
sexual and reproductive lives.	informed consent ("medical
	paternalism")
	Providing adolescents with confidential
	information and services about sexual
	and reproductive health will lead them
	to be irresponsible.
Women with disabilities are asexual,	Women with disabilities should be
sexually inactive or overly sexual, are	sterilised, including to protect them from
incapable of understanding the	the repercussions of sexual violence.
responsibilities of being a parent,	
cannot provide independent consent to	
sexual and reproductive health services,	
and need to be protected.	

From the examples provided above, the overarching theme is paternalism; that owing to gender stereotypes women are predisposed to discriminatory medical interventions. Whilst professionals may believe they are respecting a patient's autonomy by acting in what they determine to be the patient's best interests many women are left with a limited role in decision-making and do not feel that their care is presented as a choice.¹¹² Choices are often characterised as the end result of a rational decision-making process, and as the table infers, women have traditionally been disassociated with rationality. Women being unable to manage their emotions is one of the most prevalent (and longstanding) stereotypes.¹¹³ Macarthur and

¹¹² Helen Stapleton, Mavis Kirkham, Gwenan Thomas, 'Qualitative study of evidence-based leaflets in maternity care' 324 (2002) *BMJ* 639; David Lewin, Brenda Fearon, Valerie Hemmings et al, 'Women's experiences of vaginal examination in labour' 21 (2005) *Midwifery* 267.

¹¹³ Amanda Durik, Mark Vida, Jacquelynne Eccles, 'Task values and ability beliefs as predictors of high school literacy choices: A development analysis' 98 (2) (2006) *Journal of*

Shields report that emotion is tied with the concept of femininity and "irrational, disorganised behaviour".¹¹⁴ Emotions have been depicted as antithetical to rationality. Therefore, owing to the power of such stereotypes, if someone suggests a woman is emotional, the assumption follows that she cannot be thinking rationally. Such connotations serve to delegitimise women's opinions and undermines and undervalues their choices.

Women who are disabled suffer from exposure to further discriminatory attitudes and prejudices. Research indicates that there are additional barriers impeding their access to sexual and reproductive health. Women with intellectual disabilities have reported that they often feel excluded from healthcare decision-making and believe health professionals underestimate their abilities. Therefore, the decision-making process for these women appears to be one of "informed compliance rather than informed choice".¹¹⁵

The judiciary are meant to challenge these wrongful stereotypes, but as will be demonstrated through the following table, stereotypes were either explicitly addressed or implied through avenues such as stereotypes directly influencing a judge's decision and subsequent ruling, or judges neglecting to explicitly recognise the stereotype or stereotyping in question.

Educational Psychology 382 ; Agneta Fischer, Antony Manstead, 'The relation between gender and emotion in different cultures' in Agneta Fischer, *Gender and emotion: Social psychological perspectives* (CUP 2009) 71; Stephanie Shields, 'Gender and Emotion: What We Think We Know, What We Need to Know, and Why It Matters' 37(4) (2013) *Psychology of Women Quarterly* 423.

¹¹⁴ Heather MacArthur, Stephanie Shields, 'There's No Crying in Baseball, or Is There? Male Athletes, Tears, and Masculinity in North America' 7(1) (2014) *Emotion Review* 40. ¹¹⁵ Rachel Mayes, Gwynnyth Llewellyn, 'Mothering differently: Narratives of mothers with intellectual disability whose children have been compulsorily removed' 37 (2012) *Journal Intellectual Development Disabilities* 121.

2.2.3.4 Evidence of gender stereotypes

The stereotypes in these cases are socially constructed, meaning the respective women have faced prejudices based on their gender prior to the case, however, it will be demonstrated that these stereotypes are then reinforced through the judgments.

Gillick v. West Norfolk & Wisbeck Area Health Authority and another¹¹⁶

The *Gillick* case concerned a United Kingdom health and social security departmental circular advising doctors on the provision of contraception to minors. The circular stated that the prescription of contraception was a matter for the doctor's discretion and that it could be prescribed to those under 16 without parental consent.¹¹⁷ A mother with five daughters under the age of 16 sought a declaration that it would be unlawful for a doctor to prescribe contraceptives to girls under 16 without the knowledge or consent of the parent. The complainant argued, that the confidential provision of contraceptives for a girl under 16 would encourage participation by the girl in sexual intercourse and this practice offends basic principles of morality and religion.¹¹⁸ The House of Lords recognised that a girl under 16 does not lack the power to give valid consent to contraceptive advice or treatment, merely on account of her age and observed, "[t]he truth may well be that the rights of parents and children in this sensitive area are better protected by the professional standards of the medical profession than by "a priori" legal lines of division between capacity and lack of capacity to consent since any such general dividing line is sure to produce in some cases injustice, hardship, and injury to health" ... [It held that] "the law [is] in line with social experience, which is that many girls are fully able to make sensible decisions about many matters before they reach the age of 16."119

¹¹⁶ *Gillick v. West Norfolk & Wisbeck Area Health Authority and another* [1986] 1 AC 112 (England and Wales, House of Lords).

¹¹⁷ ibid [406].

¹¹⁸ ibid.

¹¹⁹ ibid [425].

Montgomery (Appellant) v Lanarkshire Health Board (Respondent) (Scotland) 120

Mrs Montgomery was around five feet tall, and was also diabetic, which often results in a larger foetus. She had raised concerns that her baby might be too big to be delivered vaginally but had not asked about 'exact risks'. Nadine Montgomery's son was born with cerebral palsy as a result of shoulder dystocia during birth. Evidence showed a 9-10% risk of dystocia where a diabetic woman gives birth via vaginal delivery, but Mrs Montgomery was not of the risk of shoulder dystocia or offered a caesarean section as an alternative. The treating obstetrician felt that if Mrs Montgomery was told of the risk she would opt for a caesarean and didn't believe this was in her best interest. It was accepted that shoulder dystocia can cause serious complications for mother and baby but also accepted that the risk of cerebral palsy was low, at around 0.1%. Mrs Montgomery claimed for negligence, arguing she should have been told of all the risks. Lady Hale's judgment reads that, "Dr McLellan referred to explaining to a mother who requested a caesarean section "why it may not be in the mother's best interest" and later expressed the view that "it's not in the maternal interests for women to have caesarean sections". Whatever Dr McLellan may have had in mind, this does not look like a purely medical judgment. It looks like a judgment that vaginal delivery is in some way morally preferable to a caesarean section: so much so that it justifies depriving the pregnant woman of the information needed for her to make a free choice in the matter."¹²¹

I.V. v. Bolivia¹²²

The Inter-American Court of Human Rights, in *I.V. v. Bolivia*, its first case concerning involuntary sterilisation, found a violation of the right to be free from discrimination based on the underlying gender stereotypes which led to sterilisation of the petitioner without her informed consent.¹²³ In 2000, I.V., a Peruvian migrant in Bolivia, went to a public hospital to deliver her child. During her caesarean section, I.V. was sterilized without her consent. She was only informed that doctors had performed a tubal ligation several days later. The Court

¹²⁰ Montgomery (Appellant) v Lanarkshire Health Board (Respondent) (Scotland) [2015] UKSC 11.

¹²¹ ibid [114].

 ¹²² *I.V. v. Bolivia*, Judgment 30 November 2016 (Inter American Court of Human Rights).
 ¹²³ ibid.

observed that the process of informed decision-making operated under the harmful stereotype that I.V., as a woman, was unable to make such decisions responsibly, leading to "an unjustified paternalistic medical intervention" restricting her autonomy and freedom.¹²⁴ The Court thus found a violation of the right to non-discrimination because she was a woman.¹²⁵ It also recognised the particular vulnerability to forced sterilisation facing certain women based on other characteristics, such as socioeconomic status, race, disability, or living with HIV.¹²⁶

This table has sought to illustrate the existence of gender stereotyping within cases concerning women and their reproductive autonomy. The analysis will now progress to review the existence and impact of stereotypes on male patients.

2.2.3.5 Comparative selection

Cases will be reviewed whereby male patients have refused consent to determine how their refusals are dealt with and if the language and dialogue differ. As previously explained, I am not disputing the existence of male stereotypes, rather, this is to demonstrate that stereotypes are used negatively with female patients and more favourably towards male patients. This is due in part to the legal concept of "reasonableness". This concept has been subject to feminist analysis in the context of discussions of the "reasonable man" as he appears in tort law and in the defence of provocation in criminal law.¹²⁷ It is argued that the notion of reasonableness has been interpreted in accordance with masculine standards and that this has remained the case, even when the "reasonable man" has been gender neutralised into "the reasonable person".¹²⁸

¹²⁴ ibid [246].

¹²⁵ ibid [249].

¹²⁶ ibid [247]-[248].

¹²⁷ Marcia Baron, 'The Standard of the Reasonable Person in the Criminal Law' in Antony Duff et al, *The Structures of the Criminal Law* (OUP 2011).

¹²⁸ Joanne Conaghan, 'Tort Law and the Feminist Critique of Reason' in Anne Bottomley, *Feminist Perspective on the Foundational Subjects of Law* (Cavendish Publishing 1996); Caroline Forell, Donna Matthews, *A Law of Her Own: The Reasonable Woman as a Measure of Man* (New York University Press 2006).

Another area which has reinforced positive male stereotypes is owing to liberal legalism, which views the subject of law as an atomised, self-interested, competitive being. This contrasts with feminist approaches which asserts the need of human relationality and interdependence.¹²⁹ Views which have somewhat ironically been derived from experiences of interconnection with others through pregnancy, childbirth, nurturing and caregiving.¹³⁰ This division represents the debate between the feminine "ethic of care" vs the masculine "hierarchy of rights", as a form of moral reasoning based on an understanding of individuals as embedded within webs of relationships rather than as disconnected free-floating entities.¹³¹ One consequence of viewing legal subjects as atomised, self-interested, self-determining beings is that legal responsibility tends to be allocated only to people who have acted intentionally.¹³² Whereas a relational, interdependent view of humanity would afford greater focus on the effects of actions.¹³³ A second aspect of the feminist critique of liberal legalism concerns the false dichotomy between autonomy and agency on the one hand, and vulnerability, victimhood and the need for protection on the other.¹³⁴ Hunter explains that in liberal legal theory, a person can occupy one or other of these positions.¹³⁵ However, gendered marking identifies autonomy as essentially masculine and vulnerability as essentially feminine.¹³⁶ Hunter continues to elaborate this theory through the example of how women often find that when they attempt to exercise agency, such as in the context of refusing consent to sexual activity or medical treatment, they are not taken seriously.¹³⁷

¹²⁹ Christine M Koggel, Amy Harbin, Jennifer J Llewellyn, 'Feminist relational theory' 18 (1) (2022) *Journal of Global Ethics* 1.

¹³⁰ Rosemary Hunter, Clare McGlynn and Erika Rackley, *Feminist Judgments: An Introduction* (Hart Publishing 2010).

 ¹³¹ Jennifer Nedelsky, 'Law, Boundaries and the Bounded Self' (1990) *Representations* 162 Joan Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care* (Routledge 1993).
 ¹³² Linda C. McClain, 'Atomistic Man' Revisited: Liberalism, Connection and Feminist Jurisprudence' 65 (1992) *California Law Review* 1177.
 ¹³³ ibid.

¹³⁴ Rosemary Hunter, 'Contesting the Dominant Paradigm: Feminist Critiques of Liberal Legalism' in Vanessa Munro, *The Ashgate Research Companion to Feminist Legal Theory* (Routledge 2016).

¹³⁵ ibid.

¹³⁶ ibid.

¹³⁷ ibid.

Conversely, it can be witnessed that male patients are afforded greater consideration when attempting to exercise their agency. For example, whilst the case, *Pennine Acute Hospitals NHS Trust and TM* (by his litigation friend, the Official Solicitor),¹³⁸ does not necessarily indicate a gender imbalance, it does give some credence to the claim that gender stereotypes can have some bearing on the capacity proceedings. In the case the judge develops a rapport with the patient over their mutual love of football. The judgment reads; "He and I discussed football, discovering we supported the same time. He had obvious enthusiasm for it and up to date knowledge."¹³⁹

The judge relates capacity to both an enthusiasm for and a knowledge of football. There has long been an association of men and sport, which heavily includes a comradery between the supporters of fellow teams and, to an extent, football remains a somewhat gendered sport. Women's teams are not given as much sponsorship or media attention as men. For example, during the recent Euro Championships a headline that frequently appeared in the newspaper is that football was "coming home" for the first time since 1966, however, the England Woman's team made it to the UEFA final in 2009.¹⁴⁰ The comradery is evident between the judge and the patient through the report where the topic of sports is a recurring theme. For example, see para 42 which states; ""I do agree with Miss Gollop that a bilateral amputation for a relatively young man of around forty-two, and who has enjoyed sports, is a profoundly traumatic prospect".¹⁴¹ Whilst this does not provide an absolute proof of stereotypes, it does heavily imply that the judge's ability to strike common ground with the patient over a mutual interest result in a somewhat empathetic approach to capacity. This case will be explored in further depth during the chapter concerning capacity in which cases from the Court of Protection are analysed using language to investigate the presence of stereotyping. For current purposes, this case illustrates that the extent to which a judge can relate to aspects

¹³⁸ Pennine Acute Hospitals NHS Trust and TM (by his litigation friend, the Official Solicitor) [2021] EWCOP 8.

¹³⁹ ibid [23].

 ¹⁴⁰ See various news articles including, Ella Bennett, 'Euros: The last time an England football team was in a major tournament final – and it wasn't in 1966' (My London 11/07/21) available at https://www.mylondon.news/news/euros-last-time-england-football-21023115
 ¹⁴¹ Pennine Acute Hospitals NHS Trust and TM (by his litigation friend, the Official Solicitor) [2021] EWCOP 8 [42].

of a patient's character, the easier it can be to develop an active and open dialogue. Open dialogue is crucial to advancing autonomy.

Feminist scholars can utilise content analysis to explore diversity and difference within a particular medium. Therefore, I will use the analysis to ask questions such as: How is language gendered in judgments? How do representations draw on gendered, sexualized stereotypes? Feminist research has revealed that one of the major stereotypes faced by women is in relation to they are overtly emotional in their thinking and actions.¹⁴² The judgments will be reviewed paying attention to how the women's actions and responses to the refusal of treatment are described by the professionals, particularly so whether negative connotations depict the women as aggressive and irrational. Reviewing the use of language and the dialogue between the professionals and the patients is the main aim of the content analysis. Judgments will be systematically reviewed, recording consistent features of each and drawing inferences about their use and meaning.¹⁴³ The limitations to this must be acknowledged in terms of access to particular information, for example transcripts of conversations. Common threads will be identified that illustrate female stereotypes are present in medico-legal dialogues via negative connotations in relation to a woman's wishes and preferences regarding medical treatment.

As earlier stated, inspiration will be taken from the Feminist Judgments Project founded by Rosemary Hunter, Claire McGlynn and Erika Rackley in which the academics sought to engage with the "real world" exercise of judgment writing.¹⁴⁴ Their work spawned a new form of critical legal scholarship, which sought to demonstrate how judgments could have been written and cases could have been described differently. Similarly to Hunter et al, this thesis will use conventional desk based legal research methods, other decisions in the relevant doctrinal area, case notes and other secondary literature and relevant policy material.

¹⁴² Leonardo Christov Moore, Elizabeth A. Simpson, Gino Coude et al, 'Empathy: Gender effects in brain and behaviour' 46(4) (2014) *Neuroscience Biobehavioural Reviews* 1; Jolien van Breen, Manuela Barreto, 'Mind the gap! Stereotype exposure discourages women from expressing the anger they feel about gender inequality' 23 (1) (2023) *Emotion* 124.
¹⁴³ Klaus Krippendorff, *Content Analysis: an introduction to its methodology* (Sage 2004).
¹⁴⁴ Rosemary Hunter, Clare McGlynn and Erika Rackley, *Feminist Judgments: An Introduction* (Hart Publishing 2010) 7.

As stated in the opening of this chapter, owing to the biological differences, it is impossible to complete a "like for like" comparison with a male patient within the Court of Protection. However, comparisons can be made more generally regarding assessments of capacity on male patients within the Court of Protection. It is worth noting at this stage that whilst inspiration will be taken from the Feminist Judgment Project, the re-writing will focus on employing a model of relational autonomy rather than on gender stereotypes. A relational approach would not guarantee the abolition of gender stereotypes, however, it would seek to navigate the damage that can be caused by such stereotypes.

Assumptions of character can impede on capacity decisions which in turn creates barriers to a patient's ability to participate in the decision-making process. A relational approach would enable greater patient participation. Theorists such as Carol Smart, drawing on the work of Michael Foucault, have observed that law is not simply a coercive force, but is also a powerful and productive social discourse which creates and reinforces gender norms.¹⁴⁵ In other words, law does not simply operate on pre-existing gendered realities, but contributes to the construction of those realities, often in a constraining or damaging way.¹⁴⁶ Femininity and masculinity tend to be constructed in dichotomous terms, which are aligned with other dichotomies such as "active/passive, culture/nature, autonomy/dependency, bounded/penetrable, universal/ particular, subject/object, self/other."¹⁴⁷ These dichotomies are hierarchical with the "feminine" side occupying the devalued position in each one. Cases chosen may be viewed as paradigmatically feminist in that they deal with subject matter of immediate concern to many women's lives, such as reproduction. The selection of cases has not been made on the basis of establishing comparisons between different types of patients; rather, to establish that gender enforced stereotypes impact upon the treatment of the patient.

 ¹⁴⁵ Carol Smart, *Feminism and the Power of Law*, (Routledge 1989).
 ¹⁴⁶ ibid

¹⁴⁷ Rosemary Hunter, Clare McGlynn and Erika Rackley, *Feminist Judgments: An Introduction* (Hart Publishing 2010) 7.

Particularly, that gender enforced stereotypes can have a negative impact on female patients and a more positive impact on male patients. The four cases concerning the female patients are as follows; *Guys and St Thomas' NHS Foundation Trust v X*,¹⁴⁸ *United Lincolnshire Hospitals NHS Trust vs CD*¹⁴⁹, *Re Z* and *NHS Trust v JP*.¹⁵⁰

Guys concerns a woman who was in the advanced stages of pregnancy when concerns were raised over her capacity and its subsequent implications for the pregnancy. The mother wanted a natural birth, however, the hospital sought powers for an emergency declaration should her health deteriorate. The case of CD concerns an application for an anticipatory declaration should the mother become incapacitated. Re Z again concerns a young pregnant woman who is subject to forced contraception against her wishes. The fourth case, JP, involves an application for a covert caesarean section on a young woman. The language in all cases reveals a pattern; women whose capacity is doubted are not provided with an active role in the decision-making process. When the women refuse their consent for the recommended treatment, it results in them being labelled as "disengaged". "aggressive" and "rude". Conversely, KG (by his Litigation Friend) X Local Authority involved a 68-year-old inpatient at Kingsgate Hospital who had been an inpatient since 2016.¹⁵¹ KG was clinically fit for discharge; however, he did not want to leave the hospital. Rather than his personal character being subject to review, focus was instead given to his condition and how "difficult" it was to treat.¹⁵² The case, *Pennine* Acute Hospitals NHS Trust and TM (by his litigation friend, the Official Solicitor)¹⁵³, discussed previously, is incredibly tragic and involves a man who was found collapsed at a bus shelter in Manchester. He too refused treatment, but instead was described as "intelligent" and "articulate.154

This section defined a feminist viewpoint as one which studies power and its relation to gender, before advancing to consider the differing feminist frameworks. Nedlesky

¹⁴⁸ Guys and St Thomas' NHS Foundation Trust v X [2019] EWCOP 35.

¹⁴⁹ United Lincolnshire Hospitals NHS Trust v CD [2019] EWCOP 24.

¹⁵⁰ NHS Trust v JP [2019] EWCOP 23.

¹⁵¹ KG (by his Litigation Friend) X Local Authority [2021] EWCOP 30.

¹⁵² ibid [22].

¹⁵³ Pennine Acute Hospitals NHS Trust and TM (by his litigation friend, the Official Solicitor) [2021] EWCOP 8.

¹⁵⁴ ibid [23].

championed the relational model of autonomy, which accords with the aim of this thesis. A relational context would take the wider social context and surrounding relations into consideration when actioning the decision-making process. Importantly, this section introduces the idea of commonality and suggests that should a judge be able to discover shared interests between his/herself and the patient, there is an increased chance of developing a more open dialogue between the two. Cases such as, *Pennine Acute Hospitals NHS Trust* and *TM*, illustrate that owing to gender stereotypes, a male judiciary may find it easier to identify with male patients. Should a relational model be adopted by the courts, it is likely that there would be a greater emphasis on the need to develop an active dialogue with patients, which would undeniably secure greater patient participation in proceedings.

2.3 Alternate Case Theory

Judgments will be analysed to determine if currently an individual model of autonomy dominates the medico-legal decision-making process and to assert that should a relational model be employed, fairer outcomes would be achieved for female patients, whereby they retained a greater sense of their autonomy. I will identify this using alternate case theory.

This section is inspired by the works of Rosemary Hunter, Clare McGlynn and Erika Rackley. Through their feminist judgments project, feminist legal scholars put theory into practice by re-writing the "missing" feminist judgments in key cases. The purpose of which is to provide a compelling illustration of how each case could have been decided differently. This section will follow a similar structure. Initially the original judgment and its decision will be explained before progressing to "re-imagine" the judgment had a relational approach to autonomy been employed through supported decision-making.

It is purported that a relational model would be better suited to dealing with issues concerning an alleged loss of capacity. To demonstrate and fully explain the rationale behind this, alternate case theory will be employed as part of the analysis of the judgments from the Court of Protection. Alternate case theory will mean that judgments will be re-written as if the relational model had been employed, including the professional medical opinion that is provided throughout the case. This will be purely speculative as the model will be based on a personal interpretation of the judgment; however, the guidelines of relational autonomy will be adhered to.¹⁵⁵ Using a relational approach towards issues of capacity would result in greater emphasis on the process of supported decision making. Supported decision-making operates based on inclusion rather than exclusion, meaning the patient's involvement in the proceedings would increase.¹⁵⁶ By increasing a patient's involvement, they would retain a greater sense of autonomy and it is likely they would be spared a great deal of distress. One of the main motivations behind a switch to relational autonomy, rests upon its holistic nature and how it enables a patient to be viewed in the entirety of their life, as opposed to just their presenting condition within the medical examination. Mackenzie and Stoljar further expand upon this, explaining that:

"Relational autonomy perspectives are premised on a shared conviction, the conviction that persons are socially embedded, and that agents' identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants, such as race, class, gender, and ethnicity. Thus, the focus of relational approaches is to analyse the implications of the intersubjective and social dimensions of selfhood and identity for conceptions of individual autonomy and moral and political agency."¹⁵⁷

¹⁵⁵ Carlos Gomez-Viseda, Yves de Maeseneer, Chris Gastmans, 'Relational autonomy in end-of-life care ethics: a contextualized approach to real-life complexities" (2020) *BMC* 50. ¹⁵⁶ Magneta R Simmons, Piers Gooding, 'Spot the difference: shared decision-making and support decision making in mental health' (2017) *Irish Journal of Psychological Medicine* 275; Carmel Davies et al, 'What are the mechanisms that support health care professionals to adopt assisted decision-making practice? A rapid realist review' (2019) *BMC Health Services Research* 960.

¹⁵⁷ Catriona Mackenzie, Natalie Stoljar, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (OUP 2000).

Dove et al, contend that we are not "independent individuals", but instead are "relational beings", whereby our identities and interests are shaped by the people and places surrounding us.¹⁵⁸

The alternate case theory will include: the original judgments, other decisions in the relevant doctrinal area, case notes and other secondary literature and relevant research and policy material. However, there are limitations to this form of study. For example, writing a judgment imposes certain constraints on the writer; courts are not democratic institutions and judges are not accountable to the public they serve.¹⁵⁹ Whilst these factors are not directly applicable to alternate case theory analysis, it is necessary to mention because they exist in practice. Several other methodological issues exist, such as judgments are confined to the issues and arguments raised by the parties in the case.¹⁶⁰ Further, there is a great difference between academic and judicial modes of writing. Judges and academics employ different methods of issuing truth claims.¹⁶¹ In academic writing, it is accepted to adopt a tentative approach and to suggest various ways of looking at an issue without the need to reach a conclusion.¹⁶² However, a judgment is bound to make truth claims. It must assert truths about the facts, and truths about the law and must apply the law to the facts through logical reasoning that leads to a true conclusion.¹⁶³ A judgment draws upon different sources of authority from those drawn upon in academic writing. Judgments are primarily legal - legislations and cases that constitute binding precedents.¹⁶⁴ There are no binding sources of authority in academic writing.¹⁶⁵

¹⁵⁸ Edward Dove, Susan E Kelly, Federica Lucivero, 'Beyond Individualism: Is there a place for relational autonomy in clinical practice and research?' (2017) 12 *Clinical Ethics* 150, 151. ¹⁵⁹ See, 'The Accountability of Judiciary' (2007) available at <u>https://www.judiciary.uk/wp-</u> content/uploads/JCO/Documents/Consultations/accountability.pdf [Accessed 01/09/2021]

¹⁶⁰ Government Legal Department, 'The judge over your shoulder – a guide to good decision making' available at

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_da ta/file/746170/JOYS-OCT-2018.pdf [Accessed 01/09/2019].

¹⁶¹ Rosemary Hunter, Clare McGlynn and Erika Rackley, *Feminist Judgments: An Introduction* (Hart Publishing 2010).

¹⁶² ibid.

¹⁶³ ibid.

¹⁶⁴ ibid.

¹⁶⁵ ibid.

This section outlined the process involved with alternate case theory in an attempt to replace what has been missing with the current individualistic model. This section will be substantial within the thesis as I plan for it to clearly prove that a move to a relational model is not only doable, but extremely practicable. This chapter on methodology now concludes with the question as to whether relational autonomy can help navigate gender imbalances.

2.4 Methodological issues

Consideration must be afforded to the methodological issues which can be encountered with such approaches. In some cases, discussion will be limited by the number of facts available. In certain cases, there may be a bare account of facts which leave several questions unanswered, further, the existence of expert evidence which can be considered at times to be questionable. It must be accepted that it is not usual for a judge, who is not a medical expert, to second guess opinions. In such cases, I will refer to evidence pointing strongly in the other direction and/or to consider how the circumstances in which expert opinions were produced may have compromised their validity.

2.5 The Court of Protection

Cases were selected using Westlaw and <u>www.bailii.org</u>, which are comprehensive online databases of United Kingdom legislation and case law. All cases had to originate from the Court of Protection. The Court of Protection was selected for two main reasons. Firstly, it is tasked specifically with implementing the Mental Capacity Act, therefore an assumption can be made that it should be best equipped to deal with matters such as 'best interests', capacity. Secondly, as will be witnessed through the case analysis, the judgments are very fact-specific which provide more rich data for my analysis in contrast to rule-based decisions. Keene et al state of the Court of Protection, that "its work provides a powerful illustration of what taking capacity seriously looks like, both inside and outside the courtroom".¹⁶⁶

¹⁶⁶ Alex Ruck Keene, Nuala B Kane, Scott Y H KIM, Gareth S Owen, 'Taking capacity seriously? Ten years of mental capacity disputes before England's Court of Protection' (2019) *International Journal of Law and Psychiatry* 56.

The Court is primarily tasked with determining whether a person has mental capacity to make specific decisions, and should a person lack capacity, they have the power to either decide on their behalf (in their best interests) or to appoint a deputy to do so. Further, the Court has the power to make declarations as to the lawfulness of acts done or to be done in relation to a person, to determine questions in respect of Lasting and Enduring Powers of Attorney and Advance Decisions to refuse medical treatment and to hear challenges against Deprivation of Liberty Safeguards ('DOLS'). The higher profile part of the Court of Protection's work is what this thesis is concerned with, as it considers questions of capacity and best interests in the health and welfare context. For reference, of the 241,670 applications made to the Court of Protection between 1st January 2008 and 1st October 2017, 1078 (0.4%) were applications relating to deprivation of liberty (Ministry of Justice).¹⁶⁷

In contrast to the civil and criminal courts, the Court of Protection has processes which,

"are essentially inquisitorial rather than adversarial. In other words, the ambit of the litigation is determined, not by the parties, but by the court, because the function of the court is not to determine in a disinterested way a dispute brought to it by the parties, but rather, to engage in a process of assessing whether an adult is lacking in capacity, and if so, making decisions about his welfare that are in his best interests."¹⁶⁸

The Court applies the test for capacity set out in section 2 of the MCA which questions whether the person before it has the capacity to make the decision(s) in question; it is also bound by the same principles in section 1, including the principle

¹⁶⁷ ibid.

¹⁶⁸ Cheshire West and Chester Council v P and M [2011] EWHC 1330 (COP) [52] per Baker J.

in s.1(3) that a person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.¹⁶⁹

Cases before the Court of Protection must submit evidence that the subject of the proceedings (the patient, known as P), lacks capacity to make the relevant decision his/herself. These proceedings are initiated by a statutory form known as a COP3. The threshold for engaging the court is set out in Section 48 of the MCA and is lower than the threshold that the court applies in making a final determination of P's capacity. The threshold was established by *Re* F (Mental Capacity: Interim Jurisdiction) [2009] EWHC B30 (Fam),¹⁷⁰ which stated there must exist "sufficient evidence to justify a reasonable belief that P may lack capacity in the relevant regard." ¹⁷¹ If that threshold is crossed, the Court has the power to make interim declarations and decisions.

The aim of this section was to justify the reasons for selecting the Court of Protection as the main judicial setting for cases referred to throughout this thesis. The section considered the creation of the court through the powers of the Mental Capacity Act 2005 and how it sets the threshold for determining if interventions to the patient's life are legitimate. The chapter now moves to advance its justification for the selection of cases for analysis. The cases considered all concern pregnancy, the reasons for which will be explored in greater depth in the following section, however, for present purposes it can be understood that pregnancy not only epitomises the exposure to stereotypes, but also showcases women, potentially, at their most vulnerable.

2.5.1 Case Selection: Why Pregnancy is Important.

The cases at the focus of this thesis are aligned by the fact they all concern patients' pregnancies. Women are already in a vulnerable position owing to the existence and

¹⁶⁹ Alex Ruck Keene, Nuala B Kane, Scott Y H KIM, Gareth S Owen, 'Taking capacity seriously? Ten years of mental capacity disputes before England's Court of Protection' (2019) *International Journal of Law and Psychiatry* 56.

 ¹⁷⁰ Re F (Mental Capacity: Interim Jurisdiction) [2009] EWHC B30 (Fam).
 ¹⁷¹ ibid [36].

prevalence of such attitudes, pregnancy adds to this threat.¹⁷² Pregnancy cases are being examined for two primary reasons, firstly that pregnant women may be seen as being more irrational due to the biological and psychological changes of pregnancy. This is often referred to as "baby brain".¹⁷³ Crawley et al expand that, "Generally, these stereotypes dictate that women are more illogical, irrational, and forgetful throughout their pregnancy ".¹⁷⁴ The prevalence and popularity of this stereotype results in undermining women's understanding of their own competence throughout their pregnancy. Choi argues that it positions intelligence, logic and competence as, "diametrically opposed to hallmarks of femininity". Choi's research resonates with the "male-order" construction of both the courts and medical profession, which have both long been routed in excessively protective paternalism.¹⁷⁵ Ultimately, the baby brain stereotype operates in legitimising the restriction of women's role in the active world of men and serves to reinforce the idea that women are helpless and incompetent. Longhurst illustrates that, the discrimination that pregnant women face due to the baby brain stereotype is underpinned by benevolent sexism and protective paternalism, which posit that pregnant women are subordinate members of society, in need of unwanted and unrequited help and advice.¹⁷⁶

¹⁷³ Sarah Young, 'Pregnancy really does cause 'baby brain' new research finds' (The Independent 16/01/18) available at https://www.independent.co.uk/life-style/baby-brainpregnancy-real-memory-loss-task-performance-worse-women-research-a8161921.html ; Sasha Davies, 'New study finds 'baby brain' is real but we're still not sure what causes it' (The Conversation 14/01/18) available at <u>https://theconversation.com/new-study-finds-babybrain-is-real-but-were-still-not-sure-what-causes-it-89916</u>; Jonathan Leake, 'Baby Brain does exist, scientists claim' (The Sunday Times 03/02/19) available at

¹⁷² Madeleine Pownall, 'The 'baby brain' stereotype and policing of pregnant women's competence' 19 (5) (2019) *Feminist Media Studies* 759; Madeleine Pownall, Mark Conner, Russell. R.C. Hunter, 'The effects of activating a 'baby brain' stereotype on pregnant women's cognitive functioning' 51 (8) (2021) *Journal of Applied Social Psychology* 809; Madeleine Pownall, Mark Conner, Russell R C Hunter, 'Blame it on her 'baby brain'? Investigating the contents of social stereotypes about pregnant women's warmth and competence' 62(2) (2023) *British Journal of Social Psychology* 692.

https://www.thetimes.co.uk/article/baby-brain-does-exist-scientists-claim-vwzsrrv7x. ¹⁷⁴ Ross Crawley, Sophie Grant, and Kim Hinshaw, 'Cognitive Changes in Pregnancy: Mild Decline or Societal Stereotype?' 8 (22) (2008) 8 *Applied Cognitive Psychology: The Official Journal of the Society for Applied Research in Memory and Cognition* 1142.

¹⁷⁵ Priscilla Choi, Carole Henshaw, Sarah Baker, and Joanne Tree, 'Supermum, Superwife, Supereverything: Performing Femininity in the Transition to Motherhood.' 23 (2) (2005) *Journal of Reproductive and Infant Psychology* 167.

¹⁷⁶ Michelle R. Hebl, Eden B. King, Peter Glick et al, 'Hostile and Benevolent Reactions toward Pregnant Women: Complementary Interpersonal Punishments and Rewards that Maintain Traditional Roles.' 92 (6) (2007) *Journal of Applied Psychology* 1499.

Secondly, pregnancy cases are considered because their interests can conflict with what is best for the foetus, thus creating a situation where the best interests of both the mother and foetus are often played out against each other, usually resulting in the foetus' interests taking priority. Longhurst reports that, "There is a discourse that pregnant women tend to be more emotional, irrational, and forgetful than nonpregnant women, and than men ... Pregnant women – their disorderly bodies and minds – [are] widely considered to be in need of a great deal of advice".¹⁷⁷ This assertion suggests that women are viewed as being incapable to make decisions themselves. Under a relational model, such an opinion would be somewhat less problematic (although still not desirable), as it would provide opportunities for women to be able to respond to such advice, rather than being prescribed it regardless of their own wishes and intentions. At present, the best interests test is supposed to take account of the incapacitated person's wishes and feelings. However, in practice, best interests' decisions are often made without direct involvement of the patient and can resemble something more akin to a substituted decision-making scheme. This tends to happen because if it is suspected the patient is incapable, the professionals move to make decisions on their behalf, rather than making decisions with them. A shift from the individualistic focus would mean the patient's surrounding support network could be utilised in terms of decision-making.

As stated, the second motivation for the inclusion of pregnancy cases is because pregnancy creates a unique set of circumstances within medical ethics because the foetus can only be accessed through an intervention on the pregnant woman.¹⁷⁸ Whilst it is true that maternal and foetal interests are usually aligned, the care of the foetus is reliant on the care of the pregnant woman and at times conflicts can arise between foetal and maternal interests. When such issues arise, they are dubbed issues of "maternal conflict". They are emotionally driven issues that involve balancing the rights of the women and the best interests of the foetus. Often, the autonomy of the mother is overruled in favour of the rights of the foetus. Harris

¹⁷⁷ Robyn Longhurst, 'Pregnant bodies, public scrutiny: Giving 'advice' to pregnant women" In *Embodied Geographies: Spaces, Bodies and Rites of Passage,* edited by Elizabeth K. Teather (Routledge 1999) 77.

¹⁷⁸ Susan Townsend, 'Ethics for the paediatrician: obstetric conflict: when fetal and maternal interests are at odds' 33 (1) (2012) Paediatric Review 33.

reports that feminist theory evaluates ethical issues from a gender-based perspective, particularly the distinctions in how women are treated in comparison with men and that there is an absence in the use of a neutral perspective in terms of decision making.¹⁷⁹ Such an issue is transatlantic. In some states across America, certain hospital policies exclude pregnant women from participating in health care decisions such as advanced directives refusing treatment.¹⁸⁰ The existence of these stereotypes implies a lack of competency of pregnant women to participate in healthcare decisions and contributes to a distorted view of women. Feminist theory can be considered in relation to this question: "If the patient were not pregnant and was refusing treatment, would her wishes be respected?" Another example would be to ask, "Is there a comparable situation in which one would consider forcing a father to undergo treatment to benefit his child?"¹⁸¹ These two questions will be considered when conducting the content analysis of the judgments.

This section began by outlining the two main reasons for the inclusion of pregnancy cases. However, perhaps the most significant and memorable, is that of the "baby brain" stereotype to which women are constantly subjected to. This stereotype clearly illustrates the problem faced by women, they are pre-judged to be unable to make decisions because of biological conditions and, as a result, are often not even invited to engage in the discussions that are being had concerning her own body owing to the existence of an individualistic conception of autonomy which defaults to a prescriptive approach of best interests. Whilst the MCA and Code of Practice suggest that patient participation should be encourage, at present, both reflect an individual model of autonomy. If a relational model were employed, whilst it cannot be guaranteed that it would result in the eradication of stereotypes, it would certainly create more opportunities for women to be given a much-needed seat at the table. The following section goes on to consider the second major part of methodology within the thesis, that of alternate case theory. Whilst I have already extensively advocated for a move to a relational model, this section will attempt to demonstrate how a relational model could operate in practice through the re-writing of judgments.

¹⁷⁹ Lucy Harris, 'Rethinking maternal-foetal conflict: gender and equality in perinatal ethics' (2000) *Obstetric Gynaecology* 786.

¹⁸⁰ Susan Meredith, *Policing Pregnancy: The Law and Ethics of Obstetric Conflict* (Ashgate Publishing 2005)

¹⁸¹ Susan Townsend, 'Ethics for the Paediatrician' 33(1) (2012) *Paediatrics in Review* 37.

2.5.2 Limitations of cases concerning pregnancy

The obvious limitation of examining the use of stereotypes employed in pregnancy cases is that such an analysis is consigned to one gender. However, as explained in the previous section, stereotypes are often epitomised during pregnancy and such cases provide clear descriptors concerning how females can be subjected to unfair prejudices and as a result, have their autonomy constrained. Nevertheless, it is still necessary to explore a comparative element, to deduce whether men too, face stereotypes to the detriment of their autonomy. Therefore, cases will be examined which feature men refusing treatment which would otherwise interfere with their bodily integrity. The language of the judges when dealing with refusals from both the male and female patients will be compared to see what differences emerge. The discrepancies will be discovered through noting the judicial response and subsequent actions to the patient's refusal. For example, does the judge believe the patient's behaviour to be "difficult", do they comment they are "agitated", or do they receive decidedly more positive connotations such as "intelligent" and "resourceful"? The language concerning how a patient is treated in such situations will be reviewed through systemic content analysis. Hall and Wright explain the benefits of such an approach, they believe such analysis is important as it enables the researcher to find common threads that link opinions, whilst providing an opportunity to comment on their significance.¹⁸² A trend becomes apparent, that often, in cases concerning pregnancy, there is a failure to establish a common ground and the patient is spoken to rather than engaged with. Coggon reports that, "judges are inclined to assess cases differently depending on the quality of the person whose autonomy is in question."¹⁸³ As a result, assumptions are often made from a judge's own moral compass. The result of this "closed-type" of conversation is that the female patients are prevented from accessing their full autonomy.

¹⁸² Mark A Hall, Roland F Wright, 'Systemic Content Analysis of Judicial Opinions' 96 (2008) *California law Review* 64.

¹⁸³ John Coggon, 'Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?' 15 (2007) *Health Care Analysis* 246.

2.6 Conclusion: Can Relational Autonomy Resolve the Gender Imbalance?

Women are currently faced with a problem; an individualistic approach to autonomy which reinforces gender stereotypes. The question which must be answered is; if gendered stereotypes are prejudicing outcomes for women, how will the employment of relational autonomy overcome those stereotypes which may be particular to a certain judge or group of judges? At present, informed consent is operated from an individualistic vantage point. Whilst the doctrine intends to protect patient autonomy, it fails to do enough to balance gender bias. In terms of reproduction, women are not provided with the balanced and comprehensive information required to promote their autonomy. A need exists for a broader framework to be developed which would support women through the decision-making process concerning their reproductive rights. It has already been established in this chapter that women are pre-disposed to require support throughout their lives, by encompassing that realisation within the medical decision-making process and encompassing the broader social context, women would retain a greater sense of autonomy within the decision-making process. All in all, a holistic approach is required as opposed to one of a clinical nature. A proposition to remedy this situation would be a comprehensive doctorpatient consultation that embodies a relational nature. The goal of relational autonomy should be used to transform the informed consent process into a more balanced and comprehensive consultation that better supports women's autonomy in the context of reproductive choices.

At present, the individualistic model does not do enough to balance the possible bias or recognise the potential for competing maternal-foetal interests in the conveyance of information. The framework is too narrow within the medical context which results in a process which is fundamentally flawed as it fails to account for the broader social context which would help minimise the influence of gender stereotypes. Furthermore, in the context of reproductive choices, where two beings are integrally intertwined, relational framework for informed consent should be instituted. The interrelated nature of women and foetus has no equal outside of pregnancy, which reinforces that an approach of individuality is incompatible when issues such as pregnancy involve at least two parties.

As has been established, traditionally, there has been an over-reliance on stereotypes by the medical profession. Stereotypical assumptions made by doctors and judges alike concerning women's motherly interests in her child can affect not only the medical treatments recommended, but also the procedures available and the information provided. For example, in the US case *Gonzalez vs Carhart*, it was stated, "While we find no reliable data to measure the phenomenon, it seems unexceptionable to conclude some women come to regret their choice to abort the infant life they once created and sustained severe depression and loss of self-esteem can follow".¹⁸⁴ Major et al have commented on such statements arguing that to make such assumptions about a woman's regret, are potentially overbroad and stereotypical, vitiates the woman's autonomy – it does not assist her or protect her".¹⁸⁵

Supported decision-making and patient centred care would protect female patients as it advocates and promotes a more interactive conversation between doctor and patient where values and interests are addressed, resulting in a more collaborative decision-making process. ¹⁸⁶ Liberal thinkers and liberal feminists have sought to minimise gender and biological difference because of the subordination that has arisen from the emphasis on difference.¹⁸⁷ They have promoted the need to respect women's choices in all contexts, rejecting claims of indifference, to avoid notions of incapacity. Relational autonomy provides an alternative understanding that acknowledge the many social and contextual constraints and pressures that may be placed on choices, while simultaneously recognising that there is value of self-determination. Dialogue and broad interacted consultations promote a relational form

http:///www.apa.org/women/prgorams/abortion/mental-health.pdf.

¹⁸⁴ Gonzalez vs Carhart 550 U.S [158]-[59].

¹⁸⁵ Brenda Major et al, Report of the APA Task Force on Mental Health and abortion (Psychological Association) available at

¹⁸⁶ Jessica Berg, Paul S Appelbaum, Charles W Lidz et al, Informed *Consent: Legal Theory and Clinical Practice* (OUP 2001) Jay Katz, *The Silent World of the Doctor and Patient* (JHUP 2001).

¹⁸⁷ John Stuart Mill, *The Subjection of Women* (Transaction Publishers 2001).

of autonomy that recognises the need to interact and understand the competing interests, influences and social pressures involved. Such dialogue will not only allow a patient to learn from doctors, but also allow a doctor to learn about the interests of particular patients and therefore not have to rely on stereotype when making recommendations.

Relational autonomy will not cast a magic spell that will remove all pre-existing stereotypes and biases that face women when it comes to deciding on medical treatment. However, an adoption of a relational model would mark a new chapter in which dialogue between the patient and practitioner was prioritised. Should patient participation increase; so, will patient autonomy.

3 A patriarchal world; the under-representation of women.

To the woman, God said, "I will greatly multiply your pain in child bearing; in pain you shall bring forth children, yet your desire shall be for your husband, and he shall rule over you." Genesis 3:16

3.1 Introduction

This chapter establishes that it is necessary to employ a feminist viewpoint when analysing the concepts of autonomy, capacity and consent through their development in medical law. A feminist viewpoint studies power and its relations to gender.¹⁸⁸ Feminist scholars cover a range of topics which include nationality, race, economic status and sexual orientation.¹⁸⁹ At the centre of all these topics is the notion that in the majority of societies, women have been systematically oppressed, whereas men have traditionally enjoyed a dominant role.¹⁹⁰ A male orientated society relates to the idea of patriarchy. Patriarchy is embedded within institutional structures (for example, access to positions of power and relationships with sources of income) that assert men and women are dichotomous and are unequal categories.¹⁹¹ Intrinsic to such dichotomies, is dominant gender ideology.¹⁹² This is the assumption that physiological sex differences between men and women are directly related to aspects of their character.¹⁹³ For example, claims that women are overtly emotional in their thinking, whilst a man's thinking is grounded in reason. Feminist theory focuses on analysing the grounds of such limitations placed on women. For the purposes of this chapter, feminist theory will largely be focused on the patriarchal implications posed by the medical profession.

¹⁸⁸ Graciela Hierro, Ivan Marquez, 'Gender + Power' (1994) 9 *Hypatia* 173.

 ¹⁸⁹ Toni- Ann Roberts, Nicola Curtin, Lauren E Duncan et al, *Feminist Perspectives on Building a Better Psychological Science of Gender* (1st edition, Springer 2016).
 ¹⁹⁰ Many Bocker, 'Batriarchy and Inequality: Towards a Substantive Feminism' 2(1) (1000)

¹⁹⁰ Mary Becker, 'Patriarchy and Inequality: Towards a Substantive Feminism' 3(1) (1999) *University of Chicago Legal Forum* 21.

¹⁹¹ ibid.

¹⁹² Amy Kroska, 'Conceptualizing and measuring gender ideology as an identity' (2000) 14 *Gender & Society* 368.

Feminist theory is of vital importance in terms of understanding the doctor-patient relationship and the subsequent implications caused by gendered differences and power relations. Generally, women have been under served by medical professionals owing to gender enforced stereotypes. Gender stereotypes are generalisations about what each sex is like. According to Social Role Theory, gender stereotypes originated from the historic split of the roles of women remaining at home and the men going to work.¹⁹⁴ This split has been widely regarded as a gendered division of labour.¹⁹⁵ In domestic settings, women have traditionally undertaken most of the housework and caretaking duties. Outside of the domestic sphere, women tend to be employed in people-orientated service occupations, rather than competitive occupations which have been filled by men.¹⁹⁶ An example of a healthcare-related profession which illustrates how gendered differences can impact occupation is nursing. Ulrich explains that "you see a picture of a man and a woman, both dressed in scrubs. Your first reaction is probably to assume that the man is a doctor, and the woman is a nurse and odds are that you would be correct."¹⁹⁷ This division of roles enforces gender stereotypes¹⁹⁸ and the ideas that claim men are more agentic than women, whilst women are more communal.¹⁹⁹ This division has also meant that female gender stereotypes are reinforced by a lower rank in socioeconomic status. This chapter firstly defines feminism through theory, explaining the implications of relational autonomy and the subsequent limits prescribed power can place on our personal freedoms. Secondly, the chapter explains the inherently male

¹⁹⁴ Alice H Eagly, *Sex Differences in social behaviour: A Social-role interpretation* (1st edition, Lawrence Erlbaum 1987); Alice H Eagly, 'Sex differences in social behaviour: comparing social role theory and evolutionary psychology' (1997) 52 *American Psychologist Journal* 1380; Anne M Koenig and Alice H Eagly, 'Evidence for the social role theory of stereotype consent: observations of groups' roles shape stereotypes' (2014) 107 *Journal of Personality and Social Psychology* 371.

¹⁹⁵ Alice H Eagly, Wendy Wood, ¹Social Role Theory of Sex Differences' in Nancy A. Naples, Renee C. Hoogland, Maithree Wickramasinghe et al, *The Wiley Blackwell Encyclopaedia of Gender and Sexuality Studies* (Wiley-Blackwell 2016).

¹⁹⁶ Richard A Lippa, Kathleen Preston, John Penner et al, 'Women's Representation in 60 Occupations from 1972 to 2010: More women in high status jobs, few women in things orientated jobs' 9 (5) (2014) *Plos one* 1, 9.

¹⁹⁷ Beth Ulrich, 'Gender Diversity and Nurse-Physician Relationships' (2010) 1 *Virtual Mentor* 41.

¹⁹⁸ Anne M Koenig and Alice H Eagly, 'Evidence for the social role theory of stereotype consent: observations of groups' roles shape stereotypes' (2014) 107 *Journal of Personality and Social Psychology* 371.

¹⁹⁹ Inge K Broverman, Susan Raymond Vogel, Donald Broverman et al, 'Sex-Role Stereotypes: A current Appraisal' (1972) 8 *Journal of Social Issues* 59.

characteristics of the medical profession, how such characteristics can result in oppression and how oppression has been accepted in the form of paternalism. Thirdly, this chapter explains the consequences of oppression and that gender inequality still exists owing to prevailing stereotypes and discrepancies of health treatment based on gender. These three sections serve to substantiate the reason why a feminist viewpoint is required.

3.2 The meaning of feminism

Feminism comprises a series of political, economic and social theories which advocate for the equality of the sexes. Feminism is not binary in its nature, there are various conceptions of feminist theory which have been developed over time to tackle different limitations placed on women. Sharma explains, "The central issues with which it grapples have spanned from suffrage (first-wave feminism) to issues of workplace equality and reproductive rights (second-wave feminism) to cultural constructions of gender and patriarchal oppression, with recognition that previous iterations of feminism often did not account for the perspectives of racialised or queer women (third-wave feminism)."200 Additionally, Lorber contends, "Any one feminist may incorporate ideas from several perspectives, and many feminists have shifted their perspectives over the years... The reason for much of the change in feminist theories is that with deeper probing into the pervasiveness of gender inequality, feminists have developed more complex views about gender, sex, and sexuality."²⁰¹ Despite the variations between the waves of feminism, four commonalities are integral to a feminist perspective. These are: "1) Gender is a central focus or subject matter of the perspective. 2) Gender relations are viewed as a problem, the site of social inequities, strains and contradictions. 3) Gender relations are not immutable: they are sociological and historical in nature, subject to change and progress. 4) Feminism is about an emancipatory commitment to change: the conditions of life that are oppressive for women need to be transformed".202 Therefore, all conceptions provide insights to gender inequalities, it is not a case of

²⁰⁰ Malika Sharma 'Applying feminist theory to medical education' (2019) 393 *The Lancet* 570, 571.

²⁰¹ Judith Lorber, *The Variety of Feminisms and their Contribution to Gender Equality* (Bibliotheks- und Informationssystem der Universität Oldenburg 1997).

²⁰² Jane L Parpart, Patricia Connelly, V. Eudine Barriteau, *Theoretical Perspectives on Gender and Development* (International Development Research Centre 2000).

whether a theory is outdated, more so, which theory is most appropriate to understand the topic at hand. The relevant topic for this chapter is the doctor patient relationship and the subsequent imbalances of power. To analyse this relationship and its implications, social constructionism will be employed as it considers the societal impacts of shared assumptions. The next section will explore how social constructionism seeks to explain the gendered differences between men and women and how the medical practice emphasises such differences through medical education and treatment disparities.

3.3 Social Constructionism

The theory of social constructionism argues that the differences between men and women are maintained by social processes. Further, gendered behaviour and disapproval of deviations from the established norms are manifestations of power and social control. The medical practice is thought to reinforce these boundary lines in a manner of ways. Significantly, stereotypes are imposed through the transition of medical knowledge. Medical knowledge provides the basis for the interpretation of illness and then ultimately, prescribed courses of treatment. Bury explains that "medical knowledge, no less than medical practice is socially constructed".²⁰³ This suggests that shared assumptions of society, aka stereotypes, feed into how medical knowledge is acquired and then practiced. Bury continues that the medical profession has a "monopoly" in dictating how illness is experienced.²⁰⁴ This claim resonates with the idea of power imbalances between the doctor and patient. Friedson further explains that illness, as a social state, is "created and shaped by human knowledge and evaluation".²⁰⁵ However, "human knowledge", as Hamberg identifies, is significantly impacted by gender blindness and preconceived stereotypes, both of which lead to the existence of gender bias. Such bias is extremely prevalent within the medical practice.²⁰⁶

²⁰³ Michael R Bury, 'Social Constructionism and the development of medical sociology' (1986) 2 *Sociology of Health & Illness* 137.

²⁰⁴ ibid 139.

²⁰⁵ Eliot Friedson, *Profession of Medicine A Study of the Sociology of Applied Knowledge* (PR edition, University of Chicago Press 1970) 212.

²⁰⁶ Katarina Hamberg, 'Gender bias in medicine' (2008) 4 Women's Health 237, 239.

Hamberg continues that woman are not offered the same treatment as men and that men are more likely to receive advance diagnostic interventions. There have been studies on a range of treatments which evidence this claim. For example, the treatment of psoriasis was used as a case study.²⁰⁷ There was an equal number of male and female patients. However, the male patients were more likely to receive clinic-based treatment, whereas the female patients were prescribed emollients and told to practice self-care.²⁰⁸ A further study of intensive care units revealed major discrepancies.²⁰⁹ Older women, in comparison with older men, were less likely to be admitted or to receive life-saving interventions.²¹⁰ This could be due to prevailing medical attitudes which consider women to be less important.²¹¹ These discrepancies are caused by what is known as the "gender order."²¹² This means that in society, the "normal" human is assumed to be a man as men are seen to be more important and more valuable than women.²¹³ To apply the gender order to the doctor-patient relationship, the patient presents herself or himself in line with what is deemed appropriate for each gender, the doctor then responds accordingly. Importantly, the power is with the doctor to interpret the patients' narratives and behaviours.

The "gender order" and the adjoining stereotypes can significantly impact the interpretation of such narratives. These narratives all feed into the social construction of the respective roles of both the doctor and the patient. O'Connell and Zampas examined the impact of stereotypes within the context of reproductive healthcare, revealing that accesses to essential treatment can be impeded.²¹⁴ Such treatment includes, access to contraceptive information, services and induced abortion and

 ²⁰⁷ Ingrid Osika, Birgitta Evengard, Fillipa Nyberg, 'Gender differences in the treatment of psoriasis' (2008) 47 *International Journal Dermatology* 144.
 ²⁰⁸ ibid

²⁰⁹ Robert A Fowler, Natasha Sabur, Ping Li et al, 'Sex and age-based differences in the delivery and outcomes of critical care' (2007) 177 *Canadian Medical Association Journal* 1513.

²¹⁰ ibid.

²¹¹ Barbara Bernstein, Robert Kane, 'Physicians' attitudes towards female patients' (1981) 19 *Medical Care* 600, Stephen Colameco, Lome A Becker, Michael Simpson, 'Sex bias in the assessment of patient complaints' (1983) 16 *Journal Family Practice* 1117.

²¹² Raewyn W Connell, *Gender* (Polity Press 2002).

²¹³ ibid.

²¹⁴ Ciara O'Connell, Christina Zampas, 'The human rights impact of gender stereotyping in the context of reproductive healthcare' (2019) 144 *International Journal of Gynaecology and Obstetrics* 116.

lead to involuntary interventions in the context of sterilisation. The United Nations' Committee on the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW) recognise that stereotyping in reproductive health care is not uncommon and can cause harm to women's individual, physical and mental wellbeing.²¹⁵ A frequently used stereotype is that women are vulnerable and emotionally volatile, rendering them incapable of making decisions about their reproductive capacity.²¹⁶ Contrastingly, stereotypes portray men as people in positions of authority, these are often likened to the role of doctors. Further solidifying the stereotypes is the obvious hierarchy in medical care, by which the doctors are the ones who hold the knowledge, whilst the patient is dependent on the information for care. To address such issues, FIGO issued an ethical guideline, "Harmful stereotyping of women in health care".²¹⁷ Recognising harmful stereotyping of women in the provision of health care and providing guidance to obstetricians and gynaecologists on identifying and avoiding stereotyping of both patients and colleagues. The guideline identified some specific stereotypes than can lead to conduct that contravenes both ethical and human rights standards, namely that women "are vulnerable and incapable of reliable or consistent decision making" and, "that they will subordinate to men such as fathers, husbands, brothers, coemployees and doctors".²¹⁸ In the context of health care, the CEDAW committee recognised that, "gender stereotypes may impact women's capacity to make free and informed decisions and choices about their healthcare, sexuality and reproduction and, in turn, also impact on their autonomy to determine their own roles in society".219

 ²¹⁵ FIGO Committee for the Study of Ethical Aspects of Human Reproduction and Women's Health. Harmful Stereotyping of Women in healthcare (2011) in *Ethical Issues in Obstetrics & Gynaecology, International – Federation of Gynaecology and Obstetrics* (2012) 28.
 ²¹⁶ Rebecca Cook, 'Modern day inquisitions, keynote address, gender justice and human

rights in the Americas convening' (2011) 65 *Miami Law Review* 792.

²¹⁷ CEDAW Committee, 'Summary of the Inquiry concerning the Philippines under Article 8 of the Optional Protocol to the Convention on the Elimination of All Forms of Discrimination Against Women [2014] (CEDAW/C/OP.8/PHL/I).

²¹⁸ Ciara O'Connell, Christina Zampas, 'The human rights impact of gender stereotyping in the context of reproductive healthcare' (2019) 144 *International Journal of Gynaecology and Obstetrics* 116.

²¹⁹ Christina Zampas, 'Legal and ethical standards for protecting women's human rights and the practice of conscientious objection in reproductive healthcare settings' (2013) 123 *International Journal Gynaecology Obstetrics* s63-65.

A key example of how gender stereotypes have infiltrated the medical profession, thus enforcing boundary lines, is the case of *IV v Bolivia*.²²⁰ As explained in the chapter on methodology, a mother underwent a c-section, during which the surgeon performed an unrequested sterilisation. He did so on the grounds that a future pregnancy could pose a potential danger. Criminal charges were brought against the physician spanning 6 years until they were dropped by the criminal court. The case was then brought to the Inter-American Commission on Human Rights, which then referred the case to the Inter American Court on Human Rights in April 2015. *IV* argued in part that the Bolivian government failed to provide effective standards on informed consent and gender stereotyping and did not maintain effective mechanisms for state oversight and supervision of health institutions. The Court issued its judgment in November 2016 where it determined that the state had failed to protect IV's human rights. The Court recognised the "unequal power relations historically characterised between men and women" and the impact of this power imbalance as it applies to the physician-patient relationship."²²¹

3.3.1 Case examples

The stereotype that women and adolescent girls cannot make "rational" decisions about their sexual and reproductive lives has resulted in requirements stipulating third-party consent from either husbands, parents or guardians in order to receive sexual and reproductive health services. CEDAW have recognised these requirements as violations of human rights as they often only apply to women, constituting a form of discrimination.²²² These practices act as a barrier to accessing

²²⁰ *IV v Bolivia* (2016) Int Am Ct HR (Ser c): No 329.

²²¹ ibid.

²²² CEDAW Committee, General Recommendation 24: on women's health, UN Doc. A/54/38/Rev.1, chap. I, para 11 ("It is discriminatory for a State party to refuse to provide legally for the performance of certain reproductive health services for women."). The CEDAW Committee has consistently condemned requirements for spousal consent in order for women to access health services. Related to this, a series of judgments from the nowdefunct European Commission of Human Rights, claims on the rights of men (fathers) in relation to foetuses when women sought to terminate their pregnancies (to require their consent) were rejected on the basis of women's pregnancy -related privacy rights because a pregnant woman is " the person primarily concerned by the pregnancy and its continuation or termination", see: R.*H. v. Norway, Decision on Admissibility*, Application No. 17004/90 (European Commission on Human Rights, 19 May 1992), para. 4; *Paton v. United Kingdom*, Application No. 8317/78 (13 May 1980) (European Commission on Human Rights); *R.H. v. Norway*, Decision on Admissibility, Application No. 17004/90 (European Commission on

health services, thereby infringing the right to health from women and adolescents.²²³

Both courts and international human rights bodies have acknowledged that adolescent girls face harmful age-based stereotypes which suggest they are too immature and lack the capacity to make responsible and informed decisions and as a result, must be protected from engaging in sexual activity. As a result, blanket parental consent and notification requirements which fail to consider the evolving capacity of adolescent rights to make autonomous and confidential decisions, have been condemned.²²⁴

A prime example of such a situation is the aforementioned case of *Gillick*,²²⁵ where the House of Lords recognised that a girl under the age of 16, does not lack the power to give valid consent to contraceptive treatment purely on account of her age, observing that:

"[t]he truth may well be that the rights of parents and children in this sensitive area are better protected by the professional standards of the medical profession than by "a priori" legal lines of division between capacity and lack of capacity to consent since any such general dividing line is sure to produce in some cases injustice, hardship, and injury to health" ... [It held that] "the law [is] in line with social

Human Rights, 19 May 1992); and generally, *Boso v. Italy*, Application No. 50490/99 (European Commission on Human Rights, September 2002).

²²³ CEDAW Committee, ibid., para 14; CRC Committee, General Comment 4: on adolescent health and development, UN Doc. CRC/GC/2003/4, paras 9, 11, 28; CESCR Committee, General Comment 22, on the right to sexual and reproductive health, UN Doc. E/C.12/GC/22, 41.

²²⁴ For example, see *Gillick v. West Norfolk & Wisbeck Area Health Authority and another* [1986] 1 AC 112 (United Kingdom, House of Lords); *Christian Lawyers Association v. National Minister of Health and other*, Case No: 7728/2000, 2004 (10) BCLR 1086

[;] Dainius Pūras, Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, UN Doc. A/HRC/32/32 (2016), paras. 57, 59-60, 113; CESCR Committee, General Comment No. 22, supra note 22, para 30; CRC Committee, General Comment No. 15: on the right of the child to the highest attainable standard of health, UN Doc. CRC/C/GC/15 (2013), paras. 31, 56. ²²⁵ The facts of Gillick are explained in the table relating to gender stereotypes under section 2.2.3.4, 'Evidence of gender stereotypes'.

experience, which is that many girls are fully able to make sensible decisions about many matters before they reach the age of 16."²²⁶

Whilst the Courts in this case ultimately decided in favour of preserving adolescent autonomy, the fact that there was even a case to begin with illustrates how stereotypes have the power and means to negatively impact upon health outcomes for women. These stereotypes exist on an international level, as demonstrated in the case of *Christian Lawyers Association v National Minister of Health and Others*.²²⁷ This case concerned an action where the applicants complained that provisions of the abortion law, which allowed abortion for adolescents under 18 without "parental consent or control" were in violation of constitutional rights to family and parental care, to be free from maltreatment, neglect and abuse, and to be in the best interests of the child. It was argued that pregnant girls are unable to make informed decisions regarding the termination of their pregnancies without parental consent or control as they are unable to "appreciate the need for and value of parental care" and to give consent which serves their best interests.²²⁸

The Court's subsequent rejection of this argument was paramount in challenging stereotypes concerning adolescents' decision-making capacity as inconsistent with their constitutional rights, including the rights to make decisions relating to reproduction and control over one's body.²²⁹ The argument suggests that a rigid, age-based approach would ignore the intellectual, psychological and emotional differences of patients. As such, the court stated:

"The argument that the provisions of the Act which are under attack are unconstitutional because they do not cater for the interest of the child is unsustainable. The legislative choice opted for in the Act serves the best interest of the pregnant girl child (section 28(2)) because it is flexible to recognise and accommodate the individual position of a girl child based on her intellectual,

²²⁶ *Gillick v. West Norfolk & Wisbeck Area Health Authority and another* [1986] 1 AC 112 (England and Wales, House of Lords).

 ²²⁷ Christian Lawyers Association v. National Minister of Health and other, Case No: 7728/2000, 2004 (10) BCLR 1086 (T) (South Africa, High Court, Transvaal Provincial Division).
 ²²⁸ ibid [13].

²²⁹ ibid [27]-[28].

psychological and emotional make up and actual majority. It cannot be in the interest of the pregnant minor girl to adopt a rigid age-based approach that takes no account, little or inadequate account of her individual peculiarities."²³⁰

However, there has not been a uniformed approach to such issues. In *Imbong v Ochoa*,²³¹ the Filipino Supreme Court ruled that it was imperative that minors should secure parental or guardian consent to receive modern contraceptives. The court stated sections of reproductive health law that permitted access to contraception in the absence of parental consent to be unconstitutional, ruling that these provisions were "anti-family". This declaration reinforced the stereotypes of adolescent girls as incapable of rational decision-making.²³²

The Committee on Economic, Social and Cultural Rights (CESR), CEDAW and Amnesty International have declared that laws criminalising abortion, or only permitting abortion in highly restrictive circumstances constitute discrimination and violations of women's right to health and privacy.²³³ These laws are underpinned by gender stereotypes, particularly so conceptions that paint women as unable to make their own decisions about reproduction, thus asserting a need for these women to be controlled. Further, these laws perpetuate and encourage the sex-role stereotype that pigeonholes women as mothers and reproductive vessels by enforcing the ramifications of criminal law for those who do not want to carry a pregnancy to term.²³⁴ This criminalisation continues to exacerbate harmful stereotypes towards

²³⁰ ibid [56]-[57].

²³¹ Imbong v Ochoa G.R. No.204819, 8 April 2014.

²³² The Court noted that the law "contains provisions which tend to wreck the family as a solid social institution. It bars the husband and/or the father from participating in the decision-making process regarding their common future progeny. It likewise deprives the parents of their authority over their minor daughter simply because she is already a parent or had suffered a miscarriage." James M. *Imbong v. Hon.* Paquito N. Ochoa, Jr., G.R. No. 204819 (2014) (Republic of the Philippines, Supreme Court).

²³³ CESCR Committee, General Comment No. 22, supra note 22, para. 34; Amnesty International, On the Brink of Death: Violence Against Women and the Abortion Ban in El Salvador (2014), 6; CESCR Committee, General Comment No. 22, para. 28; CEDAW Committee, Concluding Observations on Peru, UN Doc. CEDAW/C/PER/CO/7-8 (2014), para 36; CEDAW Committee, Statement on sexual and reproductive health and rights: Beyond 2014 ICPD Review (2014).

²³⁴ Report of the UN Working Group on the issue of discrimination against women in law and in practice, UN Doc. A/HRC/32/44 (2016).

any woman who has sought or received abortion services, or even suspected of having done so with criminal activity, thus stigmatising them as "bad girls". ²³⁵

A further example of such harmful stereotype can be witnessed in the case of *Mellet v. Ireland*.²³⁶ The woman was pregnant with a foetus who sadly had a fatal impairment and was forced to travel abroad to access a legal abortion owing to Ireland's restrictive abortion law.²³⁷ The Human Rights Committee ruled that "[Ireland]'s criminalisation of abortion subjected [the petitioner] to a gender-based stereotype of the reproductive role of women primarily as mothers, and that stereotyping her as a reproductive instrument subjected her to discrimination." ²³⁸

Further, the Committee noted that the woman had been subjected to violations of her rights to freedom from cruel, human and degrading treatment, privacy and non-discrimination on grounds of socio-economic status. ²³⁹ Additionally, concurring opinions from several Committee members also found violations based on sex and gender discrimination.²⁴⁰ Building upon this rhetoric, of women being stereotyped as mothers, the Committee stated that:

"an alternative basis for a finding of gender discrimination – that Ireland's legal regime is based on traditional stereotypes regarding the reproductive role of women, by placing the woman's reproductive function above her physical and mental health and autonomy Indeed, the State's laws appear to take such stereotypes to an extreme degree where, as here, the author's pregnancy was nonviable and any claimed purpose of protecting a foetus could have no purchase. Requiring the author to carry a fatally impaired pregnancy to term only underscores the extent to which

²³⁷ The previous law in Ireland stated that abortion would only be permitted in cases where the woman's own life was endangered by the continuation of pregnancy.

²³⁸ Whelan v. Ireland, communication No. 2425/2014, UN Doc; *Mellet v. Ireland*, Communication No. 2324/2013, UN Doc. CCPR/C/116/D/2324/2013 (2016), para 7.11 (Human Rights Committee). See also para. 3.19 in which the Committee also notes the extension of this stereotype that "women should continue their pregnancies regardless of the circumstances, their needs and wishes". This finding was reaffirmed in a subsequent case brought before the Human Rights Committee against Ireland concerning the abortion law. CCPR/C/119/D/2425/2014 (2017), para 7.12. (Human Rights Committee).

 ²³⁵ Espinoza González v. Peru, Judgement of November 20, 2014 (Preliminary Objection, Merits, Reparations, and Costs), para. 272 (Inter-American Court of Human Rights).
 ²³⁶ Mellet v. Ireland, Communication No. 2324/2013.

²³⁹ *Mellet v. Ireland*, ibid [7.11].

²⁴⁰ ibid Annex I [3]-[5], Annex II [16].

the State party has prioritised (whether intentionally or unintentionally) the reproductive role of women as mothers."

Furthermore, the Committee has recognised that the discrimination faced by women is social constructed and as such permeates through women's lives to such an extent that it results in differing levels of treatment:

"[i]nequality in the enjoyment of rights by women throughout the world is deeply embedded in tradition, history and culture, including religious attitudes" and has admonished States parties to ensure that such attitudes are not used to justify violations of women's rights. In numerous prior cases, the Committee has invalidated as discriminatory both legislation and practices that reflected gendered stereotypes of women's social and biological role ... Recognition that differential treatment of women based on gender stereotypes can give rise to gender discrimination is also in accord with the approach of other human rights bodies."²⁴¹

Another international example concerns the case of *L.C. v Peru* which encompassed a tragic set of circumstances.²⁴² The CEDAW Committee found that Peru had violated the human rights of a minor who had continuously been sexually assaulted and then denied legal abortion services. The minor, on discovering she was pregnant, attempted to commit suicide by jumping from a building. However, healthcare practitioners delayed the necessary spinal surgery required for her recovery because of her pregnancy. As a result, the minor was paralysed. Whilst Peruvian law generally criminalises abortion, it can be authorised in limited circumstances if the pregnancy should pose a risk to the woman's health and in this case, the minor had made several attempts to receive an abortion on this basis. However, the hospital failed to accommodate these requests. CEDAW observed that the decision to delay the required spinal surgery was based on a "gender stereotype that understands the exercise of a woman's reproductive capacity as a duty rather than a right" and "considering her reproductive capacity of greater importance than

²⁴¹ ibid Annex II [14]-[15].

²⁴² *L.C. v. Peru*, Communication No. 22/2009, UN Doc. CEDAW/C/50/D/22/2009 (25 November 2011) 7.7.

her human rights", in violation of her right to non-discrimination, including in the field of health care.²⁴³

Other courts have relied upon patriarchal beliefs concerning the role of women in the family and the stereotype of the women's natural role in society is to reproduce and be a mother. In El Salvador, abortion is criminalised in all circumstances. "Manuela" (a pseudonym) was a woman suffering from advanced Hodgkin's lymphoma, she was convicted of aggravated homicide and sentenced to 30 years in prison after suffering obstetric complications which had been misdiagnosed as an attempted abortion.²⁴⁴ In the trial, the judge referred to Manuela as "easy" because she was pregnant outside of marriage and stated that "her maternal instinct should have prevailed" and that "she should have protected the foetus".²⁴⁵

The UK courts are similarly "guilty" of employing stereotypes of women requiring the protection of others such as legislatures, physicians and judges. A prime example being the English High Court *Axon* case.²⁴⁶ This ruling was somewhat of a double-edged sword. The judge ruled that intellectually mature adolescents had the power to make reproductive health decisions, including on abortion, without parental consent. Further ruling that they are entitled to a level of confidentiality comparable to that available to adults. However, the judgment was not as empowering as it appeared on face value. The judge applied the stereotype that women are incapable of exercising judgment on abortion by themselves, and that they remain required to satisfy health and social conditions for the procedure as determined by physicians. Thus, illustrating that the choices of young women, even those of adult capacity, are

²⁴³ ibid.

²⁴⁴ See, e.g., Case No. 310-2013, Decision of 28 May 2013 (El Salvador, Supreme Court of Justice, Constitutional Chamber); Center for Reproductive Rights, Marginalized, Persecuted, and Imprisoned: The Effects of El Salvador's Total Criminalization of Abortion (2014), 13; Amnesty International, On the Brink of Death, supra note [31]-[38].

²⁴⁵ Center for Reproductive Rights, ibid., pp 13, 59; Amnesty International, On the Brink of Death 38.

²⁴⁶ *R* on the Application of Axon v. Secretary of State for Health [2006] England and Wales High Court 37 (Administrative Court); Case No CO-5307-2004.

continually subjected to the restrictive stereotypes of women applied by legislators, physicians and judges.²⁴⁷

This section has served to illustrate that discriminatory and harmful stereotypes about sexuality and gender roles operate both to deny women access to contraception, as well as force certain women, and gender non-conforming individuals, to adhere to certain contraceptive methods, resulting in the undermining of their autonomy.

3.3.1.1 Analysis

As demonstrated for the above case studies, relationships between individuals and institutions, particularly so the balance of power, formulate common perceptions of gender and illness. Such perceptions can account for the existence of gendered health disparities. A feminist social constructionism, as explained by Friedman, is deeply concerned with the "concepts, practices, entities and attributes that constitute oppression". Friedman further elaborates that "Western feminists often explain male dominance and female subordination by arguing that (white, heterosexual) men and their patriarchal discourses predominate in the social construction process, creating a reality that both serves and is understood in ways that serve the interests of white heterosexual men".²⁴⁸ Gendered health disparities can be moulded by collective opinion. For example, Simoni explains that issues such as "how the body is perceived, how illness is experiences and the practice of medicine"²⁴⁹ can all feed into the enforcement of such disparities.

An area of healthcare in which a clear discrepancy is obvious is that between the provision of Viagra in comparison to birth control. Baker reported that Viagra had only been available for a few months before men were refused coverage of the drug, which resulted in lawsuits for a wrongful denial of benefits.²⁵⁰ Conversely, a suit had never been brought for the lack of provision of birth control. Further, Baker reveals that a "1994 study by the Alan Guttmacher Institute showed only half of large group

 ²⁴⁷ Joanna Erdman, 'Moral authority in English and American law', in Susan Williams,
 Constituting equality: gender equality in comparative constitutional rights (CUP, 2009) 107.
 ²⁴⁸ ibid.

²⁴⁹ Zachary Simoni, *Gender, Illness and Social Construction* (John Wiley & Sons 2014).

²⁵⁰ Debra Baker, 'Viagra Spawns Birth Control Issue' (1998) 84 ABA Journal 36.

insurance plans provide any form of coverage for birth control. Out of the companies that do, only 15% allow women their choice of the five methods currently available".²⁵¹ Shockingly, Richard Coorsh, spokesman for the Health Insurance Association of America in Washington DC, says there is a clear distinction between Viagra, which has been approved as a cure for a medical dysfunction and contraception which he calls a "lifestyle drug"; birth control is merely preventative and is not medically necessary.²⁵² More recently, the Trump administration greatly increased ways for companies to opt out of offering contraception.²⁵³ Viagra is not taxed; therefore, insurance companies cover the drug meaning it is widely accessible. Trump introduced new rules to the Affordable Care Act which has "vastly expanded the range of companies that could opt out of an Affordable Care act mandate that required employers to cover contraception at no cost for the employee, on the basis that contraceptives are morally offensive to the employer". This amendment has led to cases such as *Little Sisters v Pennsylvania*²⁵⁴ and *Trump v* Pennsylvania.²⁵⁵ The Little Sisters are a religiously affiliated employer who are urging the Supreme Court to bless the Trump administration's decision to give employers an unconditional religious exemption from the contraceptive coverage requirements of the Affordable Care Act and declare the ACA's religious accommodation unlawful.

Despite such overwhelming discrepancies in treatment, elements of commonality between both sexes continue to exist. There are universal experiences, or "rites of passage" that all humans will experience as a result of biological certainty. We are all born, we grow, we age, we experience illness and ultimately, we all die. Bricknell explains that collective perceptions of reality amongst society still exist.²⁵⁶ The prevalence of such perceptions then create "social constructs". Conrad and Baker expand that "a social construct is an idea that appears to refer to some obvious, inevitable, or naturally given phenomenon that has been created by a particular

²⁵¹ ibid.

²⁵² ibid.

²⁵³ Jeanna Kinkella, 'Letter: Insurance covers Viagra but not birth control under new rules?' *The Mercury News* (March 08, 2019).

²⁵⁴ Little Sisters v Pennsylvania (2020) USSC [19]-[431].

²⁵⁵ Trump v Pennsylvania (2020) USSC [19]-[454].

²⁵⁶ Louise Bricknell, 'The Trouble with Feelings: Gender, sexualities and Power in a gender regime of competitive sailing' (1999) *Journal of Sport & Social Issues* 159.

society at a particular time".²⁵⁷ Illness is an example of a social construct. The impact societies can have on perceptions of illness is monumental. Specifics of the surrounding culture and community will have physical consequences on the construction of an illness. For example, many societies do not believe in the existence of premenstrual syndromes. A recent report by WaterAid and UNICEF has revealed that there are several harmful cultural taboos concerning menstruation which include the restriction of women's freedom of movement and mandatory isolation. For example, women may be prohibited from visiting religious buildings when on their periods, they may be banned from touching other people, including their own babies and are forced to eat meals separately from men. Further, within many parts of Indian culture, menstruation is deemed to be dirty and impure.²⁵⁸ Additionally, menstruation is associated with the existence of evil spirits, shame and embarrassment surrounding sexual reproduction. In some cultures, for example, women bury the cloths used during menstruation to prevent them being used by evil spirits.^{*259}

Within societies, doctors are meant to hold impartial views and ground medical decisions within scientific fact. However, Lorber and Moore have reported that "stereotypes may influence diagnosis and social circumstances may be ignored".²⁶⁰ Social circumstances can relate to factors which might impact on a person's health; gender and socio-economic status are two major determinants. However, it has been reported that medical norms do not take account of such factors and instead are based on "white middle-class conceptions of male bodies and therefore anything that is inherently female, such as menstruation or menopause is branded as abnormal".²⁶¹ The construction of Western medicine in light of the "male model"²⁶² exemplifies such gendered differences.

²⁵⁷ Peter Conrad, Kerstin Barker, 'The social construction of illness: key insights and policy implications' (2010) 51 *Journal of Health and Social Behaviour* 67.

²⁵⁸ Suneela Garg and Tanu Anand, 'Menstruation related myths in India: strategies for combating it' (2015) 4 *Journal Family Medical Primary Care* 184.

²⁵⁹ ibid.

²⁶⁰ Judith Lorber, Lisa Moore, *Gendered Bodies Feminist Perspectives* (2nd edition, OUP 2010).

²⁶¹ ibid.

²⁶² ibid.

The stereotype of women as the weak sex is extremely prevalent. Premenstrual syndrome for example, is often constructed in Western societies as a "sign of female susceptibility or weakness".²⁶³ The portrayal of females as the inferior sex is further illustrated by Simoni who explains, "the structure of Western medicine is gendered because most specialists, medical school instructors, administrators and policy makers are men".²⁶⁴ Such a dominance has ramifications on the perception of illnesses in female patients and the subsequent treatment they receive. Friedman recognises this within the feminist theory of social constructionism, stating that, "dominant persons, institutions, practices and above all, dominant discourse are a prominent feature of feminist theories of social construction"²⁶⁵ and that "these dominance factors are theorized as being the causes of oppressive practices and oppressed identities which are brought about to serve the interests of socially dominant persons and groups".²⁶⁶ Further, the medical profession enforces gendered differences between the roles of nurses and doctors, with the roots of each role representing the respective roles of the mother as the nurse and the father as the doctor.²⁶⁷ Davies has reported that "training courses highlight that nurses are trained to provide motherly, tender love and care or TLC". Simoni concurs, stating that "the emotional needs of the patient are solely the responsibility of the nurse whereas the diagnosis and attention to symptoms are the doctor's responsibility. There are severe implications for women's health owing to such socially constructed norms. For example, the ONS as well as academics such as Payne, Emslie and Hunt report that worldwide, "women are at a higher risk of sexually transmitted diseases, contract infections due to genital mutilation and have restricted access to modern medical care".268

This section has covered much important ground in terms of understanding the current structure of the doctor-patient relationship and what factors help maintain the power distinctions. Pre-conceived ideas about gender stereotypes influence the

 ²⁶³ Zachary Simoni, *Gender, Illness and Social Construction* (John Wiley & Sons 2014).
 ²⁶⁴ ibid.

²⁶⁵ Marilyn Friedman, 'Nancy J Hirschmann on the Social Construction of Women's Freedom' (2006) 4 *Hypatia* 182.

²⁶⁶ ibid.

²⁶⁷ Ben Ulrich, 'Gender Diversity and Nurse-Physician Relationships' (2010) 12 *Virtual Mentor* 41.

²⁶⁸ ibid.

formation of medical knowledge which is continuously reflected in the availability of treatment plans to female patients. The "gender order" which classes men as the default human being, continues to exemplify the boundary lines between male and female patients. The implications of such a position become evidence in terms of health care coverage and treatment of pain. Further still, the gender order resonates with cultural depictions of gender which view females and female health as deviations from the norm. It is clear that the way the medical profession views and treats females continues to fuel the existence of gender stereotypes. Namely, society views male needs as superior to female needs, Hirschman summarises that it is obvious that feminism needs social constructionism to challenge patriarchy.²⁶⁹ The patriarchal implications for women are examined in the following section which concerns the notion of relationships. It has been established through this exploration of social constructionism that societal stereotypes cause women to be viewed as the weaker sex. The next section evaluates the consequences of this stereotype in terms of how and if women can live independently.

3.4 The notion of relationships

Relationships are important as they help establish who we are and how we are treated in society. The next chapter in this thesis deals with relational autonomy, therefore, it is necessary to outline how and why relationships are significant in terms of feminist theory. Our relationship with the outside world and those within it has implications for how we think, act and speak daily. From the moment we are born, we are the subject of our surroundings. As babies and then as children, we are fully within the control of our parents/other authority figure and are raised in accordance with their beliefs and decisions. Parents are the source of authority that provide the power to enable courses of action, whether it is as menial as what clothes we want to wear, to more serious matters of practicing a religion or attending school and receiving an education. The decision-making power ultimately lies with the parents' meaning children are dependent on that relationship as a means of survival. As a result, we are conditioned to consider others when we make choices throughout our

²⁶⁹ ibid.

lives. In addition to our decisions being shaped by external forces, Dove et al believe our whole being is impacted and constructed in accordance with our social surroundings. Dove et al refer to us as "relational beings" and believe that our identities and interests are shaped by the people and places surrounding us.²⁷⁰ McKenzie further explains "that persons are socially embedded, and that agents' identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants, such as race, class, gender and sexuality".²⁷¹

Indeed, a significant social determinant is a person's economic status; we are either enabled or restrained by our financial resources.²⁷² This argument relates to theories of intersectionality. Intersectionality is a theoretical framework which seeks to explain how aspects of a person's social and political identity, such as gender, race and class, could combine to create unique modes of discrimination.²⁷³ The basics of this concept relate to the idea that multiple forms of domination interact and can fuse to form new forms.²⁷⁴ The context of the term refers to the civil rights and women's movements between 1955-1980. Crenshaw developed the term as a critique of the legal system which viewed race discrimination and sex discrimination as separate wrongs.²⁷⁵ For the purposes of this chapter, the combination of inequalities relates largely to gender, class and poverty. Intersectionality explains that neither of these inequalities trump the other, instead, they combine to create further discrimination.

The determinants of gender, class and poverty have implications on a person's relationship with society.²⁷⁶ A person's well-being and life chances should not be pre-

²⁷⁵ Kimberlé Crenshaw, On Intersectionality: Essential Writings (New Press 2019).

²⁷⁰ Edward Dove, Susan Kelly, Federica Lucivero, 'Beyond individualism: is there a place for relational autonomy in clinical practice?' 12 (3) *Clinical Ethics* 150, 151.

²⁷¹ Catriona Mackenzie, Natalie Stoljar, *Relational autonomy: feminist perspectives on autonomy, agency, and the social self* (OUP 2000) 4.

²⁷² World Health Organisation, 'Social determinants of health' available at https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1 [Accessed 10/08/2023].

²⁷³ Kimberle Crenshaw, On Intersectionality: Essential Writings (New Press 2019).

²⁷⁴ Linda Gordon, 'Intersectionality' Socialist Feminism and contemporary Activism: musings by a Second-Wave Socialist Feminist' (2016) 28 *Gender and History* 340.

²⁷⁶ Fran Bennett, Mary Daly, 'Poverty through a Gender Lens: Evidence and Policy Review on Gender and Poverty' (2014) Department of Social Policy and Intervention (University of Oxford) available at:

determined by their background, evidencing the relevance of feminist theory. The European Institute for Gender Equality conducted a review on poverty, gender and intersecting inequalities in the EU.²⁷⁷ The review revealed that owing to existing gender inequalities in both the public and private sphere, women are constantly placed at an increased risk of poverty within the EU.²⁷⁸ Further, the review explained that "gender roles, stereotypes and structural inequalities weaken women's opportunities in the labour market devalue their work".²⁷⁹ The consequence of less opportunities to work and earn a sustainable income creates an increased dependency on others.²⁸⁰ The reliance on beneficence provides uncertainty and possible instability. The review reveals that almost one in four people in the EU is at risk of poverty or social exclusion and that women make up over half of that analysis. Another reason which contributes to the risk of poverty is that women are nearly four times more likely to work on a part-time basis than men (32% against 8%). Interestingly, women's limited economic independence can create a related risk of poverty for men.²⁸¹ The European Institute for Gender Equality has revealed that men are more likely to be the main or sole breadwinner. The impact of the limited economic independence evidences itself most in older age groups.²⁸² For example, in 2014 the gender gap for pensions was 40%.²⁸³

Overall, the data provided by the EU proves the intersectional theory, that there are numerous facets of poverty and factors that exaggerate vulnerabilities among men and women. It is evident that women's lower position in society creates an increased

²⁷⁷ EIGE, 'Poverty, gender and intersecting inequalities in the EU: Report' (2016) available at: https://eige.europa.eu/publications-resources/publications/poverty-gender-and-intersecting-inequalities-in-the-eu?language_content_entity=en [Accessed 10/08/2023].
 ²⁷⁸ ibid.

²⁷⁹ ibid.

https://www.spi.ox.ac.uk/sites/default/files/Gender_and_poverty_Bennett_and_Daly_final_12 _5_14_28_5_14.pdf [Accessed 11/08/2023].

²⁸⁰ European Commission, 'Labour Market Participation' (2022) available at <u>https://commission.europa.eu/strategy-and-policy/policies/justice-and-fundamental-rights/gender-equality/women-labour-market-work-life-balance/womens-situation-labour-market_en [Accessed 11/08/2023].</u>

 ²⁸¹ EIGE, 'Poverty, gender and intersecting inequalities in the EU: Report' (2016) available at: https://eige.europa.eu/publications-resources/publications/poverty-gender-and-intersecting-inequalities-in-the-eu?language_content_entity=en [Accessed 10/08/2023].
 ²⁸² ibid.

²⁸³ EMPL in Focus, 'The gender gap in pensions in the EU' (2019) available at: <u>https://www.europarl.europa.eu/RegData/etudes/BRIE/2019/631033/IPOL_BRI(2019)63103</u> <u>3 EN.pdf</u> [Accessed 29/07/203].

reliance on external relationships. Oshana had the view "that external circumstances- social and political conditions, impinge strongly on individual freedom".²⁸⁴ As demonstrated, when individual freedom is compromised owing to factors such as gender, class and poverty, women's independence is greatly impacted. This section has illustrated that factors of poverty, class and gender intersect to create environments in which women are increasingly vulnerable. Women are pre-disposed to lack independence and therefore require the support of a third party. This weakness is incredibly relevant in terms of the perception and treatment of women in healthcare. Traditionally, males have dominated the medical profession, thus, questions concerning the possible oppression of disadvantaged women arise.

3.5 Why is feminism relevant to medical law?

As explained, medicine was traditionally dominated by white, heterosexual, upper class men which raises concerns of potentially prejudicial attitudes towards women and their available treatment options. Men and subsequent masculinity have featured heavily in the medical profession, Sharma expands that "The so-called fathers of modern medicine were largely white, heterosexual, cisgender men—with the culture of medicine recreating itself in this image ever since."²⁸⁵ As a result of the dominant male influence, Scully and Bart reveal that medical texts often create a gender stereotype, which depict women as "irrational, sexually passive and maternal".²⁸⁶ Bleakley responds to claims of a gender stereotype, arguing that a dominant cultural form exists which is "based on a particular kind of logic that embraces heroism, rationalism, certainty, the intellect, distance, objectification, and explanation before appreciation".²⁸⁷

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²⁸⁴ Ericka Tucker, 'Power, Freedom and Relational Autonomy' in Aureila Armstrong, *Spinoza and Relational Autonomy: Being With Others* (EUP 2019).

²⁸⁵ Malika Sharma 'Applying feminist theory to medical education' (2019) 393 *The Lancet* 570-578.

 ²⁸⁶ Diana Scully and Pauline Bart, 'A funny thing happened to me on the way to the orifice: women in gynaecology textbooks' (1973) 78 *American Journal of Sociology* 1045.
 ²⁸⁷ Alan Bleakley, 'Gender matters in medical education' (2013) *Medical Education* 47.

Feminism can help understand the dynamics of the male dominant relationship and uncover how power operates in medical contexts. Sharma continues that the dominance is reflected in medical education where trainees mainly learn about male diagnosticians and scientists and are taught mainly by men in leadership positions.²⁸⁸ Historically, medicine has been subjected to gendering, creating a patriarchy which has resulted in barriers for feminist research and practice. Aultman and Borges have explored the gendering of medicine, revealing that such a patriarchy has had ripple effects, include harassment, a wage gap, and gender segregation in specialities and medical leadership.²⁸⁹

Such effects led to the development of the women's health movement which sought to address the gender bias and male domination in medical practice and enterprise.²⁹⁰ Scholars from across the globe highlighted that health systems failed to consider women's health issues and related social contexts, patronised women and their experiences and disregarded their lived experiences.²⁹¹ For example, there are visible discrepancies in medical textbooks, many of which are either absent of gender-specific knowledge or when referenced is done so in a demeaning and sexist manner.²⁹² A systemic visual content analysis was conducted on 6044 images in which sex/gender could be identified from a range of 17 major anatomy textbooks

²⁸⁸ Malika Sharma, 'A feminist in the academy' (2017) 189 *Canadian Medical Association Journal* 1398.

²⁸⁹ Delese Wear, Julie Aultman, Nicole Borge, 'Retheorizing sexual harassment in medical education: women students' perceptions at five US medical schools (2007) 19 *Teaching and Learning in Medicine* 20.

²⁹⁰ Ayelet Shai, Shahar Koffler, Yael Hashiloni-Dolev, 'Feminism, gender medicine and beyond: a feminist analysis of 'gender medicine' 20 (177) (2021) *International Journal for Equity in Health* 1.

²⁹¹ Mary Walsh, 'The rediscovery of the need for a feminist medical education' 49 (1979) *Harvard Educational Review* 447; Kirsti Malterud, 'Strategies for empowering women's voices in the medical culture' (1993) 14 *Health Care for Women International* 365; Petra Verdonk, Yvonne Benschop, Hanneke de Haes Toine Lagro-Janssen, 'From gender bias to gender awareness in medical education' (2009) 14 *Advances in Healthcare Science Education Theory Practice* 135.

 ²⁹² Anja Dijkstra, Petra Verdonk, Antoine Lagro-Janssen, 'Gender bias in medical textbooks: examples from coronary heart disease, depression, alcohol abuse and pharmacology' (2008) 42 *Medical Education* 1021.

Edward Halperin, 'The pornographic anatomy book? The curious tale of the Anatomical Basis of Medical Practice' (2009) 84 *Academic Medicine Journal Association American Medical Colleges* 278.

published during the period from 2008 to 2013.²⁹³ The results indicated that the representation of gender in images from anatomy textbooks remain predominantly male except within sex specific sections. It was often believed by educators that gender was purely a feminist political issue rather than a medical concern.²⁹⁴ Whilst the amount of female medical professionals has increased, Bleakley argues that the change is insufficient to rectify the gendered differences and power imbalances.²⁹⁵ Further, Bleakley asserts that a feminist theoretical approach is required to transform the cultural effect on medical practices.²⁹⁶

Both the practice and education of medicine are tainted by what Bleakley identifies as "andragogy" which he believes imposes male biases throughout the system.²⁹⁷ Bleakley's assertions are backed up by studies which reveal women in medicine are given less rewards for doing the same job as men.²⁹⁸ Furthermore, not only are women under-represented in key positions, women's career aspirations are continuously failed through the inadequate provision of resources and the necessary infrastructure to aid their goals.²⁹⁹ More worryingly, it would seem that the overwhelming male dominant characteristics of medical enterprise have resulted in a loss of confidence in female practitioners, as overall, women doctors consistently rate themselves as less capable than male doctors.³⁰⁰ Certain scholars have questioned whether the masculine culture of medicine is a result of biological dominance, further questioning what limits can be placed on a biological approach to medicine. The study asks whether women would have a monopoly on feminisation,

²⁹³ Rhiannon Parker, Theresa Larkin, Jon Cockburn, 'A visual analysis of gender bias in contemporary anatomy textbooks' 180 (2017) *Soc Sci Med* 106.

²⁹⁴ Petra Verdonk, Yvonne Benschop, Hanneke de Haes, Toine Lagro-Janssen, 'Should you turn this into a complete gender matter?' Gender mainstreaming in medical education.' (2009) 21 *Gender and Education* 703.

 ²⁹⁵ Alun Bleakley, 'Gender matters in medical education' (2013) 47 *Medical Education* 59.
 ²⁹⁶ ibid.

²⁹⁷ ibid.

²⁹⁸ Thomas Fysh, Geraint Thomas, Harold Ellis, 'Who wants to be a surgeon? A study of 300 first year medical students' (2007) 2 *BMC Medical Education* 7.

²⁹⁹ Wienke Boerma, Atie van den Brink-Muinen, 'Gender-related differences in the organisation and provision of services among general practitioners in Europe: a signal to health care planners' (2000) 38 *Medical Care* 993.

³⁰⁰ Russell Wolosin, Sabina Gesell, 'Physician gender and primary care patient satisfaction: no evidence of 'feminisation'' (2006) 15 *Quality Management in Health Care* 96.

or could men also act as agents in feminising a patriarchal culture.³⁰¹ However, as it stands, the "gaze" in medicine has remained purely patriarchal. Foucault believes medicine to be so exclusive that he has interpreted the "male gaze" as the "medical gaze".³⁰² Finally, Bordo summaries the succinct differences between how the roles of men and women are interpreted with regards to the medical profession. He argues that "the body is 'the province of the female', whereas men, by contrast, want 'to stand clear of the flesh, to maintain perspective on it'.³⁰³

Overall, this section clarifies that medicine is a male-dominated profession which encourages the stereotyping of women as irrational beings. There is a clear contrast visible which associates men with logic and women with emotion. The consequences of such gendering led to the development of the women's health movement, which has achieved some successes in terms of increasing the number of females within the medical profession. However, gender bias continues to prevail, both in education and in practice which causes extreme power imbalances between the doctor and patient.³⁰⁴ The power imbalances create issues of inequity and oppression, both of which will be examined in the following section.

3.5.1 The power imbalances between the doctor and patient resonate with feminist theories in cross-over issues of equity, oppression and justice.

Sherwin related that questions of dominance and oppression are essential dimensions of feminist ethical analysis.³⁰⁵ Further, Rogers explained, "Economic and material disadvantage are important dimensions of inequity in the genesis of ill health; however, the less tangible aspects of inequity are equally important. These

³⁰¹ Anna Westerstahl, Kerstin Segesten, Cecilia Bjorkelund, 'GPs and lesbian women in the consultation: issues of awareness and knowledge' (2002) 20 *Scandinavian Journal Primary Health Ca*re 203; Katarina Hamberg, 'Gender perspective relevant in many medical school subjects. Essential to perceive men and women holistically' (2003) 100 *Lakartidningen* 4078. ³⁰² Alan Bleakley, J Bligh, 'Who can resist Foucault?' (2009) 34 *Journal Medical Philosophy* 368, 370.

³⁰³ Susan Bordo, *Unbearable Weight: Feminism, Western Culture and the Body* (1st edition, University of California Press 1993) 5.

 ³⁰⁴ Linda Gordon, "Intersectionality', Socialist Feminism and Contemporary Activism: Musings by a Second-Wave Socialist Feminist' 28 (2) (2016) Gender & History 340.

³⁰⁵ Susan M Wolfe, *Feminism and bioethics: beyond reproduction* (OUP 1996) 52.

include lack of power, oppression, diminished opportunities, and discrimination; this is familiar territory for feminists."³⁰⁶ The case of *Geduldig v Aiello* ³⁰⁷ is a clear example of the oppression women can face. Aiello suffered a disability as a result of complications during her pregnancy. She was ineligible for benefits from California's Disability Fund, thus filed a suit alongside three other disabled women. The District Court held the statute unconstitutional, however, the State appealed to the Supreme Court where the decision was reversed and the statute upheld. The Court held that pregnancy exclusions did not differentiate between women and men but between "pregnant women and nonpregnant persons".³⁰⁸ Manian comments that the case was infamous in its decision "that pregnancy discrimination is not sex discrimination under the Equal Protection Clause of the Fourteenth Amendment."³⁰⁹ The *Geduldig* decision upheld a California state disability insurance program that denied benefits for pregnancy-related disability, while granting benefits for virtually every other disabling event ranging from prostatectomies to cosmetic surgery."³¹⁰

A women's propensity to economic and material disadvantage, coupled with the dominance and possible oppression of the medical profession can result in health inequities. Gender equity represents a key cross over theme between issues in feminist theory and issues within public health care. The concept of gender equity refers to "fairness of treatment for women and men, according to their respective needs. This may include equal treatment or treatment that is different, but which is considered equivalent in terms of rights, benefits, obligations and opportunities".³¹¹

Doyal recognises that the most significant differences between the female and male sex are the respective reproductive systems. For the differences to be respected in terms of equality of treatment, there needs to be a consideration of the possible

³⁰⁶ Wendy Rogers 'Feminism and public health ethics' (2006) 32 *Journal of Medical Ethics* 351.

³⁰⁷ Geduldig v Aiello 417 U.S 484 (1974).

³⁰⁸ ibid.

 ³⁰⁹ Maya Manin, 'Geduldig v Aiello, 417. U.S 484 (1974) in Feminist Judgments Rewritten Opinions of the United States Supreme Court (1st edition, CUP 2016).
 ³¹⁰ ibid.

³¹¹ Alex Michalos, *Encyclopaedia of Quality of Life and Well-Being Research* (1st edition, Springer 2014).

social constraints.³¹² Women are at "a considerable disadvantage in comparison with men"³¹³ as to realise their full potential for health, most will require access to resources to allow them control over their fertility and at times, those which will ensure healthy pregnancy and childbirth. Men, by contrast, not only have a lower risk of contracting sexually transmitted diseases, but once the initial conception has happened, men are free from any further risks in terms of fatherhood. A woman's reproductive health status is greatly affected by socioeconomic and cultural factors. Doyal explains that women's reproductive health status is profoundly affected by who they are and where they live.³¹⁴ For example, access to safe contraception, abortion and childbearing. Pregnancy has resulted in many deaths on an international scale that could have been avoided had there been sufficient access to trained healthcare workers.³¹⁵ The Sustainable Development Goals has set a target to ensure universal access to sexual and reproductive services, including family planning and education, into national strategies by 2030.³¹⁶ However, at present, limited access to resources such as these is one of the major reasons behind the high levels of maternal mortality.³¹⁷ The World Health Organisation reported that the "uptake of reproductive, maternal and child health services is higher in richer households than in poorer ones, based on 96 countries with data. Differences in coverage by house- hold wealth are largest for antenatal care and improved sanitation",³¹⁸ evidencing Roger's assertion that economic and material disadvantage are strongly connected in the nexus of ill health.

³¹² Lesley Doyal, 'Gender equity in health: debates and dilemma' 51 (2000) *Social Science Medicine* 931.

³¹³ ibid.

³¹⁴ ibid.

³¹⁵ ibid.

³¹⁶ World Health Organisation, SDG Target 3.7 available at

https://www.who.int/data/gho/data/themes/topics/indicator-groups/indicator-groupdetails/GHO/sdg-target-3.7-sexual-and-reproductive-health#:~:text=Indicator%20Groups-,SDG%20Target%203.7%20%7C%20Sexual%20and%20reproductive%20health%3A%20B y%202030%2C,reproductive%20health%20into%20national%20strategies [Accessed 02/08/2023].

 ³¹⁷ World Health Organisation, 'Maternal Mortality' (February 2023) available at https://www.who.int/news-room/fact-sheets/detail/maternal-mortality [Accessed 02/08/2023].
 ³¹⁸ ibid.

In terms of healthcare, equity is a central issue which represents connections between poverty, disadvantage, oppression and poor health.³¹⁹ Relative poverty is a key contributor to increased mortality both nationally and internationally. Therefore, in societies where there are greater levels of inequities, higher risks also exist for the development of health conditions.³²⁰ Wolfe believed that "A feminist bioethics should begin with attention to those historically least served and most harmed." 321 Economic disadvantage is a significant factor of inequity in terms of healthcare, however, there are other important dimensions such as power, oppression and discrimination. Rogers reports that the female gender represents a risk factor for increased inequity. The implications of gender discrimination and poverty provide direct implication to the ill health of women.³²² These correlations occur throughout a woman's life cycle,³²³ for example, "female infanticide, inadequate food and medical care, physical abuse, genital mutilation, forced sex and early childbirth are directly responsible for the deaths of many women across the globe".³²⁴ In 2019, the World Health Organisation published a report titled "Breaking Barriers Towards more gender-responsive equitable health system."³²⁵ The report revealed some startling statistics which reinforce the seriousness of problems arising from gender inequity. For example, according to data from 98 national health surveys 2010–2017, an estimated 40% of women of reproductive age (ages 15–49) did not have four or more antenatal care visits during pregnancy, as recommended by WHO, and 38% of sexually active women in need of contraception were not using a modern method.³²⁶

³¹⁹ Wendy Rogers 'Feminism and public health ethics' (2006) 32 Journal of Medical Ethics 351

³²⁰ Norman Daniels, Bruce Kennedy, Ichiro Kawachi, 'Why justice is good for our health: the social determinants of health inequalities' 128 (1999) Daedalus 215; Michael Marmot, 'Social Determinants of health inequalities' 365 (2005) The Lancet 1099.

³²¹ Susan M. Woolf, *Feminism and bioethics: beyond reproduction* (OUP 1996) 2. ³²² Mel Bartley, Amanda Sacker, David Firth et al, 'Dimensions of inequality and the health of women' in Hilary Graham, Understanding Health Inequalities (OUP 2000) 58 and Lesley

Doyal, 'Gender equity in health: debates and dilemma' (2000) 51 Social Science Medicine 931.

³²³ Lesley Doyal, What makes women sick: gender and the political economy of health (Macmillan Press 1995).

³²⁴ United Nations Population Fund, The State of World Population 2000 (UNFPA 2001, CH 2) Available at http://www.unfpa.org/swp/2000/english/index.htm Accessed [13/05/2020]. ³²⁵ World Health Organisation, 'Breaking Barriers towards more gender responsive and equitable health systems' (2019) available at https://cdn.who.int/media/docs/defaultsource/documents/gender/gender-gmr-2019.pdf?sfvrsn=905f494f 5&download=true [Accessed 03/08/2023].

More so, gender inequality is reflected in the delivery of health services. As well as typically being the primary – usually unpaid – caregivers in their household,³²⁷ women also make up 70% of health and social workers.³²⁸ They are also paid less than men and have fewer leadership and decision-making roles in the health sector.³²⁹ This data evidences that social, cultural and financial restraints greatly impede upon a woman's ability to act autonomously, particularly so in terms of health care and medical decisions.

To summarise, women have a propensity to economic and material disadvantage. There is an unequal access to health resources, this is of particular relevance in a reproductive context. Access to adequate reproductive healthcare is significantly impacted by socioeconomic and cultural factors. Socioeconomic inequities have direct implications for the ill health of women. Women are at a disadvantage purely because of their biological sex, they are predisposed to be poor and therefore suffer ill health due to limited access to resources and oppressive attitudes. A form of accepted oppression in the medical profession is known as "paternalism". The next section examines this concept and the consequences it has had on the treatment of women.

3.5.2 Paternalism dominated the medical profession for decades which often resulted in the undue treatment of women.

Paternalism is the thinking or behaviour of people in authority that results in them making decisions for other people that prevents them from taking responsibility of their own lives.³³⁰ Drolet explains, "broadly defined, paternalism is an action

³²⁷ Office for National Statistics, 'Full Story: The gender gap in unpaid care provision: is there an impact on health and economic position?' (2021) available at

https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellb eing/articles/fullstorythegendergapinunpaidcareprovisionisthereanimpactonhealthandecono micposition/2013-05-16 [Accessed 01/08/2023].

³²⁸ House of Lords Library, 'The women and girls in the fight against Covid-19' (08/02/2022) available <u>https://lordslibrary.parliament.uk/the-women-and-girls-in-the-fight-against-covid-19/#:~:text=Women%20in%20the%20health%20and,by%20the%20NHS%20are%20women [Accessed 10/08/2023].</u>

³²⁹ ibid.

³³⁰ Peter Lepping, Tom Palmstierna, Bevinatialli N. Raveesh, 'Paternalism v autonomy- are we barking up the wrong tree?' 209(2) (2018) *The British Journal of Psychiatry* 95.

performed with the intent of promoting another's good but occurring against the other's will or without the other's consent."³³¹ In medicine, it refers to acts of authority by the physician in directing care and distribution of resources to patients.³³² Paternalism in medicine has been active within the profession for centuries and prior to the introduction of human rights legislation, a patient was very much the product of the doctor's decisions. Davis reveals that women and their right to autonomy have suffered most under paternalism.³³³ Brazier and Miola continue that under paternalism risk disclosure was limited.³³⁴

There are different levels of medical paternalism. Paternalism can be understood as a "surrogate decision", whereby the physician makes the decision on behalf of the patient.³³⁵ The decision must be made for the patient's own good. Such decisions are usually made when the patient has a decreased decision-making capacity, for example if they were to be unconscious or suffering from a psychiatric disorder. A paternalistic action does automatically contravene a person's autonomy, but the nature of the attitude does not respect a person's right to make an autonomous choice.³³⁶ Beauchamp and Childress have explained that the most important aspect of autonomy is to respect the autonomous decisions of the patients.³³⁷ Accordingly, the greater the level of paternalistic decisions, the less the patient's autonomy is respected. Unfortunately, paternalism has often been actioned in ways which has unfairly contravened a women's right to autonomy.

³³¹ Brian. C Drolet, Candace White 'Selective Paternalism' (2012) 14 *Virtual Mentor* 582, 583.

³³² ibid.

³³³ Kathy Davis, *Power Under the Microscope: Towards a Grounded Theory of Gendered Relations in Medical Encounters* (Sage Publishing 1988).

³³⁴ Margaret Brazier, José Miola, 'Bye-bye Bolam: A medical litigation revolution?' (2000) 8 *Medical Law Review* 85.

³³⁵ Sandviken Bremberg, *New Tools for Parents—Suggestions to New Forms of Parental Support* (Red 2004).

³³⁶ Niklas Juth, Christian Munthe, *The Ethics of Screening in Healthcare and Medicine – Serving Society or serving the patient?* (Springer 2005).

³³⁷ Tom Beauchamp and James Childress, *The Principles of Biomedical Ethics* (OUP 2019).

3.5.3 There are gendered issues in public health which require a feminist analysis to determine the connections between gender, disadvantage, and the distribution of power.

The term gender relates to "socially constructed norms that impose and determine roles, relationships and positional power for all people across their lifetime. Gender interacts with sex, the biological and physical characteristics that define women, men and those with intersex identities"³³⁸ The power in relation to gender has been conceptualised by feminists as a resource to be "redistributed, as domination and as empowerment". The connections between gender and power usually result in patriarchal structures whereby women are subordinate to the dominate male. Gender equality refers to "the equal rights, responsibilities and opportunities of women and men and girls and boys (implying that the interests, needs and priorities of both women and men are taken into consideration, recognising the diversity of different groups of women and men".³³⁹ However, the opportunities available to women are largely limited by oppressive attitudes which are represented by gender stereotyping.

Women are stereotyped as care givers which often results in negligent attitudes towards women when women they require care themselves. A recent article in The Lancet revealed that "gender inequalities contribute to increased levels of stress and anxiety: among women through their socially prescribed role as caregivers".³⁴⁰ Dr Parveen further elaborates on the gender stereotype, explaining that "As women still tend to shoulder the main responsibilities for running the home and childcare they tend to soldier on and concentrate on looking after others.'³⁴¹ The result of the stereotype has meant that women are raised to accept pain and to tolerate the

³³⁸ Global Health 50/50, available at <u>https://globalhealth5050.org/gender-and-global-health/</u>[Accessed 10/05/20].

³³⁹ UN Women, available at

<u>https://www.un.org/womenwatch/osagi/conceptsandefinitions.htm</u> [Accessed 10/05/20] ³⁴⁰ Geordan Shannon, Melanie Jansen, Kate Williams et al, 'Gender equality in science, medicine and global health: where are we at and why does it matter?' (2019) *The Lancet* 560.

³⁴¹ Jo Waters, 'Just why do women face a fight for equal health' (Community Practitioner 07/11/19) Available at <u>https://www.communitypractitioner.co.uk/features/2019/11/just-why-do-women-face-fight-equal-health [Accessed 11/05/20].</u>

discomfort that comes from being a woman and to focus on looking after others. Significantly, when women do voice their pain, it is often under-estimated, whilst men's pain can be over-estimated.³⁴² For example, menstruation is still a neglected area of health, one in ten women and girls cannot afford sanitation products. Four contemporary health movements are attempting to change the gender landscape, these include: MeToo³⁴³ and #NiUnaMenos;³⁴⁴ intersectional feminism;³⁴⁵ the evolving recognition of men and masculinities;³⁴⁶ and the global transgender rights movement.³⁴⁷ Such movements have developed because it has become widely accepted that gender creates socio, economic and health disadvantages for women.

The health disadvantages that arise from restrictive gender norms result in large scale excesses in mortality and morbidity on a global scale. Inequalities are transformed into legitimate health risks through a variety of factors including, "discriminatory values, norms, beliefs, and practices; differential exposures and susceptibilities to disease, disability, and injuries; biases in health systems; and biases in health research."³⁴⁸ At each level, gender discrimination has detrimental outcomes for female health.³⁴⁹ One area of concern which is greatly influenced by harmful gender norms is the issue of interpersonal violence, including violence against women.³⁵⁰ All of these issues contribute to the increased levels of stress and

³⁴⁵ UN Women, 'Intersectional feminism: what it means and why it matters right now' (01/07/2020) available at <u>https://www.unwomen.org/en/news/stories/2020/6/explainer-intersectional-feminism-what-it-means-and-why-it-matters</u> [Accessed 23/10/2023].

 ³⁴² Diane E Hoffmann, Anita J Tarzian, 'The Girl Who Cried Pain: A Bias Against Women in the Treatment of Pain' (29) (2003) *Journal of Law, Medicine and Ethics* 13.
 ³⁴³ 'MeToo' available at: https://metoomvmt.org/ [Accessed 29/09/2023].

³⁴⁴ Marcela A Fuentes, '#NiUnaMenos #NotOneWomanLess' in Ayse Gul Altinay, Maria Jose Contreras, Marianne Hirsch et al, *Women Mobilizing Memory* (Columbia University Press 2019).

³⁴⁶ See for example, Stephen Burrell, Sandy Ruxton, Nicole Westmarland, 'Changing Gender Norms; Engaging with Men and Boys' (2019) Government Equalities Office available at

https://assets.publishing.service.gov.uk/media/60008afad3bf7f33b0de61f1/Changing_Gende r_Norms-_Engaging_with_Men_and_Boys.pdf [Accessed 23/10/2023].

³⁴⁷ See, Global Action for Trans Equality, 'GATE campaigns globally for trans, gender diverse and intersex equality' at <u>https://gate.ngo/</u> [Accessed 23/10/2023].

³⁴⁸ Geordan Shannon, Melanie Jansen, Kate Williams et al, 'Where Are We At and Why Does it Matter?' in Soloman Benator and Gillian Brock, *Global Health Ethical Challenges* (CUP 2021).

³⁴⁹ ibid.

³⁵⁰ World Health Organisation, 'Violence Against Women' (March 2021) available at <u>https://www.who.int/news-room/fact-sheets/detail/violence-against-women</u> [Accessed 04/08/2023].

anxiety among women and can be attributed to the constraints that arise from women having to perform their socially prescribed role as caregivers. Forced gender roles can cause low morale, low self- esteem and low productivity.³⁵¹ Further, many women are not able to access the resources in to help them grow and establish themselves independently to the role they have been given. ³⁵²

This section articulates that connections between gender and power result in the subordination of women which causes increased health risks and higher mortality rates. Subordination increases women's levels of stress and anxiety as they are often forced to focus on caring for others rather than themselves. The following section investigates the quality of care received when women do seek medical treatment.

3.5.4 Further, when women do receive treatment, it is of a lesser quality than that received by men.

Hoffmann and Tarzian have identified that women are more likely to be given sedatives for their pain and men to be given pain medication.³⁵³ It has been reported that women are more likely than men to be undertreated or even inappropriately diagnosed. Research into the reasons behind this has revealed the following, "women complain more than men; women are not accurate reporters of their pain; men are more stoic so that when they do complain of pain it's real".³⁵⁴ Faherty and Frier studied the administration of pain medication after abdominal surgery and found that physicians prescribed less pain medication for women aged 55 or older than for men in the same age group.³⁵⁵ Another study revealed that after undergoing a coronary artery bypass graft, female patients received sedatives more often than male patients, inferring that female patients were perceived as anxious rather than in

³⁵³ Diane E Hoffmann, Anita J Tarzian, 'The Girl Who Cried Pain: A Bias Against Women in the Treatment of Pain' (2003) *Journal of Law, Medicine and Ethics* (29) 13.
 ³⁵⁴ Lanlan Zhang, Elizabeth A. Reynolds Losin, Yonsi K Ashar, 'Gender Biases in Estimation of Others' Pain' 22(9) (2021) *The Journal of Pain* 1048.
 ³⁵⁵ ibid [55].

³⁵¹ Caitlin Stamarski, Leanne S. Son Hin, 'Gender Inequalities in the workplace: the effects of organizational structures, processes, practices and decision maker's sexism' 16(6) (2015) *Frontiers of Psychology* 5.

³⁵² ibid.

pain.³⁵⁶ Breitbart uncovered in a study of 360 AIDS patients that women were significantly more likely than men to receive inadequate analgesic therapy.³⁵⁷ A hypothesis titled "Yentl syndrome" has been developed which follows that women are more likely to be treated less seriously when they first seek medical help, a need exists for them to "prove that they are as sick as male patients".³⁵⁸ This hypothesis is supported by a recent study conducted by the British Heart Foundation which reports that "Inequalities in the way women with heart attacks are cared for compared to men are costing lives" over 10 years, 8243 women's lives were needlessly lost in England and Wales because they didn't receive the same standard of care as men – from diagnosis of a heart attack right through to aftercare."³⁵⁹

Building on this, Jackson reveals that in medicine, man is regarded as the default human being and that any deviation to that is atypical, abnormal and deficient.³⁶⁰ As man is regarded as the default patient it causes a wave of ignorance regarding female patients and their pain. Further, Jackson has reported that women also account for three-quarters of all those who suffer from autoimmune conditions, 'almost half of all these women with these diseases will have been told by their doctors that they're hypochondriacs or "too concerned with their own health".³⁶¹ The British Heart Foundation has recently reported that women have been historically under-represented in clinical research, including cardiovascular trials.³⁶² More so, that "as a result, many diagnostic tests and treatments have been based on data gathered from men".³⁶³ Health conditions relating to the female reproductive system,

³⁵⁶ Amanda Williams, 'Analysis: Women's pain is routinely underestimated and gender stereotypes are to blame' (UCL News 09/04/2021) available at:

https://www.ucl.ac.uk/news/2021/apr/analysis-womens-pain-routinely-underestimated-and-gender-stereotypes-are-blame [Accessed 06/05/2023].

³⁵⁷ William Breitbart, Barry Rosenfeld, Steven Passik et al, 'The undertreatment of pain in ambulatory AIDS patients' 65 (1996) *Pain* 243.

³⁵⁸ ibid.

³⁵⁹ British Heart Foundation, *Bias and biology: how the gender gap in heart disease is costing women's live* (2019) available at <u>https://www.bhf.org.uk/-/media/files/heart-matters/bias-and-biology-briefing.pdf?la=en</u> [Accessed 04/05/2023].

³⁶⁰ Gabrielle Jackson, *Pain and Prejudice: A call to arms for women and their bodies* (Piatkus 2019).

³⁶¹ ibid.

 ³⁶² British Heart Foundation, *Bias and biology: how the gender gap in heart disease is costing women's live* (2019) available at <u>https://www.bhf.org.uk/-/media/files/heart-matters/bias-and-biology-briefing.pdf?la=en</u> [Accessed 04/05/2023].
 ³⁶³ ibid.

such as periods, endometriosis and the menopause have been significantly undervalued and under-researched in healthcare, leading to a lack of awareness of the pain and issues that can arise as a result.³⁶⁴

Women receive lower quality medical treatment than men. Women are discriminated against owing to the preconceived gender stereotypes which have infiltrated the medical profession. This section clearly explains that gender alone results in significant disadvantages in terms of receiving medical treatment. This disadvantage is further exacerbated by women who are in poverty as the following section reveals.

3.5.5 10. In addition to the disadvantages brought by gender stereotype, a further disadvantage for women exists due to the correlation between ill health and poverty

Doyal reports that "Discrimination and inequality have both a direct and indirect impact throughout life".³⁶⁵ The direct effects of discrimination and inequality have been identified by the WHO in the 2015 Millennium Goals announcing that, "Women and girls account for roughly half of the world's population but form the majority of poor and hungry people. Ten million more girls than boys are out of primary school; two thirds of the world's illiterate young people are women The disproportionate impact of poverty on women and girls is not an accident, but the result of systematic discrimination."³⁶⁶ Poverty relates back to a person's ability to earn an income. Unfortunately, gendered differences result in economic determinants of health and illness. Work is often split into two categories, domestic labour and manual labour. Manual labour relates to work that is performed outside of the home which generates

³⁶⁴ Gabrielle Jackson 'I'm not a hypochondriac. I have a disease. All these things that are wrong with me are real, they are endometriosis.' *The Guardian (September 8th 2015)* Available at: <u>https://www.theguardian.com/society/2015/sep/28/im-not-a-hypochondriac-</u>i... [Accessed 10/05/20].

Maya Dusenbery, *Doing harm: the truth about how bad medicine and lazy science leave women dismissed, misdiagnosed, and sick* (Harper 2018).

³⁶⁵ Lesley Doyal *What makes women sick: gender and the political economy of health* (1st edition, Macmillan Press Ltd 1995).

³⁶⁶ Action Aid, 'Hit or Miss? Women's rights and the Millennium Development Goals (2015) Available: <u>https://www.actionaid.org.uk/sites/default/files/doc_lib/aamdg.pdf</u> [Accessed 10/05/20].

an income. Domestic labour is work which is done within the household, such as childcare, food preparation and cleaning. Generally, men are much more likely to participate in manual labour than women are.³⁶⁷ Whilst productive and reproductive work are valued differently dependent on the relevant culture, productive work usually brings greater autonomy and decision-making power.³⁶⁸

A lower socio-economic position poses greater risks to a person's health and wellbeing. A cross sectional study of British adults revealed that people in the most disadvantaged socio-economic positions reported increased rates of affective disorders and minor physical illnesses than those in higher positions.³⁶⁹ In addition to the barriers faced by a lower socio-economic position, women face greater barriers to healthcare because of their gender. The lower social status of women impacts the response received by women when they are affected by stigmatising illnesses, such as HIV/AIDS, leprosy, tuberculosis, and mental illness. Whilst it is true that men too experience significant discrimination and from society, women are more marginalised by these health problems.

3.6 Conclusion

The purpose of this chapter is to set out why a feminist approach will be employed with regards to analysing the concepts of consent, capacity and autonomy in medical law. In order to achieve this goal, it was necessary to define feminism through theory, explaining the implications of relational autonomy and the subsequent limits prescribed power can place on our personal freedoms. Secondly, the chapter explained the inherently male characteristics of the medical profession, how such characteristics can result in oppression and how oppression has been accepted in the form of paternalism. Thirdly, this chapter explains the consequences of oppression and that gender inequality still exists owing to prevailing stereotypes and discrepancies of health treatment based on gender.

³⁶⁷ Eva Rathgeber, Carol Vlassoff, 'Gender and tropical diseases: a new research focus' 37 (1993) *Social Science and Medicine* 513.

³⁶⁸ Carol Vlassoff, 'Gender Differences in Determinants and Consequences of Health and Illness' (2007) *Journal of Health Population and Nutrition* 25, 47.

³⁶⁹ Jennie Popay, Mel Bartley, Charlie Owen, 'Gender inequalities in health: social position, affective disorders and minor physical morbidity' (1993) 36 *Social Science Medicine* 21.

This chapter has reviewed many different factors that can impact on the existence of gendered differences and how those gendered differences place women at a disadvantage in terms of being able to access adequate and appropriate healthcare. It has been demonstrated that there are clear links between women being of a lower socio-economic rank, having less power to act autonomously and as a result, often struggle to receive medical attention. Furthermore, it has been evidenced that when women are able to access medical attention, the treatment they receive is often substandard. Women are subjected to demeaning attitudes, which often paint women as hysterical, overly emotional people who are not able to tolerate pain. A consequence of such dismissive attitudes has been an increased mortality rate for women, demonstrated for example, by recent studies conducted by The British Heart Foundation.³⁷⁰ Research demonstrated throughout the chapter has revealed that women are more likely to have their physical symptoms ignored and are more likely to have pain ascribed to a supposed mental health problem and as a result are at a higher chance of severe misdiagnosis of conditions such as heart disease and as such are more likely to suffer strokes.³⁷¹

On review of the literature encountered throughout the chapter, the overwhelming theme is that women are penalised for being women. The medical profession bases itself on a male standard patient.³⁷² The dictum demonstrated throughout the courts, the information presented in medical textbooks and the teaching carried out by

³⁷⁰ British Heart Foundation, *Bias and biology: how the gender gap in heart disease is costing women's live* (2019) available at

https://www.bhf.org.uk/informationsupport/support/women-with-a-heart-condition/women-and-heart-

disease#:~:text=How%20the%20gender%20gap%20costs,the%20scale%20of%20the%20pr oblem. [Accessed 11/05/20].

³⁷¹ Jennie Popay, Mel Bartley, Charlie Owen, 'Gender inequalities in health: social position, affective disorders and minor physical morbidity' (1993) 36 *Social Science Med*icine 21; Carol Vlassoff, 'Gender Differences in Determinants and Consequences of Health and Illness' (2007) *Journal of Health Population Nutrition* 25 (1) 47; Gabrielle Jackson 'I'm not a hypochondriac. I have a disease. All these things that are wrong with me are real, they are endometriosis.' *The Guardian (September 28th 2015)* Available

at: <u>https://www.theguardian.com/society/2015/sep/28/im-not-a-hypochondriac-i...</u> [Accessed 10/05/20].

³⁷² Geordan Shannon, Melanie Jansen, Kate Williams et al, 'Gender equality in science, medicine and global health: where are we at and why does it matter?' (2019) *The Lancet* 560.

universities, are all displays of male-centric attitudes.³⁷³ The prevalence of such attitudes has meant that women, for the most part, are still regarded as an inferior sex. Whilst it is true that advances have been made in the fight for equality, for example, with regards to period poverty, huge discrepancies remain.³⁷⁴ Women are still expected to conform to the gender roles of predominately being a carer for others. Women still tend to undertake many of the responsibilities for running the home and childcare and expected to prioritise the needs of others above their own. As a result of the pressure for women to place increased value on social relationships, particularly those with men, they have less independence.³⁷⁵ Such a pattern creates a cycle where women gradually become more and more reliant on the benevolence of others. A consequence of the intense social pressure leads to further health difficulties and problems for women. Research indicates that issues of low esteem, anxiety and depression are higher in females than males.³⁷⁶ Overall, the above illustrates why there is a role for feminist theory in analysing medical cases involving women and their treatment.

The remainder of the thesis focuses on the concepts of autonomy and capacity. The purpose of which is to ascertain how a person's objection to medical treatment may be impeded. The following chapter deals with autonomy. Autonomy is the dominant concept within this thesis, because if constrained, the right to self-determination is lost. Autonomy and self-determination relate to a person's capability of dictating the course of their own life. Without an autonomous individual, any subsequent questions of whether the relevant information is understood, or if the individual

³⁷³ Mel Bartley, Amanda Sacker, David Firth et al, 'Dimensions of inequality and the health of women' in Hilary Graham, *Understanding Health Inequalities* (OUP,2000) 58-78 and Lesley Doyal, 'Gender equity in health: debates and dilemma' (2000) 51 *Social Science Medicine* 931.

³⁷⁴ Jo Waters, 'Just why do women face a fight for equal health' *Community Practitioner* (November 7th 2019) Available at

https://www.communitypractitioner.co.uk/features/2019/11/just-why-do-women-face-fightequal-health [Accessed 11/05/20].

Diane E Hoffmann, Anita J Tarzian, 'The Girl Who Cried Pain: A Bias Against Women in the Treatment of Pain' (29) (2003) *Journal of Law, Medicine and Ethics* 13.

³⁷⁵ Jennie Popay, Mel Bartley, Charlie Owen, 'Gender inequalities in health: social position, affective disorders and minor physical morbidity' 36 (1993) *Social Science Medicine* 21; Lesley Doyal *What makes women sick: gender and the political economy of health* (Macmillan Press Ltd 1995).

³⁷⁶ ibid.

wishes to proceed with treatment, lose meaning. A person's right to selfdetermination can be affected by a number of factors, an extremely prevalent factor is gender. The feminist analysis and viewpoint outlined in this chapter will be employed when reviewing the autonomous rights of individuals to uncover any potential bias.

4 Autonomy: self-rule and the role of social context

4.1 Introduction

"...the capacity to be one's own person, to live one's life according to reasons and motives that are taken as one's own and not the product of manipulative or distorting external forces, to be in this way, independent"³⁷⁷

vs

"the social context within which all individuals exist and acknowledges the emotional and embodied aspects of decision-makers."³⁷⁸

This chapter explores the concept of autonomy and aims to assert how relational autonomy is a tool to mitigate the detrimental impact faced by women owing to the impact of gender enforced stereotypes on medical decision-making. Autonomy and self-determination relate to a person's capability of dictating the course of their own life.³⁷⁹ Autonomy refers to the right of self-government and self-determination is the process by which a person can action that right. The more autonomy is constrained, the more likely it is that the right to self-determination will be unsuccessful. However, a person's right to self-determination can be affected by several factors; a prevalent one being gender.³⁸⁰ This chapter asserts that the traditionally employed individualistic conceptions of autonomy favour aspects of rationality. Further, that the way in which rationality is constructed can adversely affect women.³⁸¹ From the 1980s onwards, the feminist movement sought to advocate for relational autonomy

https://plato.stanford.edu/archives/fall2020/entries/autonomy-moral/ [Accessed 25/01/2023]. 380 Lorraine Code, *What Can She Know? Feminist Theory and the Construction of Knowledge* (Cornell University Press 1991).

³⁸¹ Jennifer K Walker, Laine Friedman, 'Relational Autonomy: Moving Beyond the Limits of Isolated Individualism'(2014) *American Academy of Paediatrics* available at <u>https://pediatrics.aappublications.org/content/pediatrics/133/Supplement_1/S16.full.pdf</u> [Accessed 29/07/2020].

³⁷⁷ John Christman, 'Autonomy in Moral and Political Philosophy' (2020) *The Stanford Encyclopaedia of Philosophy*) available at

<u>https://plato.stanford.edu/archives/fall2020/entries/autonomy-moral/</u> [Accessed 25/01/2023]. ³⁷⁸ Jennifer K Walter, Laine Friedman Ross, 'Relational autonomy: moving beyond the limits of isolated individualism' 133 (2014) *Pediatrics* 16.

³⁷⁹ John Christman, 'Autonomy in Moral and Political Philosophy' (2020) *The Stanford Encyclopaedia of Philosophy*) available at

to recognise gendered differences in order to remove any bias or prejudice that would impact upon a woman's autonomy.³⁸² Relational autonomy suggests that a person conducts themselves in terms of their inter-personal relations and mutual dependencies.³⁸³ However, critics of relational autonomy have identified some flaws within the theory: undue influence and paternalism.³⁸⁴ Undue influence poses a danger in terms of overbearing family members causing oppression, this can be likened to clinicians exerting their influence through paternalism.³⁸⁵ Notwithstanding such critique, the aim of this chapter is to advocate for a shift from individual to relational autonomy.

The chapter is twofold; it initially explores individual autonomy (where it is asserted the problems lie) then continues to review how relational autonomy is a better fit to reviewing issues of female health as it accounts for the wider context of the patient. Thereby, rather than further perpetuating the inequalities faced by women, it makes room for them. Stereotypes are so engrained within society that they have practical, "real-life", consequences on women. As explained in "A patriarchal world; the underrepresentation of women", women are more likely to be the primary carer, earn less money and as a result depend on others.³⁸⁶ Relational autonomy takes these factors into consideration, it views people within the web of their social context, rather than through an atomised lens of an individual being capable of self-rule. By doing so, this affords women a greater sense of empowerment, it allows the narrative to change and rather than being weighed down by the consequences of social constructionism, it can help women overcome these consequences. Women

³⁸² Catriona Mackenzie, Natalie Stoljar, *Relational Autonomy: Feminist Perspective on* Autonomy, Agency and the Social Self (OUP 2000). ³⁸³ ibid.

³⁸⁴ Edward Dove, Susan Kelly, Federica Lucivero, Mavis Machion, Sandi Sheensa, Barbara Prainsack, 'Beyond individualism, Is there a place for relational autonomy in clinical practice and research?' (2017) 12 Clinical Ethics; "Paternalism" is defined in subsection 4.6.2. ³⁸⁵ Francis X Baker, Colleen M Gallagher, 'Identifying and Managing Undue Influence From Family Members in End-of-life Decisions for Patients with Advanced Cancer' (2017) 13 Journal of Oncology Practice 702.

³⁸⁶ Nidi Sharma, Subho Chakrabarti, Sandeep Grover, 'Gender differences in caregiving among family - caregivers of people with mental illnesses' 22; 6(1) (2016) World Journal Psychiatry 7; Joukje Swinkels, Theo van Tilburg, Ellen Verbakel et al, 'Explaining the Gender Gap in the Caregiving Burden of Partner Caregivers' 74(2) (2019) The Journals of Gerontology 309.

can present themselves in their entirety, whether that be a mother, a partner, a daughter, a sister – but above all, as a woman.

To re-iterate, women's exercise of their autonomy in respect of medical decisionmaking is impeded by the presence of stereotypes which influence judicial assessments of capacity and best interests. Stereotypes cannot be ignored; rather than discounting their existence (as is done under individual autonomy), relational autonomy accommodates the wider context of the patient, for example, it allows for stereotypes associated with emotions as a means of communication. Friedman has explained that a reliance on individualistic conceptions such as the "in-control" agent serves to prioritise self-sufficiency in decision-making and highlights a decisionmakers capacity to "have reason to transcend one's emotional experience."387 Conversely, relational autonomy highlights the social context within which all individuals exists and most importantly, acknowledges the emotional and embodied aspects of decision making. The in-control model asserts patients should avoid "emotional persuasion" in decision-making.³⁸⁸ Whereas a relational approach acknowledges the importance of others in decision-making and believe clinicians have a responsibility to engage with the patients' emotional experiences, offering clear guidance when patients are faced with a decision. Emotions are of paramount importance to relational theorists, who believe that emotions, as well as imagination and non-verbal communication are essential elements of human decision-making.³⁸⁹ Further stipulating that relationships with family, friends and communities hold significant weight; an area that is commonly neglected by individualistic theories of

³⁸⁷ Jennifer K Walker, Laine Friedman, 'Relational Autonomy: Moving Beyond the Limits of Isolated Individualism'(2014) *American Academy of Paediatrics* available at <u>https://pediatrics.aappublications.org/content/pediatrics/133/Supplement_1/S16.full.pdf</u> [Accessed 29/07/2020].

³⁸⁸ ibid.

³⁸⁹ Paulina Taboada, Eduardo Bruera, 'Ethical decision-making on communication in palliative cancer care: a personalist approach' 9(5) (2001) *Support Care Cancer* 335; Nicola Grignoli, Valentina Benardo Di, Roberto Malacrida, 'New perspectives on substituted relational autonomy for shared decision-making in critical care' 22 (1) *Critical Care* 260; Aleksandra Glos, 'Solidarity in healthcare – the challenge of dementia' (49) (2016) *Diametros* 1 ; Jennifer K Walker, Laine Friedman, 'Relational Autonomy: Moving Beyond the Limits of Isolated Individualism'(2014) *American Academy of Paediatrics* available at <u>https://pediatrics.aappublications.org/content/pediatrics/133/Supplement_1/S16.full.pdf</u> [Accessed 29/07/2020].

autonomy.³⁹⁰ Rather than models of self-sufficiency, decision making should be made in consultation with and in consideration of others. Such an approach would further support female patients against the prejudicial bias that exists within both medical and legal contexts.³⁹¹

Now that the context of the debate between the different strains of autonomy has been considered, the chapter will advance to discuss theories of individualistic conceptions of autonomy.

4.2 Theories of individualistic conceptions of autonomy

"Crudely stated, the charge is that the concept of autonomy is inherently masculinist, that it is inextricably bound up with masculine character ideals, with assumptions about selfhood and agency that are metaphysically, epistemologically, and ethically problematic..."³⁹²

There are various conceptions of autonomy, however, at a minimum individual autonomy is the idea of self-rule that is free from both controlling inferences by others and from any limitations that could prevent a meaningful choice.³⁹³ Varelius

³⁹⁰ Paulina Taboada, Eduardo Bruera, 'Ethical decision-making on communication in palliative cancer care: a personalist approach' 9(5) (2001) *Support Care Cancer* 335; Ho Mun Chang, 'Sharing death and dying: advance directives, autonomy and the family '18 (2) (2004) *Bioethics* 87; Anita Ho, 'Relational autonomy or undue pressure? Family's role in medical decision-making' 22 (1) (2008) *Scandinavian Journal Caring Sciences* 128; Nicola Grignoli, Valentina Benardo Di, Roberto Malacrida, 'New perspectives on substituted relational autonomy for shared decision-making in critical care' 22 (1) (2018) *Critical Care* 260.

³⁹¹ Megan S Wright, 'End of life and autonomy: the case for relational nudges in end-of-life decision-making law and policy' 77 (2017) *Maryland Law Review* 1002.

³⁹² Catriona Mackenzie, Natalie Stoljar, Relational Autonomy Feminist Perspectives on Autonomy, Agency and the Social Self (OUP 2000) 3.

³⁹³ Jukka Varelius, 'The value of autonomy in medical ethics' (2006) 9 *Medical Health Care Philosophy* 377.

gives the example of an autonomous individual being analogous to the way an independent government manages its territories and sets its policies.³⁹⁴ Varelius goes on to explain that in contrast a person who is in some respect controlled by others would be of diminished autonomy.³⁹⁵ Thus inferring that should someone require help with their decisions, they would not qualify as an autonomous individual.

4.2.1 Philosophical underpinnings of individual autonomy

The philosophical origins of individual autonomy are situated in the Modern era and can be accredited to the works of René Descartes,³⁹⁶ John Locke,³⁹⁷ Immanuel Kant³⁹⁸ and John Stuart Mill.³⁹⁹ Within contemporary bioethics, these ideals are expressed in the notion of "respect for autonomy", forming one of the four principles articulated by Beauchamp and Childress in Principles of Biomedical Ethics.⁴⁰⁰ Further, any interpretation of autonomy is underpinned by perspectives of what a human being is, otherwise termed as a "particular philosophical anthropology". The most common conceptions are described in terms of self-determination,⁴⁰¹

³⁹⁴ ibid.

³⁹⁵ ibid.

³⁹⁶ John Carriero, *Descartes and the Autonomy of the Human Understanding* (Routledge 1990).

³⁹⁷ John Baites, *The Empire of Habit: John Locke, Discipline and the Origins of Liberalism* (Boydell & Brewer 2016).

³⁹⁸ Oliver Sensen, *Kant on Moral Autonomy* (CUP 2012).

³⁹⁹ Raphael Cohen-Almagor, 'Between Autonomy and State Regulation: J.S. Mill's Elastic Paternalism' 87 (342) *Philosophy* 557.

⁴⁰⁰ Tom L. Beauchamp and James F. Childress, Principles of Biomedical Ethics (OUP 2019).
⁴⁰¹ Ho Mun Chan, 'Sharing death and dying: advance directives, autonomy and the family'
18(2) (2004) *Bioethics* 87; Anita Ho,' The individualist model of autonomy and the challenge of disability' 5(2-3) (2008) *Journal Bioethical Inquiry* 193; Tziporah Rosenberg, Jenny Speice, 'Integrating care when the end is near: ethical dilemmas in end-of-life care' 31(1) (2013) *Families Systems Health* 75; Fiona Wilson ,Christine Ingleton, Merryn Gott, Clare Gardiner, 'Autonomy and choice in palliative care: time for a new model?' 70(5) (2014) *Journal Advanced Nursing* 1020; Aleksandra Glos, 'Solidarity in healthcare – the challenge of dementia' (49) (2016) *Diametros* 1; Nicola Grignoli, Valentina Benardo Di, Roberto Malacrida, 'New perspectives on substituted relational autonomy for shared decision-making in critical care' 22 (1) (2018) *Critical Care* 260.

independency,⁴⁰² self-interest⁴⁰³ and self-reliance⁴⁰⁴ and are anchored by Christian and Western roots, the idea of personal identity, free will, and individual responsibility gave birth to a liberal conception of agency.⁴⁰⁵

4.2.2 Individualistic conception of autonomy

In accordance with an individualistic understanding of human beings, autonomy can be defined as "the ability to make individual, fully-informed, and independent decisions".⁴⁰⁶ In order to qualify as "autonomous" there are three conditions that need to be satisfied; firstly, the action has to be considered "authentically intended".⁴⁰⁷ Secondly, that it is free from external interference, be it from health professionals, family and friends, or society in general.⁴⁰⁸ Thirdly, that the agent is competent and sufficiently informed.⁴⁰⁹

⁴⁰² Sharon Ikonomidis, Peter Singer, 'Autonomy, liberalism and advance care planning' 25(6) (1999) *Journal Medical Ethics* 522; Aleksandra Glos, 'Solidarity in healthcare – the challenge of dementia' (49) (2016) *Diametros* 1; Barbara Prainsack, 'The "we" in the "me" solidarity and health care in the era of personalized medicine' 43(1) (2018) *Science Technology Human Values* 21.

⁴⁰³ Jennifer Walter, Lainie Ross, 'Relational autonomy: moving beyond the limits of isolated individualism' 133 (2014) *Pediatrics* 16; Paul Walker, Terrence Lovat, 'Concepts of personhood and autonomy as they apply to end-of-life decisions in intensive care' 18(3) (2015) *Medicine Health Care Philosophy* 309.

⁴⁰⁴ ibid.

⁴⁰⁵ Paul Walker, Terrence Lovat, 'Concepts of personhood and autonomy as they apply to end-of-life decisions in intensive care' 18(3) (2015) *Medicine Health Care Philosophy* 309; Barbara Prainsack, 'The "we" in the "me" solidarity and health care in the era of personalized medicine' 43(1) (2018) *Science Technology Human Values* 21.

⁴⁰⁶ Aleksandra Glos, 'Solidarity in healthcare – the challenge of dementia' (49) (2016) *Diametros* 1.

⁴⁰⁷ Catriona Mackenzie, Wendy Rogers, 'Autonomy, vulnerability and capacity: a philosophical appraisal of the mental capacity act' 9(1) (2013) *International Journal Law in Context* 37; Alistair Wardrope, 'Authenticity and autonomy in deep-brain stimulation' 40 (8) (2014) *Journal of Medical Ethics* 563; Roy Gilbar, José Miola, 'One size fits all? On patient autonomy, medical decision-making, and the impact of culture' 23(3) (2014) *Medical Law Review* 375.

⁴⁰⁸ Catriona Mackenzie, Wendy Rogers, 'Autonomy, vulnerability and capacity: a philosophical appraisal of the mental capacity act' 9(1) (2013) *International Journal Law in Context* 37.

⁴⁰⁹Anne Donchin, 'Autonomy, interdependence, and assisted suicide: respecting boundaries/crossing lines' 14(3) (2000) *Bioethics* 187; Jennifer Walter, Lainie Ross, 'Relational autonomy: moving beyond the limits of isolated individualism' 133 (2014) *Pediatrics* 16.

4.2.3 Individual autonomy in practice.

Whilst this chapter advocates for a shift from individual autonomy, its alleged merits must be considered in order for the narrative to remain free of bias, such viewpoints will be acknowledged (but also, countered). Academics such as Levine are in favour of an individualistic understanding of autonomy, particularly within the field of medicine, as they believe it to remedy the paternalistic nature of the doctor-patient relationship.⁴¹⁰ Further, King and Moulton assert that applying individualistic autonomy provides clarity in terms of constructing the boundaries for how and for whom decisions should be made. Additionally, King and Moulton believe that an individualistic version of autonomy eases the burden on healthcare professionals in the following ways: "1) Protecting autonomy is more easily aligned with existing legal principles and precedents, 2) Promoting patient autonomy may relieve the physicians of some responsibility and liability, 3) Emphasizing patient autonomy coincides with and supports the recent shift towards consumerism in medicine and 4) Promoting autonomy appears less paternalistic than beneficence, but still permits physicians to control the flow of information".⁴¹¹ Note, that none of the criteria listed by King and Moulton focus on the patient. The vein in which their justifications for individual autonomy are all based upon benefits for the clinician. Whilst a valid justification would be that individual autonomy allows doctors to better understand their patients and respond to their needs accordingly, this does not appear to be the focus of such claims.

Below is a table to summarise the body of literature concerning the alleged benefits of an individual conception of autonomy:

Claim	Rebuttal
Individual autonomy has served to	Individual autonomy only benefits
protect patients against paternalism.412	patients who are classed as capacious
	and is inadequate for patients who

⁴¹⁰ Robert L Levine, *Ethics and Regulation of Clinical Research* (YUP 1988).

⁴¹¹ Jaime King, Benjamin Moulton, 'Rethinking informed consent: the case for shared decision making' (2006) *American Journal of Law and Medicine* 429, 491.

⁴¹² Denise Dudzinski, Sarah Shannon, 'Competent patients' refusal of nursing care' 13(6) (2006) *Nursing Ethics* 608.

	require further support in the decision-
	making process.
Putting patients' values, interests, and	Individual autonomy and empowerment
beliefs at the centre of healthcare	only work on a prima facie level and
decisions empowers them. ⁴¹³	again, only really works for patients who
	are deemed to have the capacity to
	refuse treatment.414
Application of the principle of autonomy	Under individual autonomy, the
in real-life situations has contributed to	development of patients' rights is limited
the development of patient's rights,	to those who are able to be self-
including privacy, confidentiality, self-	sufficient in the decision-making
determination, and primacy of truth-	process. It does not help further the
telling in end-of-life scenarios.415	rights of those who cannot be atomised
	agents.
Individual autonomy is consistent with	This claim is acknowledged. Individual
the best-interests standard.416	autonomy is consistent with the current
	best-interests standard; however, this
	thesis asserts that when making such
	decisions, the focus should be on the
	patient within the wider context, not
	simply on the patient as they present in
	the clinical setting. 417

⁴¹³ Kelli Stajduhar, Laura Funk, Eva Jakobsson, Joakin Öhlén,' A critical analysis of health promotion and 'empowerment' in the context of palliative family care-giving' 17(3) (2010) *Nursing Inquiry* 221.

⁴¹⁴ Anita Ho, 'The individualist model of autonomy and the challenge of disability' 5(2-3) (2008) *Journal Bioethical Inquiry* 193.

⁴¹⁵ Lalit Kumar Radha Krishna, Deborah Watkinson, Ng Beng Yeong,' Limits to relational autonomy—the Singaporean experience' 22(3) (2015) *Nursing Ethics* 331.

⁴¹⁶ Ho Mun Chan, 'Sharing death and dying advance directives, autonomy and the family' 18(2) (2004) *Bioethics* 87.

⁴¹⁷ Catriona Mackenzie, Wendy Rogers, 'Autonomy, vulnerability and capacity: a philosophical appraisal of the mental capacity act' 9(1) (2013) *International Journal Law Context* 37.

4.2.4 Critiques of individual autonomy

It is undisputed that respect for autonomy is generally considered as a corner stone in medical ethics. However, the mainstream interpretation of this idea has been subject to various critiques. Four main critiques will be considered in this section; misconception of the individual self, inadequate portrayal of decision-making, failure to incorporate reality and shortcomings in current practices, laws, and policies.

4.2.4.1 Misconception of the individual self

Relational theorists argue that individual autonomy represents a misconception of the "individual self".⁴¹⁸ For example, individualists advance ideas that the "autonomous agent" should be an "atomistic self",⁴¹⁹ "sovereign and unified",⁴²⁰ "self-transparent to their individual beliefs and values" ⁴²¹ and "self-interested in their strategic choices". ⁴²² However, relationists assert that such conceptions are too abstract and fails to incorporate the surrounding context. ⁴²³

To continue with the narrative of autonomy equating to self-rule, the work of Christman will be considered. Christman explains that "to be autonomous is to be one's own person, to be directed by considerations, desires, conditions, and characteristics that are not simply imposed externally upon us, but are part of what

⁴¹⁸ Jennifer Walter, Lainie Ross, 'Relational autonomy: moving beyond the limits of isolated individualism' 133 (2014) *Pediatrics* 16; Paul Walker, Terrence Lovat, 'Concepts of personhood and autonomy as they apply to end-of-life decisions in intensive care' 18(3) (2015) *Medical Health Care Philosophy* 309.

⁴¹⁹ Sharon Ikonomidis, Peter Singer, 'Autonomy, liberalism and advance care planning' 25(6) (1999) *Journal Medical Ethics* 522; Lalit Kumar Radha Krishna, Deborah Watkinson, Ng Beng Yeong,' Limits to relational autonomy—the Singaporean experience' 22(3) (2015) *Nursing Ethics* 331.

⁴²⁰ ibid.

⁴²¹Anne Donchin, 'Autonomy, interdependence, and assisted suicide: respecting boundaries/crossing lines' 14(3) (2000) *Bioethics* 187.

⁴²² Anita Ho, 'The individualist model of autonomy and the challenge of disability' 5(2-3) (2008) *Journal of Bioethical Inquiry* 193.

⁴²³ Paul Walker, Terrence Lovat, 'Concepts of personhood and autonomy as they apply to end-of-life decisions in intensive care' 18(3) (2015) *Medicine Health Care Philosophy* 309.

can be considered one's authentic self'.⁴²⁴ Further explaining that, "the ability to rule oneself will lie at the core of the concept, since a full account of that capability will surely entail the freedom from external manipulation characteristics of independence". It is of Christman's opinion that autonomy of self-rule comprises two components; competence conditions and authenticity conditions.⁴²⁵ He explains that competency refers to "various capacities for rational thought, self-control, and freedom from debilitating pathologies, systemic self-deception."⁴²⁶ Further, that "authenticity conditions often include the capacity to reflect upon and endorse one's desires, values and so on".⁴²⁷ The act of reflecting and endorsing one's own desires creates an "in-control" model of autonomy. Walter and Ross explain that the "incontrol agent" model prioritises self-sufficiency in decision-making and highlights a decision- maker's capacity to have reason transcend one's emotional experience."⁴²⁸ This suggests that the "in-control" model favours rational thinking over emotional thinking.

Further, Code shares her critique of the character ideal of the "autonomous man".⁴²⁹ She believes this character ideal is at the heart of the "autonomy-obsession" of contemporary Western culture.⁴³⁰ Self-sufficient independence is central to this character ideal, which Code believes acts both descriptively and prescriptively to advocate for the notion that human beings are capable of leading self-sufficient, isolated, independent lives. Code portrays autonomy as synonymous with traits such as self-sufficiency, independence and self-reliance; suggesting that the autonomous individual is focused on maximising personal gains and views interactions through the lens of self-interest, explaining that:

⁴²⁴ John Christman, 'Autonomy in Moral and Political Philosophy' (2020) *The Stanford Encyclopaedia of Philosophy*) available at

https://plato.stanford.edu/archives/fall2020/entries/autonomy-moral/ [Accessed 25/01/2023] 425 ibid.

⁴²⁶ ibid.

⁴²⁷ ibid.

⁴²⁸ Jennifer K Walker, Laine Friedman, 'Relational Autonomy: Moving Beyond the Limits of Isolated Individualism'(2014) *American Academy of Paediatrics* available at <u>https://pediatrics.aappublications.org/content/pediatrics/133/Supplement_1/S16.full.pdf</u> [Accessed 29/07/2022].

⁴²⁹ Lorraine Code, *What Can She Know? Feminist Theory and the Construction of Knowledge* (Cornell University Press 1991).

⁴³⁰ ibid.

"The autonomous man is—and should be —self-sufficient, independent, and self-reliant, a self-realizing individual who directs his efforts toward maximizing his personal gains. His independence is under constant threat from other (equally self-serving) individuals: hence he devises rules to protect himself from intrusion. Talk of rights, rational self- interest, expediency, and efficiency permeates his moral, social, and political discourse. In short, there has been a gradual alignment of autonomy with individualism."

This ideal is problematic for several reasons. It supports valuing substantive independence over other values, in particular over those arising from relations of interdependence, including trust, loyalty, friendship, caring and responsibility. Secondly, it promotes a stripped-down conception of agents as "atomistic bearers of rights"⁴³² where agents are reduced to an "interchangeable sameness".⁴³³ Thirdly, it suggests that values, social practices, relationship, and communities that are based on cooperation and interdependence impede upon, or at least, compromise autonomy. Code is not purporting that we abandon the notion of autonomy altogether, rather, that we should remove the idea of self-sufficiency and replace it with a relational view centred on the recognition that persons are "second persons" who only become persons in relations with others. Baier shares this view of humans as "second-persons", meaning that, "the development of persons requires relations" of dependency on other persons: "persons are essentially successors, heirs to persons who formed and cared for them, and their personality is revealed in both their relations to others and in their response to their own recognised genesis". This view is anti-individualism, not anti-autonomy.

4.2.4.2 Inadequate portrayal of decision-making

According to proponents of relational autonomy, discussions concerning decisionmaking have a propensity to consider generic patients in idealised circumstances. However, in emotionally demanding situations (such as ones considering obstetric

⁴³¹ ibid.

⁴³² ibid.

⁴³³ ibid

complications), the circumstances are usually both physically and emotionally demanding, which can impact a patient's ability to (a) choose (b) articulate their choice. Prescriptive discussions of autonomy tend to interpret it as an "all-or-none affair". In other words, if the patient is judged as competent, the healthcare team must follow the patient's decisions. However, if the patient lacks one of the three conditions required for autonomy, then the role of decision-maker is passed onto somebody else to act in the patient's best interests. However, this binary approach is problematic for patients who, for example, may suffer with fluctuating cognitive symptoms, or those who can be considered autonomous for certain actions, but not others. Coggon and Miola suggest that autonomy is not an absolute matter, that one simply is or is not autonomous. Instead, they question whether autonomy is "graded", or "context-specific", meaning someone could be more, or less autonomous; a graded approach to autonomy aligns much more with theories of relational autonomy.⁴³⁴ Further, individual autonomy portrays decision-making as an isolated discrete event, as opposed to a dynamic on-going process.⁴³⁵ Further, critics believe that decision-making is not an entirely rational act.⁴³⁶ Rather, relational theorists have emphasised the role emotions, imagination and non-verbal communication as essential elements of human decision-making.437

4.2.4.3 Failure to incorporate social reality

The third critique relates to a failure of individual autonomy to incorporate social reality. Particularly so, it does not recognise the importance of particular relationships, such as family, friends and communities.⁴³⁸ In practice, it often transpires that when a patient is faced with a critical decision in relation to medical care, people will decide in consultation with and in consideration of others.⁴³⁹ This

⁴³⁴ John Coggon, José Miola, 'Autonomy, liberty and medical decision-making' 70(3) (2011) *Cambridge Law Journal* 523, 524.

⁴³⁵ Anita Ho, 'The individualist model of autonomy and the challenge of disability' 5(2-3) (2008) *Journal of Bioethical Inquiry* 193.

⁴³⁶ Jennifer K Walker, Laine Friedman, 'Relational Autonomy: Moving Beyond the Limits of Isolated Individualism'(2014) *American Academy of Paediatrics* available at <u>https://pediatrics.aappublications.org/content/pediatrics/133/Supplement_1/S16.full.pdf</u> [Accessed 29/07/2022].

⁴³⁷ ibid.

⁴³⁸ Anita Ho, 'The individualist model of autonomy and the challenge of disability' 5(2-3) (2008) *Journal of Bioethical Inquiry* 193.

⁴³⁹ Megan Wright, 'End of life and autonomy: the case for relational nudges in end-of-life decision-making law and policy' 77 (2017) *Maryland Law Review* 1062.

contradicts the individualistic concepts and self-sufficiency and independence.⁴⁴⁰ Encompassing the social reality of a patient is a key feature within relational assessments of autonomy and this will be discussed in further depth in the forthcoming section.

4.2.4.4 Shortcomings in current practices, laws, and policies The final critique of this section confers the deficiencies in current practices, laws and policies, covering issues such as:

- An over emphasis on individual exercise of control ⁴⁴¹
- A focus on legal documents that leads to procedural formalism ⁴⁴²
- Inappropriate priority of written communication ⁴⁴³
- A lack of applicability in conditions of uncertainty⁴⁴⁴

Mackenzie and Rogers argue that relying on cognitive tests to assess mental capacity fails to adequately capture the reality of many patients. Health and emotions are inevitably connected.⁴⁴⁵ For example, anxiety, excitement, grief, confusion and relief often work as indicators during the various stages of illness and recovery. Further, emotions can influence how patients process information related to their prognosis or treatment related information.⁴⁴⁶ Despite this, there is little emphasis on

⁴⁴⁰ ibid.

⁴⁴¹ Jukka Varelius, 'The value of autonomy in medical ethics' 9 (3) *Med Health Care Philosophy* 377.

⁴⁴² Carlos Gomez Virseda, Yves de Maeseneer, Chris Gastmans, 'Relational Autonomy: what does it mean and how is it used in end-of-life care?' A systematic review of argument - based ethics literature' 26(20) (2019) *BMC Med Ethics* 76.

⁴⁴³ Basil Varkey, 'Principles of Clinical Ethics and Their Application to Practice' 30 (1) (2021) *Medical Principles Practice* 17.

⁴⁴⁴ John Coggon, 'Mental Capacity Law, Autonomy and best interests: an argument for conceptual and practical clarity in the Court of Protection' 24(3) *Medical Law Review* 396. ⁴⁴⁵ Helena Hermann, Manuel Trachsel, Bernice.S Elger, Nikola Biller-Andorno, 'Emotions and Value in the Evaluation of Medical Decision-Making Capacity: A Narrative Review of Arguments' (2016) 7 *Frontiers Psychology* 765; Santhanam Sundar, 'On emotions and clinical judgment' (2020) *British Medical Journal* 370; Irene Y. Zhang, Joshua M.Liao, "Incorporating emotions into clinical decision-making solutions" 3 *Healthcare* (2021) 1; Shimon M Glick, 'The Emotions in Bioethical Decision-making' (2022) 95 (3) *Yale Journal Biology Medicine* 355.

⁴⁴⁶ Desiree Kozlowski, Marie Hutchinson, John Hurley, Joanne Rowley, Joanna Sutherland, 'The role of emotion in clinical decision making: an integrative literature review' (2017) *BMC Medical Education* 255; Linda M Isbell, Julia Tager, Kendall Beals, Guanyu Li, 'Emotionally

emotions in many clinical decision-making tools and intervention.⁴⁴⁷ Rather, existing frameworks have seemingly focussed on targeting and testing cognition - how people understand and then act upon information regarding health and disease.

Section 2 MCA 2005: Inability to make decisions

(1) For the purposes of section 2, a person is unable to make a decision for himself if he is unable—

(a)to understand the information relevant to the decision,

(b)to retain that information,

(c)to **use or weigh that information** as part of the process of making the decision, or

(d)to communicate his decision (whether by talking, using sign language or any other means).⁴⁴⁸

Note, in the above extract there is no requirement to ask how a patient feels about a decision. Instead, understanding refers to a patient's ability to comprehend information about their disorder, potential treatments and the related risks and benefits. Appreciation refers to the patient's ability to recognise that they are suffering from a particular condition and further, the ability to acknowledge the consequences of that condition, including the potential treatment options. Reasoning relies on the patient's ability to understand information rationally and then to use logic to assess the potential risks and benefits. Finally, communication refers to the patient's potential to convey a choice.⁴⁴⁹ This traditional approach has been criticised by many academics for being too procedural and failing to take proper account of

evocative patients in the emergency department: a mixed methods investigation of providers' reported emotions and implications for patient safety' (2020) 29 *BMJ Quality and Safety* 1;Theresa Treffers, Paul Martin Putora, 'Emotions as Social Information in Shared Decision Making in Oncology' 98 (6) (2020) *Oncology* 430.

⁴⁴⁷ Irene Y. Zhang, Joshua M. Liao, "Incorporating emotions into clinical decision-making solutions" 3 (2021) *Healthcare* 1.

⁴⁴⁸ Mental Capacity Act 2005 s2.

⁴⁴⁹ Paul Appelbaum, Thomas Grisso, 'The MacArthur treatment competence study: mental illness and competence to consent to treatment' 19 (1995) *Law Human Behaviour* 105.

non-cognitive factors,⁴⁵⁰ with many calling for a fuller acknowledgment of emotional factors within assessments.⁴⁵¹ Whilst clear thinking can benefit the decision-making process, placing too much reliance on cognition can result in an under-emphasis on emotions, i.e., a focus on what people think about treatment decisions without considering how a patient might feel about them.⁴⁵² Emotions are a valuable asset that can provide crucial information of a patient's condition. Sociologists have defined emotions as useful aids to assist the decision-making process citing benefits such as making decisions easier to arrive at, improving the confidence of patients and reducing interpersonal conflict.⁴⁵³ Further, they can inform dialogues with personal values and as such are essential to ensuring decisions give weight to patients wishes and preferences. Therefore, it seems incomplete for an assessment to consider a patient's cognitive reactions to information whilst excluding a patient's emotional reaction.

We are relational beings, whose identities and interests are shaped by our connections to others, and it is through these relations that we develop our sense of identity and our capacity for exercising self-determination. The chapter will now progress to consider relational autonomy in greater depth. Relational autonomy is often characterised by an oppositional response to the individualistic interpretations of autonomy.

⁴⁵⁰ Louis C Charland, 'Cynthia's dilemma: consenting to heroin prescription' 2 (2002) *American Journal Bioethics* 37; Natalie Banner, 'Can procedural and substantive elements of decision-making be reconciled in assessments of mental capacity?' 9 (2013) *International Journal Law Context* 71.

⁴⁵¹ Helena Hermann, Manuel Trachsel, Bernice S. Elger, 'Emotion and Value in the Evaluation of Medical Decision-Making Capacity: A Narrative Review of Arguments' 7 (2016) *Frontiers in Psychology* 2.

⁴⁵² Patricia Benner, Ronda G Hughes, Molly Sutphen, 'Clinical Reasoning, Decision making and Action: Thinking Critically and Clinically' in *Patient Safety and Quality: An Evidence Based Handbook for Nurses* (AHRO, 2008); Gustavo Saposnik, Donald Redelmeier, Christian C Ruff et al, 'Cognitive biases associated with medical decisions: a systematic review' (2016) 16 *BMC Medical Informatics and Decision Making* 138.

⁴⁵³ Amanda M Gengler, 'Emotions and Medical Decision-Making' 83(2) (2020) *American Sociological Association* 1

4.3 Theories of relational conceptions of autonomy

A relational approach, "makes the relational dimension of human experience central"⁴⁵⁴

Beginning in the 1980s, there has been a growing recognition that differences in gender could impact on aspects of knowledge and that such knowledge could impact upon medical care. The focus of relational approaches is to analyse the implications of the intersubjective and social dimensions of selfhood and identity for conceptions of individual autonomy and moral and political agency.⁴⁵⁵ The relational view of autonomy believes that none of us are autonomous beings as dictated by the "incontrol" model described above. Similar to the sentiments of Code and Brazier, Dove et al, contend that we are not "independent individuals", but instead are "relational beings", whereby our identities and interests are shaped by the people and places surrounding us.⁴⁵⁶

Thus, advocates of relational autonomy argue that autonomy requires interdependence rather than independence.⁴⁵⁷ Relational notions of autonomy assert that our social surroundings and personal relationships enable us to develop our capacity for self-determination. Feminist scholars have strongly criticised the individualistic conception for excluding values such as mutual responsibility, cooperation and care towards others.⁴⁵⁸ This does not mean that individual

⁴⁵⁴ Jennifer Nedelsky, 'Reconceiving Autonomy: Sources, Thoughts and Possibilities' (1989)
1 Yale Journal of Law and Feminism 7.

⁴⁵⁵ Catriona Mackenzie, Natalie Stoljar, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (OUP 2000).

 ⁴⁵⁶ Edward Dove, Susan E Kelly, Federica Lucivero, 'Beyond Individualism: Is there a place for relational autonomy in clinical practice and research?' (2017) 12 *Clinical Ethics* 150.
 ⁴⁵⁷ See, Catriona Mackenzie, Natalie Stoljar, *Relational autonomy: feminist perspectives on autonomy, agency, and the social self* (OUP 2000).

⁴⁵⁸ See, Wendy. A Rogers, 'Feminism and public health ethics' 32(6) (2006) *Journal of Medical Ethics* 351; Seema Mohapatra, Lindsay F. Wiley, 'Feminist Perspectives in Health Law' 47 *Journal of Law, Medicine and Ethics* (2019) 103; Katy Jenkins, Lata Narayanaswamy & Caroline Sweetman, 'Introduction: Feminist Values in Research' 3 (2019) Gender and Development 415.

autonomy shuns all responsibility; if that were the case, we would be living in a world akin to "The Purge" in a lawless society. Individual autonomy carries with it a sense of responsibility, which was alluded to through brief overview of Kant's philosophy in the earlier section. However, whilst mutual responsibility rests on the idea of an individual acting as part of a collective, the onus remains on the individual and the individual's actions. This is perhaps best explained through Article 5 of the Universal Declaration of Bioethics and Human Rights which states; "Autonomy and individual responsibility for those decisions and respecting the autonomy of others, is to be respected".⁴⁵⁹ In this scenario, the individual's actions remain central. However, this does not adequately account for the way decisions are made in our society. As outlined in the previous section, individual autonomy is too reductive and does not adequately account for important aspects of how decisions are made.

The idea of mutual responsibility within a relational context works much better. For example, intimacy and autonomy are mutually supportive.⁴⁶⁰ The element of intimacy supports the inclusion of the latter values of co-operation and care towards others. The combination of intimate care and cooperation creates an environment far more suited to ideas of a mutual collective as opposed to a rational, in-control model of autonomy.⁴⁶¹ Coggon and Miola argue that when too much emphasis is placed upon rationality, it prevents many people from having the power of choice and further limits the number of available options.⁴⁶² Dove et al highlight that many feminist scholars believe that for these reasons, individualistic autonomy offers an impoverished or incomplete view of the human condition.⁴⁶³ Dove argues that "relational autonomy can be viewed as a conception of autonomy that places the individual in a socially embedded network of others".⁴⁶⁴ Further that "relationships (with family, community

 ⁴⁵⁹ UNESCO Universal Declaration of Bioethics and Human Rights (2005) Article 5
 ⁴⁶⁰ Robert Selman, 'Fostering Intimacy and autonomy' in W Damon, *Child development today and tomorrow* (Jossey-Bass Inc, 1988) 109.

⁴⁶¹ Vikki A. Entwistle, Stacy M. Carter, Alan Cribb et al, 'Supporting Patient Autonomy: The Importance of Clinician patient Relationships' 25(7) (2010) *Journal of General Internal Medicine* 741.

 ⁴⁶² John Coggon, José Miola, 'Autonomy, Liberty and Medical Decision-Making' 70 (3)
 (2011) *Cambridge Law Review* 523.

⁴⁶³ Edward Dove, Susan E Kelly, Federica Lucivero, 'Beyond Individualism: Is there a place for relational autonomy in clinical practice and research?' (2017) 12 *Clinical Ethics* 150, 153. ⁴⁶⁴ ibid.

and society), responsibility, care interdependence are key attributes of relational autonomy" and that "people develop their sense of self and form capacities and life plans through the relationships they forge on a daily and long-term basis".⁴⁶⁵ Dove's argument builds upon narratives developed by Kenny, Sherwin and Nedelsky, whose work suggests that our social surroundings and relationships are crucial for developing autonomy.⁴⁶⁶ Since social surroundings and relationships are integral to the development of autonomy, a person cannot be viewed in isolation to their life – their circumstances must be taken into account, particularly so when deciding upon medical treatment.

We live our lives through our relationships, as humans we are constructed by a web of connections and from the moment we are born, we live within the context of others. We do not think and act completely independently and our decisions in life are impacted by those around us. Connection is vital for humankind; we do not work well in isolation. An experience to draw upon would be the Covid-19 pandemic. The world was thrust into an unparalleled mode of existence and forced within the confines of our homes. There are many relevant points to draw from this to substantiate my claim that relations are important to human functioning. Firstly, the world had to adapt to maintain connections remotely, society realised we could not simply cut our ties from one another and remain independent individuals until the pandemic was over. Secondly, there was a great concern for individuals who were by themselves in "single households" - as they would be without the care, cooperation and mutual responsibility, that we need to not only thrive, but to survive. Communities came together to help those vulnerable and in need and to offer support and compassion in a time of unknown despair. As stated, we do not live our lives as isolated individuals, we live our lives through our families, our friends, our neighbours and our colleagues. Not all harmonious and motivated by positive intent, of course, but we live in a world of relations, nonetheless.

⁴⁶⁵ ibid.

⁴⁶⁶ Francoise Baylis, Nuala P Kenny, Susan Sherwin, 'A relational account of public health ethics' (2008) 1 *Public health Ethics* 196; Jennifer Nedelsky, *Law's Relations: A Relational Theory of Self, Autonomy and Law* (OUP 2011).

The question of boundaries is relevant to this thesis, as boundaries have the power to define relationships. In particular, the question of whether practitioners should be included within the relational spectrum when deciding on treatment. Realistically, the practitioners are an intrinsic part of the decision-making process, as their contributions are often unique as they can provide specialist, medical expertise. I think it is important for the doctor to offer their professional opinion and for that to be considered from a relational point of view on behalf of the patient, i.e., the advice is given considering the patient's individual circumstances and the patient can consult family members (or others) if so desired. In respect of the concerns raised by Dove et al regarding potential undue influence, this is discussed later in this chapter through the work of Baker and Mackenzie.

Further evidence to support a transition to relational autonomy can be found through a study conducted by Dove et al, "Re-contacting patients with new genomic and health findings",⁴⁶⁷ which inferred that relational autonomy is better suited to clinical practice. Dove et al considered whether former patients should be contacted if new information emerged regarding clinical genetics. A dilemma ensued; the patient's "right to not know" versus the practitioner's conscientious responsibility. Dheensa and colleagues observed that understandings of information-sharing have been "based on an inaccurate conceptualisation of patients as separate from others, free from social or familial constraints".⁴⁶⁸ The "Mainstreaming Genetics: Re-contacting Patients in a Dynamic Healthcare Environment" project suggests that generally, patients hold an expectation to be contacted, whilst healthcare providers are more concerned about the availability of resources. Further, the project found that most clinical genetic services do re-contact patients, albeit not on a standardised basis. The project evaluated the option of a "partnership" model which would cover the responsibility for making contact.⁴⁶⁹ The aim of the partnership would be to engage in a dialogue between professionals and patients about expectations and understandings. In this model, the clinician would hold the information and the onus

⁴⁶⁷ Ibid [160].

⁴⁶⁸ Sandi Dheensa, Angela Fenwick and Anneke Lucassen, 'Is this knowledge mine and nobody else's? I don't feel that' Patient views about consent, confidentiality and information sharing in genetic medicine' (2016) 42 *Journal of Medical Ethics* 174.

⁴⁶⁹ Susan Kelly, Timothy Spector, Lynn Cherkas et al 'Evaluating the consent preferences of UK research volunteers for genetic and clinical studies' 10 (3) (2015) PLoS *One* 1.

would be on the patient to request it. There are problems when a doctor withholds information until a patient requests it. Patients might not have the knowledge or insight to be aware of the questions they could ask. A better focus would be on the dialogue of shared information. If the practitioner has an understanding of the patient's life, background and support network, they would be able to make an informed judgment as to the patient's foresight and consequentially pre-empt questions to ensure the patient is fully involved in the decision-making process. Further support for an adoption of a relational approach comes from Entwistle et al who argue that a relational concept of autonomy within a clinical context could be extremely beneficial in helping clinicians recognise how their interactions and relationships with their patients can either enable or impair patients' autonomy.⁴⁷⁰ Again, this research supports the idea that a relational approach encourages practitioners to focus on the consequences of interactions and subsequent influences, as such, the wider context of a patient's life.

Beauchamp and Childress defined autonomous decisions as "those made intentionally and with substantial understanding and freedom from controlling influences."⁴⁷¹ Increased dialogue would help improve the patient's understanding, therefore increasing their autonomous rights. As-capacity is task specific, some patients may require further assistance to enable them to participate in the decision-making process. This could even extend to patients who are technically "competent" but lack the confidence to decide between healthcare options. Davies and Elwyn believe that in such scenarios, patients may feel "abandoned rather than autonomous" should the clinician simply present the patient with options and then asks them to choose one.⁴⁷² A relational approach could help alleviate such concerns as it does not put all the focus on the individuals' capabilities, but rather, the dialogue between the individual and the doctor. Placing the onus on the individual patient and simply discharging a burden of care through the provision of information can result in unfortunate outcomes. Miola and Brazier recognise this as a

⁴⁷⁰ Vikki A Entwistle, Stacy M Carter, Alan Cribb and Kirsten McCaffery, 'Supporting Patient Autonomy: The Importance of Clinician-Patient Relationships' (2010) 25 (7) *Journal General International Medicine* 741.

 ⁴⁷¹ Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (OUP 2019).
 ⁴⁷² Myfanwy Davies, Glyn Elwyn, 'Advocating mandatory patient 'autonomy' in healthcare: adverse reactions and side effects' 16 (2008) *HealthCare Analysis* 315.

"core problem", believing that the courts ignore the element of patient understanding.⁴⁷³ They assert that judges follow the logic that the mere disclosure of information results in autonomy for the patient. The relationship between information and autonomy is seen explicitly in the case of Chester v Afshar, where it was stated: "Part of the imbalance between doctor and patient is due to the patient's lack of information, and, on one view, it is the function of the law to redress the imbalance by providing patients with the "right" to be given that information, or perhaps more accurately imposing a duty on doctors to provide it. ... [A] patient with no rights is a citizen who is stripped of his or her individuality and autonomy, as well as her clothes, as soon as she walks into the surgery or the hospital".⁴⁷⁴ For Lord Hope it is apparent that the barrier to autonomy was the lack of information and the solution was to require that such information be given from the doctor to the patient. Miola and Brazier report that as a result, Chester was heralded as a huge victory for autonomy, however, they assert that claim was misguided.⁴⁷⁵ They believe that there was a "fundamental flaw" in the judgment, as it is not the provision of information itself that will guarantee that an autonomous decision is made.⁴⁷⁶ Such a ruling only guarantees that the information has been passed from the doctor.

To continue the examination of the doctor-patient relationship and any inherent boundaries, the chapter will move on to consider autonomy within a healthcare context questioning; what is patient autonomy and how is it best respected?

4.4 Autonomy within a healthcare context

"The principle of respect for autonomy is usually associated with allowing or enabling patients to make their own decisions about which health care interventions they will or will not receive."

⁴⁷³ Margaret Brazier, José Miola, 'Bye-Bye Bolam: A medical Litigation Revolution?' 8(2000) *Medical Law Review* 1.

⁴⁷⁴ Chester v Afshar [2004] UKHL 41 [58].

⁴⁷⁵ ibid.

⁴⁷⁶ ibid.

⁴⁷⁷ Vikki Entwistle, Stacy M. Carter, Alan Cribb, Kirsten McCaffrey, 'Supporting Patient autonomy: The Importance of Clinician-patient Relationships' 25 (7) (2010) *International Journal of Obstetrics & Gynaecology* 741.

4.4.1 The impact of autonomy on clinical practice

Walker and Friedman identify a conundrum in terms of respecting patient autonomy in clinical practice.⁴⁷⁸ They state that whilst clinicians may value respecting a patient's autonomy in decision making, it can be unclear how to transfer the respect to clinical practice. As previously explained, the individualistic conception of autonomy represents the "in-control" model, which, "prioritizes self-sufficiency in decision making and highlights a decision makers capacity to have reason transcend one's emotional experience".⁴⁷⁹ The "in-control" model believes patients should avoid both the influence of others and emotional persuasion in decision making. Further, that providers should only play a limited role, providing the medical expertise but not interfering with the individual's decision-making process. Gilbar and Miola observe that, in absence of a relational approach, the impact of a patient's cultural background might not be considered within the decision-making process, which can create difficulties for some patients when making decisions about treatments.⁴⁸⁰

An approach based on relational theory would ensure the involvement of both parties; therefore, no sacrifices would be made in terms of patient autonomy. The issue over how respect for autonomy could be transferred to clinical practice would be eradicated if an effective dialogue were created with the patient, thus by installing a process of supported decision making. A case study concerning end of life decisions concluded that supported decision making was the "ethical gold standard".⁴⁸¹ Supported decision making would ensure that patients, relatives and healthcare professionals would be seen as "cooperative partners in the decision".⁴⁸²

 ⁴⁷⁸ Jennifer Walker, Laine Friedman Ross, 'Relational Autonomy: Moving Beyond the Limits of Isolated Individualism' 133 (2013) *American Academy of Paediatrics* 16.
 ⁴⁷⁹ ibid.

⁴⁸⁰ Roy Gilbar, José Miola, 'One size fits all? On patient autonomy, medical decision-making, and the impact of culture" 23(3) (2015) *Medical Law Review* 375.

⁴⁸¹ Carlos Gomez Virseda, Yves de Maeseneer, Chris Gastmans, 'Relational autonomy: what does it mean and how is it used in end-of-life care? A systematic review of argument-based ethics' 20 (1) (2019) *BMC Medical Ethics* 15, 8.

⁴⁸² Nicola Grignoli, Valentina Di Bernardo, Roberto Malacrida, 'New Perspectives on substituted relational autonomy for shared decision-making in critical care' (2018) 22 *Critical Care* 260.

Research in supported decision-making shows that the process requires the traditional positions of different stakeholders be reinterpreted. The reinterpretation places the patient at the centre and emphasises that their best interests are achieved through a respectful dialogue.⁴⁸³ Professional guidance from bodies such as the GMC echoes this research, as their material focuses heavily on the dialogue between doctors and patients. Their guidance on decision making features "The seven principles of decision making and consent" which states that "decision-making is an ongoing process focussed on meaningful dialogue: the exchange of relevant information specific to the individual patient".⁴⁸⁴ This document emphasises that supported-decision making is the key to respecting patient autonomy in clinical practice.

Furthermore, within clinical practice and research, McLean reports that respect for autonomy is closely linked to the value of privacy and notion, or practice, of consent.⁴⁸⁵ O'Neill comments that, "for proponents of autonomy rights for patients, the physician's obligations to the patient of disclosure, seeking consent, confidentiality and privacy are established primarily (and perhaps exclusively) by the principle of respect for autonomy".⁴⁸⁶ Dove et al further clarifies that "voluntary informed consent acts as the process by which one (legally) autonomous individual allows or refuses another individual to perform an action relating to her".⁴⁸⁷ However, within the context of judicial decisions, the focus tends to rest on the nexus of the patient's interests versus the interests of healthcare professionals. A consequence of this conundrum has been the establishment of an objective standard, known as the "reasonable patient". The reasonable standard will be covered in greater depth

⁴⁸³ Ho Mun Chang, 'Sharing death and dying: advance directives, autonomy and the family' (2000) 18 (2) *Bioethics* 87; Paul Walker, Terence Lorat, 'Concepts of personhood and autonomy as they apply to end-of-life decisions in intensive care' (2015) 18 *Medical Healthcare Philosophy* 309-15.

⁴⁸⁴ General Medical Council, 'Decision making and consent' (9/11/2020) available at <u>https://www.gmc-uk.org/-/media/documents/updated-decision-making-and-consent-guidance-english-09_11_20_pdf-</u>

^{84176092.}pdf?la=en&hash=4FC9D08017C5DAAD20801F04E34E616BCE060AAF [Accessed 04/10/2020].

⁴⁸⁵ Shelia McLean, Autonomy, *Consent and the Law* (Routledge 2010).

⁴⁸⁶ Onora O'Neill, Autonomy and Trust in Bioethics (CUP 2002).

⁴⁸⁷ Edward Dove, Susan Kelly, Federica Lucivero, Mavis Machion, Sandi Sheensa, Barbara Prainsack, 'Beyond individualism, Is there a place for relational autonomy in clinical practice and research?' 12 (2017) *Clinical Ethics* 150, 152.

during the chapter on "Capacity", for present purposes it is sufficient to understand that this standard requires the doctor to provide the information necessary for an average patient, not accounting for any specifics or individualities. McLean expands upon the nature of individualistic autonomy, reporting that currently, decision-making is overly focussed on the process, as opposed to the substance of a decision:

"It is the decision-making aspect of autonomy that dominates in law: (legally defined) decision-making ability predicts the status of competence and thereby the right to act autonomously. The individual is supreme, and once judged competent is entitled to make decisions on the basis of his or her own concerns and interests, subject only to the caveat that they do not harm third parties. This individualistic model of autonomy is largely unconcerned with what the decision is, rather it is interested in the right to make it."⁴⁸⁸

The initial position of legal capacity assessments is to determine if an individual is competent. Dove et al believe a formulaic approach to consent follows on the assumption that patients can be given information and make an independent decision based on that information.⁴⁸⁹ This legal position reflects the ideals of individualistic autonomy; the emphasis is placed on who counts as an autonomous person and the procedural conditions of exercising choice, rather than on what constitutes a good decision. It mirrors the values of individualistic autonomy of assertion and exercise of choice. Lohmus summarises that, "this form of autonomy pays attention to the procedural conditions of one's choices, how a decision is made rather than what is decided. If certain necessary conditions on the decision-making process are in place, the choice counts as autonomous, regardless of the value (or lack of value) of the object chosen. As a result, the primary concern and focus for

⁴⁸⁹ Edward Dove, Susan Kelly, Federica Lucivero, Mavis Machion, Sandi Sheensa, Barbara Prainsack, 'Beyond individualism, Is there a place for relational autonomy in clinical practice and research?' (2017) 12 *Clinical Ethics* 150-165 General Medical Council, 'Decision making and consent' (9/11/2020) available at <u>https://www.gmc-uk.org/-/media/documents/updated-decision-making-and-consent-guidance-english-09_11_20_pdf-</u>

84176092.pdf?la=en&hash=4FC9D08017C5DAAD20801F04E34E616BCE060AAF [Accessed 04/01/2023].

⁴⁸⁸ Shelia McLean, *Autonomy, Consent and the Law* (Routledge 2010).

this type of autonomy shifts to the chooser – we have to be deemed competent to make autonomous choices."⁴⁹⁰

This section has identified the difficulties that can be encountered when transferring respect for autonomy to clinical practice and how, as a result, clinical practice often resorts to an individualistic conception of autonomy. Whilst the GMC showcases the need for a meaningful dialogue within their guidance on capacity, the narrative focuses on suggested steps by which (a) a patient can make a choice or (b) how a choice can be made on behalf of the patient.⁴⁹¹ The guidance does not go far enough in terms of promoting patient participation. Further, it stems from a discussion of capacity, not of autonomy. The two concepts have been constructed within an intercalated nature, that one must be capable to be autonomous. However, this assumption is a consequence of ideas concerning individual autonomy; that someone must be self-sufficient to be able to make a choice. Admittedly, everyone is presumed to have capacity until proven otherwise, but this should extend to an acceptance that everyone has autonomy, alongside an obligation as to how people can be best supported to fulfil their autonomous rights. Capacity requires a threshold that patients must be able to retain and weigh information, and if a patient fails at this criterion, despite being able to express their feelings, they are rendered incapable and the focus of the conversation changes from being spoken with, to being spoken about. In these situations, the GMC, MCA and Code of Practice speak of taking "reasonable" and "practicable" steps to include the wishes and preferences of the patient. However, "reasonability" and "practicability" are subjective terms - they do not guarantee patient participation. Instead, it seems that these clauses provide a legitimate reason to make a decision irrespective of the patient; to do as the GMC stipulates, "you are responsible for deciding the overall benefit".492

⁴⁹⁰ Katri Lohmus, *Caring Autonomy: European Human Rights Law and the Challenge of Individualism* (CUP 2015).

⁴⁹¹ General Medical Council, 'Decision making and consent' (9/11/2020) available at <u>https://www.gmc-uk.org/-/media/documents/updated-decision-making-and-consent-guidance-english-09_11_20_pdf-</u>

^{84176092.}pdf?la=en&hash=4FC9D08017C5DAAD20801F04E34E616BCE060AAF [Accessed 04/01/2023] ⁴⁹² ibid

The focus on self-sufficiency and cognitive thinking are two factors which impede upon patient participation in medical decision-making. As explained, both these traits are representative of individualistic conceptions of autonomy. A move towards a dialogue based on relational theories which encompass a patient's emotions would be likely to increase the participation of patients who fail to reach the cognitive standard of rational thinking. Provisions exist within the MCA 2005, the adjoining Code of Practice and GMC guidance which allude to provisions of emotional dialogue - however, there is nothing explicit which clearly sets out steps for aiding such engagement. As a result of the vagueness, there is an inconsistency in application, meaning not all patients are provided with the opportunity to participate fully within the decision-making process. There is a need to move away from the rhetoric that emotions impede upon a patient's ability to communicate.⁴⁹³ A requirement exists for an emotional dialogue between the practitioner and the patient. There is an increasing awareness of the importance of emotions in the Code of Practice. For example, the 2007 refers to the term "emotion" on seven occasions, however, the latest draft from 2022 refers to the term 15 times; more than double the amount. Despite a growing acknowledgment of the importance of emotions in medical dialogues, provisions for such conversations are not consistently translating into practice.

The decision-making aspect of autonomy is domineering. As previously explored in the chapter on Feminism, women can often face barriers to healthcare and decision-making owing to socio-economic status and gender-imposed stereotypes. Doyal reports that "Discrimination and inequality have both a direct and indirect impact throughout life".⁴⁹⁴

⁴⁹³ Jacquille Haribhai-Thompson, Karen McBride-Henry, Caz Hales, Helen Rook,
'Understanding of empathetic communication in acute hospital settings: a scoping review'
(2022) 12 *BMJ Open* 1; Valeria Donisi, Cinzia Perlini, Maria Angela Mazzi et al, 'Training in communication and emotion handling skills for students attending medical school: Relationship with empathy, emotional intelligence and attachment style' 105 (9) (2022) *Patient Education and Counselling* 2871.

⁴⁹⁴ Lesley Doyal *What makes women sick: gender and the political economy of health* (1st edition, Macmillan Press Ltd 1995).

4.4.2 Women's autonomy in clinical practice

The previous section considered how the law and autonomy are interpreted within a medical context, often resulting in an individualistic approach. However, Donchin believes such an approach to be insufficient to determining patient autonomy within healthcare. She argues that "Any tenable conception of personal autonomy is bound to be subject-centred; but a social conception that is relational... will take into account the need for a network of personal relationships, to develop and sustain competencies necessary to act as self-determining, responsible agents".⁴⁹⁵ On the view that autonomy is developed and exercised in a social context, it follows that it is necessary to create fair and supportive social contexts. Concurrently, Ells, Hunt and Chambers-Evans contend, that a fair and supportive social context will enable the establishment of relationships which permits individuals to develop and exercise their autonomy.⁴⁹⁶ A fair and supportive social context should encourage individuals to "participate in decisions, to ask questions and voice their feelings or concerns".⁴⁹⁷ However, if someone is in a restrictive environment which prevents individuals from making decisions and stops people from voicing their feelings or concerns, people are denied the opportunity to develop and exercise their autonomy.

Osamor and Grady have reported evidence which suggests a correlation between poverty and a lack of autonomy.⁴⁹⁸ Their research focuses on women in developing or low-income countries, finding that women in such situations often have limited autonomy and control over their health decisions. The research indicates that women's ability to attend to their health and utilize health care facilities depends in

⁴⁹⁵ Anne Donchin, 'Autonomy and interdependence: quandaries in genetic decision-making' (2000) in Catriona Mackenzie and Natalie Stoljar, *Relational Autonomy: Feminist Perspectives on autonomy, Agency and the Social Self* (OUP 2000) 192.

⁴⁹⁶ Carolyn Ells, Matthew Hunt & Jane Chambers Evans, 'Relational autonomy as an essential component of patient centred care' 4 (2) (2011) *International Journal of Feminist Approaches to Bioethics* 79.

⁴⁹⁷ Susan Dodds, 'Choice and control in feminist bioethics' in Catriona Mackenzie and Natalie Stoljar, *Relational Autonomy: Feminist Perspectives on autonomy, Agency and the Social Self* (OUP 2000) 229.

⁴⁹⁸ Pauline E Osamor and Christine Grady, 'Women's autonomy in healthcare decision making in developing countries: a synthesis of the literature' (2016) 8 *International Journal of Women's Health* 191.

part on their decision-making autonomy.⁴⁹⁹ However, their ability to make decisions is often limited owing to strong social structures that rigidly define the roles of men and women. Abrams has conducted research into women's health care in Western countries and has revealed that women's autonomy can be an "illusion" in terms of medical decision making.⁵⁰⁰ Abrams research focuses on obstetric decision making. His report finds that whilst patients in every other medical context have complete autonomy to refuse treatment against medical advice, childbirth is viewed anomalously because of the duty to the foetus. In 2013 a forced caesarean section was carried out in the UK on a woman of Italian nationality, which Shami Chakrabarti, the director of Liberty, said: "At first blush this is dystopian science-fiction unworthy of a democracy like ours. Forced surgery and separation of mother and infant is the stuff of nightmares."⁵⁰¹ Whilst there were claims of incapacity in this case, the principle remains unchanged: women are more likely to be subjected to treatment interventions owing to their biological being and therefore are subjected to a weaker conception of autonomy.

Cahill reports of a period between 1992-1996 whereby several women in the UK were forced by the courts to have caesarean sections against their will.⁵⁰² Analysis revealed a "blanket assumption of maternal incompetence".⁵⁰³ Further still, the research revealed that in practice, obstetrician's care was different to what was expected by policy, as concerns appeared to focus more on the foetus over the pregnant woman. This introduces the idea of 'maternal autonomy' a concept unique to the female sex which highlights how women are disadvantaged in terms of exercising their autonomy owing purely to their biological nature. Annas describes pregnant women as "a foetal container, a non-person without rights to bodily

⁴⁹⁹ ibid.

⁵⁰⁰ Jamie R Abrams, 'The Illusion of Autonomy in Women's Medical Decision-Making' (2014) 42 *Florida State Law Review* 17.

⁵⁰¹ Chloe Hamilton, 'Forced C-Section was the stuff of nightmares: social services condemned for forcibly removing unborn child from woman' (The Independent, 01/12/13) available at: <u>https://www.independent.co.uk/news/uk/home-news/social-services-forcibly-remove-unborn-child-from-woman-by-caesarean-after-she-suffered-mental-health-breakdown-8975808.html [Accessed 15/08/2023].</u>

⁵⁰² Heather Cahill, 'An Orwellian Scenario: Court Ordered Caesarean section and women's autonomy' (1999) 6 *Nursing Ethics* 494.

integrity".⁵⁰⁴ Wood-Goldbeck comments that, "In no other field of healthcare are paternalistic practices more likely to be witnessed and yet, at the same time, be increasingly unacceptable to patients".⁵⁰⁵ Cahill believes the major issue facing maternal autonomy is the assumption of incompetence.⁵⁰⁶

In 1998 the landmark case of St George's Healthcare NHS Trust v S ⁵⁰⁷ reached the Court of Appeal. Whilst this case predates the MCA, it is indicative of attitudes in clinical practice and serves as a good example regarding cases of the treatment of pregnant women and their refusal of consent. The case involved a competent woman and her refusal of treatment. The case concerned a 29-year-old woman who was 36 weeks pregnant. The woman, called Miss S, had registered with a practice in London when she was diagnosed as having pre-eclampsia. Miss S was advised to have her pregnancy induced early, however, despite advice of two doctors and a social worker, she refused to do so. As a consequence of her refusal, the social worker applied under section 2 of the Mental Health Act 1983 for S's admission to Springfield Hospital for "assessment". Two doctors signed the necessary written recommendations and S was admitted to Springfield Hospital against her will. She was then transferred, against her will, to St George's Hospital. Considering her continuing refusal of consent to treatment, an application was made ex parte on behalf of the hospital authority. As a result, Hogg J granted a declaration which dispensed of S's consent to treatment. That night she was delivered of a baby girl by Caesarean section. It is imperative to highlight that Miss S retained capacity throughout all proceedings. The case was brought to the Court of Appeal whereby Lord Justice Judge ruled that even if his or her own life depended on receiving medical treatment, an adult of sound mind was entitled to refuse it.⁵⁰⁸ This was a reflection on the autonomy of each individual and the right of self-determination. Lord Justice Judge continued that whilst pregnancy increased the personal

⁵⁰⁴ George J Annas, 'Protecting the liberty of pregnant patients' (1987) 316 *North England Journal of Medicine* 1214.

⁵⁰⁵ Sandy Wood-Goldbeck, 'Women's autonomy in childbirth – we may advise and persuade but never coerce' (1997) 314 *British Medical Journal* 1143.

⁵⁰⁶ Heather Cahill, 'An Orwellian Scenario: court ordered caesarean section and women's autonomy' 6(6) (1999) *Nursing Ethics* 494.

⁵⁰⁷ *St George's Healthcare NHS Trust v S* (1998) 3 All ER 673. ⁵⁰⁸ ibid [673].

responsibilities of a woman, it did not change her entitlement to decide to receive medical treatment.⁵⁰⁹ Whilst this judgment was certainly an advancement in terms of a woman's autonomy, it also highlights the presence of prejudicial attitudes within the medical profession and the healthcare sector, the harmful consequences of which resulted in a woman being physically compelled to a psychiatric facility because professionals believed her to be mentally ill for wanting a vaginal birth.

A more recent survey conducted in 2013 revealed that such prejudicial attitudes towards pregnant women remained active in the medical practice.⁵¹⁰ The survey considered maternity care provider's perceptions of women's autonomy. Like all healthcare consumers, pregnant women are entitled to make autonomous decisions about their medical care, however, the survey revealed some contradictory assumptions. Confusion still exists amongst maternity professionals in situations when a woman's decisions could lead to increased harm of the foetus. The sample taken was 336 midwifes and doctors, from both the public and private sectors in New Zealand. The results demonstrated a poor understanding of their legal accountability and of the rights of the woman and her foetus. Both midwives and doctors believed the final decision should rest with the woman, however, each group stated that the needs of the woman may be overridden for the safety of the foetus. This again reflects ideas that allude to relational autonomy, as the mother to be is not being considered as an individual, but at the same time, it appears to substitute the autonomy of the female patient for the inferred autonomy of the foetus. Substituted autonomy is not the same as relational autonomy. Whilst this survey was conducted in New Zealand, it is indicative of Western attitudes and stereotypes which portray women, not as individuals in their own right, but as mothers and as care givers. Such stereotypes are visible in the UK through research conducted by organisations such as The Equality and Human Rights Commission who published a report on the impact of maternity discrimination.⁵¹¹ The survey was composed of 3,254 mothers in

⁵⁰⁹ ibid [674].

⁵¹⁰ Sue Kruske, Kale Young, Bec Jenkinson and Ann Catchlove, 'Maternity Care Providers' Perception of Women's Autonomy and the Law' (2013) 13 *BMC Pregnancy and Childbirth* 84.

⁵¹¹ The Equality and Human Rights Commission, 'Pregnancy and maternity discrimination research findings' (2018) available at <u>https://www.equalityhumanrights.com/en/managing-pregnancy-and-maternity-workplace/pregnancy-and-maternity-discrimination-research-findings</u> [Accessed 29/09/2020].

Great Britain and 50% of the sample described a negative impact on their job opportunities, status or security owing to stereotypes related to being a mother. Furthermore, recent research by Villarmea and Kelly into the epistemic stereotypes about women in labour, revealed "more often than not" supported decision making occurred selectively.⁵¹² Often, the process morphed into "consenting the patient",⁵¹³ whereby "the clinician lists the options and positive complications of each option and then invites the woman to sign a consent form."⁵¹⁴ The report further states that "consciously or unconsciously, professionals do not always engage in true shared decision making with women during labour because they take them to be obviously not in full capacity",⁵¹⁵ as "a woman in labour is considered far from meeting the usual characterization of an ideally rational agent".⁵¹⁶

4.5 Case studies: illustrating the issues of individual autonomy and the alternate solutions of a relational model.

"it's **my** body".⁵¹⁷

This section will consider two cases as the judicial discourse evidence of an individualistic approach to autonomy, which also allows for a comparative approach to be taken had a relational model been implemented. *AI Hamwi v. Johnston* and Another,⁵¹⁸ will be featured as the "starting point" to outline the issues within individual autonomy. The chapter will progress to consider the more recent case of

⁵¹² Stella Villarmea, Brenda Kelly, 'Barriers to establishing shared-decision-making in childbirth: Unveiling epistemic stereotypes about women in labour' (2020) 26 *Journal of Evaluation in Clinical Practice* 515, 516.

⁵¹³ ibid.

⁵¹⁴ ibid.

⁵¹⁵ ibid [517]. ⁵¹⁶ ibid [518].

⁵¹⁷ Oxford University Hospitals NHS Foundation Trust and Z (by her litigation friend, the Official Solicitor) [2020] EWCOP 20 [12].

⁵¹⁸ AI Hamwi v. Johnston and Another [2005] E.W.H.C. 206 74.

 $Re Z^{519}$ to illustrate that the MCA 2005 and adjoining Code of Practice have not been successful in changing how doctors interact with patients.

4.5.1 Al Hamwi

In the case of AI Hamwi,⁵²⁰ Mrs AI Hamwi claimed damages in respect of the birth of her seriously disabled son and the subsequent costs involved with raising him. Her family had a history of having children with significant mental and physical impairments. When Mrs AI Hamwi became pregnant again, she attended her GP surgery and having explained her family history, requested for her foetus to be tested for Downs Syndrome. The GP explained the pregnancy was too far advanced for such a test, but that she would make an early referral for an antenatal screening. However, the GP failed to write the letter and as a result Mrs Al Hamwi did not attend the screening until she was 17 weeks pregnant. During this consultation, the possibility of an amniocentesis was discussed; it was accepted at trial that the consultant had made a record of the consultation in the medical notes and throughout its course Mrs Al Hamwi had changed her mind. Proceedings were issued against the two defendants; firstly, it was claimed that the GP had been negligent in failing to make the referral and secondly, that the consultant had failed to properly explain the risks of amniocentesis. Mrs Al Hamwi asserted that the consultant had led her to believe the amniocentesis carried with it a 75% risk of miscarriage, but the figure was only 1%. The Court found that whilst the GP had committed a breach of duty, no damage had occurred and that the consultant had delivered information regarding the risks in a "proper" manner and thus, there was no breach of duty. The use of the word "proper" is concerning. Whilst it may have been in accordance with the regulations, those regulations failed the patient. There is a significant margin between a 1% risk and a risk of 75%. Miola explains that this case raises questions about just how far the law will take its commitment to autonomy with respect to risk disclosure.⁵²¹ The decision that there was no breach of duty infers that

⁵¹⁹ Oxford University Hospitals NHS Foundation Trust and Z (by her litigation friend, the Official Solicitor) [2020] EWCOP 20.

⁵²⁰ ibid.

⁵²¹ José Miola, 'Autonomy ruled ok?' (2006) 14 *Medical Law Review* 108.

the Court was following an individualistic conception of autonomy, whereby it was the duty of Mrs Hamwi, "the agent" to make a decision independent of the role of the doctor.

A fundamental issue in this case concerns whether a duty exists to ensure the information provided is understood by the patient .522 Simon J stated that Mrs AI Hamwi "may have been confused" by the information provided to her.⁵²³ However in the judgment Simon J rejected the claim that it is a clinician's duty to ensure that the patient understood the information as "too onerous".⁵²⁴ He stated, " A patient may say she understands although she has not in fact done so ... it is common experience that misunderstandings arise despite reasonable steps to avoid them. Clinicians should take reasonable and appropriate steps to avoid them. Clinicians should take reasonable and appropriate steps to satisfy themselves that the patient has understood the information which has been provided, but the obligation does not extend to ensuring that the patient has understood".⁵²⁵ Thus, the judge accepted that the provision of the leaflet was an "appropriate way of conveying information".⁵²⁶ Miola reports that Simon J. did not elaborate on what might constitute 'reasonable steps', other than to note that they had indeed been taken in the case of Miss Kerslake.⁵²⁷ From reviewing the judgment, it appears that Miss Kerslake did not investigate why Mrs AI Hamwi had suddenly changed her mind, when she had previously seemed so keen to undergo the test.⁵²⁸ Therefore, as Miola elaborates, the commitment to 'taking steps' to see that the patient has understood the information may be seen as somewhat less than onerous itself.

The judge's acceptance of the leaflet as appropriate and sufficient in terms of the provision of information is worrying. The duty of the physician was discharged by simply handing out a leaflet; there is no communication in that transaction of information, the onus is placed entirely on the patient. The leaflet sets an objective

⁵²² ibid.

⁵²³ Al Hamwi v. Johnston and Another [2005] E.W.H.C. 206 74.

⁵²⁴ ibid [69].

⁵²⁵ ibid.

⁵²⁶ ibid [54].

⁵²⁷ José Miola, 'Autonomy ruled ok?' (2006) 14 *Medical Law Review* 111.

⁵²⁸ Simon J. held that to cross-examine the patient regarding her understanding of the risks would be 'inappropriate', thus, approving of Miss Kerslake's actions in this respect.

standard, no personal issues or difficulties are accounted for. It is extremely troubling that such a standard was deemed acceptable by the Court. A model of supported decision-making under relational autonomy would have been far more beneficial to Mrs Al Hamwi, as it would have ensured she was not abandoned to make the decision of her own accord without any professional help. Had even a question been asked by the doctor to check if Mrs Al Hamwi had the literary skills required to read and digest the information in the leaflet, it would have been apparent that further help was required. The lasting impression from the judgment is that the imparting of information is the critical factor and less consideration is given to the actual understanding on the part of the patient.⁵²⁹

More than fifteen years after *AI Hamwi*, it seems that not a great deal has changed in terms of the approach taken by practitioners towards helping patients who require further assistance with articulating their questions and concerns regarding their pregnancies. A need for a relational approach is still prevalent and can be witnessed through an analysis of a recent Court of Protection case, Re Z.⁵³⁰ The Court of Protection was established in 2007 under the powers of the Mental Capacity Act 2005. It has jurisdiction over the property, financial and personal welfare of people who lack the mental capacity to make decisions for themselves. The Court of Protection hears cases which often harbour an emotional element; someone having their right to autonomy questioned over an alleged lack of capacity. Cases regarding the treatment of pregnant women are particularly sensitive regarding medical decision-making. Whilst this case is premised on the issue of capacity, it is the approach of the court that is of current interest. The case of Re Z⁵³¹ illustrates how an individualistic conception of autonomy is ill-suited in terms of catering for the emotional element of decision-making and the existence of the MCA, Code of Practice and GMC guidance fails to remedy this.

 ⁵²⁹ José Miola, 'Autonomy ruled ok?' (2006) 14 *Medical Law Review* 111.
 ⁵³⁰ Oxford University Hospitals NHS Foundation Trust and Z (by her litigation friend, the Official Solicitor) [2020] EWCOP 20.
 ⁵³¹ ibid.

As discussed earlier within the chapter, at present, whilst the foundations are in place to kickstart a dialogue about supported decision making, these ideals are not transferring successfully into practice. This is due to the vagueness of certain requirements of the MCA 2005, MCA Code of Practice and the loopholes within the GMC guidance.

Initially, I will set out the relevant sections of the MCA 2005; Sections 4(4) 4(6) and 4(7).

Section 4 (4) MCA 2005 dictates: "He must, so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him."⁵³² The issue within this subsection is the inclusion of the words "so far as reasonably practicable". This is vague and subjective. Whilst there will undoubtedly be an element of subjectivity as to how a person may participate, i.e., people how different communication styles, I think the word "reasonably" can act as a way to discharge this obligation. In other words, this provision can be overlooked should a practitioner state it was not feasible to secure patient participation. As the earlier narrative explored, autonomy does not have to be absolute, it is a graded concept whereby (so long as someone is conscious)⁵³³ they are able in some ways to express an emotion in relation to the decision.

S4(6) goes on to state: "He must consider, so far as is reasonably ascertainable" the person's past and present wishes and feelings, his beliefs and any other considerations which could be relevant to the decision.⁵³⁴ I agree that all of these elements should be included within the supported decision-making regime, however, my problem yet again is with the inclusion of "so far as is reasonably ascertainable". The MCA does not spell out a criterion or a definition to explain what standard "reasonably ascertainable" sets, (as established by the discussion of *Al Hamwi*) and it is open to interpretation of the practitioner/assessor, reverting the narrative to one

⁵³² Mental Capacity Act 2005, s4.

 ⁵³³ Note, cases where a patient is unconscious i.e. a coma, will be applicable to s4(6) and s4(7).
 ⁵³⁴Mental Capacity Act 2005, s6.

of "doctor knows best" and reversing the logic to imply that an "in-control" model of autonomy premised on self-sufficiency is preferable.

The final section to consider of the MCA is 4(7) which alludes quite clearly to a relational approach. It stipulates that the views of anyone named by the person as someone to be consulted on the matter in question, anyone engaged in caring for the person or interested in his welfare, any done of a lasting power of attorney, or any deputy appointed for the person by the court.⁵³⁵ However, a caveat exists yet again, where this requirement is only valid "if it is practicable and appropriate to consult them". As with s4(6), "practicable and appropriate" are ambiguous and do not go far enough to secure a relational approach.

The Code of Practice goes a step further in attempting to provide for emotional responses, stating: "Expressions of pleasure or distress and emotional responses will also be relevant in working out what is in their best interests" ⁵³⁶ and acknowledges that, "gaining emotional support from close relationships are important factors in working out the persons own best interests".⁵³⁷ However, what appears to be lacking is guidance as to how "emotions" can be successfully implemented within the practitioner patient dialogue so that patients are treated consistently and receive the same level of care.

The GMC guidance is similarly vague. Section 88 states that with patients lacking capacity "reasonable steps" should be taken to determine whether there is evidence of the patients previously expressed values and preferences, that "may be legally binding".⁵³⁸ I believe that the patients previously expressed values and preferences should be considered, whether they are "legally binding", or not. The section continues that if there is no third party with "legal authority" or if there is no such legal document, the practitioner is "responsible for deciding what would be the overall

⁵³⁵ ibid [s7].

⁵³⁶ Department for Constitutional Affairs, 'Mental Capacity Act 2005, Code of Practice' Issued by the Lord Chancellor on 23 April 2007 in accordance with sections 42 and 43 of the Act, 5.40.

⁵³⁷ ibid [5.48].

⁵³⁸ GMC, 'Guidance on professional standards and ethics for doctors' (2020) s88, available at: <u>https://www.gmc-uk.org/-/media/documents/gmc-guidance-for-doctors---decision-making-and-consent-english_pdf-84191055.pdf</u> [Accessed 26/01/2023]

benefit".⁵³⁹ Again, this reverts to paternalistic conception of decision-making which favours concepts of rationality over emotions. Further, section 91 explains, "you should allow enough time, if possible, for discussions with those who have an interest in the patient's welfare."⁵⁴⁰ Once more, there is the subjective inclusion of "if possible", which is open to interpretation by the practitioner. These vague provisions appear more problematic when considering the section on "Time and Resource Constraints" which acknowledges that, "Being able to meet a patient's individual needs for information and support depends, in part, on the time and resources available to you and your colleagues in the organisations where you work."⁵⁴¹ It has been well-publicised that the NHS is currently under huge pressure owing to staffing shortages, increased patient admissions and industrial action over salaries.⁵⁴² With this in mind, the "reasonable", "appropriate" and "practicable" caveats seem even more troublesome.

Even if a practitioner were to have the time to consult families or loved ones about a proposed treatment, owing to the subjectivity of the clause, the nature of that involvement is somewhat sporadic. In the House of Lords Select Committee, Moira Fraser of the Carers Trust reported that families had the impression that "professionals pick and choose when to involve them".⁵⁴³ Furthermore, families who disagreed with the decision being made found they were excluded on the grounds that "they are not acting in the best interests of the person whom they care for".⁵⁴⁴ The Committee further revealed reports from Mencap which explained that families of adults with learning disabilities were not being consulted by medical staff as they should be and as a result many "think that the only way that they can assist in the decision-making of an adult with a learning disability is by becoming a welfare

⁵³⁹ ibid.

⁵⁴⁰ ibid [s91].

⁵⁴¹ ibid [s60].

⁵⁴² Adrian O'Dowd, 'Government should declare "national emergency" over NHS crisis, say peers' 380 (2023) *British Medical Journal* 147.

⁵⁴³ House of Lords, Mental Capacity Act 2005: post-legislative scrutiny, Select Committee on the Mental Capacity Act 2005, Report of Session 2013-2014 available at:

https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139.pdf [Accessed 28/01/2023]

⁵⁴⁴ ibid [47].

deputy".⁵⁴⁵ This evidence supports my claim that whilst on paper the MCA and the GMC guidance suggest an adoption of a relational model, it does not translate into practice. For these reasons, there is a gap which needs to be bridged in order to clearly enunciate the steps required between the practitioner, the patient and third-party support in order to successfully secure patient participation in practice.

4.5.2 ReZ

The facts concerned a young woman, referred to as Z, who had a rare chromosomal abnormality syndrome, which caused her to suffer from cognitive impairment and a bicornate uterus. Z was 35 weeks pregnant and had experienced four previous pregnancies. One child had sadly died when only 6 days old and the other three had been taken into care. As complications had occurred in all previous pregnancies, a caesarean section had been booked to deliver the baby. Z had been assessed as having the capacity to make decisions about her ante-natal care and her mode of delivery.⁵⁴⁶ However, Oxford University Hospitals NHS Foundation Trust believed Z lacked the capacity to make decisions about contraception and owing to her obstetric history and current pregnancy, they believed it to be in her best interests to have an intrauterine contraceptive device inserted at the time of her caesarean section. Z stated she did not want the device fitted, but that she would be willing to have longlasting contraceptive injections and that she would be helped by her nurse to attend the necessary appointments. Whilst she did not fully articulate the reasons behind her refusal, she repeatedly stated "it's my body".⁵⁴⁷ However, the application of the hospital was granted, meaning that Z was fitted with the device against her wishes.

The judgment summarised an interview, (which was conducted under the existing MCA, Code of Practice and GMC guidance) involving Z and the medical

⁵⁴⁵ House of Lords, Mental Capacity Act 2005: post-legislative scrutiny, Select Committee on the Mental Capacity Act 2005, Report of Session 2013-2014, pg 43 available at: <u>https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139.pdf</u> [Accessed 28/01/2023].

⁵⁴⁶ The judgment does not specify who conducted the capacity assessment, "She has been assessed to have capacity to make decisions about her ante-natal care generally and her mode of delivery specifically" in *Oxford University Hospitals NHS Foundation Trust and Z* (by her litigation friend, the Official Solicitor) [2020] EWCOP 20 [3].

⁵⁴⁷ Oxford University Hospitals NHS Foundation Trust and Z (by her litigation friend, the Official Solicitor) [2020] EWCOP 20 [12].

professional, Dr Camden Smith. The interview revealed that Z did not understand why the court might be involved with her decision about contraception, or why the doctors might be worried about her understanding of the issue. However, what is unclear, is whether the lack of understanding was due to issues of incapacity on Z's behalf, or because of a failure of the professionals to provide information to Z in a manner which she could understand.⁵⁴⁸ For example, the report stated, 'Z did not understand that she had a solicitor to advocate on her behalf",⁵⁴⁹ highlighting that the onus of proving capability is placed on Z. There is an implicit emphasis purporting it was Z who did not understand and therefore, the problem was a result of Z's inability to process the information. This highlights that the court followed an entirely individualistic view of autonomy. It was up to Z to understand the relevant information, if she failed to do so, that was her fault alone. However, the report does not address whether Z was ever told that she had a solicitor. According to the Mental Capacity Act 2005, patients should be supported, wherever possible, to take part in the decision-making process. Without knowing the extent to which Z was aware she had a solicitor; it is hard to reach a solid conclusion on the matter. However, the uncertainty paves way for queries such as, had Z been able to consult with a solicitor, would she have received the help required to articulate her reasons in such a way as to satisfy the Court? This question is purely speculative as there is no available information to answer it, but it serves to highlight that the outcome might have been different had additional support was provided.

Dr Camden Smith concluded that Z lacked the capacity to conduct proceedings due to her inability to understand the relevant information, "put simply, Z did not understand that her learning disability might affect her ability to make decisions."⁵⁵⁰ Whilst capacity will be discussed in full during the next chapter, in order to fully understand the nature of the case it is necessary to know that capacity is constructed in the same vein as the concept of innocence in a criminal trial; you are presumed to have it until proven otherwise. In the case of Z, it appears this did not

⁵⁴⁸ The judgment does indicate that the doctor did try to convey this information by drawing parallels with Z's prior family court experience. However, Z did not understand this, this again is a reason why the vagueness of "reasonable steps" is unacceptable, attempts should have been made to relate to Z on a level which she could comprehend. ⁵⁴⁹ ibid [15]. ⁵⁵⁰ ibid

apply and that her capacity was approached from the outset with a negative outlook, focussing on reasons to exclude Z from the proceedings, rather than those to include her. In the judgment it is acknowledged that Z expressed her desires to be present for the hearing, however, it was soon stated that "it was not possible for the arrangements to be finalised prior to the start of the hearing".⁵⁵¹ Again, it is not made clear whether this decision was communicated to Z. There is an overwhelming sense that the professionals and the Court actively sought to exclude Z from the proceedings and to minimise her involvement with the case wherever possible. This theory seems more plausible when it becomes clear that the only reason why Z eventually participated in the hearing was because she made contact with the Trust expressing her wishes to be involved.

This sequence of events seems contradictory to the ethos embodied within the MCA, Code of Practice and GMC Guidance. These instruments allege to harbour an environment which promotes the participation of the patient to the fullest extent possible. It is obvious that something is failing in the translation from theory to practice.

Once Z's participation was enabled and she expressed her opinion to the court, a somewhat dismissive attitude is apparent. For example, Z was able to identify a method of contraception she was willing to receive, further still, Z offered a plan to ensure the delivery of that contraception and clearly stated that she did not want the intrauterine device, expressing awareness that it was her body. Yet, the judgment focuses solely on the fact that, "she was unable to articulate why a long-lasting contraceptive injection was her preferred method of contraception other than by saying it's my body".⁵⁵² Other than the telephone interview with Dr Smith and Z's last-minute addition to the hearing, her personal involvement is significantly lacking. There is no indication that any process took place in order to consider Z's intentions. It would appear that Z's refusal to accept the doctor's preferred method of contraception is a significant factor in relation to determining both her capacity, and

⁵⁵¹ ibid [10].

⁵⁵² Oxford University Hospitals NHS Foundation Trust and Z (by her litigation friend, the Official Solicitor) [2020] EWCOP 20 [12].

that of her best interests. As previously elucidated, in absence of a clear guide as to what constitutes reasonable and appropriate steps to involve the patient, it seems that this area was somewhat neglected.

In relation to the physical pregnancy and birth control, Z had displayed an understanding that it was her body, that she would be required to receive contraceptive treatment and further, had clearly and continuously stated she did not wish to have the intrauterine contraceptive device fitted. The case of Re B⁵⁵³ concerned a woman with learning disabilities and her usage of the internet and social media. In *Re B*, the Code of Practice was heavily relied upon in the statutory framework to reaffirm the Mental Capacity Act and the principle of preservation of self-choice.⁵⁵⁴ The judgment stressed that, 'it is important to assess people when they are in the best state to make a decision, if possible".⁵⁵⁵ This case supports the idea that capacity legislation is designed to reinforce the rights of the patient, not to legitimise the withdrawal of rights. Applying this logic to Z, why then, could a compromise not be made to agree on an alternative method of contraception? The report continuously refers to Z as "high risk"⁵⁵⁶ and details that Z was unable to comprehend her own health status, thus suggesting Z did not, or could not, take the issues surrounding her contraception seriously. Dr Smith's report states that when questioned on her preference towards the contraceptive injection, Z was unable to provide an answer other than stating, "I just have. I'm having the injection."⁵⁵⁷ More so, when questioned on her compliance, Z replied, "I will have the injection".⁵⁵⁸ It is not explained if Z was given any support to help explain her opinions or whether a decision was made based on her face value response. If the GMC medical guidance had been followed, which clearly dictates seven principles that are required to secure supported decision making, it is highly likely that Z would have been able to express herself in a clearer manner, one which was more likely to be accepted by the

⁵⁵³*Re B (Capacity – social media-care and contact)* [2019] EWCOP 3.

⁵⁵⁴ ibid.

⁵⁵⁵ ibid [4.46].

⁵⁵⁶ "Risk" is referred to 37 times in the judgment.

⁵⁵⁷ Oxford University Hospitals NHS Foundation Trust and Z (by her litigation friend, the Official Solicitor) [2020] EWCOP 20 [26].

courts.⁵⁵⁹ As stated, the failure with the GMC guidance is that the "practicable steps" requirement is too vague and if resources feel pressured to make a timely decision, they can be ignored. The GMC guidance should have prevented this, but it failed to, more so, it seems that no-one noticed that this provision of the guidance remained unfulfilled. I suggest that owing to an over-reliance on notions of individual autonomy, the onus seems to rest on the patient proving themselves, rather than an active effort on behalf of the professionals to work on their inclusion.

As already stated, the problematic area for Z is that she was unable to articulate why she did not want the intrauterine contraceptive device. Whilst the judgment does not specifically reference whether Z understood the consequences of unprotected sex, it does state that Z could "not understand why the court might be involved with respect to her decision about contraception; why Drs A and B might be worried about her understanding of that issue; or why Drs A and B had spent significant amounts of time exploring her decision in respect of contraception with her."560 There is no effort to understand Z's confusion, under the individualistic approach which prides itself on a model of absolute autonomy, her lack of complete understanding is simply attributed to a presumed incapacity. Again, it is important to stress that this occurred under the Mental Capacity Act and the Code of Practice illustrating an abundant failing in the legislation. The burden was discharged because an attempt had been made. All reports agreed that Z lacked the capacity to make the decision about contraception and the intrauterine contraceptive device. The Court believed Z was unable to evaluate the risks should she become pregnant again and relied on her inability to explain why she believed the injection to be better. When any lay person attends the GP to receive contraception, no such requirement to explain the reasons behind their contraceptive preferences exists. No-one is asked to justify their reasons behind their choice, they are simply presented with the available options.

⁵⁵⁹ GMC, 'Decision Making and Consent' (2020) 7 Available at <u>https://www.gmc-uk.org/-</u>/media/documents/updated-decision-making-and-consent-guidance-english-09_11_20_pdf-84176092.pdf?la=en&hash=4FC9D08017C5DAAD20801F04E34E616BCE060AAF [Accessed 04/08/2022].

⁵⁶⁰ Oxford University Hospitals NHS Foundation Trust and Z (by her litigation friend, the Official Solicitor) [2020] EWCOP 20 [15].

Coggon's research on the varied understandings of autonomy addresses this subjective bias that can exist regarding autonomous decisions.⁵⁶¹ He explains that in theory, respect for autonomy can be secured when an adult's right to refuse treatment is held at law to be absolute. However, Coggon continues that, "this apparently simple statement does not hold true in practice".⁵⁶² This highlights my earlier critique that the legislation currently in place to protect and implement supported decision making such as the MCA and Code of Practice does not necessarily translate into tangible results. Coggon elaborates that the judiciary have been able to interpret the concept to reach decisions that reflect their own moral judgments of patients or decisions made in particular cases, resulting in an "inconsistent application of the principle".⁵⁶³ From this perspective, it would seem that judges hold the power to either empower or limit autonomy. Relating this to the above facts of Re Z, she was deemed as being incapable because she could not expand upon the reasoning for her refusal. Coggon recognises that some arguments have been made which assert a decision can only be autonomous if it is made in full knowledge.⁵⁶⁴ However, he interprets this view as a means of limiting action, more so, that it can be by underhand means. Coggon argues that no-one has absolute knowledge and to impose such a demand allows those with power to assume control should they believe a person is making an unusual decision. In the case of Z, it is quite apparent that Z's rejection of the IUD was viewed as unacceptable as she was unable to provide reasoning which the Court deemed sufficient. Coggon believes that the law equates capacity to concurrence; where the patient agrees with the option identified as "best" by either a judge or medical practitioner. This logic would certainly seem to align with the decision in Z where it had been determined, prior to the hearing, that the IUD was viewed as achieving the "best outcome". Additionally, Coggon states that where a judge is unsympathetic with the patient, it is possible that the patient will face what can amount to an indifferent or even punitive understanding of autonomy. If we apply this theory to not only *Re Z*, but to cases in other chapters such as the one concerning capacity, we can see that female patients are distinguished on their precise differences to the judiciary.

 ⁵⁶¹ John Coggon, 'Varied and Principled Understanding of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?' 15 (2007) *Healthcare Analysis* 235.
 ⁵⁶² ibid.

⁵⁶⁴ ibid [245].

Furthermore, the judgment is absent of any indication of whether any aids or resources were provided which would have helped Z articulate her decision, none are mentioned in the judgment. According to the NICE guidelines on supported decision-making, it is specified that in accordance with the Mental Capacity Act Code of Practice, Principle 2, the patient should be asked how they want to be supported and who they would like to have involved in the decision-making process.⁵⁶⁵ Additionally, there is an obligation to "support people to communicate so that they can take part in decision-making. Use strategies to support the patient's understanding and ability to express themselves".⁵⁶⁶ On review of the proceedings and discussion regarding Z's capacity, it appears that Z was judged on her inabilities, rather than being helped to express her wishes. Had a relational approach been employed, Z's inabilities wouldn't have been the defining factor of the case. Instead, Z would have been given the opportunity to fully express her wishes in a clear and cogent manner. Most importantly, the NICE guidelines state that in cases where "the consequences of the decision would be significant" health and social care practitioners should refer to other services that could help support decision-making when the persons' level of need requires specialist input.⁵⁶⁷ As already stated, the potential consequences of having a child are significant. Rather than enlist such support, it was simply considered that Z lacked any understanding relating to her compliance with the injection.

To frame this situation through an individual autonomy vs a relational autonomy lens would look as follows; under individual autonomy it is the patient's responsibility to maintain her contraception. As doubts existed over Z's ability to manage this, the IUD was decided to be the best course of action for achieving the desired result (Z refraining from further pregnancies). However, under a relational model, Z could have been "supported" to attend the necessary appointments required to maintain the effectiveness of the injection, it would have been a collective action, whereby

⁵⁶⁵ National Institute for Health and Care Excellence, 'Decision-making and mental capacity' (December 2017) 233, 1.2.3
 ⁵⁶⁶ Ibid, 1.29
 ⁵⁶⁷ Ibid, 1.2,16

responsibility was shared to help support Z's autonomous choice concerning her preference of contraception.

Knowles J does acknowledge that the injectable method, as preferred by Z, would be the least restrictive approach. However, she continues that the injectable would not "achieve the purpose for which contraception was sought, namely, to prevent the very serious risks to Z's physical health which further pregnancies would undoubtedly bring. Z's poor compliance with not only past injectable contraceptives but with medical treatment in this pregnancy militated against me endorsing Z's wish to have an injectable contraceptive."⁵⁶⁸ Therefore, it was concluded that it was in Z's best interests to have an intrauterine contraceptive device inserted at the time she has her caesarean on 3 April 2020. It must be stressed that this decision was made under the ambit of the Mental Capacity Act and Code of Practice, yet completely undermined Z's autonomy in the guise of "best interests".

The case of *Re Z* will be revisited in the "Capacity: united we stand, divided we fall, why supported decision-making is necessary to empower patients". The section "Court of Protection cases" will feature a series of judgments that have been "re-imagined" from a relational autonomy viewpoint.

The thesis will now advance to consider the potential negative consequences of a move towards relational autonomy through an exploration of undue influence and paternalism.

⁵⁶⁸ Oxford University Hospitals NHS Foundation Trust and Z (by her litigation friend, the Official Solicitor) [2020] EWCOP 20 [33].

4.6 Threats to autonomy: undue influence and the re-emergence paternalism

"The doctrine of undue influence does not question the person's ability to understand the choice that they made. Rather it looks at the issue of whether the decision was made freely, to the extent that it reflects the exercise of the person's autonomy."⁵⁶⁹

4.6.1 Undue Influence

One of the potential negative consequences of relational autonomy, is that of undue influence. Undue influence is when a person is induced to act otherwise than by their own free will. Mackenzie and Stoljar outline three ways in which problems can occur: "First, oppressive social relationships can unduly influence, and sometimes even hijack, the formation of an agent's desires, beliefs, and emotional attitudes. Second, these relationships affect the development of 'competencies and capacities necessary for autonomy, including the capacities for self-reflection, self-direction, and self- knowledge.' Finally, these relationships affect an individual's ability to bring his or her autonomous desires or choices to fruition."⁵⁷⁰ Academics such as Thalberg, Friedman, Meyres and Noggle have revealed that should a person be manipulated or oppressed, it could mean that the judgments that person then makes are tainted by that oppression.⁵⁷¹

Case law illustrates that undue influence exerted on patients by third parties is often focused on two types of belief – either religious, or a belief in an alternative therapy.⁵⁷² In the case of *Re T* Lord Donaldson identified two main considerations when determining if an influence has been inappropriate.⁵⁷³ The first considers the

⁵⁶⁹ Cameron Stewart, Andrew Lynch, 'Undue influence, consent and medical treatment' 96 (12) *Journal of Royal Society Medicine* 598.

⁵⁷⁰ Catriona Mackenzie, Natalie Stoljar, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (OUP 2000).

⁵⁷¹ Marilyn A Friedman, 'Autonomy and the split-level self' 24 (1986) *The Southern Journal of Philosophy* 19; Irving Thalberg, 'Hierarchical Analyses of Unfree Action' (1989) reprinted in Christman ed 123; Diana Meyres 'Autonomy and Feminine Socialization' 84 (11) (1989) *Journal of Philosophy* 619, Robert Noggle, 'Autonomy and the Paradox of Self-Creation' in *Personal Autonomy: New Essays* (CUP 2004).

⁵⁷² Cameron Stewart, Andrew Lynch, 'Undue influence, consent and medical treatment' (2003) *Journal of the Royal Society of Medicine* 96 (12) 598.

⁵⁷³ Re T (Adult: Refusal of Medical Treatment) [1992] 4 All ER [662].

strength of will of the patient. For example, should the patient be experiencing pain or depression, or be on medication, it could impair their ability to withstand the influence of third parties. The second relates to the patient's relationship with the persuading party. It is thought that the stronger or closer the relationship, the higher the chance of the persuader to successfully influence the decision of the patient. Such relationships are particularly relevant when religious beliefs form the basis for the refusal of treatment.

The relationship between undue influence and the law of consent in consideration of adult relationships came to the fore in the case of Mrs U v Centre for Reproductive *Medicine*.⁵⁷⁴ The case concerned a married couple who were attempting to conceive a child through IVF. After a consultation with a specialist nurse, Ms Hinks, Mr U altered his consent form to stipulate that in the event of his death, his sperm should perish. Mr U died unexpectedly, and Mrs U argued that the centre should continue to store his sperm, so that she could continue with the IVF programme. Her argument was based on the premise that Mr U's initial consent still prevailed, as the amendments made were because of the undue influence of Ms Hinks. In the judgment, the court considered Re T and concluded that whilst Mr U had succumbed to the "firmly expressed request of Ms Hinks and under some pressure... to prove undue influence, Mrs U has to show something more than pressure". 575 Mrs U appealed the decision on the grounds that the court had set the test for undue influence too high. The Court of Appeal rejected this argument the test for undue influence remained that "the weaker party's will must have been so overborne as to prevent its independent exercise".576

Conversely, the case of *Re* T^{577} provides an example of when the third party was found to have exerted undue influence. Miss T's parents separated when she was 3 years old. A major marital problem was the mother's faith, she was a "fervent Jehovah's Witness'. The mother had custody; however, it was granted on grounds

⁵⁷⁴ Mrs U v Centre for Reproductive Medicine [2002] EWCA Civ 565.

⁵⁷⁵ Centre for Reproductive Medicine v Mrs U (unreported, High Court of Justice, Family Division, The President, 25 January 202) [28].

⁵⁷⁶ Cameron Stewart, Andrew Lynch, 'Undue influence, consent and medical treatment' (2003) *Journal of the Royal Society of Medicine* 96 (12) 598.

which forbade the mother from raising T as a Jehovah's Witness. Whilst T was never baptised, she was raised by her mother with the view to her becoming a Jehovah's Witness. Miss T left her mother's home when she was 17 to live with her paternal grandmother, during this period, she revived her relationship with her father. Miss T was 34 weeks pregnant when she involved in a road traffic collision. She attended hospital but was not x-rayed due to her pregnancy and was advised to take an analgesic and rest. Her condition worsened and she returned to hospital reporting increased chest pains. She was diagnosed as suffering from pleurisy or pneumonia and was prescribed antibiotics and an analgesic, pethidine.

Interestingly, the patient assessment form contained the entry: "Religious beliefs and relevant practices: Jehovah's Witness (ex) but still has certain beliefs and practices". Importantly, it is not clear when this was written, as the writing differed to other entries, such as Miss T's name and the name of the consultant. Miss T's condition steadily worsened; accordingly, she was prescribed more pethidine.⁵⁷⁸ Her father, who was in attendance, noted a reduction in T's awareness and was informed by nursing staff that it was a side effect of the drugs.⁵⁷⁹ Miss T's father had also expressed his anxiety concerning any complications which might arise from her mother's religious beliefs. Upon the arrival of Miss T's mother, the pair were left alone for an unknown period. Following which, Miss T made a statement to a staff nurse, who reported it had "come out of the blue",⁵⁸⁰ that she did not want a blood transfusion as she had been a Jehovah's Witness and still maintained some of the beliefs. At this point, it is important to note that Miss T did not require a blood transfusion.

Soon after this admission, Miss T went into labour. A decision was made to deliver the baby by caesarean section. An exchange followed with Dr F regarding blood transfusions, to which T initially consented and then withdrew consent. The midwife produced a form of refusal of consent to blood transfusions, which Miss T signed, and the midwife countersigned. It was not explained to Miss T, "that it may be necessary to give a blood transfusion so as to prevent injury to my health, or even to

⁵⁷⁸ ibid [655].

⁵⁷⁹ ibid.

⁵⁸⁰ ibid [656].

preserve my life".⁵⁸¹ Unfortunately, the baby was delivered still born. T's condition deteriorated and she was admitted to intensive care. The ICU consultant wanted to administer a blood transfusion but felt unable to do so owing to Miss T's earlier expressed wishes. Therefore, Miss T was put on a ventilator and paralyzing drugs were administered.

It is from these circumstances that the court proceedings began which resulted in the administration of the blood transfusion. The Court of Appeal considered "whether Miss T was fit to make a decision not to have a blood transfusion and whether she made a genuine decision of her own volition or whether her decision is to be impugned by the undue influence of her mother".⁵⁸² On appeal, the Court of Appeal found that her refusals were invalid because of incapacity and also because they did not cover the extreme situation that had arisen. Additionally, T's refusals would have been invalidated because of the undue influence of the mother. In discussing undue influence Lord Donaldson MR explored some of the potential problems in terms of establishing undue influence, particularly so in relation to determining the distinction between third party support and third-party persuasion:

'A special problem arises if at the time the decision is made the patient has been subjected to the influence of some third party. This is by no means to say that the patient is not entitled to receive and indeed invite advice and assistance from others in reaching a decision, particularly from members of the family. But the doctors have to consider whether the decision is really that of the patient...The real question in each such case is, does the patient really mean what he says or is he merely saying it for a quiet life, to satisfy someone else or because the advice and persuasion to which he has been subjected is such that he can no longer think and decide for himself? In other words, is it a decision expressed in form only, not in reality?"⁵⁸³

Likewise, the case of *Allcard v Skinner*⁵⁸⁴ Lindley LJ spoke of undue influence, stating, "But the influence of one mind over another is very subtle, and of all

⁵⁸¹ ibid [655].

⁵⁸² ibid [660].

⁵⁸³ ibid [662].

⁵⁸⁴ Allcard v Skinner (1887) 36 Ch D 145.

influences, religious influence is the most dangerous and the most powerful".⁵⁸⁵ The Court of Appeal believed that Miss T, during her childhood, had been subjected to the religious beliefs of her mother and in her weakened medical state, under the influence of drugs, the pressure of her mother had greater effect. Thus, it was concluded that Miss T was subjected to the undue influence of her mother which vitiated her decision.

Therefore, a need exists to manage undue influence for relational autonomy to succeed. As enunciated in the case of Re T, clinicians cannot honour their professional obligation to respect the autonomy of their patients if family members are undermining the patient's ability to make medical decisions freely. There is a clear distinction between relational autonomy and undue influence. Relational autonomy can involve the voluntary subordination of their own treatment preferences to those of family members. Further, as stated in the discussion of Re Z, a form of relational autonomy can embody a collective action. In Re Z, the patient's preferences were clear by her repeated objections and statements that "it's my body", the third party required in that situation, the nurse, to help Z attend the necessary appointments, was there as a supportive, not a coercive role. Whereas in cases of undue influence, the patient unwillingly gives in to the emotional appeals of family members.⁵⁸⁶ Within a clinical setting, Baker and Gallagher assert that it is possible to manage undue influence.⁵⁸⁷ Managing undue influence is a lengthy and complicated process. Namely, because clinicians can only spend a limited amount of time with each patient, but also due to issues of sensitive surrounding familial members and the potential risk of alienating caregivers. Schafer, Putnik, Dietal et al, recognise that whilst some patients will have the autonomy to make their own decisions, many appreciate the input of family members.⁵⁸⁸

⁵⁸⁵ ibid [183].

⁵⁸⁶ Francis X Baker, Colleen M Gallagher, 'Identifying and Managing Undue Influence From Family Members in End-of-life Decisions for Patients with Advanced Cancer' (2017) 13 *Journal of Oncology Practice* 702.

⁵⁸⁷ ibid.

⁵⁸⁸ Christof Shafer, Kurt Putnik, Barbara Dietl et al, 'Medical decision making of the patient in the context of the family. Results of a survey' (2006) 14 *Support Care Cancer* 952.

Baker and Gallagher believe the first step to managing undue influence is to distinguish "between family input that informs patient autonomy and family input that overrides it".⁵⁸⁹ Yet, as most healthcare professionals follow an individualistic understanding of autonomy, any familial input could be viewed as an interference. However, owing to the growing recognition of relational autonomy, it is accepted that so long as it is done on a voluntary basis, patients may follow the advice of their family. Voluntariness in terms of a patient setting refers "to a patient's right to make health care choices free of any undue influence".⁵⁹⁰ Baker and Gallagher believe undue influence can be recognised in the following ways, "In the inpatient setting, the patient may agree to pursue additional therapy after visitation from family members, despite having previously expressed a clear desire not to pursue additional therapy. Patients may display visible anxiety when discussing or administering the new treatment plan, or they may refuse procedures. Clinicians may also notice a family member consistently speaks for the patient, even when the patient is capable of speaking for him or herself.⁵⁹¹ Baker and Gallagher advise that if undue influence is suspected, clinicians should pursue the following course of intervention; first, to consult with other members of the medical team in order to determine whether the patient has expressed any specific treatment preferences to one of them.⁵⁹² Then, should any information emerge which supports further enquiry, the second step should be speaking to the patient in order to ascertain their "authentic: treatment preferences.⁵⁹³ Should the patient express any unease with the current treatment plan, the clinician can then offer to call a family meeting, however, should the patient decline this request, the clinician must respect their wishes, as to do otherwise would be paternalistic.⁵⁹⁴ When and if the meeting takes place and both the patient and family members can speak freely, the patient should then be empowered to decide

⁵⁸⁹ Francis X Baker, Colleen M Gallagher, 'Identifying and Managing Undue Influence From Family Members in End-of-life Decisions for Patients with Advanced Cancer' (2017) 13 *Journal of Oncology Practice* 702.

⁵⁹⁰ Edward Etchells, Gilbert Sharpe, Mary J Dykeman, Eric M Meslin, Peter A Singer, 'Bioethics for clinicians: 4 Voluntariness' 155 (8) (1996) *Canadian Medical Association Journal* 1083.

⁵⁹¹ Francis X Baker, Colleen M Gallagher, 'Identifying and Managing Undue Influence From Family Members in End-of-life Decisions for Patients with Advanced Cancer' (2017) 13 *Journal of Oncology Practice* 702.

⁵⁹² ibid [705].

⁵⁹³ ibid.

⁵⁹⁴ ibid.

upon a treatment plan.⁵⁹⁵ The plan put forward by Baker and Gallagher seems pragmatic and offers a reasonable solution to the possibilities of undue influence. However, whilst these steps seem viable in theory, the time and care it would take to put these into practice, could mean that they are not delivered effectively. In the following chapter on capacity, undue influence is further investigated through an exploration of the wills-based model.

This section has investigated the problem of undue influence and considers the potential consequences for patients if they are subject to overwhelming pressure from family members or significant others. To understand how undue influence operates in practice, a range of cases were reviewed to determine what is required to pass the threshold of undue influence. Overall, it is accepted that undue influence is an issue for relational autonomy, however, it is an issue that can be managed. The next section looks at another concern for the relational approach; rather than it being the influence of personal parties, the influence of professionals on treatment decisions is now considered with the role of paternalism.

4.6.2 Paternalism

As explained in the previous chapter on Feminism, paternalism is the thinking or behaviour of people in authority, that results in third parties making decisions for people, which prevents them from taking responsibility of their own lives.⁵⁹⁶ Therefore, Christman asserts that paternalism directly affronts autonomy.⁵⁹⁷ There are two types of paternalistic interventions, those which are "interpersonal" (governed by social and moral norms) and those which are "policy" (required by formal or legal rules). Christman explains that there is an underlying assumption that acts of paternalism are carried out with the intention of advancing the good of whom

⁵⁹⁵ ibid.

⁵⁹⁶ See 'Feminism', for further information, Brian. C Drolet, 'Selective Paternalism' (2012) 14 *Virtual Mentor* 582,

⁵⁹⁷ John Christman, 'Autonomy in Moral and Political Philosophy' (2020) *The Stanford Encyclopaedia of Philosophy*) available at

https://plato.stanford.edu/archives/fall2020/entries/autonomy-moral/ [Accessed 11/10/2023].

the intervention is being made.⁵⁹⁸ However, Christman identifies a contradiction that "respect for autonomy is meant to prohibit such interventions because they involve a judgment that the person is not able to decide for herself how best to pursue her own good".⁵⁹⁹ Christman considers the scenario of when a person is under the influence of external pressures which are significantly impacting on their ability to make independent choices, however, he believes so long as the person retained the ability to reflect and consider their decision, the external influence would be a lesser harm than an intervention.⁶⁰⁰ The boundary between intervention and acceptance is often dictated by whether the patient is deemed to be capable to make that decision. In a healthcare context, the barriers of intervention are mapped out by the clinicians, as is the role of autonomy.

Sjostrand explains that if autonomy is viewed as a value as opposed to a right, at times, patients' decisions should be overruled to protect or promote their own autonomy. She dubs this "paternalism in the name of autonomy".⁶⁰¹ Sjostrand's contention directly affronts the utilitarian theory posited by J.S Mill. Mill wrote that "it is a misapprehension of the utilitarian mode of thought, to conceive it as implying that people should fix their minds upon so wide a generality as the world, or society at large. The great majority of good actions are intended, not for the benefit of the world, but for that of individuals, of which the good of the world is made up."602 Mill believed that "the ethically good person" is not required to worry about the projects of those outside his particular concern, "except so far as is necessary to assure himself that in benefiting them he is not violating the rights of anyone else," where "rights" are "legitimate and authorized expectations".⁶⁰³ Therefore, the conflict is, Sjostrand contends interventions as required to save and preserve autonomy, whereas Mill believes autonomy to be an entirely individual right. In agreement with the utilitarian viewpoint, Christman states that autonomy is often viewed as the opposite to paternalism. Beauchamp and Childress' define paternalism as, "the intentional

⁵⁹⁸ ibid.

⁵⁹⁹ ibid.

⁶⁰⁰ ibid.

⁶⁰¹ Manne Sjostrand, Stefan Eriksson, Niklas Juth, Gert Helgesson, 'Paternalism in the Name of Autonomy' (2013) 38 *Journal of Medicine and Philosophy* 710.

⁶⁰² John Stuart Mill, 'In Defense of Utilitarianism' in *Conduct & Character: Readings in Moral Theory* (Wadsworth Publishing 1999) 118.

⁶⁰³ ibid.

overriding of one person's known preferences or actions by another, where the person who overrides justifies the action by the goal of benefiting or avoiding harm to the person whose preferences or actions are overridden".⁶⁰⁴ A paternalistic act involves two components ; "interference" and "motive".⁶⁰⁵ For an action to be paternalistic, it must be motivated by concern for the person's own good and wellbeing. Stojstrand contends that if autonomy is viewed as something that benefits patients, there is no need for autonomy and paternalism to be in opposition to one another. She explains that "if autonomy is valuable, then arguably it may be justifiable not to respect a person's autonomous choice or action at one point, if this leads to greater autonomy for that person overall".⁶⁰⁶ In practice, Stojstrand's model seems to be reminiscent of a best interests' assessment and as explained, these are often conducted from an individualistic viewpoint.

There are two strains of paternalism: "weak paternalism" regarding noncompetent patients and "strong paternalism" regarding competent patients. The Mental Capacity Act 2005 defines a competent patient as one who is able to take a decision for her or himself, i.e. who can understand and retain the information relevant to the decision, weigh that information as part of the process of making the decision, and communicate that decision (s 3(1)).⁶⁰⁷ The distinction between a competent patient and an incompetent patient is crucial: whereas consent is required before treating the former, it is not required from the latter. Beauchamp and Childress explain that in weak paternalism, an intervention is made on the grounds of beneficence or nonmaleficence to prevent actions that are substantially non-autonomous. For weak paternalism, a person's lack of autonomy is necessary to override his/her decision, whereas strong paternalism concerns interventions which are intended to benefit a person who acts substantially autonomously.⁶⁰⁸ Instances that concern interventions of weak paternalism are generally more easily accepted. Examples of weak paternalism can include patients with reduced consciousness, those with psychotic disorders, or if they are suffering from dementia. Each of these issues diminish a

 ⁶⁰⁴ Tom Beauchamp, James Childress, *Principles of Biomedical Ethics* (OUP 2001) 178.
 ⁶⁰⁵ Manne Sjostrand, Stefan Eriksson, NiklasJuth, Gert Helgesson, 'Paternalism in the Name of Autonomy' 38 (2013) *Journal of Medicine and Philosophy* 710.

⁶⁰⁶ See subsection 4.5.2 for a discussion of *Re Z*.

⁶⁰⁷ Mental Capacity Act 2005.

⁶⁰⁸ Tom Beauchamp, James Childress, *Principles of Biomedical Ethics* (OUP 2001) 176.

person's competence which could affect the patient's ability to process information adequately. Stojstrand provides the example of a confused patient with encephalitis who resists the treatment that is required to restore his mental capacity. This type of paternalism is largely uncontroversial.⁶⁰⁹ However, policies that permit strong paternalism for the sake of autonomy are more difficult to justify. An example of a strong paternalistic intervention would be the case of a Jehovah's Witness refusal of treatment. Varelius asserted that, "if autonomy is of objective value, then respect for autonomy in the Jehovah's Witness case implies that the patients' refusal ought to be disregarded in order to safeguard the patients' future autonomous life".⁶¹⁰ Caplan provides a further example of strong paternalism for the sake of autonomy in cases of rehabilitation medicine. He states that often, patients with severe injuries reject treatment after an accident or stroke. Caplan writes that mandating treatment after a severe injury is normal practice in rehabilitation medicine; "short-term infringement of autonomy is tolerated in the name of long-term autonomy".⁶¹¹ Such policies are more difficult to justify as allowing strong paternalism for the benefit of autonomy runs the risk of becoming self-defeating.612

Glick and Fiske identified two interpretations of paternalism; "dominative paternalism" based on the idea that women are not fully competent adults and "protective paternalism" based on men's dyadic dependence on women as wives, mothers, and romantic objects, who should be loved, cherished and protected by men.⁶¹³ Both interpretations infer an obvious need for a feminist model to healthcare, to alleviate impact caused by gender-imposed stereotypes. In practice, a feminist outlook could be applied through the process of supported decision-making which embodies the relational approach. Supported decision-making is vital to feminist

 ⁶⁰⁹ Manne Sjostrand, Stefan Eriksson, Niklas Juth, Gert Helgesson, 'Paternalism in the Name of Autonomy' 38 (2013) *Journal of Medicine and Philosophy* 710, 713.
 ⁶¹⁰ Jukka Varelius, 'Autonomy, wellbeing and the case of the refusing patient' 9 (2006) 9

Medicine Health Care and Philosophy 117, 121. ⁶¹¹ Arthur Caplan, 'Denying autonomy in order to create it: The paradox of forcing treatment upon addicts' (2008) 103 *Addiction* 1919, 1920.

⁶¹² Manne Sjostrand, Stefan Eriksson, Niklas Juth, Gert Helgesson, 'Paternalism in the Name of Autonomy' (2013) 38 *Journal of Medicine and Philosophy* 710.

⁶¹³ Peter Glick, Susan T Fiske, 'The ambivalent sexism inventory: differentiating hostile and benevolent sexism' 70 (1996) Journal *Personality & Social Psychology* 491, 493.

practice as it allows for patients to be empowered and knowledgeable about their health care needs.⁶¹⁴

Feminists accept that there is an obvious hierarchy within medical practice, including physical barriers such as greeting the patients in the waiting room, taking a health history when the patient is dressed and retaining medical records.⁶¹⁵ A way to address the hierarchy is through patient participation. Andrist explains that "the concept of participation is important; providers must consider that people will vary regarding their ability and desire to share in decision making". Further and most importantly, Andrist recognises that there will be patients who still rely on the institutional authority of medicine and who are unwilling to bear the responsibility of making their own decisions, despite the amount of information they are given.⁶¹⁶ Therefore, this research quite clearly suggests, that to an extent, a need for paternalism still exists; some people rely on the trained skill and expertise of the doctor. However, there is an important caveat to be added to the traditional idea of "doctor knows best". To both satisfy feminist critics and to minimise the impact of prejudicial stereotypes, patients must be involved in the process. At a minimum, efforts need to be made to include the patient in the relevant proceedings, however, as demonstrated through the case of *Re Z*, current practice is failing to achieve this consistently. Research indicates that most patients want all the information regarding their problem, but some do not wish to participate in the decisions concerning treatment options. Therefore, such research inadvertently advocates for a relational approach to decision making, whereby the role of the doctor is largely unchanged, but that of the patient is elevated to ensure open communication between both parties.

This concluding section has outlined the potential problems of paternalistic interventions, but also the potential benefits of such interventions. Overall, this section asserts that a balance is needed to ensure an effective doctor-patient

⁶¹⁴ Linda Andrist, 'A Feminist model for women's healthcare' (1997) 4 *Nursing Inquiry* 268. ⁶¹⁵ ibid.

⁶¹⁶ ibid.

relationship exists and that the key to such a relationship is an effective dialogue which encompasses emotions.

4.7 Conclusion

"Both values and emotions underpin every aspect of a decision-making process."617

This chapter has revealed, that in its traditional formation, autonomy was very much an individualistic notion which advocated for self-determination and freedom from external sources.⁶¹⁸ It has been evidenced that autonomy was traditionally taken to mean "self-determination" and embodies the idea of self-rule.⁶¹⁹ Such a conception prized itself on an "in-control" model, which strongly favoured rationality over emotion.⁶²⁰ This in itself indicates, that owing to the social construction of females, the model favoured the male stereotype. The discussion built to consider the criticisms and challenges of an individualistic model of autonomy through the development of a relational approach.⁶²¹ The theory surrounding relational autonomy and the ideas of interdependence rather than independence, are much more supportive of women's rights. Namely, because they recognise that women are often in a position when they are reliant on others.⁶²² This does not mean that women are non-autonomous individuals, more so, that women might need support to enable their autonomous actions.

⁶¹⁷ Polychronis Voultsos, 'The role of values and emotions in patients' healthcare decision making' 3 (2020) *Aristotle Biomedical Journal* 1.

⁶¹⁸ John Christman, 'Autonomy in Moral and Political Philosophy' (2020) *The Stanford Encyclopaedia of Philosophy* available at

https://plato.stanford.edu/archives/fall2020/entries/autonomy-moral/ [Accessed 11/10/23]. ⁶¹⁹ John Coggan, 'Autonomy, liberty and medical decision making' (2011) 70 *The Cambridge Law Journal* 523.

⁶²⁰ Jennifer K Walker, Laine Friedman, 'Relational Autonomy: Moving Beyond the Limits of Isolated Individualism' (2014) *American Academy of Paediatrics* available at <u>https://pediatrics.aappublications.org/content/pediatrics/133/Supplement_1/S16.full.pdf</u> [Accessed 29/07/2020].

⁶²¹ Catriona Mackenzie, Natalie Stoljar, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (OUP 2000).

⁶²² Francoise Baylis, Nuala Kenny, Susan Sherwin, 'A relational account of public health ethics' (2008) 1 *Public health Ethics* 196, Jennifer Nedelsky, *Law's Relations: A Relational Theory of Self, Autonomy and Law* (OUP 2011).

However, as of yet, relational autonomy has not been successfully implemented throughout medical practice.⁶²³ Despite publications from authorities such as the General Medical Council which dictates clear and coherent rules to professionals for allowing patients to be part of the decision-making process, such guidance does not clearly translate into practice. This chapter has critiqued the GMC guidance, alongside that of s4 of the MCA, explaining that owing to the vagueness of the respective requirements of "practicable" and "reasonable steps" the instruments are insufficient safeguards for promoting patient participation. The solution is for the practitioner-patient dialogue to encompass a more holistic approach and adopt a relational approach to the decision-making process, which moves away from the ideas of rationality and self-sufficiency traditionally associated with autonomy. Additionally, to assert that like capacity, a right to autonomy is not absolute and people should be entitled to express their autonomy through an expression of their emotions and not an expression of logic.

As discussed in the chapter 3, medical knowledge is infiltrated with a gender bias that assumes males as the standard patient. It has been accepted that women are predisposed to a weaker conception of autonomy owing to their gender. However, this disposition is strengthened by paternalism, which continues to follow stereotypical assumptions that believe women to be irrational and incapable. This was demonstrated most clearly when considering maternal autonomy and the cases of forced caesarean sections.⁶²⁴ The following chapter will go on to consider the concept of "capacity"; how capacity assessments are conducted, to demonstrate the impact of gender and to reinforce how relational autonomy can be adopted through supported decision-making.

⁶²³ Roy Gilbar, José Miola, 'One size fits all? On patient autonomy, medical decision-making and the impact of culture' 23 (2015) *Medical Law Review* 375.

⁶²⁴ Heather Cahill, 'An Orwellian Scenario: Court Ordered Caesarean section and women's autonomy' 6 (1999) *Nursing Ethics* 494.

5 Capacity: united we stand, divided we fall, why supported decision making is necessary to empower patients.

5.1 Introduction

This chapter establishes two findings in relation to the concept of capacity. Firstly, that a relational approach is required during capacity assessments to ensure that a person is supported to maximise their ability, either to make decisions themselves, or to increase their participation in the decision-making process. Assessments must focus on and encourage supported decision making. Secondly, this chapter demonstrates that a person's gender can be an influential factor regarding the outcome of capacity assessments owing to gender related assumptions and stereotypes. Importantly, this chapter shows that the way in which the courts approach capacity assessments disproportionately affect women because of unconscious biases. Such bias is revealed through an analysis of language used in judgments and through the comparison of analogous cases where men's capacity and subsequent autonomy appears to be treated with greater respect.

This chapter begins by examining the definition of capacity from a statutory viewpoint; the Mental Capacity Act 2005 (MCA). The test of capacity is then considered further, where it is revealed that academics such as Williamson, Graham and Cowley are calling for the framework of the MCA to be understood in a much broader context, including any social and cultural implications. Should the MCA be understood in such a context, it would undeniably favour feminist theory. Feminist theory advocates that everyone should be understood within their social context, whereas a functional approach is far narrower and is restricted to the individual decision that needs to be investigated at that moment in time. It fails to account for external factors that may directly or indirectly influence a person's decision. The procedural approach is both investigated and evaluated alongside supported decision making to illustrate that a move towards a relational approach would enhance patient autonomy. Supported decision-making is an integral component to the success of a relational approach and should enable the patient to participate in

the decision-making process to their greatest ability. However, as is revealed through my analysis of a series of cases from the Court of Protection, in practice, supported decision-making is often compromised by the dominance of best interests (as it is currently framed) and ultimately, a lack of resources available to the proceedings.⁶²⁵ This chapter also demonstrates that often in practice, "best interests" is actually "clinical best interests". Further, it is also demonstrated how gender poses additional barriers to patient participation in terms of patients making decisions regarding their treatment and care owing to pre-existing stereotypes. The selected cases reveal that the MCA differs in practice to theory and when it comes down to practicalities, best interests is often constructed in such a way that fails to give priority, or even consideration, to the patient's wishes and desires.⁶²⁶ Overall, it is demonstrated that a relational approach to capacity would secure a far more favourable outcome in terms of enhancing patient autonomy.

5.2 Context: Supported Decision Making and Relational Autonomy

Prior to delving into the main body of the chapter, a few distinctions must be made clear to ensure understanding and coherency of argument. The first, is that the differences between supported and substituted decision making be understood. This thesis argues that supported decision making should be employed alongside a relational approach to maximise patient autonomy and participation. It can be inferred through the MCA 2005 in section 4(4) by which it states, "(4) He must, so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him." Supported decision-making is widely accepted as a core feature of good healthcare. It can be described as a tool which enables people with disabilities to retain their decision-making capacity by choosing supporters to help them make choices. Principle 4 of the NHS constitution states that "Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment."⁶²⁷ Carmona reports that most NHS

 ⁶²⁵ Both physical resources in terms of staff and financial resources owing to budget cuts.
 ⁶²⁶ The rationale for the selection of cases is explained in the chapter on Methodology.
 ⁶²⁷ Chris Carmona, 'Shared decision-making: summary of NICE guidance' 373 (2021) *British Medical Journal* 1.

practitioners and commissioners acknowledge that this and consultation is not always offered.⁶²⁸ The argument of this thesis is to extend the "collaborative process" to include third party support for the patient to aid their understanding and articulation of the decision-making process.

Substituted Decision Making is entirely different. This decision-making model enables a proxy to make decisions on behalf of another person who is incapable, therefore, believing the concerned individual cannot make a decision for himself or herself.⁶²⁹ According to the best interests standard, the surrogates should base their decision on what treatment would best accommodate the patient's interests, broadly conceived.⁶³⁰ This standard is justified by the principle of beneficence.⁶³¹ During the Court of Appeal hearing of *Aintree vs James*,⁶³² it was asserted that the best interests standard assumes a generic view of interests: the interests a 'reasonable' person would have in the circumstances. However, when the case reached the Supreme Court, Lady Hale clarified that it must be a decision-specific evaluation of individual preferences which 'consider [s] matters from the patient's point of view'.⁶³³ Whilst Baroness Hale's opinion was (and is) reflective of the pre-existing legal framework, the judgment was thought to be significant as decisions made through the prism of the patient's likely, or actual wishes, had not always been recognised in case law. However, in the decade that has passed since Aintree, it seems that its precedent has not been cohesive in ensuring the centrality of the patient in the decision-making process. Rather it seems that in cases concerning patients who lack capacity, "best interests" precede, often in an implicit form of substituted decisionmaking. Substituted decision making is an embodiment of paternalism as it actively

⁶²⁸ ibid.

⁶²⁹ W.M Irenka Suto, Isabel C.H Clare, Anthony Holland, 'Substitute financial decisionmaking in England and Wales: a study of the Court of Protection' 24(11) (2002) *Journal of Social Welfare and Family Law* 37.

⁶³⁰ Giles Birchley, 'The theorisation of 'best interests' in bioethical accounts of decision making' 22(1) (2012) *BMC Medical Ethics* 1, 7.

⁶³¹ Helen J Taylor, 'What are 'best interests'? A Critical Evaluation of 'best interests' decision-making in clinical practice' 24(2) (2016) *Med Law Review* 182.

⁶³² Aintree University Hospitals NHS Foundation Trust (Respondent) v James (Appellant) [2013] UKSC 67.

⁶³³ ibid [45].

seeks to remove the patient from the decision-making process.⁶³⁴ Substituted decision-making will not be considered in this chapter.

5.3 The Definition of Capacity

Hotopf defines capacity as a legal, clinical, ethical and social construct.⁶³⁵ Prior to delving into the analysis concerning capacity it is important to note the following: legal capacity is the formal ability to hold and to exercise rights and duties. Mental capacity differs, it is the decision-making skills and the competencies of a person. Mental capacity varies from person to person. Mental capacity forms the basis of this discussion.

Mental incapacity is an impairment of mind which may occur on a temporary basis or in some cases, it can be a permanent state from which the patient may never recover.⁶³⁶ For example, a person may experience a temporary loss of capacity if they are under the influence of alcohol or narcotics, while a more permanent loss might happen because of dementia, mental disability, or serious brain injury. Mental incapacity encompasses a range of conditions which can include severe learning difficulties, diseases such as alzheimer's, or disabilities induced from trauma. Series explains that "within law and legal scholarship there are different models of legal personality and legal capacity".⁶³⁷ Coggon believes that "the law provides – on its face – two concepts: those who have, and those who lack capacity."⁶³⁸ Further, he suggests that mental capacity law presents three sorts of patients: "First, there are patients who have capacity. Then, within the category of those who lack capacity, there are two further concepts of the patient: those who once had relevant capacity

⁶³⁴ I do accept the caveat for when patients are unconscious, a decision will need to be made without the direct involvement of the patient (unless they have signed an advanced decision).

⁶³⁵ Matthew Hotopf, 'The assessment of mental capacity' 5 (2005) *Clinical Medicine* 589. ⁶³⁶ Note, incapacity can arise suddenly for example through traumatic brain injury.

⁶³⁷ Lucy Series, 'Relationships, Autonomy and legal capacity: mental capacity and support paradigms' 40 (2015) *International Journal of Law and Psychiatry* 80.

⁶³⁸ John Coggon, 'Mental Capacity Law, Autonomy and Best Interests: An argument for conceptual and practical clarity in the Court of Protection' 24 (2016) *Medical Law Review* 396, 398.

but are deemed now to lack it and those whose values cannot be (satisfactorily) ascertained."639

In its simplest form, a legal personality can be occupied by anyone that carried with them some kind of right. The most prominent of the models within judicial and academic thinking is that of the "responsible subject". Series explains that this model is instilled within the concept of mental capacity.⁶⁴⁰ It refers to an individual's ability to make a particular decision and should that person lack "mental capacity", third parties can make decisions on their behalf. This chapter advocates away from the notion of individual responsibility and instead argues that a relational model be adopted, particularly as the responsible subject prides themselves on rationality,⁶⁴¹ a trait which has long been associated with the male sex, often leading to some prejudicial opinions against women. ⁶⁴²

Coggon utilises *Ms B v An NHS Hospital Trust* ⁶⁴³ to explain the consequences of being declared as having capacity. In the case of Ms B, life preserving interventions were found to be unlawful because the patient refused consent to the invasion of her bodily integrity. When deemed capable, 'respect should be given to the specific patient's conception of her interests including when her life is at stake'.⁶⁴⁴ In Ms B's case, the Court held she had capacity, thus her view of her interests and refusal of consent should prevail over her carer's view that she failed to properly understand her interests. Notably, the case of *Re T* (Adult: Refusal of Treatment)⁶⁴⁵ stipulated that a patient with capacity has an absolute right to refuse treatment or choose

⁶⁴³ *Ms B v An NHS Hospital Trust* [2002] EWHC 429 (Fam) [2002] 2 All ER 449.

⁶³⁹ ibid.

⁶⁴⁰ Lucy Series, 'Relationships, autonomy and legal capacity: Mental capacity and support paradigms' 20 (2015) *International Journal of Law and Psychiatry* 80.

⁶⁴¹ Ngaire Naffine, *Law's Meaning of Life* (Hart, 2009) 362, 364.

⁶⁴² See Chapter 3 for an in-depth discussion on the characteristics linked to rationality, with particular reference to the work of Delese Wear, Julie Aultman, Nicole Borge, 'Retheorizing sexual harassment in medical education: women students' perceptions at five US medical schools 19 (2007) *Teaching and Learning in Medicine* 20 ; Alan Bleakley, 'Gender matters in medical education' 47 (1) (2013) *Medical Education* 59; Malika Sharma, 'A feminist in the academy' 189 (2017) *Canadian Medical Association Journal* 1398.

⁶⁴⁴ John Coggon, 'Mental Capacity Law, Autonomy and best interests: An Argument for Conceptual and Practical Clarity in the Court of Protection' 24 (2016) *Medical Law Review* 396, 399.

⁶⁴⁵ Re T (Adult: Refusal of Treatment) [1993] Fam 95.

between treatments that are offered for rational or irrational reasons, or for no reason at all.

To recap the basic definitions; mental capacity refers to the decision-making skills and the competencies of a person, mental incapacity occurs where there is an impairment of mind which impedes upon a person's ability to action their decisionmaking skills and competencies. Importantly, it has been shown that those who have capacity are legally entitled to refuse any and all medical intervention but those who lack capacity cannot. It is therefore important to be able to distinguish the two on the basis of the MCA and the MCA Code of Practice. That is the focus of the following sections, starting with a brief overview of the Act and its motivations for introduction.

5.4 Mental Capacity Act 2005 and The Code of Practice

The Mental Capacity Act (2005) came into force in England and Wales in October 2007. The MCA provides a statutory framework for dealing with people who may lack the ability to deal with decisions regarding their treatment, welfare or finances. Diamond explains that the introduction of the MCA bridged a huge gap in statutory provisions for decision making on the behalf of mentally incapacitated adults.⁶⁴⁶ The Act is underpinned by two basic concepts: the concept of capacity and the concept of best interests.⁶⁴⁷ Fundamentally, only if an adult (a person over the age of 16) lacks capacity, can actions be taken on his or her behalf. Thus, capacity is assessed in a functional order. The functional approach will be discussed in depth later in this chapter, but for present purposes it is sufficient to understand that, as a result of it, a person may have the capacity to make one decision but not another. Best interests relate to the process that once a person is declared incapable, decisions must be made on behalf of that person in their best interests. Importantly there is currently no statutory definition of best interests, there is only guidance in the form of a statutory checklist.

⁶⁴⁶ Bridgit C Diamond, *Legal Aspects of Mental Capacity* (Wiley Blackwell, 2016) 1.

⁶⁴⁷ The Mental Capacity Act 2005.

The aim of the Act is to preserve the individual's right to self-determination as far as possible, whilst also ensuring protection and care in the best interests of those unable to make their own decisions.⁶⁴⁸ The Act is supported by a Code of Practice, intended to aid clinicians and health professionals in using the act to ensure that capacity is properly assessed, that decisions made on behalf of those lacking capacity are made in their best interests, and further, to provide legal protection for those responsible for such decisions. The principles of the MCA are based on the common law established in landmark legal rulings and manifold consultation papers by the Law Commission.⁶⁴⁹ The need for the MCA arose after a number of difficult cases in the early 1990s which highlighted a gap in legislation in relation to how to treat adults who lack the capacity to make a decision. Should a person be incapable of making a particular decision, a paternalistic intervention may be made on his behalf to protect the individual's health and welfare. I agree with the premise of the MCA and it cannot be denied that a gap existed concerning the need to protect and help those adults who may struggle when making certain decisions. However, paternalism is not the right fit. Rather, the approach should be one of empowerment. Paternalism takes away from a person's right to decide upon outcomes relating to their own life. Paternalism replaces the patient's voice with the voice of the practitioner. The MCA should focus on ways to promote capacity and work to enable decision making for those within the ambit of its protection.

In this section I will outline the key principles enshrined within Section 1 of the Act, elaborating on aspects such as the provision concerning "practicable steps". The segment will then advance to consider Section 2 of the Act and the process involved with conducting capacity assessments, including the "causative nexus" in relation to the second stage of the assessment process. Further, s2(3) of the Act is explored in greater depth to question whether superficial judgments could be made about a person in relation to their gender. Finally, s4 of the Act is reviewed to outline the statutory provisions of best interests and whether the test is effective in relation to respecting patient autonomy and considering the views of the patient.

⁶⁴⁸ Richard Jones, *Mental Capacity Act Manual* (Sweet & Maxwell 2012).

⁶⁴⁹ Law Commission Reports (No. 129, 1993; No. 128, 1993; No. 119, 1991).

5.5 The Principles of the MCA 2005

The Act is underpinned by a set of five key principles set out in Section 1. These principles are "designed to emphasise the underlying ethos of the Act and make clear that the legislation is concerned with balancing autonomy and dignity with protection for those who lack capacity".⁶⁵⁰

The five key principles are:

- 1) A person must be assumed to have capacity unless it is established that he/she lacks capacity
- A person is not to be treated as unable to make a decision unless all practicable steps to help him or her to do so have been taken without success.
- A person is not to be treated as unable to make a decision merely because he or she makes an unwise decision
- 4) An act done, or a decision made under this act for or on behalf of a person who lacks capacity must be done, or made, in his/her best interests.
- 5) Before the act is done or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

The principles of the MCA point towards a conception of mental capacity that has important legal, ethical and political dimensions. Should it be determined that a patient lacks capacity, a clinician is then entitled to make decisions on the patient's behalf in his best interests. This places a lot of power and responsibility within the hands of the decision-maker. To avoid an overly paternalistic approach, much emphasis has been placed in the MCA on evaluating the process of decisionmaking, not solely on its content or outcome. Therefore, the ethos behind these principles is one of encouragement. Each appear to promote patient participation; there is an emphasis on securing the freedoms of the patient, as opposed to restricting their actions. For example, Section 1(2) of the MCA stipulates that "A

⁶⁵⁰ Gordon Ashton et al, *Court of Protection Practice* (Jordan Publishing 2009).

person must be assumed to have capacity unless it can be established, he lacks capacity".⁶⁵¹ This presumption can only be rebutted on the balance of probabilities which sets a civil standard of proof. The burden to establish incapacity rests on the person making the claim of incapacity. As it will transpire through case discussion, the claims of incapacity are often initiated by the medical practitioner during the decision-making process. Often, issues arise over a physician seeking to "protect" patients from what they deem to be "bad" decisions.⁶⁵² The subjective nature of the functional test for incapacity can lead to mislabelling a decision as incapacitated as to afford the individual welfare protection.⁶⁵³ The second concerns those whose vulnerability is caused by reason other than mental incapacity. In clinical practice, the propensity for practitioners to decide that P lacks capacity on the basis that the decision is harmful is well documented.⁶⁵⁴ Section 5 protects decision makers from liability provided they have taken reasonable steps to establish that P lacks mental capacity. Williams et al refer to the 'concertina effect' where best interests and capacity assessments are conflated with the result that best interests determines whether an individual has capacity.⁶⁵⁵ Banner argues that the procedural legal test for mental capacity fits poorly with clinical reality where substantive elements may legitimately contribute to capacity assessment.⁶⁵⁶ In other words, the content of the decision may be relevant to the assessment of understanding. For example, the decision of a patient with anorexia nervosa to refuse food might be seen as evidence of an inability to use or weigh information about related treatment.

Further, Section 1(2) explains the requirement of "practicable steps". This addition is designed to maximise patient participation. For example, this could be including a

⁶⁵¹ Mental Capacity Act 2005.

 ⁶⁵² Emma Cave, 'Protecting Patients from their Bad Decisions: Rebalancing Rights, Relationships and Risk' 25(4) (2017) *Medical Law Review* 527.
 ⁶⁵³ ibid.

⁶⁵⁴ Select Committee on the Mental Capacity Act 2005, *Mental Capacity Act 2005: Post-Legislative Scrutiny*, HL Paper 139 (March 2014), 56–58.

⁶⁵⁵ Val Williams and others, *Making Best Interests Decisions: People and Processes* (Mental Health Foundation 2012) 3.2.

⁶⁵⁶ Natalie F Banner, 'Can Procedural and Substantive Elements of Decision-Making Be Reconciled in Assessments of Mental Capacity?' 9(1) (2013) *International Journal of Learning and Change* 71.

translator for people to speak in their native language.⁶⁵⁷ It could also include utilising specific types of communication equipment or types of languages such as Makaton. Additionally, a need might exist to enlist the services of a specialist, such as a speech and language therapist. Alternatively, a person may need to write down their decision if they are experiencing problems with their speech. Other modes of communication must also be considered such as blinking an eye or squeezing a carer's hand. The second aspect of the "practicable steps" involves wider issues concerning the environment surrounding the patient and any subsequent support.658 As explained earlier, the MCA hints at a relational approach through s4(7) as it does acknowledge the potential importance of third parties. However, the wording suggests that the decision to involve this additional support rests with the practitioner carrying out the best interest's assessment. Further, the consultation would occur between the practitioner and the third party. This is insufficient for promoting patient autonomy for several reasons. Firstly, this still fails empowering the individual's voice. The conversation should happen between the patient and their third party to help discuss, articulate, or even just to provide emotional support during the decision-making process. It should not happen between the practitioner and the third party to decide on behalf of the patient, and therefore substitute the patient's involvement. Secondly, the requirement states that a consultation should happen if it is "practicable" and "appropriate". As explained in the introduction, practicable is too subjective a requirement; in other words, practicable is a requirement which can easily be ignored. This is supported by the House of Lords Select Committee which found, ""4. The rights and responsibilities of the different stakeholders which are properly conferred under the Act are largely unknown. This makes the effective exercise of those rights, and the proper discharge of those responsibilities almost impossible.⁶⁵⁹ There should be a more stringent criteria to spell out the exemptions to contacting the third party, i.e., it should be assumed that the third party will be

⁶⁵⁷ Ruth Hardy, 'Mental capacity: the principle of 'all practicable steps' (2017) in Adults, Mental Capacity Act, available at: <u>https://www.communitycare.co.uk/2017/11/01/mentalcapacity-principle-practicable-steps/</u> [Last accessed 29/05/21]. ⁶⁵⁸ Mental Capacity Act 2005, S4(7).

⁶⁵⁹ 'Mental Capacity Act 2005: post-legislative scrutiny – Select Committee on the Mental Capacity Act', 'Chapter 3: The five core principles: is the Act working as intended?' 106 available at

https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/13907.htm [Accessed 10/08/2023].

consulted alongside the patient unless e.g., there has been a track record of abuse or undue influence. Otherwise, the requirement can be all too easily dismissed owing to fears of (a) elongating the process (b) interfering with the professionals proposed plan (c) causing the patient to reflect and choose an alternative course of treatment which the practitioner may consider to be a "bad choice".⁶⁶⁰ Therefore, whilst the MCA seems fitting with my asserted model of relational autonomy on paper, in practice it appears that its aims translate into something different. Another example being section 1(2) which advocates for patient involvement, yet again, this is not always followed. For example, see the extensive discussion of Re Z in the chapter concerning autonomy. Capacity is meant to be judged in accordance with the requisite function, yet in practice it often appears that in certain circumstances, blanket judgments are made. The patient involvement is substituted for paternalism established through an assessment of best interests which then negates the role of the individual when participating in the decision-making process.

Thus far we have discussed mental capacity and the coinciding legislation, however, the discussion will now advance to consider the CRPD which focuses instead on legal capacity and how participation should be maximised for people with disabilities.

5.6 The impact of the CRPD

5.6.1 Background of CRPD

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is regarded as a "ground-breaking treaty".⁶⁶¹ The CRPD provides a framework that was created by and for people with disabilities which can be utilised as a guide to achieve

⁶⁶⁰ Emma Cave, 'Protecting Patients from their Bad Decisions: Rebalancing Rights, Relationships and Risk' 25(4) (2017) *Medical Law Review* 527.

⁶⁶¹ Lucy Series, Anna Arstein-Kerslake, Piers Gooding et al, 'The Mental Capacity Act 2005, the Adults with Incapacity (Scotland) Act 2000 and the Convention on the Rights of persons with Disabilities: The Basics' available at:

https://www.39essex.com/docs/newsletters/crpd_discussion_paper_series_et_al.pdf#page% 3D1 [Accessed 13/06/2021].

universal rights protection for people with disabilities.⁶⁶² Civil society organisations and disabled people's organisations (DPOs), were included along with governmental representatives throughout the negotiation process.⁶⁶³ The CRPD is monitored at an international level through its treaty body, the UN Committee on the Rights of Persons with Disabilities (CRPD Committee). It is important to note that the CRPD does not create any new rights, however, it does recast existing human rights in the context of disability, adding a greater sense of clarity for human rights concerns. Importantly, The CRPD is legally binding for all states that have signed and ratified it, including the United Kingdom. However, due to the doctrine of duality in international law, the CRPD is not directly enforceable in the UK (unlike the ECHR by virtue of the HRA 1998).

5.6.2 The Right to Legal Capacity on an Equal Basis

Article 12 of the CRPD enshrined the right to legal capacity on an equal basis as subsidiary to the right to equal recognition before the law. Series explains that the right to legal capacity on an equal basis includes both a "static" and an "active" element.⁶⁶⁴ Further enunciating that the static element is the right to be a person and a holder of rights before the law. The active element refers to the right to be a legal agent whose decisions are respected and validated by the law.⁶⁶⁵ As stated, the CRPD does not explicitly refer to the term "mental capacity", however, Series explains that "mental capacity" is often used as a foundation for either granting or denying "legal capacity" to individuals in relation to particular decisions.⁶⁶⁶ Article 12(2) commands the enjoyment of legal capacity to be equal for all persons – regardless of whether they suffer from a disability, therefore, it challenges any systems that deny capacity on the basis of disability or impairment. Furthermore, Article 12(3) of the CRPD establishes an obligation on states to 'take appropriate measures to provide access by persons with disabilities to the support they may

⁶⁶² ibid.

⁶⁶³ ibid.

⁶⁶⁴ ibid.

⁶⁶⁵ ibid.

⁶⁶⁶ ibid.

require in exercising their legal capacity.' Series et al explain that when Article 12 (3) is read in conjunction with Article 12 (1 and 2) it is apparent that substituted decision-making systems are disallowed because they discriminatorily deny the exercise of legal capacity.⁶⁶⁷ The General Comment provides clarification on several core interpretative issues concerning Article 12 as it provides definitions of "support to exercise legal capacity" and "substituted decision-making". Support to exercise legal capacity is defined as follows:

"Support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making. Article 12, paragraph 3, does not specify what form the support should take. "Support" is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity."⁶⁶⁸

5.6.3 The CRPD & MCA 2005

Algharni et al state "A number of its provisions indirectly challenge the orthodoxy of the MCA and soon, serious questions were being asked about the compatibility of the MCA with the UNCRPD values and requirements".⁶⁶⁹ On review, the provision which causes the most contention is Article 12, as it stipulates that those with disabilities should enjoy legal capacity on an equal basis to others.

Article 12 differs in crucial ways in relation to the capacity impairments that are contained in the MCA 2005. In General Comment No. 1 (2014), the committee rejects the functional test for capacity and requires that a "will & preferences" paradigm be employed and that all substituted decision-making regimes be abolished. Such a preference is aligned with the aims of this chapter which advocates for a focus on supported decision making and a move to relational autonomy. I do not believe it necessary for the MCA to be abolished, rather, I think it

⁶⁶⁷ ibid.

⁶⁶⁸ Committee on the Rights of Persons with Disabilities, General Comment No. 1 – Article 12: Equal Recognition Before the Law, Paragraph 15, UN Doc. No. CRPD/C/GC/1, adopted at the 11th Session (April 2014).

⁶⁶⁹ Amel Alghrani, Paula Case and John Fanning, 'Editorial: The Mental Capacity Act 2005 – Ten Years On; (2015) 24 *Medical Law Review* 311, 314.

needs greater clarity in determining the strength of the patient's wishes during the decision-making process. Alghrani, Case and Fanning agree, arguing that the MCA should be bolstered by "the inclusion of a stronger statement of the primary importance of the individuals wishes and feelings and by the inclusion of enhanced support requirements and that the terminology of best interests be replaced by a terminology of rights".⁶⁷⁰ I agree that at present, s4(4) of the MCA is insufficient for securing the involvement of the patient. I have argued this point earlier, but "reasonably practicable" is an objective standard and a standard of reasonableness is not a fair one to employ as it fails to account for the individual needs of each patient. Peterson, Karlawith and Largent consider that a finding of incapacity should not render a person incapable of participating in the decision-making process and that they should still be able to retain a sense of autonomy over their lives.⁶⁷¹ Francis and Silvers explain that a "capacity impairment is not necessarily a barrier to people having views and preferences (acting autonomously in a thin sense) or having values and a sense of selfhood and seeking to formulate ways in which to give effect to these (acting autonomously in a thicker sense)."⁶⁷² More so, both believe that the fact a person may require assistance or support in reaching should decisions, should not render the patient's actions any less autonomous.

It is true that the MCA is compliant with a support model to a certain extent, for example, S.4 (4) which stipulates a requirement that the person in respect of whom a best interest's decision is being made, "should be permitted and encouraged to participate in the process and that his or her ability to participate should be improved and requiring consultation with relevant others in order to determine the persons best interests and his or her wishes and feelings". The support element is further enhanced by the provision made for the appointment of an Independent Mental Capacity Advocate to provide support in designated circumstances. However, Donnelly explains that such a model is limited not least because, "its sole focus is on supporting participating in individual decisions but rather on developing and

⁶⁷⁰ ibid.

 ⁶⁷¹ Andrew Peterson, Jason Karlawith, Emily Largent, 'Support Decision Making with People at the Margins of Autonomy' 21 (2020) *The American Journal of Bioethics* 4.
 ⁶⁷² Leslie Francis and Anita Silvers, 'Thinking about the Good: Reconfiguring Liberal Metaphysics (or Not) for People with Cognitive Disabilities' in Feder Kittay and Licia Carlson, *Cognitive Disability and its Challenge to Moral Philosophy* (Wiley-Blackwell 2010).

individual's autonomy in a broader and more profound sense".⁶⁷³ For example, in the case of *ITW v Z*,⁶⁷⁴ Munby J acknowledged that wishes and feelings "will always be a significant factor to which the court must play close regard", however, the weight to be attached to said wishes and feelings will "always be case-specific and fact specific". This case involved an elderly woman who had been the victim of financial abuse by a neighbour. Furthermore, Munby J enunciated how a person's wishes and feelings might be constrained by the court's overall assessment of what is in the person's best interests.

A panel of experts conducted a review of the MCA to determine whether it was compatible with the UK's international human rights obligations under the United Nations Convention on the Rights of Persons with Disabilities. However, a "disturbing consensus" emerged, that the MCA in its current form was not compliant with the requirements of the CRPD.⁶⁷⁵ Firstly, it was agreed that the MCA does not go far enough to provide support to persons who may lack decision-making capacity. Section 1(3) of the MCA states that A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success". However, as earlier stated, what "practicable steps" are required fails to be clarified. There is a lack of clarity in both the act and the code of practice about what form this support should take, or who has a legal obligation to provide it.⁶⁷⁶ Secondly, it was agreed that cases will always exist where people who suffer from disabilities will be unable to make their own decisions, even if all possible forms of support had been implemented. If legal capacity is going to be recognised in these individuals, regardless of whether they can make decisions or not, that recognition cannot take

⁶⁷⁵ Professor Wayne Martin, 'Consensus Emerges in Consultation Roundtables: The MCA is Not Compliant with the CRPD' Mental Capacity Discussion Paper: CRPD and MCA Compatibility Consultation available at <u>http://repository.essex.ac.uk/14227/1/UNCRPD-MCA-</u> <u>Compatibility-Discussion-Paper-Final-5-8-14.pdf</u> [Accessed 20/06/2021].

⁶⁷³ Mary Donnelly, 'Best Interests in the Mental Capacity Act: Time to say Goodbye?' 24 (3) (2016) *Medical Law Review* 318, 328.

⁶⁷⁴ *ITW v Z and M* [2009] EWHC 2525 (Fam).

⁶⁷⁶ Lucy Series, Anna Arstein-Kerslake, Piers Gooding et al, ' The Mental Capacity Act 2005, the Adults with Incapacity (Scotland) Act 2000 and the Convention on the Rights of persons with Disabilities: The Basics' available at:

https://www.39essex.com/docs/newsletters/crpd_discussion_paper_series_et_al.pdf#page%3D1 [Accessed 13/06/2021].

the form as the exertion of active legal capacity. Further, that safeguards should be implemented to respect the rights and preferences of such individuals.

From reviewing the purpose of the CRPD and the potential of Article 12, it is obvious that the MCA is lacking in its scope to provide for the will and preferences of an incapacitated patient to be incorporated into the decision-making process. This is in part because of the MCA's continued reliance on a functional approach, which fails to account for the social context in which the decision is being made. By failing to widen the ambit of the decision-making process, opportunities for participation are limited. The dialogue becomes one of deciding on behalf of the patient, rather than with the patient. The MCA is not completely flawed as it does have an allowance for a family member to be consulted (again, only if reasonable) when the decision is being made. However, this is a substituted model of decision making and it does not do enough to be compatible with the CRPD and to enhance the autonomy of the patient. The way in which "best interests" is currently constructed is simply a different name for "substituted decision making". Too little is said in either the Act or the Code of Practice about what form this support should take, or who has the legal obligation to provide it. The "practicable steps" method needs strengthening urgently to work more effectively. I think the practicable steps should be detailed and specified and involve a meaningful discussion with both the patient and their support to ascertain what particular steps are needed to support that particular patient in making their decision.

This section has outlined the statutory framework of the CRPD and fundamentally, has clarified how the MCA is operating in contradiction to Article 12(2). Thus far, throughout this chapter, a considerable amount of legislation and theory has been discussed to evidence the need for reform. The chapter now progresses to review both the theory and legislation in practice through an analysis of recent cases within the Court of Protection.

5.7 Decision Making Regimes and the Functional Test

This chapter argues that an emphasis needs to be placed on supported decision making and a move towards a relational approach.⁶⁷⁷ In its simplest terms, relational capacity refers to the ability to relate which is important within healthcare, particularly where issues of incapacity arise. Initially, I will explain what approach the law currently employs and why this is insufficient. Secondly, I will explain the basics of relational capacity and why it is the superior model before advancing to the process of supported decision making and how relational capacity would add further benefit. Finally, I will explain how the functional test is geared towards supporting a substituted decision-making regime.

As the MCA is intended to operate on an ethos of protecting individual autonomy and avoiding undue paternalism, it advocates for a procedural account of capacity and employs a functional test. A procedural account of capacity refers to an individual's ability to act on behalf of oneself, from which problems can arise as its emphasis remains on content neutrality and rational cognition.⁶⁷⁸ Critiques of procedural accounts of capacity have highlighted that often, they do not match up with clinical experience. For example, clinicians may consider a patient to lack capacity even if he passes all the procedural requirements of the test.⁶⁷⁹ This is particularly true in mental health contexts where often, it is the decision outcome, such as a treatment refusal, that alerts clinicians to the fact that there may be a mental impairment influencing the decision-making process. For example, the case of *Re T* stated, "doctors faced with a refusal of consent have to give very careful and detailed consideration to the patient's capacity to decide".⁶⁸⁰ Conversely, doctors (often) do

⁶⁷⁸ Natalie F Banner, 'Can procedural and substantive elements of decision-making be reconciled in assessments of mental capacity?' (2013) 8 *Journal Law Context* 71. ⁶⁷⁹ Bernard Gert & Charles Culver, 'Defining Mental Disorder' in Jennifer Rudden, *The Philosophy of Psychiatry: A Comparison* (OUP 2004).

⁶⁷⁷ See supporters of the relational approach such as: Jennifer Walter, Lainie Ross, 'Relational autonomy: moving beyond the limits of isolated individualism' 133 (2014) *Paediatrics* 16; Edward Dove, Susan Kelly, Federica Lucivero et al, 'Beyond individualism: Is there a place for relational autonomy in clinical practice and research?' 12(3) (2017) *Clinical Ethics* 150; Carlos Gómez-Vírseda, Yves Maeseneer, & Chris Gastmans, 'Relational autonomy in end-of-life care ethics: a contextualized approach to real-life complexities' 21 (2020) *BMC Med Ethics* 50.

⁶⁸⁰ Re T (adult: refusal of medical treatment) [1992] 4 All ER 649 (CA) 662.

not question decisions which agree with their recommendations even if the individual in question may have capacity issues. By relying on a procedural account of capacity, wider factors relating to patient's setting can be overlooked, by transferring to a relational account of capacity, it is likely there would be an increase in empathy and understanding as opposed to a focus on procedures. A relational approach would take a more holistic view and encourage an active dialogue to take place with the patient and the practitioner whereby a subjective test is employed instead of the objective reasonable standard. An approach of increased empathy on behalf of the clinical professionals is well suited to the process of supported decision making.

Currently, the functional test aims to track the structure of reasoning or process of thought required to make context specific decisions. Kong explains that "in theory this simultaneously mitigates issues that plague other tests of capacity, thus protecting the autonomy of individuals with impairments whilst installing substituted decision-making mechanisms that safeguard the welfare of those lacking capacity".⁶⁸¹ However, the problem with such mechanisms is that whilst in theory they seem amenable to patient rights and appear to help protect autonomy, in practice they are often not fully utilised and instead a decision is reliant on the best interests approach.⁶⁸² This theory will be examined in further depth in the section which considers recent cases that have come before the Court of Protection in terms of assessing capacity.

The essence behind the functional approach can be summarised by the case of *Saulle v Nouvet*,⁶⁸³ in which it was stated that the MCA is grounded in "the philosophy … that those who suffer from disability shall be assisted to live normal lives and to make choices about those lives to the greatest extent possible".⁶⁸⁴ The functional approach dictates that a singular diagnosis cannot determine the capacity of an individual.

⁶⁸¹ ibid.

⁶⁸² Susan Stefan, 'Silencing the different voice: competence, feminist theory and law' 47 (1993) University of Miami Law Review 763, 783.
⁶⁸³ Saulle v Nouvet [2007] EWHC 2902 QB.
⁶⁸⁴ ibid

Therefore, it is important to distinguish between the three types of decision making: supported decision-making, shared decision-making and substituted decisionmaking. The latter refers to when a proxy makes decisions on behalf of another person who is deemed incapable, therefore, the concerned individual has no right to make a decision for himself or herself. Shared decision-making refers to a set of skills and practices that clinicians can adopt in order to engage in a collaborative decision-making process for healthcare decisions.⁶⁸⁵ The Office of the High Commissioner for Human Rights defined supported decision-making as simply, 'the process whereby a person with a disability is enabled to make and communicate decisions with respect to personal or legal matters'.⁶⁸⁶ Supported decision-making is based on the idea that no one is 'purely' autonomous and that the majority of people constantly make decisions with support from others.⁶⁸⁷ Supported decision-making advocates this interdependence and encourages people to support but can override decisions of people who are suffering from a mental health crisis in the case of an emergency.⁶⁸⁸ In the following section, S4 MCA and the application of best interests, it is important to note that paternalism and substituted decision making have been dominant. Whether formally through guardianship⁶⁸⁹ or mental health legislation or informally, for example, in healthcare settings or social care contexts whereby decisions are made for people).⁶⁹⁰ Following a supported decision-making regime

⁶⁸⁵ Tammy Hoffmann, Paul P Glaziou, Ruairidh Milne et al, 'Better reporting of interventions: template for intervention description and replication (TIDier) checklist and guide' 348 (2014) *British Medical Journal* 1, 4.

⁶⁸⁶ OHCHR (2007) 89 available at

https://www.ohchr.org/Documents/Press/OHCHR_Report_07_Full.pdf [Accessed 05/06/21]. ⁶⁸⁷ Magneta Simmons, Piers Gooding, 'Spot the difference: Shared decision-making and supported decision-making in mental health' 34(4) (2017) *Irish Journal of Psychological Medicine* 275; Ilan Wiesel, Elizabeth Smith, Christine Bigby et al, 'The temporalities of supported decision-making by people with cognitive disability' 7 (2020) *Social & Cultural Geography* 23.

 ⁶⁸⁸ Andrew Peterson, Jason Karlawish & Emily Largent, 'Supported Decision Making With People at the Margins of Autonomy' 21 (2021) *The American Journal of Bioethics* 4.
 ⁶⁸⁹ Detention Under Guardianship Section 7 Order of the Mental Health Act 1983 – The Law and Your Rights. If you or a loved one are place in Detention Under Guardianship Section 7 Order of the Mental Health Act, it gives a guardian – often a local services authority – certain powers over you.

⁶⁹⁰ Piers Gooding, 'Supported Decision-Making: A Rights-Based Disability Concept and Its Implications for Mental Health Law' 20 (2012) *Psychiatry, Psychology and Law* 431; Sarah Gordon, Tracey Gardiner, Kris Gledhill et al, 'From Substitute to Supported Decision Making: Practitioner, Community and Service-User Perspectives on Privileging Will and Preferences in Mental Health Care' 19 (10) (2022) *International Journal Environmental Research Public Health*.

which advocates for a relational approach to capacity is likely to result in patients' wills and preferences playing a greater role, thereby enhancing patient autonomy and allowing patients to directly participate rather than having their preferences inferred by third parties. Simmons and Gooding draw on an analogy of a wheelchair, which I believe to be fitting to expand upon this point; "In crude terms, supported decision-making promotes the idea that just as people who use wheelchairs are entitled to ramps in order to access buildings, so too people with mental health-related disability are entitled to support to exercise choices about their lives."⁶⁹¹ Through a relational approach it provides the person with an opening to participate, rather than being excluded from the discussion based on their alleged incapacity.

Whilst the term "supported decision-making" does not directly appear in the Convention of the Rights of Persons with Disabilities (CRPD), it has become a key feature in debates concerning how human rights should be applied to areas of law, policy and practice, in which substituted decision-making, and paternalism have traditionally dominated.⁶⁹² The OHCHR elaborates:

"With supported decision-making, the presumption is always in favour of the person with a disability who will be affected by the decision. The individual is the decision maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of the individual. Even when an individual with a disability requires total support, the support person(s) should enable the individual to exercise his/her legal capacity to the greatest extent possible, according to the wishes of the individual."⁶⁹³

Furthermore, the OHCHR acknowledges that supporting people to make decisions in practice, will take many forms. For example, those assisting a person can

⁶⁹¹ Magneta Simmons, Piers Gooding, 'Spot the difference: Shared decision-making and support decision-making in mental health' 34 (4) (2017) *Irish Journal of Psychological Medicine* 275, 276.

⁶⁹² Jill Stavert, 'Supported Decision-Making and Paradigm Shifts: Word Play or Real Change?' 57 (2021) *Frontiers in Psychiatry* 1, 2.

⁶⁹³ Department of Economic and Social Affairs United Nations, 'Chapter 6 : From provisions to practice: implementing the convention' in *Handbook For Parliamentarians On The Convention on The Rights of Persons with Disabilities* (2007) available at: <u>http://archive.ipu.org/PDF/publications/disabilities-e.pdf</u> [Accessed 03/11/2023].

communicate the individual's intentions to others or help him/her understand the available choices. This could help raise awareness that a person with significant disabilities remains a person with a history, interests and aims in life and is still capable of exercising his or her capacity.⁶⁹⁴ Within a medical context, Pathare and Shields expand that supported decision-making could consist of organisations, networks, provisions or agreements with the aim of assisting the individual with the mental illness.⁶⁹⁵ However, they continue to explain that in supported decision-making, the individual will always retain the role as primary decision maker. Nevertheless, it is acknowledged that autonomy can be communicated in a number of ways, therefore the provision of support in different forms and intervals can assist in the expression of autonomous decisions.⁶⁹⁶

Critics believe that mental capacity law follows an individualistic model that heavily relies on medical expertise,⁶⁹⁷ which contradicts the standards of clinical practice where capacity assessments tend to be relational and dialogical. Stefan states "Although competence is a matter of dynamic or dialogue between doctor and patient, legal doctrines set up this dialogue so that the powerful half of the conversation remains entirely invisible."⁶⁹⁸ I agree with Stefan that owing to the current construction of capacity assessments, the patient's wishes are often substituted for professional expertise. This emerges in two ways "(1) overdependence on medical expertise contributes to the minimisation of the voice of individuals whose capacity is being assessed and (2) the idea that capacity reflects intrapersonal cognitive skills, can contribute to or detract from these decision-making abilities".⁶⁹⁹ I believe the latter to be the more prevalent issue. Assumptions regarding a person's ability to communicate are often made should it be believed

⁶⁹⁴ ibid.

⁶⁹⁵ Soumitra Pathare, Laura Shields, 'Supported Decision-Making for Persons with Mental Illness: A Review' 34 (15) *Public Health Reviews* 1,4.

⁶⁹⁶ ibid.

⁶⁹⁷ Jacquinea Azétsop, Stuart Rennie, 'Principlism, medical individualism, and health promotion in resource-poor countries: can autonomy-based bioethics promote social justice and population health?' 5 (2010) *Philosophy Ethics Humanities Medicine* 1; Sam Wilson, 'Mental capacity legislation in the UK: systematic review of the experiences of adults lacking capacity and their carers' 41 (5) (2017) *BJPsych Bulletin* 260; Brian Murray, 'Mental capacity: Different models and their controversies' 23 (6) (2017) *BJ Psych Advances* 366.
⁶⁹⁸ Susan Stefan, 'Silencing the different voice: competence, feminist theory and law' (1993) 47 *University of Miami Law Review* 763, 783.

that a person lacks capacity.⁷⁰⁰ Herring poses a solution that "at least part of the assessment of capacity should be the extent to which the person within their support group of family and or friends is able to make choices [and] give sufficient weight to the way that others can enable the person lacking capacity to make a decision".⁷⁰¹ I concur that Herring's idea could improve capacity assessments as he recognises that humans are social beings and that the idea of individual autonomy in the sense that people make decisions without considering the opinions of loved ones, or the obligations surrounding their social situations, is extremely rare. More so, by enabling the role of third parties to assist those who may struggle with communicating their decisions would help to maximise the individual's right to selfdetermination. My main argument against the individualistic approach is that the end result is often contradictory to its intended purpose. Asserting the individual has to be able to make the decision alone, often results in the decision being taken away from the individual. A relational approach does not mean the decision is removed from the patient and passed around, rather it takes a holistic view to the process by providing the individual with as much support as possible to be able to communicate their true wishes and desires regarding treatment.

Additionally, Kong identifies that legal applications of the functional test often make two philosophical contestable assumptions, "(i) autonomy is individualistic rather than a relational concept (ii) capacitous reasoning is an intrapersonal rather than interpersonal act, reflective of the individuals own cognitive process".⁷⁰² Both these assumptions are problematic as they ignore the realities of decision making, the functional test attempts to make a square peg fit a round hole. It simply is not the correct method for ensuring empowerment and involvement of patients. Further, the second claim that capacity only exists within the individual's mind is inaccurate. Capacity exists in relation to decisions; decisions are made in the context of situations. Whilst a person may consider reasons within their own mind, those reasons and the weighting given to them are often drawn from the reality of the patient's life, their family, their home, their commitments. It is very rare for an

⁷⁰⁰ *Re* Z (Rev 1) [2020] EWCOP 20.

⁷⁰¹ Jonathan Herring, *Caring and the law* (Bloomsbury 2013) 157.

⁷⁰² Camilla Kong, *Mental Capacity in Relationships: Decision-making, Dialogue and Autonomy* (Cambridge Bioethics and Law 2017) 22.

individual to be able to make decisions in complete isolation devoid of empathy for the wider context.

This section has explained the current decision-making regime and how it is ill-suited to the promotion of capacity for all and further, that individualistic notions of autonomy are not conducive to an inclusive decision-making process. This section has proposed that a shift to a supported decision-making model and an adoption of a relational outlook would greatly benefit both patient capacity and autonomy.

5.8 Capacity Assessments

The test for capacity has been designed to assist clinicians and decision makers when determining whether a patient's decision is autonomous, or whether it suggests a lack of autonomy.⁷⁰³ If the latter prevails, it can be overruled because the person lacks the capacity concerning the matter at the material time the decision is being made. The first stage of a capacity assessment is to establish whether an impairment or disturbance exists in the functioning of the mind or brain and whether this is temporary or permanent. Only if this criterion is fulfilled does assessment proceed to the second stage. The second stage involves concluding if this impairment or disturbance results in an inability to make or communicate decisions. Examples of such impairments include delirium, coma, severe brain damage, dementia and severe learning difficulties. The relationship between the impairment of, or disturbance, in the functioning of the mind and/or brain and the inability to understand, retain, use or weigh information/communicate the decision is known as the "causative nexus".⁷⁰⁴ The Court of Appeal have emphasised that impairment

⁷⁰³ John Coggon, José Miola, 'Autonomy, Liberty, and Medical Decision-Making' 70 (3) (2011) *Cambridge Law Journal* 523; John Coggon, 'Mental Capacity Law, Autonomy, and best Interests: An Argument for Conceptual and Practical Clarity in the Court of Protection' 24 (3) (2016) *Medical Law Review* 396, Jonathan Pugh, *Autonomy, Rationality, and Contemporary Bioethics* (OUP 2020).

⁷⁰⁴ Alex Ruck Keene, Nuala B Kane, Scott Y.H Kim et al, 'Taking capacity seriously? Ten years of mental capacity disputes before England's Court of Protection' 62 (2019) *International Journal of Law and Psychiatry* 56.

must not merely be present alongside functional inability but must be the causal basis of inability ⁷⁰⁵

Therefore, if an individual is judged as having capacity, their choice will be respected and subsequently they will be classed as autonomous. However, should it be decided that a person lacks mental capacity, then the ability to decide will be removed (provided that it is in their best interests). Such a binary approach has proved problematic. In 2014 the House of Lords Select Committee considered the problems of applying theory to practice, largely citing that the presumption of capacity is significantly misinterpreted, stating:

"The presumption of capacity, in particular, is widely misunderstood by those involved in care. It is sometimes used to support non-intervention or poor care, leaving vulnerable adults exposed to risk of harm. In some cases, this is because professionals struggle to understand how to apply the principle in practice. In other cases, the evidence suggests the principle has been deliberately misappropriated to avoid taking responsibility for a vulnerable adult."⁷⁰⁶

The above statement provides a strong justification for my argument that the current standards and tests are insufficient to protect a patient's autonomy and that change is needed. The guidance is not translating well into practice. There needs to be some additional support to ensure that those who may be subject to capacity procedures are treated fairly and with respect to their personal integrity.

This is supported further through the Select Committee who called for, "A fundamental change of attitudes among professionals is needed in order to move from protection and paternalism to enablement and empowerment." There is a recognition that change needs to happen and to fulfil the goals of empowerment, the change must be to a relational model of autonomy. A relational approach would break down the power dynamic and make it harder for paternalism to prevail and

⁷⁰⁵ ibid.

⁷⁰⁶ Mental Capacity Act 2005: post-legislative scrutiny - Select Committee on the Mental Capacity Act 2005 [3] available at

https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/13904.htm [Accessed 31/03/2021].

overpower the role of the patient. Further, the binary nature of capacity needs to be addressed. Capacity is too complex to be divided into those who a) have capacity or b) lack capacity. There needs to be some allowance for those who need extra help and support to articulate themselves to meet the capacity requirements. As Clough states, "the creation of this stark binary perpetuates the 'othering' of those deemed to lack capacity and justifies differential legal treatment. Those who do not fit neatly into this constructed binary fall outside of the margins."⁷⁰⁷ This evidences that there is a need for further support within the decision-making process and this could be provided through adopting a relational approach. A relational approach to autonomy would add further aspects to capacity assessments as it would force the professionals to pay due diligence to the wider context surrounding the patient's life to determine the best course of action for improving their understanding, which could be the involvement of a third party as stipulated earlier.

5.9 Inability to make decisions

The test to establish an inability to make decisions rests on the criteria of whether the patient can: (a) understand the information relevant to the decision; (b) retain that information; (c) use or weigh that information as part of the process of making the decision; (d) communicate their decision (whether by talking, using sign language or any other means). If an individual cannot demonstrate any one of these four abilities despite efforts being made to assist the decision-making process, then s/he can be deemed to lack capacity.

An important caveat exists in s2(3) of the Act which states: "A lack of capacity cannot be established merely by reference to (a) a person's age or appearance or (b) a condition of his, or an aspect of his behaviour which might lead others to make unjustified assumptions about his capacity."⁷⁰⁸ The purpose of this section is to guard against superficial judgments and bias. The importance of this is twofold (1) The MCA recognises that subjectivity can intercede capacity judgments and opinions

⁷⁰⁷ Beverly Clough, 'Disability and Vulnerability: Challenging the Capacity/Incapacity Binary'16 (3) (2017) Social Policy and Society 469, 471.

⁷⁰⁸ Mental Capacity Act 2005 s2(3).

may be formed which could be biased (2) It seeks to limit the ambit of control professionals have when exercising their "professional judgment". Yet again though, this is another aspect of the MCA which translates poorly into practice. There is a considerable amount of literature which demonstrates that "aspects of behaviour" are considered when forming the basis of medical opinion. Note, this is not exclusive to capacity assessments, judgments are made constantly on patient's reactions, demeanour and questions and should the patient not present themselves in accordance with what the professional deems "proper" they can often be met with a somewhat dismissive attitude illustrate with an example from the material you have studied. Throughout the course of this thesis, it will be argued that women are referred to by reference to gender stereotypes and pre-determined assumptions of their character. For example, in the case of ReZ, the mother was young and suffered a chromosol disability. She was therefore neglected during the decisionmaking process regarding her contraceptive treatments as they didn't believe her to able to articulate herself fully. Another example being when Mrs Pearce in Pearce vs Bristol United Healthcare was referred to as "child-like", or when Mrs Whitehouse was referred to "as difficult, nervous and at times aggressive patient".⁷⁰⁹ It must be noted, that there is the possibility that Mrs Whitehouse was difficult, nervous and potentially aggressive. However, to describe her using the words "child-like" is both demeaning and patronising. Children are unable to make decisions for themselves and require someone to look after them and make decisions on their behalf, by using such a term to describe Mrs Whitehouse, it conforms to gender stereotypes that women are helpless and unable to make decisions for themselves.

Despite the obvious prevalence of gender in medical settings, the MCA fails to reference gender as a means by which incapacity cannot be inferred. As established in Chapter Three, it is widely acknowledged that gender induced stereotypes impact upon medical treatment and the subsequent perception of illnesses in patients. Therefore, it must be questioned whether "superficial judgments"⁷¹⁰ could be made about a person in relation to their gender and whether gender should be listed as a protected characteristic. Traditionally, medicine has been dominated by male

⁷⁰⁹ ibid.

⁷¹⁰ Camilla Kong, *Mental Capacity in Relationships: Decision-making, Dialogue and Autonomy* (Cambridge Bioethics and Law 2017).

ideology. Medical textbooks were written from a male perspective, male qualities of rationality were given primacy in assessments, therefore, given the dominance of male characteristics and how male stereotypes are generally complimentary, it is unsurprising that the MCA did not account for the possibility of female stereotypes as ground for assumptions of incapacity.⁷¹¹

5.10 Bias in capacity assessments

This section will review academic opinion and judgments so that it can be determined if bias exists within capacity assessments and what outcome that might have on the case. Kong questions whether findings of capacity are manipulated to enable the process of best interests decision-making, thus superseding the patient's right to subjective decision making.⁷¹² As established in the previous chapter on autonomy, the significance of the element of choice in our lives makes the value of autonomy a central component of a liberal society. However, Kong explains that "despite its alleged universal importance, the right to make decisions about one's life has only been extended to individuals with mental impairments very recently."⁷¹³ As established within the second chapter on autonomy, a relational approach is preferable in terms of ensuring every person has the opportunity to fulfil their own potential and utilise their right to choose. Therefore, capacity should be approached from the same viewpoint as a "means to exercise autonomy in the context of impairment and disability".⁷¹⁴

A substantial amount of research has been conducted concerning the existence of bias in capacity assessments, Stammers and Bortolotti prepared a brief for policy

⁷¹¹Anja Dijkstra, Petra Verdonk, Antoine Lagro-Janssen, 'Gender bias in medical textbooks: examples from coronary heart disease, depression, alcohol abuse and pharmacology' (2008) 42 *Medical Education* 1021; Edward Halperin, 'The pornographic anatomy book? The curious tale of the Anatomical Basis of Medical Practice' (2009) 84 *Academic Medicine Journal Association American Medical Colleges* 278.

⁷¹² Camilla Kong, 'The Phenomenology and Ethics of P-Centricity in Mental Capacity Law'42 (2023) *Law and Philosophy* 145.

⁷¹³ Camilla Kong, *Mental Capacity in Relationships: Decision-making, Dialogue and Autonomy* (Cambridge Bioethics and Law 2017) 1.

⁷¹⁴ ibid.

makers and mental health and social care professionals titled, "Mitigating the risk of assumptions and biases in assessments of mental capacity". ⁷¹⁵The briefing outlines how the functional approach underdetermines decisions, describing the risks for stereotypes and assumptions to affect outcomes. Stammers and Bortolotti advocate for a need to create specific training for professionals who use the MCA to aid them in recognising the role of value judgments in capacity decisions to lessen the effects of stereotypes and assumptions so that decision making can improve.

It is widely accepted that human decision making can be impacted by the influence of preconceptions which can result in low quality reasoning.⁷¹⁶ A significant factor is that of implicit social biases. Such biases have been described as "fast, automatic and difficult to control processes that encode stereotypes and evaluative content, and influence how we think and behave".⁷¹⁷ To enunciate this point, many studies have illustrated that people who have received a psychiatric diagnoses are thus associated with concepts such as dangerous, incompetence, unpredictability or helplessness.⁷¹⁸ Another study was conducted which involved the task of participants reading descriptions of individuals, which differed only for whether the person was described as having a learning disability. The results showed an overall perception that those described as having a learning disability were seen as less

⁷¹⁵ Sophie Stammers, Lisa Bortolotti, 'Mitigating the risk of assumptions and biases in assessments of mental capacity' (University of Birmingham, 23/03/2020) available at: <u>https://www.birmingham.ac.uk/documents/college-artslaw/ptr/perfect/mental-capacity-brief.pdf</u> [Accessed 21/10/2023].

⁷¹⁶ For example, see Amos Tversky, Daniel Kahneman, 'Judgment under Uncertainty: Heuristics and Biases' 185 (4157) (1975) *Science* 1124; Raymond Nickerson, 'Confirmation Bias: A Ubiquitous Phenomenon in Many Guises.' 2(2) (1998) *Review of General Psychology* 175; Thomas Gilovich, et al, *Heuristics and biases: The psychology of intuitive judgment* (Cambridge University Press, 2002).

⁷¹⁷ Jules Holroyd, Kathy Puddifoot, 'Implicit Bias and Prejudice' in Miranda Fricker, Peter J Graham, David Henderson, et al, *Routledge Handbook of Social Epistemology* (Routledge, 2019) Chapter 30.

⁷¹⁸ Bethany Teachman, Joel Wilson, Irina Komarovskaya, 'Implicit and explicit stigma of mental illness in diagnosed and healthy samples' 25 (2006) *Journal of Social and Clinical Psychology* 75; Nicolas Rüsch, Patrick W Corrigan, Andrew R Todd, 'Automatic stereotyping against people with schizophrenia, schizoaffective and affective disorders' 18 (2011) *Psychiatry Research* 34; Katherine Puddifoot, 'Disclosure of mental health : philosophical and psychological perspectives', 26(4) (2019) *Philosophy, psychiatry, and psychology* 333; Michelle Clare Wilson, Katrina Scior, 'Implicit Attitudes towards People with Intellectual Disabilities: Their Relationship with Explicit Attitudes, Social Distance, Emotions and Contact' 10 (9) (2015) *PLoS ONE*; Brian Taylor, *Decision Making, Assessment and Risk in Social Work* (Sage 2017) Chapter 5.

emotionally stable than those without it.⁷¹⁹ Again, further research shows that people hold negative implicit biases against other members of other marginalised groups, for example, people of colour, women and those with physical disabilities.⁷²⁰ Such associations can impact our interactions with a person who has a diagnosis (or social attribute) regardless of whether there is any reason to believe that person will exhibit any of the behaviours associated with these characteristics. Research has shown that people are more likely to remember information about an individual if it is consistent with a social stereotype.⁷²¹

For example, an experiment was conducted in which participants aimed to hire the best candidate for the role of police chief. Men rated particular qualifications as more relevant to the job when they are held by male candidates, as opposed to when they are held by female candidates.⁷²²

Importantly, such implicit biases have been evidenced as affecting medical professionals, ⁷²³ including medical students who have previously had no direct experience of people with mental health problems.⁷²⁴ Research into mental healthcare professionals from an organisation specialising in psychosocial care found that those found to have higher levels of negative implicit bias would be less likely to help a person with a mental illness.⁷²⁵ A further study of 407 professional

⁷¹⁹ Department of Health 'Review of the Mental Health Act 1983 Report of the Expert Committee' (1999); Thomas Kallert, Juan Mezzich, John Monahan, *In Coercive Treatment in Psychiatry: Clinical, Legal and Ethical Aspects* (Wiley 2013); Sheila Wildeman, 'Protecting rights and building capacities: Challenges of global mental health policy in light of the Convention on the Rights of Persons with Disabilities'41 (1) (2013) *Journal of Law, Medicine and Ethics* 48.

⁷²⁰ Jules Holroyd, 'Implicit Bias, Awareness and Imperfect Cognitions' 33 (2015) *Consciousness and Cognition* 511; Jules Holroyd, Dan Kelly, D, 'Implicit Bias, Character, and Control' in Alberto Masala, Jonathan Webber, *From Personality to Virtue Essays on the Philosophy of Character* (OUP 2016).

⁷²¹ ibid.

⁷²² Eric Luis Ulhmann, Geoffrey L Cohen, 'Constructed Criteria: Redefining Merit to Justify Discrimination.' 16 (6) (2005) *Psychological Science* 474.

⁷²³ Katherine Puddifoot, 'Stereotyping Patients.' 50 (1) (2019) *Journal of Social Philosophy* 69.

⁷²⁴ Maciej Kopera, Hubert Suszek et al, 'Evaluating explicit and implicit stigma of mental illness in mental health professionals and medical students' 51(5) (2015) *Community Mental Health Journal* 628.

⁷²⁵ Loren Brener, Grenville Rose, et al, 'Implicit attitudes, emotions, and helping intentions of mental health workers toward their clients' (6) (2013) *Journal of Nervous and Mental Disease* 460.

clinicians and 275 clinical psychology graduate revealed that those harbouring negative implicit biases are more likely to over diagnose.⁷²⁶

As explained, assessments of mental capacity under the MCA are not completely determined by procedural criteria, so the possibility exists that stereotypes and assumptions may impact outcomes. This risk exists at the level of (a) deciding how to communicate information relevant to a treatment decision before assessing capacity; (b) interpreting the assessment criteria (such as the ability to use or weigh information); and (c) deciding what counts as being in the best interests of the individual if it is found that the person lacks the capacity to make a decision. This links back to the argument that the "practicable" requirement for patient involvement is too vague. What it means to provide a patient with information relevant to a decision is also open to interpretation and will involve different approaches for different patients. For example, research shows that for some patients with intellectual disabilities, using picture books to explain matters enables a greater degree of patient participation in decisions about their treatment and lives.727 However, a recent report by NICE found that various stakeholders experienced assumptions being made about an individuals' capacity, particularly those with intellectual disabilities, dementia, or who were in long term residential care.⁷²⁸ The NICE report warns that "people may not be receiving care they would have chosen had they been supported and given the opportunity to express their preferences".729 Thus, it is abundantly clear that whilst the MCA 2005 appears to have the intention of patient involvement, owing to pre-existing biases and a lack of clarity for translating the guidance in practice, patients are often failed by the system in terms of receiving the required help to exercise their desires.

⁷²⁸ National Institute for Health and Care Excellence (2020). 'Decision making and mental capacity.' In development [GID-QS10127], Available online at:

⁷²⁶ Tara S Peris, Bethany A Teachman, et al, 'Implicit and explicit stigma of mental illness: Links to clinical care' 196 (10) (2008) *Journal of Nervous and Mental Disease* 752.
⁷²⁷ Silvana Mengoni, Bob Gates, et al, 'Wordless intervention for people with epilepsy and learning disabilities (WIELD)' 6(11) (2016) *British Medical Journal Open* 1; Sheila Hollins, Barry Carpenter, et al, 'Using Wordless Books to Support Clinical Consultations' 12(4) (2017) *The Journal of Mental Health Training, Education and Practice* 260.
⁷²⁸ National Institute for Health and Care Excellence (2020). 'Decision making and mental

https://www.nice.org.uk/guidance/indevelopment/gidqs10127 [Accessed 11/11/23]. ⁷²⁹ ibid.

In a US study 89% of 395 medical professionals with an expertise in capacity assessment identified as a 'common' or 'very common' possibility that, among general practitioners, as long as the patient agrees with the doctor's recommendation, the doctor will not consider whether that the patient may lack capacity.⁷³⁰ Additionally, Appelbaum's survey of studies revealed that in over 90% of cases where patients sought to refuse treatment for a mental disorder, they were found to lack capacity.⁷³¹

Kong provides examples concerning the issue of external influence on mental capacity and the subsequent decision-making process.⁷³² Three of the four examples are based on women, these women were not chosen randomly, but as Kong explains, are representations of all "common scenarios".⁷³³ This suggests women are more likely to be in situations whereby their capacity is doubted. This claim has some grounding by reviewing data on gender balances within mental capacity assessments. For example, the data collected by Jayes, Palmer and Enderby for their research, "An exploration of mental capacity assessment within acute hospital and immediate care settings in England"⁷³⁴ produced some intriguing results. The sample from the hospital trust included "significantly more female participants than male" which the researchers described as a "noteworthy" … "gender imbalance". Whilst this data collection took place within one hospital trust, it is reported that many findings are broadly consistent with evidence provided in previous studies.⁷³⁵

Kong provides some examples, the first of which follows: "A woman with down syndrome can understand why one would use contraception and the implications

⁷³⁰ Linda Ganzini, 'Pitfalls in assessment of decision-making capacity' 44 (2003) *Psychosomatics* 239.

⁷³¹ Paul Applebaum, *Almost a Revolution: Mental Health Law and the Limits of Change* (OUP 1994); Mary Donnelly, 'From autonomy to dignity: treatment for mental disorders and the focus for patient rights' 26 (2008) *Law in Context* 46.

 ⁷³² Camilla Kong, 'Problems with Mental Capacity' in Camilla Kong, Mental Capacity in Relationship Decision-Making, Dialogue and Autonomy (Cambridge Core 2017).
 ⁷³³ ibid [2].

⁷³⁴ Mark Jayes, Rebecca Palmer, Pamela Enderby 'An exploration of mental capacity assessment within acute hospital and immediate care settings in England' 39 (21) (2016) *Disability Rehabilitation* 2148.

and risks of not using it; she does not wish to become pregnant. Yet she still refuses to use contraception due to the coercive influence of her husband who wants a baby and threatens to leave her if she starts using birth control".736 Another being, "A woman with cognitive impairments is coerced into marrying in a foreign country due to family influence, even as this does not express her own preferences".⁷³⁷ These scenarios need to be women to evidence the prominent gender imbalance within capacity assessments. To expand, in the first example, forcing her to become pregnant is different from the male equivalent of your partner becoming pregnant. Further, regarding the second example, a woman being sent to a foreign country for an arranged marriage is different from a man due to how most societies with arranged marriages are organised. From the data reviewed above, it appears a women's capacity is more likely to be questioned as opposed to a man's capacity. This could be because women tend to have higher rates of internalising disorders (for example, depression, anxiety), whilst men experience more externalising symptoms (violence, substance abuse). Smith et al explain that these patterns are often attributed to gender differences in socialisation, including expectations associated with traditional gender roles.738

The previous chapter advocated for a relational approach to autonomy which must also extend to capacity. The context in which decisions are made and the prevailing factors must be considered when judging a person to be capable or not. Kong explains that "the realm of legal practice currently pulls in opposite directions, recognising, on one hand, the interpersonal source of capacity: that the assessment of mental capacity can often turn on the relationships surrounding individuals with impairment".⁷³⁹ I suggest that Kong is alluding to the potential for undue influence. Undue influence is when a patient's consent to or refusal of treatment may be

⁷³⁶ Camilla Kong, *Mental Capacity in Relationships: Decision-making, Dialogue and Autonomy* (Cambridge Core 2017) 1.

⁷³⁷ ibid.

⁷³⁸ Dena Smith, Dawne M Mouzon, Marta Elliott, 'Reviewing the Assumptions About Men's Mental Health: An Exploration of the Gender Binary' 12 (1) (2018) *American Journal of Men's Health* 78.

⁷³⁹ Camilla Kong, *Mental Capacity in Relationships: Decision-making, Dialogue and Autonomy* (Cambridge Core 2017) 2.

vitiated by the influence of another person. This could be a relative, a friend or even a healthcare practitioner.⁷⁴⁰ ⁷⁴¹

A commitment of the law, moving towards a supported decision-making approach would help create further guidance in terms of distinguishing relationships that help foster and sustain capacity from those which undermine it. A way in which to manage the aspect of undue influence within a decision-making context would be to determine what "appropriate influence" involves and then to understand influence as undue when it is not appropriate. For example, support cannot both be appropriate and constitute undue influence. Wishart has conducted research investigating the role of values in law concerning undue influence.⁷⁴² Her research has demonstrated how societal norms concerning the parent-child relationship can demonstrate what circumstances justify an inference to undue influence when an adult child guarantees a parent's debt. Further explaining that a finding of undue influence would be made when the standard expectations of the relationship are transgressed. Wishart explains, "In a society where family interests and deference to parents are highly valued, a decision that reflects these norms is unlikely to be deemed unduly influenced."⁷⁴³ According to Chen-Wishart, this is not merely a matter of what happens in practice, it is the transgression of these norms that justifies state interference to vitiate a transaction on grounds of undue influence. The question to follow Wishart's hypothesis is what values should be accepted as constituting the relationship between the supporter and the patient and what do they mean in practice? A solution could come from adopting the wills-based model identified by Lord Donaldson. His guidance concerning when a person's will could overborne stipulates three areas to be given consideration: (i) the strength of the person's will, including factors such as exhaustion, pain or depression; (ii) the relationship

⁷⁴⁰ Cameron Stewart, Andrew Lynch, 'Undue Influence, consent and medical treatment' (2003) 12 *Journal of The Royal Society of Medicine* 598.

⁷⁴¹ Undue influence is explained in detail in the chapter Autonomy: from the rational to the emotional, why a relational approach is required for an effective patient-practitioner dialogue. Under the section "Threats to autonomy: undue influence and the re-emergence paternalism".

⁷⁴² Mindy Chen-Wishart, 'Undue Influence: Beyond Impaired Consent and Wrong doing Towards a Relational Analysis' in *Mapping the Law: Essays in Memory of Peter Birks* (OUP 2006) 201

⁷⁴³ ibid.

between the people in question, with influence often being more powerful in certain kinds of relationships such as parent and child; and (iii) that certain kinds of arguments can be particularly forceful, for example, those based on religious or cultural norms and expectations.⁷⁴⁴ I believe this criteria to be relevant towards developing an approach for undue influence in the context of support and could be used as guidance for avoiding inappropriate influence within the third-party relationship.

Donnelly questions whether decision makers can remain unbiased in their assessments of capacity.⁷⁴⁵ She reports that there is a shortage of studies in this area and claims that the legal system leaves it to the medicals to largely determine capacity, meaning that capacity carries with it a medical, rather than a legal definition.⁷⁴⁶ Abernethy reported that assessors are the "gate-keepers who can frustrate other specialists in their drive to treat".⁷⁴⁷ A concern exists that if an assessor has therapeutic motivations it could lead to a conclusion that patients who refused to comply with a proposed treatment lack capacity.⁷⁴⁸

Donnelly further reports that communication difficulties can arise between the patient and the assessor when they do not share a common background.⁷⁴⁹ Factors can include, race, gender, education and culture. Feminist research on mental health has highlighted the influence of gender stereotyping in terms of dictating the way in which women are viewed and judged within mental health systems.⁷⁵⁰ Stefan has argued

⁷⁴⁴ Julian Craigie, 'Conceptualising Undue Influence in decision making support for people with mental disabilities' 29 (2021) *Medical Law Review* 48, 77.

⁷⁴⁵ Mary Donnelly, 'Capacity assessments under the Mental Capacity Act 2005: Delivering on the functional approach?" (2009) 29 *Legal Studies* 464.

⁷⁴⁶ ibid.

⁷⁴⁷ Virginia Abernethy, 'Judgments About Patient Competence: Cultural and Economic Antecedents' in Mary Ann Gardell Cutter, Earl E. Shelp, *Competency: A Study of Informal Competency Determinations in Primary Care* (Springer 1991) 22.

⁷⁴⁸ Expert Committee Review of the Mental Health Act 1983 (HMSO 1999).

⁷⁴⁹ Mary Donnelly, 'Capacity assessments under the Mental Capacity Act 2005: Delivering on the functional approach?" (2009) 29 *Legal Studies* 464.

⁷⁵⁰ Ivor Broverman et al, 'Sex role stereotypes and clinical judgements of mental health' 34 (1970) *Journal of Consulting and Clinical Psychology* 1; Phyllis Chesler, *Women and Madness* (Doubleday 1972) ; Elaine Showalter, *The Female Malady: Women, Madness and English Culture:* 1830-1985 (Pantheon 1985).

that the gender stereotyping of "feminine" behaviour may lead to a greater probability of women's capacity being doubted and found lacking.⁷⁵¹

Miles and August conducted a study which examined approximately 30 cases where patients wanted to refuse life-saving treatment.⁷⁵² The study revealed that the court employed different approaches depending on whether the patient was male or female. Men's opinions were deemed to be thoughtful and rational, while women were regarded as unreflective, emotional or immature.⁷⁵³ Research by Sheldon and Thompson reveals that there appears to be a correlation between women who refuse caesarean sections and findings of incapacity. They suggest that whilst the law permits a woman with capacity to place foetal life in danger by refusing medically indicated treatment, "the courts' vision of normality is so challenged by any woman who actually avails herself of her right in this regard that her decision will automatically lead to her capacity being called into question". ⁷⁵⁴

The MCA 2005 has resulted in judgments which assert "the intrapersonal source of capacity, namely the causative nexus between mental disorder and the inability to decide".⁷⁵⁵ This chapter does not claim that all capacity assessments neglect to involve the patient in terms of the decision-making process. However, the aim of this thesis is to bring attention to the need to increase this participation, particularly so for female patients. Kong recognises that "individuals who might be found to lack capacity on these criteria may in fact be able to make their own decisions given a supportive relational environment",⁷⁵⁶ therefore she argues that mental capacity must be viewed as a relational concept that can be enhanced through intersubjective dialogue.

⁷⁵¹ Susan Sherwin, *No Longer Patient: Feminist Ethics and Health Care* (Temple University Press, 1992) 93; Susan Stefan, 'Silencing the different voice: competence, feminist theory and law" 47 (1993) *University of Miami Law Review* 763; Barbara Secker, 'Labelling patient (in) competence: a feminist analysis of medico-legal discourse' 30 (1999) *Journal of Social Philosophy* 295.

⁷⁵² Steven Miles & Allison August, 'Courts, gender and the right to die' (1990) 18 *Law, Medicine and Healthcare* 85.

⁷⁵³ ibid [119].

⁷⁵⁴ Sally Sheldon and Merisa Thompson, *Feminist Perspectives on Healthcare Law* (Cavendish Publishing 1998) 89.

⁷⁵⁵ ibid.

⁷⁵⁶ ibid.

This segment has considered the potential bias that can exist within capacity assessments. The work of Kong was drawn upon to illustrate that implicit bias can impact capacity assessments. A need was identified for the law to move towards a supported decision-making approach to help improve capacity assessments by encompassing the social context surrounding individuals, whilst also creating boundaries against the potential for undue influence. How capacity assessments transpire in practice will now be considered through an exploration of some cases from the Court of Protection.

5.11 Court of Protection cases

The Court of Protection (CoP) in English law is a superior court of record created under the Mental Capacity Act 2005. It has jurisdiction over the property, financial affairs and personal welfare of people who lack mental capacity to make decisions for themselves. Three cases from the CoP will be considered from a feminist viewpoint to determine whether gender is either an explicit or implicit factor in terms of judgments relating to capacity. The three cases are sufficient to demonstrate the problems inherent within capacity assessments, as they provide different perspectives on a similar issue. I will examine how much weight is given to the patient's wishes, as opposed to relying solely on clinical expertise. The cases selected will all concern pregnancies, the reasons behind this decision are two-fold. First, this thesis is analysing medical law from a feminist perspective, therefore, the matter for key consideration is the medical treatment of women. It is important to note that it will not be possible to compare the treatment of women's decision making in pregnancy to the treatment of men owing to their biological construction. Further, as established in Chapter 3, reproduction is the only area of medicine whereby the knowledge and training of medical expertise is not based on a male standard approach. All other health conditions and illnesses are taught to medical students

from the perspective of a male's body.⁷⁵⁷ The second reason for examining cases concerning pregnancy is uniformity and to clearly be able to witness the reasoning for any differentiation in application of capacity assessments, i.e., the woman's background, physical demeanour and relationship status. Dominant gender ideology will be considered.⁷⁵⁸ This is the assumption that physiological sex differences between men and women are directly related to aspects of their character.⁷⁵⁹ For example, claims that women are overtly emotional in their thinking, whilst a man's thinking is grounded in reason. Rationality is a key component of the functional capacity test; therefore, this could be an avenue through how gender stereotypes impact medical treatment.

5.11.1 Background

The CoP received extensive criticism from the press as it was accused of being a "dark, secret court where life changing decisions were made away from public scrutiny".⁷⁶⁰ For example, headlines have included, "Agony of Woman Locked Up by Secret Court for Trying to Get Dad Out of Care Home"⁷⁶¹ and "That Sinister Court Mocks Justice Again".⁷⁶² The Court of Protection operates on a fine line between open justice and the right to a private life for those who are alleged to lack capacity. A roundtable event titled "Transparency in the Court of Protection" was held in 2014 at the Nuffield Foundation headquarters, including a range of members of the

⁷⁶¹ Andy Dolan, Steve Doughty, Tamara Cohen et al, 'Agony of woman locked up for six weeks by secret court just for trying to get her Dad out of care home: The terrifying moment police descended to cart me off to jail' *Daily Mail* (24/04/2013) available at <u>https://www.dailymail.co.uk/news/article-2314346/Agony-woman-jailed-secret-Daughter-locked-trying-save-father-care-home-tells-terrifying-police-swoop.html</u> [Accessed 11/09/2023].

⁷⁵⁷ Petra Verdonk, Yvonne Benschop, Hanneke de Haes et al, 'Should you turn this into a complete gender matter?' Gender mainstreaming in medical education.' (2009) 21 *Gender and Education* 703.

⁷⁵⁸ Amy Kroska, 'Conceptualizing and measuring gender ideology as an identity' (2000) 14 *Gender & Society* 368.

⁷⁵⁹ ibid.

⁷⁶⁰ Amel Alghrani, Paula Case and John Fanning, 'Editorial: The Mental Capacity Act 2005 – Ten Years On' 24(3) (2016) *Medical Law Review* 311, 312.

⁷⁶² Christopher Booker, 'That sinister court mocks justice again' *The Telegraph* (31/01/2015) available at: https://www.telegraph.co.uk/comment/11381676/That-sinister-court-mocks-justice-again.html [Accessed 11/09/2023].

judiciary, lawyers, journalists, civil servants and researchers. All participants agreed that media reporting on the CoP cases and the publication of judgments were important for the following reasons: "To enhance public understanding of the CoP's work; To protect against miscarriages of justice; - To promote public confidence in the court; - 'Open' and 'accessible' judgments were said to be important for access to justice for litigants in person who might not have access to law reports or legal advice." There was unanimous agreement that there were some serious shortcomings with current arrangements for media access and reporting on CoP cases. Transparency reforms were introduced in 2014, however, these raised new concerns regarding the intense media interest. Around 90% of applications made to the CoP are largely uncontroversial and concern issues regarding property and finances.⁷⁶³ However, the remaining 10% involve "health and welfare decisions".⁷⁶⁴ These are usually extremely emotional cases concerning people who have allegedly lost their capacity.

Alghrani et al explain that "P's participation⁷⁶⁵ in CoP proceedings can provide an important safeguard against excessive "medicalisation" or paternalistic professional practices. However, it is often the case that P will lack litigation capacity and is heavily dependent on their litigation friend to afford them a voice".⁷⁶⁶ Series et al have revealed that the CoP operates on a model of "low participation" which is incompatible with the CRPD.⁷⁶⁷ Low participation refers to the fact that when the consultation took place concerning the court's rules in 2006 nobody asked whether the person the case is about should always meet the judge, or what practical issues might arise if P attended court in person. The court has begun adjusting through the development of Rule 3 A which states the judge must consider in each case how P

⁷⁶³ Lucy Series, Phil Fennell, Julie Doughty, Adam Mercer, 'Welfare cases in the Court of Protection: A Statistical Overview' (2017) *The Nuffield Foundation* available at <u>https://sites.cardiff.ac.uk/wccop/files/2017/09/Series-Fennell-Doughty-2017-Statistical-overview-of-CoP.pdf</u> [Accessed 15/08/2022].

⁷⁶⁴ ibid.

 ⁷⁶⁵ P is the standard nomenclature for the patient. This is specific to these kinds of cases.
 ⁷⁶⁶ Amel Alghrani, Paula Case and John Fanning, 'Editorial: The Mental Capacity Act 2005 – Ten Years On' 24 (2015) *Medical Law Review* 311, 313.

⁷⁶⁷ Lucy Series, Phil Fennell, Julie Doughty, Adam Mercer, 'Welfare cases in the Court of Protection: A Statistical Overview' (2017) The Nuffield Foundation available at <u>https://sites.cardiff.ac.uk/wccop/files/2017/09/Series-Fennell-Doughty-2017-Statistical-overview-of-CoP.pdf</u> [Accessed 15/08/2022].

could participate in the proceedings and whether they should meet the judge and how (if at all) they should be represented. Allen, Bartlett and Keene have conducted a detailed interrogation into the role of litigation friends. A litigation friend can be introduced into proceedings should a person lack capacity to take their own decisions and not be directly involved in the proceedings. A 'litigation friend' is a person who can conduct the proceedings on their behalf and therefore a crucial part of the working of the Court of Protection, ensuring that those whom the proceedings concern have their voice heard before the Court.⁷⁶⁸

Allen, Bartlett and Keene highlight that the distinction between "representing P" and "acting on P's behalf" is essential, in order to bring attention to the conflicts within this role which can often result in P's wishes and feelings being underrepresented in court.⁷⁶⁹ The authors allege that P should be entitled, the same as anyone else, to advance "unwise arguments" to the Court of Protection. Case has also commented on this approach by stating "uncritically accepting the use of insight in expert evidence on capacity assessment without clear attempts to map this lack of insight into the statutory test for incapacity is argued to potentially give credence to therapeutic values which seem in conflict with the many autonomy promising provisions of the MCA".⁷⁷⁰ Case's view is reminiscent of the critique of the MCA in terms of whether it served to fulfil its purpose of giving weight to P's beliefs. Such criticism has resulted in commentators questioning "whether the MCA has already exceeded its shelf life".⁷⁷¹ As I explained earlier, I do not think it's the case of abolishing the MCA, rather, it needs reforming.

⁷⁶⁸ Alex Ruck Keene, 'Acting as a litigation friend in the Court of Protection' (2014) Available at: <u>https://www.39essex.com/wp-content/uploads/2015/01/Acting-as-a-Litigation-Friend-in-the-Court-of-Protection-October-</u>

^{2014.}pdf#:~:text=The%20person%20who%20lacks%20(or,the%20proceedings%20on%20th eir%20behalf. [Accessed 14/06/2021].

⁷⁶⁹ Neill Allen, Peter Bartlett and Alex Ruck Keene, 'Litigation Friends or Foes? Representation of 'P' before the Court of Protection' 24 (2016) Medical *Law Review* 333, 335.

⁷⁷⁰ Paula Case, 'Dangerous Liaisons? Psychiatry and Law in the Court of Protection – Expert Discourses of 'Insight' (and compliance) 24 (2016) *Medical Law Review* 360, 378.

⁷⁷¹ Amel Alghrani, Paula Case, John Fanning, 'Editorial: The Mental Capacity Act 2005 – Ten Years On' 24 (3) (2016) *Medical Law Review* 311, 314.

5.11.2 Case Analysis

The cases have been selected on the basis that each provide a different set of circumstances concerning mothers and their pregnancies/children. As established in the chapter on Feminism, women's health needs have, at times, been underestimated by medical professionals owing to gender enforced stereotypes. The inclusion criteria for the case selection had three main components; that the cases featured women who were in the late stages of pregnancy, that their capacity was being disputed and that the time frame for these cases was between 2019 and 2020 when the chapter was written. The cases seek to demonstrate the problems inherent within capacity assessments, whilst providing different perspectives on a similar issue. A significant motivation for examining cases concerning pregnancy is that of uniformity; to clearly be able to witness the reasoning for any differentiation in the application of capacity assessments, for example, the woman's background, physical demeanour and relationship status. The cases, Guys and St Thomas' NHS Foundation Trust v X; United Lincolnshire Hospitals NHS Trust vs CD, Re Z and NHS Trust v JP, will be evaluated in terms of, (a) the involvement of the patient and (b) the outcome of the decision. This analysis is being conducted to review the effectiveness of the current scheme and whether it is impacted by implicit biases which have unfair outcomes for the patients.

5.11.2.1 Guys and St Thomas' NHS Foundation Trust v X

The case of *Guys and St Thomas' NHS Foundation Trust v X*⁷⁷² is an example of a case in which the medical professionals attempted to follow a process of supported decision-making, but when X failed to agree with their decision, a case was filed for incapacity. The facts are as follows: a declaration regarding capacity and orders for serious medical treatment relating to X, a woman who was in the advanced stages of her pregnancy, was made. X who had had multiple previous admissions to hospital with psychotic symptoms and had various diagnoses, including acute and transient

⁷⁷² Guys and St Thomas' NHS Foundation Trust v X [2019] EWCOP 35.

psychotic disorder; bipolar disorder; schizoaffective disorder and personality disorder was in the late stages of pregnancy and was over term. The baby was at risk of being stillborn and the Trust was asking the court to give permission for any medical intervention necessary to ensure the baby was born safe and well. The Court made the declarations sought, ruling that the P lacked capacity and was unable to reconcile her conflicting beliefs (on the one hand of wanting a natural birth and also wanting a live, well and safely born baby) in a way that she was able to balance the pros and cons.

The first point to acknowledge is that X opposed the application. Initially, the language towards X seemed positive, the Justice claimed that P acted with "admirable dignity in a situation which must have been extremely difficult for her".⁷⁷³ It is worth noting that the Justice in this case was female. This is relevant as feminist literature suggests that some cases can result in different outcomes if heard by a female judge.⁷⁷⁴ The initial source of tension arose over a disagreement with a hospital concerning whether X had attended all appointments.⁷⁷⁵ 24 hours prior to the hearing, the clinical team explained to X that they considered the baby was compromised and there was a high risk of still birth.⁷⁷⁶ The hospital discussed with X the interventions (induction of labour and/or c section) that may be required to secure a safe delivery of the child due to the level of difficulties and risk. X declined all interventions, however, she stated that she wished for the baby to be born alive and for steps to be taken to achieve that.

Owing to X's refusal, it appears that concerns arose over her capacity. As illustrated earlier in this chapter, studies suggest that a patient's refusal of treatment can trigger a capacity assessment. It seems that it was X's refusal which prompted a review of her psychiatric history to legitimise the capacity assessment. Further, it was stated that 'during the pregnancy X has had a 6-week admission to an inpatient psychiatric unit earlier this year'. As capacity is defined as being task specific and that it can only be judged in accordance with the decision at hand, X's previous mental health

⁷⁷³ ibid [3].

⁷⁷⁴ See the earlier section regarding Decision Making Regimes and reasons for a Relational Approach the work of the Feminist Judgments Project.

⁷⁷⁵ ibid [14].

⁷⁷⁶ ibid [16].

problem, without anything further, is insufficient to justify a capacity assessment in this case. Linn et al assert that it is important to acknowledge that not all people with a mental illness will lack decision-making capacity and, conversely, not all people who lack capacity to make decisions will have a mental illness; capacity is not just 'a mental health issue'.⁷⁷⁷

Para 19 of the judgment states that two capacity assessments were conducted which concluded that X did not have capacity to make decisions about her obstetric management.⁷⁷⁸ However, no details of these assessments are listed, therefore we do not know what steps were taken to ensure X had the full opportunity to participate in the process.⁷⁷⁹A third capacity assessment was carried out as explained in para 20 of the judgment where more information is available. It states: "his view is that X's beliefs, which he considered are a product of her mental ill health, are preventing her from being able to reasonably weigh up the pros and cons of the proposed treatment."⁷⁸⁰ The doctor continues to consider X's wishes that her unborn baby's health and well-being is the most important consideration, however, states that: "she still refuses the options as to medical intervention to achieve this".⁷⁸¹ There is no documentation included to see what attempts, if any, had been made to communicate the seriousness of the situation to X. This suggests that the Court employed a substituted decision-making regime, whereby X's beliefs were represented by proxy of a third party.

The judgment continues to consider a phone conversation the Justice had with X which reveals that, "X confirmed she had seen the relevant documents, although had had limited time to consider them. However, she was able to articulate the parts that she disagreed with and confirmed she wanted her baby to be delivered well and safely, she had strong views about wanting to have a natural birth and was very

⁷⁷⁷ Khin Linn, Chris Sayer, et al, 'Reflections on mental capacity assessments in general hospital' (2013) *British Medical Journal*, available at

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3645068/pdf/bcr-2012-008538.pdf [Accessed 26/05/2021].

⁷⁷⁸ Guys and St Thomas' NHS Foundation Trust v X [2019] EWCOP 35 [19].

⁷⁷⁹ It is important to note that whilst they were not mentioned in the judgment, these materials could have been included in the bundle of evidence. ⁷⁸⁰ ibid [20].

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⁷⁸¹ ibid.

concerned about any medical intervention against her wishes."782 This statement suggests that X was able to both understand and retain the relevant information. Further, the mention of "limited time" is guite problematic. As has been discussed extensively in this chapter, the MCA 2005 S4 states that "all practicable" steps must be taken to help the patient's participation. Providing X with limited time constraints could have impeded her ability to read and understand the relevant information. Despite this, the Justice concurred with the Trust and issued a finding of incapacity. Para 17 of the judgment states that X showed limited insight in relation to her previous mental ill health.⁷⁸³ Again, this begs the question of relevance to the current proceedings and suggests that the evidence presented to the court carries with it an implicit bias against X's previous medical history. Admittedly, the inclusion of X's previous mental health conditions could suggest that a wider context is already being considered. If so, such an approach is quite problematic as it contradicts the notion that capacity should be judged in relation to the task at hand and that decisions should be made at a time which best support the individual's capacity. Throughout the judgment, emphasis was continuously put on the risk of foetal distress by the practitioners, ignoring the hypocrisy of such a concern given the nature of the proceedings against the mother. By placing the mother under the stress of proceedings, undoubtedly the foetus could be placed under distress. Significantly, the postscript reveals the baby was born the following day with no need for surgical intervention. Therefore, the stress and turmoil experienced by X was completely unnecessary.784

Initially, X was included in the decision-making process (at the hospital), however, her refusal of consent appears to have prompted capacity proceedings. A further observation from this case is that pregnancy cases are interesting in terms of best interest assessments as the Court considers two sets of assessments, one for the unborn child and one for the mother. In this case, the focus was on the wellbeing of the unborn child, rather than the mother's wishes for a natural birth.⁷⁸⁵

⁷⁸² ibid [16].

⁷⁸³ ibid [17].

⁷⁸⁴ It is reported at [21] that X was very concerned about any medical intervention against her wishes.

⁷⁸⁵ However, the two are inadvertently linked as the mother had indicated she wanted her baby delivered safely and well, ibid [21].

Applying a supported decision-making regime would have been far more favourable to preserving patient autonomy. For example, it would have meant instead of X being "given" the documents which she considered in the early hours of the morning by herself,⁷⁸⁶ she would have had the opportunity to discuss the documents with a practitioner and ask any questions she felt necessary for clarification. Further, alongside the proposed implementation of the relational model, X would have also been able to consult a third-party member for support. An additional change would have been the information provided to the Court. We are told in para 10 that the Court only received "limited information" about X's background. Had supported decision-making been effectively employed, time and care should have been taken to know and to understand the wider context of X's life. The major difference a supported model would have made can be witnessed in para 17 regarding the proposed course of medical treatment. We are informed that "X" was advised she would ideally need to undergo a caesarean section, whereas this was against her wishes, and she declined all interventions. However, X stated that she wished for the baby to be born alive and for steps to be taken to achieve that. Thus, X acknowledges she is willing to participate in treatment to help the birth of the baby. It seems that there was a clash, the doctor thought one course of action was required, whilst the mother to be preferred an alternative. There should have been further effort to ensure: 1) the patient's understanding of the necessary medical information, 2) a mutual understanding regarding the proposed course of treatment. It should not have been a case of opinion vs opinion, but a combined and collaborative approach. As it stands, under the substituted model, medical expertise trumped maternal opinion and the refusal of consent equated to a finding of incapacity.

5.11.2.1.1 Re-imagined Guys and St Thomas' NHS Foundation Trust v X

The case before us is one of an urgent nature. It concerns an application for a declaration regarding capacity and adjoining orders for serious medical treatment relating to a patient who will be identified as X.

⁷⁸⁶ ibid [7].

X is in the advanced stages of her pregnancy and on that note, the Court wishes to express its disapproval for the manner in which these proceedings have been sought. Healthcare professionals need not be reminded of how stressful pregnancy can be;⁷⁸⁷ and as such, potential problems, particularly ones as serious as those before us today, should be addressed in advance, with due consideration of the implications timing constraints can cause. The Trust's timing failure has undoubtedly had a negative impact on X.

The serious medical treatment being sought is that of a caesarean section for the delivery of X's baby, which is noted to be against her wishes.

Owing to the time sensitive aspect of this case, the Court regrettably cannot implore that the trust follows the appropriate steps mandated by the Mental Capacity Act which are designed to provide for the protection and advocation of patients wishes and preferences.⁷⁸⁸ Instead, the court will have to reside itself to basing its judgment on the limited information provided.

It appears that X is without any third-party support. We are aware that this is her first pregnancy and that the father of the unborn child is out of contact. As far as any other parties are concerned, all we know is that X has had a history of difficult relationships and that X experienced trauma in her childhood. Thus, it appears that X is a vulnerable young woman in desperate need of emotional support. Having the knowledge that X has a history of difficult relationships and the possibility of abuse from family members during her childhood, we do not understand why there is no reference to the relevant support agencies. Domestic abuse refers to "any incident of threatening behaviour, violence or abuse (psychological, physical, sexual, financial or emotional) between adults who or have been intimate partners or family members, regardless of sexuality".⁷⁸⁹ Domestic abuse victims suffer from increased risks of

 ⁷⁸⁷ Mary E Coussons-Read, 'Effects of prenatal stress on pregnancy and human development: mechanisms and pathways' 6(2) *Obstetric Medicine* 52.
 ⁷⁸⁸ Mental Capacity Act 2005, s4.

 ⁷⁸⁹ Home Office, 'Cross-government definition of domestic violence – a consultation.
 Summary of responses' (September 2012) available at:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_da ta/file/157800/domestic-violence-definition.pdf [Accessed 12/09/2023].

preterm birth, low birthweight and SFGA babies".⁷⁹⁰ If X has a history of domestic abuse, an act of bodily intervention against her will could cause significant distress and mandate specialist support. Had this case been brought to us sooner we would have ordered for an independent mental capacity advocate to be appointed to X. As it stands, X is alone in advocating for her wishes regarding her birth plan.

We are told that X has a history of mental health difficulties; further, there is a presumption that X also has issues with alcohol and substance abuse, although no evidence has been provided as to the latter. We are concerned that this claim has not received sufficient consideration. Whilst we do not know how long the trust has been aware of this possibility, use of drugs and alcohol during pregnancy pose manifold risks. These include maternal death, miscarriage, still-birth, low birth weight, physical malformations and neurological damage.⁷⁹¹ X should have been referred to the relevant support service for assistance.

X attended the trust's hospital on the 23rd July when she was 42+3 weeks pregnant. We are aware there had been two previous scans which raised concerns owing to a reduction in foetal growth. Additionally, there had been earlier tests which revealed a high risk of Downs Syndrome. Again, the Court is perplexed that given X's history and status as a vulnerable patient, why matters regarding her pregnancy were not advanced at an earlier stage so that due process could have been implemented. This failing became increasingly apparent when we learnt that X had a 6-week inpatient admission to a psychiatric unit earlier this year. It seems that X has fallen through the gaps in our healthcare system.

⁷⁹⁰ This refers to small for gestational age, see: Royal College of Obstetricians & Gynaecologists, 'Small-for-Gestational-Age Fetus, Investigation and Management (Greentop Guidelines No.3' available at <u>https://www.rcog.org.uk/guidance/browse-all-guidance/green-top-guidelines/small-for-gestational-age-fetus-investigation-and-management-green-top-guideline-no-31/</u> [Accessed 23/09/2023] and Brian Donovan, Cassandra Spracklen, Marin Schweizer et al, 'Intimate partner violence during pregnancy and risk for adverse infant outcomes: a systematic review and meta-analysis' 123 (8) (2016) *BJOG – An International Journal of Obstetrics and Gynaecology* 1289.

⁷⁹¹ Joshua Cornman-Homonoff, Devon Kuehan, Sofia Aros et al, 'Heavy prenatal alcohol exposure and risk of still birth and preterm delivery' 25(6) *The Journal of Maternal-Fetal & Neonatal Medicine* 860.

It appears that X's condition only attracted attention when she attended the most recent scan appointment, where a request was made by the clinical team for a capacity assessment. Which, when conducted, determined X lacked the requisite capacity to make decisions about her obstetric care. Unfortunately, we have not been provided with any details of what steps the capacity assessment entailed or any reasoning to substantiate their findings.

However, on the 24th July an additional capacity assessment was conducted by Dr Y, which is slightly more forthcoming in its provision of information. During this assessment, Dr Y discovered that X held "strongly fixed religious beliefs that were at times contradictory". Religion is a protected characteristic, and it is quite disappointing that time has prevented this from being explored further. X's religious beliefs would be protected by Article 14 ECHR. Article 14 prohibits discrimination in the application of other human rights and entitles people to equal treatment in their maternity care.⁷⁹² As such it is unlawful for NHS organisations or individual caregivers within the NHS to discriminate against pregnant people on grounds such as religion. Further, the Equality Act 2010 offers protection against discrimination and harassment.⁷⁹³ It recognises nine protected characteristics with religion being one.⁷⁹⁴ Dr Y's assessment continued, revealing X was unable to "reasonably weigh up the pros and cons of the proposed treatment". Despite this finding, Dr Y's report continues that X was able to express her current wishes for her "unborn baby's health and well-being to be the most important consideration". This sentiment expressed by X illustrates an awareness of her condition which the court believes has not been fully appreciated.

⁷⁹² European Court of Human Rights, 'Guide on Article 14 on European Convention on Human Rights and on Article 1 of Protocol No.12 to the Convention' (Updated 31/08/22) available at

https://www.echr.coe.int/documents/d/echr/Guide_Art_14_Art_1_Protocol_12_ENG#:~:text= %E2%80%9CThe%20enjoyment%20of%20the%20rights,%2C%20birth%20or%20other%20 status.%E2%80%9D [Accessed 23/09/2023]. ⁷⁹³ The Equality Act 2010, s10.

⁷⁹⁴ Birthrights, 'Human rights in maternity care: the key facts' (May 2021) available at <u>https://www.birthrights.org.uk/factsheets/human-rights-in-maternity-care/#:~:text=lt%20recognises%20nine%20'protected%20characteristics,belief%2C%20sex %20or%20sexual%20orientation [Accessed 21/09/2023].</u>

When the court spoke with X during the telephone hearing in the early hours of this morning, X confirmed that she had seen the relevant documents but had limited time to consider them. However, X had the ability to articulate the parts she disagreed with and confirmed she wanted her baby to be delivered well and safely, although retaining her strong views about wanting to have a natural birth and her concerns about medical interventions contrary to her wishes.

It is a great shame that X was not afforded the opportunity to receive the additional support which could have helped her have an active role within the decision-making process and as such, avoid the need to bring the case before us. There has been a disconnect between X expressing her wishes and the best interests' assessment that was conducted. It does not appear that the appropriate steps were taken to put X at ease, that any reasonable consideration was given to her religious beliefs, or that any assistance was provided in relation to trying to maximise X's understanding. As it stands, X's failure to agree with the relevant medical opinion is the trigger of the case before us, rather than X having received the relevant care and consideration prior to this stage.

Despite the Court's sentiments concerning the way in which X's condition has been managed; it agrees that owing to the pressing time constraints and the priority of a safe delivery, the Court approves the Trust's application for serious medical treatment without consent. Concerning the approval for a declaration of capacity, the court is not satisfised with the conduct of such assessments. This then becomes an extremely troublesome issue for the court owing to the advanced stages of the pregnancy. There is simply not time to employ the necessary assistance to duly conduct supported decision making. As such the Court is deeply conflicted. However, the court must go on the limited evidence and therefore endorses the trust's finding of incapacity.

5.11.2.2 United Lincolnshire Hospitals NHS Trust v CD

The second pregnancy case, United Lincolnshire Hospitals NHS Trust v CD,⁷⁹⁵ concerns a different set of circumstances. This time the focus of the case was the

⁷⁹⁵ United Lincolnshire Hospitals NHS Trust v CD [2019] EWCOP 24.

application of an anticipatory declaration should the mother become incapacitated. The facts are as follows:

An application was made by the NHS Trust for the court to make an anticipatory and contingent declaration in the event that the pregnant CD became incapacitated. The application was granted. The novel issue in this case was that CD, who was pregnant, did not at the time of the hearing lack capacity to make decisions in respect of the birth, the treatment and necessary procedures in connection therewith. However, based on her history, her clinicians were agreed that there was a substantial risk that she may lose capacity in relation to such decisions at a critical moment in her labour. The Court was therefore asked to make an anticipatory and contingent declaration in relation to the birth plan, in the event that the pregnant CD became incapacitated. The application was successful, Mr Justice Francis acknowledged the difficulties inherent with trying to marry the absence of legal authority with the welfare of the patient saying:

"I acknowledge that I am not currently empowered to make an order pursuant to section 16(2) because the principle enunciated in section 16(1), namely incapacity, is not yet made out. However, as I have already said, there is a substantial risk that if I fail to address the matter now, I could put the welfare, and even the life, of CD at risk and would also put the life of her as yet undelivered baby at risk. As I have said, I am not prepared to take that risk. I am prepared to find that, in exceptional circumstances, the court has the power to make an anticipatory declaration of lawfulness, contingent on CD losing capacity, pursuant to section 15(1)(c)."

Similarly, to the previous case discussion, it becomes apparent that in the case of pregnancies, it is not only the best interests of the mother that are considered. This adds further confusion to the legal landscape and infers a need for a relational approach to decision-making, as it acknowledges that human beings are inherently connected to one another. For example, the judgment states:

"It is, of course, common ground that every possible step should be taken to act in the best interests of CD and to promote her welfare and, as part of that process, to protect her unborn child. Whilst it is of course the case that the unborn child's best interests cannot be taken into account per se, it is obvious both from the evidence received and as a matter of common sense that the loss of the baby would have a profound negative impact on CD".⁷⁹⁶

The character of CD is brought into disrepute, para 5 of the judgment reveals that "All those who have treated CD recently acknowledge that her presentation is variable and that at times she may be choosing to disengage rather than being unable to engage."⁷⁹⁷ It may be that the reason for the inclusion of CD's alleged attitude was to demonstrate she was incapable of making decisions. Similarly to the earlier case of *Guys*, it appears that issues concerning capacity seem to arise when a patient does not conform to the expected medical norms. Conversely, this observation could be used to support CD's capacity. Choosing not to engage is a deliberate choice and it indicates that CD can do that.

The differentiating factor of CD is that she was deemed to have capacity at the time of the hearing, therefore she played a more active role in the proceedings. The judgment states that: "All are agreed that, for so long as CD retains capacity to make decisions about her obstetric care and the delivery of a baby, she will of course be allowed to do so, even if those decisions are considered unwise".⁷⁹⁸ However, the judgment continues that should her mental health deteriorate, and capacity is lost, "I consider that it would be in the best interests to try for a normal vaginal delivery and this is consistent with either CD's expressed wishes or best interests".⁷⁹⁹ There are two things to note from this caveat. Firstly, the language of the statement is interesting as the Justice states it would be in "the" best interests, not "CD's", not even "hers". Therefore, it remains slightly ambiguous as to whether the Justice is referring to the best interests of the unborn baby, the hospital or CD. Secondly, the extract states that should she lose that capacity, the hospital would follow conduct that either aligns with CD's expressed wish **or** her best interests. This is important as it is clearly identified that the best interests' decision is separate to CD's expressed wish. Therefore, illustrating that should CD retain capacity, she would have been included in the decision-making process and their wishes respected. However, her

⁷⁹⁶ ibid [4].

⁷⁹⁷ ibid [5].

⁷⁹⁸ ibid [4].

⁷⁹⁹ ibid [7].

wishes are then disregarded if capacity is lost, and best interests take over. Best interests are meant to accommodate the wishes of the patient; however, this judgment illustrates that in terms of incapacity, best interests are seemingly delivered on an objective standard. This is supported by the definition provided by the CRPD General Comment No. 1 – Article 12, which recognises that when a decision is made believed to be in the objective patients "best interests" it is representative of a substituted-decision making regime.⁸⁰⁰

Under a supported decision-making model, the trajectory of this case would appear to be quite different. Namely, the purpose of supported decision making is to promote the participation of the patient, whereas the purpose of this hearing was to effectively mute the participation of CD. CD had capacity; supported decision making is to help promote a patient's capacity to the best of their ability. Whereas in this case, the professionals wanted to circumvent this and presume a future loss of capacity. It was found that CD was "Able to discuss her views on all the stages and interventions possible during labour and delivery... her priority was the health of her baby, and she was able to express that even where interventions she dislikes such as cannulation were required, she would engage for the sake of her baby." ⁸⁰¹ CD was compliant. It seems that an implicit bias impacted decisions made regarding CD owing to her mental illness. As explored earlier, stereotypical connotations can illustrate someone as dangerous or unstable owing to them suffering from a mental illness. However, we are informed that CD is complying with the medication Olanzapine.⁸⁰² CD identified two methods of delivery, including that of a caesarean section under a general anaesthetic. Supported decision making would have ensured a dialogue which considered the wills and preferences of CD and worked to produce an outcome which did not completely override her wishes. A further observation to make is that if CD had undergone a caesarean under general anaesthetic, I do not understand how CD could have posed any plausible risk to the safe delivery of the baby. Again, there seems to have been a complete disregard of CD's wishes and instead they have been substituted for the doctor's opinion.

⁸⁰⁰ Committee on the Rights of Persons with Disabilities, General Comment No. 1 – Article 12: Equal Recognition Before the Law, Paragraph 15, UN Doc. No. CRPD/C/GC/1, adopted at the 11th Session (April 2014).

⁸⁰¹ United Lincolnshire Hospitals NHS Trust v CD [2019] EWCOP 24 [5] ⁸⁰² ibid.

5.11.2.2.1 Re-imagined: United Lincolnshire Hospitals NHS Trust v CD [2019] EWCOP 24

This Court has been tasked with a decision which encompasses not only questions of what has happened, but also those which ask what could happen. The latter presents manifold problems as it is not often within the Court's jurisdiction to adjudicate within the remit of subjective probabilities.

This case has resulted over questions concerning arrangements for a birthing plan. The expectant mother is 35 weeks pregnant and is currently detained under the MHA owing to her schizophrenia. The application before the Court is for the approval of an anticipatory and contingent declaration should CD become incapacitated during the course of her labour.

At present, it is accepted that CD has the relevant capacity to make decisions regarding her labour and as such, we are left to grapple with an extremely sensitive matter.

From reviewing the relevant medical history (that has been made available) it is apparent that CD has suffered with fluctuating capacity. When the trust initiated this application on 17th May, it was determined that CD was lacking the relevant capacity to make decisions for herself.⁸⁰³ However, as of June 3rd, all parties were in agreement that CD has now regained such capacity and is able to decide for herself.⁸⁰⁴ However, due to the presiding nature of CD's condition, the trust is concerned that should CD's capacity once again fluctuate, her decision making abilities would be compromised, "at a critical moment in her labour" and that there would be no time to go to court at that point.⁸⁰⁵

⁸⁰³ United Lincolnshire Hospitals NHS Trust v CD [2019] EWCOP 24 [11]. ⁸⁰⁴ ibid [3].

⁸⁰⁵ ibid.

Therefore, the Trust's application for an anticipatory contingent declaration is as follows:

"1. CD has capacity to make decisions regarding her obstetric care and the delivery of her baby.

2. Once CD's membranes have ruptured (either spontaneously or artificially) and in the event that CD is assessed as lacking capacity to make decisions about her obstetric care and labour and the delivery of her baby it is lawful for the applicant to deliver care and treatment to her in accordance with the care plan annexed to the order.

3. To the extent that the arrangements set out at paragraph 3 and the care plan amount to a deprivation of CD's liberty, this is authorised, providing always that any measures used to facilitate or provide the arrangements shall be the minimum necessary to protect the safety of CD and those involved in her transfer and treatment, and that all reasonable and proportionate steps are taken to minimise distress to CD and to maintain her dignity."⁸⁰⁶

This Court takes no issue with the primary fact of this case; it is clear that CD has previously suffered with fluctuating capacity. However, it does not seem ethical to hold a patient's past against them when determining the course of their future. We must review the situation as it currently stands. We have been informed by the relevant healthcare professionals that, "her mental health has, happily, been improving with the administration of olanzapine and her capacity was therefore kept under regular review".⁸⁰⁷

Further, "on 24th May 2019, a LPFT nurse and her IMCA/IMHA found that she was 'able to discuss her view on all the stages and interventions possible during labour and delivery …her priority was the health of her baby and she was able to express that even where interventions she dislikes such as cannulation were required she would engage in the intervention for the sake of her baby".

⁸⁰⁶ ibid.

⁸⁰⁷ ibid [5].

Additionally, we have been informed by Dr S, a consultant psychiatrist employed by Lincolnshire partnership NHS Trust that CD had improved and on balance he considers she has the capacity to make decisions about the delivery of her baby.⁸⁰⁸ By all accounts it appears that CD is presenting as a compliant patient who has engaged with the required services and is able to express herself both clearly and articulately.

We are aware that CD has consistently expressed the wish to have a vaginal delivery; however, CD has recognised that if this cannot be done, she does not want an epidural and instead has requested a general anaesthetic and a caesarean section.⁸⁰⁹ Such evidence satisfies s3 MCA 2005 as CD is able:

(a) to understand the information relevant to the decision

(b) to retain that information

(c) to use or weigh that information as part of the process of making the decision
(d) to communication his decision (whether by talking, using sign language or any other means). ⁸¹⁰

It is the aspect of capacity that sits somewhat uncomfortably with the court. The patient, by all accounts has the requisite capacity for the decision at hand. Granted, there are concerns for, per se, the longevity of said capacity, but currently there is no doubt that CD is of sound mind. Thus, the court is quite frankly confused as to how this case is even before us, when it would seem perfectly rational for CD to have planned for an advance decision to accommodate for her wishes should her capacity decline, as opposed to the application for an anticipatory declaration.

Under an advance decision, it would be possible to embody the ethos of the Trust's anticipatory declaration whilst maintaining respect for CD's autonomy.⁸¹¹

⁸¹⁰ Mental Capacity Act 2005, s3.

⁸¹¹ Birthrights, 'Mental capacity and maternity care' (2021) available at <u>https://www.birthrights.org.uk/factsheets/mental-capacity-and-maternity-care/</u> [Accessed 13/09/2023].

⁸⁰⁸ ibid [6].

⁸⁰⁹ ibid [7].

It is somewhat surprising that given CD's diagnosis that she has not been advised on such an option. If a pregnant patient has a condition that might (under the MCA) cause them to lose capacity either during pregnancy or labour, they can be entitled to formulate an advance decision to ensure their wishes are respected during labour.⁸¹² Most importantly, an advance decision can dictate what treatments the patient wishes to refuse.⁸¹³ Granted an advance decision can require a witness and we are aware that it has been impossible to locate CD's family and/or friends, but this is quite frankly irrelevant as anyone can be a witness.

It is important to clarify the nature of an advance decision; it cannot demand specific treatments; it can only protect the refusal of treatments.⁸¹⁴ The refusal of treatment is what is of relevance to CD as she has stated that she does not want to receive an epidural. Such a decision would have the same effect as a contemporaneous decision and must be followed by healthcare professionals.⁸¹⁵

We are concerned that the appropriate support has not been afforded to CD. The court is aware that women with multiple disadvantages report fewer positive experiences and outcomes than women without multiple disadvantages.⁸¹⁶ Therefore, we would like to utilise this opportunity to make a difference and to ensure that CD and other women like her are not prevented from having their voices heard.

Recently there have been a series of reports revealing that, "...women with social risk factors are more likely to experience paternalistic care and highlighted the impact of health care professionals' assumptions based on race, class, ability, age,

⁸¹² ibid.

 ⁸¹³ Mental Capacity Act 2005 Code of Practice, 11.10 available at <u>https://assets.publishing.service.gov.uk/media/5f6cc6138fa8f541f6763295/Mental-capacity-act-code-of-practice.pdf</u> [Accessed 20/09/2023].
 ⁸¹⁴ ibid.

⁸¹⁵ Birthrights, 'Mental capacity and maternity care' (2021) available at <u>https://www.birthrights.org.uk/factsheets/mental-capacity-and-maternity-care/</u> [Last Accessed 13/09/2023].

⁸¹⁶ Jenny McLeigh, Maggie Redshaw, 'Maternity experiences of mothers with multiple disadvantages in England: A qualitative study' 32(2) (2019) *Women Birth* 178; Hannah Rayment Jones, James Harris, Angela Harden et al, 'How do women with social risk factors experience United Kingdom Maternity Care? A realist synthesis' 46(3) (2019) *Birth issues in perinatal care* 461.

and other sources of oppression."⁸¹⁷ The decision of the Trust to seek an anticipatory declaration embodies such paternalistic care. It appears that in terms of assessing CD's best interests, a stance has been taken which negates the relational nature of decision-making which is alluded to within the MCA and instead has been substituted for an approach of "doctor knows best".

The Court is clear in its agreement that the welfare of CD must take paramountcy. Further, owing to the stage of CD's pregnancy the issue before us is time sensitive. Whilst the Court is sympathetic to the urgent nature of this decision, it remains confused as to why a plan is being sought which could effectively amount to a deprivation of liberty.⁸¹⁸

Unfortunately, we have not been provided with the details of the full care plan. However, we have been informed that there is an "expectation that CD will comply with what is proposed, but also includes fall back options, including for appropriate minimal restraint, should this not be the case".⁸¹⁹ What follows further adds to the Court's confusion as it is detailed that restraint might be required to deliver the general anaesthetic for a caesarean section. This sentiment contradicts earlier information that was provided to the Court. To re-iterate, we were advised that if a vaginal delivery cannot be achieved, that CD "wants a general anaesthetic and a caesarean section".⁸²⁰ Thus, the suggestion that restraint would be required to achieve this feels like an overtly paternalistic action.

Compliance does not present as a concern to the Court. CD has already expressed consent to a caesarean section should it be necessary for the sake of a healthy delivery of her baby. The power of medical discourse is profound; it depicts pregnancy and childbirth as perilous, something that needs to be controlled to ensure nothing goes wrong. Such attitudes result in a reduction of choice for women.

⁸¹⁷ Hannah Rayment Jones, James Harris, Angela Harden et al, 'How do women with social risk factors experience United Kingdom Maternity Care? A realist synthesis' 46(3) (2019) *Birth issues in perinatal care* 461, 467.

⁸¹⁸ United Lincolnshire Hospitals NHS Trust v CD [2019] EWCOP 24 [3] ⁸¹⁹ ibid [16].

⁸²⁰ ibid [7].

Even patients who have never before had their capacity questioned can attract concern over their abilities should they refuse advice.

With women like CD who either suffer or have a history of mental illness, medical domination is even more prominent.⁸²¹ Themes of risk and control permeate every case.⁸²² Let us not forget it is the women who are meant to be in control of their pregnancy and delivery;⁸²³ in CD's case even her compliance fails to secure adequate participation.

The Mental Capacity Act advocates that individuals be empowered to make decisions and that all practicable steps must be taken to support the process before someone is deemed as lacking the capacity to make decisions.⁸²⁴ Therefore, the Court purports that the best way forward to secure the autonomy of patients like CD is through greater facilitation of advance decision-making. Women should be afforded maximum opportunities to participate in discussions around possible treatments and interventions throughout their pregnancy and their wishes must carry significant weight in the determination of best interests.⁸²⁵ Should such wishes be documented they would have the same validity as a woman's refusal when she is in labour.

The wider issue before us today concerns the decision of when a trust's intervention in childbirth should come before the Court. Echoing the sentiment of Keehan J in

⁸²¹ Cecilia Tasca, Mariangela Rapetti, Mauro Giovanni Carta et al, 'Women And Hysteria In The History of Mental Health' 8 (2012) *Clinical Practice and Epidemiology Mental Health* 110.

⁸²² Judith A. Lothian, 'Risk, Safety, and Choice in Childbirth' 21(1) (2012) *Journal Perinatal Education* 45; Patricia Leahy-Warren, Helen Mulcahy, Paul Corcoran et al, 'Factors influencing women's perceptions of choice and control during pregnancy and birth: a cross-sectional study' 21 667 (2021) *BMC Pregnancy Childbirth* 1-12.

⁸²³ Virginia Ballesteros, 'A stigmatizing dilemma in the labour room: Irrationality or selfishness?' 28(5) (2022) *Journal of Evaluation in Clinical Practice* 875.

⁸²⁴ Social care institute for excellence, 'Mental Capacity Act 2005 at a glance' (Last updated October 2022) available at: <u>https://www.scie.org.uk/mca/introduction/mental-capacity-act-2005-at-a-glance</u> [Last Accessed 28/09/2023].

⁸²⁵ Birthrights, 'Mental capacity and maternity care' (2021) available at <u>https://www.birthrights.org.uk/factsheets/mental-capacity-and-maternity-care/</u> [Last Accessed 13/09/2023].

NHS Trust Ors v FG [2014] EWCOP 30, the following guidance surrounding pregnant women who have mental health problems must be re-iterated:

"... in a number of recent cases there has not been a full appreciation or understanding of:

- (a) The planning to be undertaken in such cases
- (b) The procedures to be followed
- (c) The timing of an application to the Court of Protection and/or the Family Division of the High Court and
- (d) The evidence required to support an application to the court"826

It is the latter requirement which commands our attention, the Court is not fully satisfied that the available evidence constitutes sufficient grounds for an application to the Court. Perhaps most pertinent to our case at hand is Keehan's observation that, "no doubt in the vast majority of such cases it will not be necessary to make an application to the Court of Protection or to the Family Division of the High Court. I should emphasise that P is assumed to have capacity in accordance with the provisions of s (2) MCA, unless it is established to the contrary, even if she is detained under the provisions of the Mental Health Act 1983".⁸²⁷

Keehan further identified a potential issue of relevance to Lincolnshire NHS Trust regarding their proposed use of restraint. He noted:

"The potential use of restraint complicates matters", ⁸²⁸ and "the distinction between actions which amount to restraint only, and those which become a deprivation of liberty might be difficult, but it is of critical legal significance because s.4 A (1) prevents clinicians performing acts which amount to a deprivation of liberty as part of care and treatment under s.5".⁸²⁹

828 ibid [92].

⁸²⁶ NHS Trust & Ors v FG [2014] EWCOP 30.

⁸²⁷ ibid [82].

⁸²⁹ ibid [93].

As such, there are four potential grounds under which an application can be made to pursue an authorisation of a DOL. Out of the four, it is the first which warrants our deliberation. Category one explains, "the interventions proposed by the Trust probably amount to serious medical treatment within the meaning of COP Practice Direction 9E, irrespective of whether it is contemplated that the obstetric treatment would otherwise be provided under the MCA or MHA."⁸³⁰

However, it was confirmed by our honourable friend Keehan J that neither delivery of a baby per se,⁸³¹ or an uncomplicated planned caesarean section ⁸³² would amount to a serious medical treatment within the meaning of PDgE. Applying this rhetoric to the case at hand, it confounds the Court. CD had already provided consent to a caesarean section should it be required. With regards to the proposed use of restraint; such concern could be avoided had the Trust agreed to CD's wishes to receive a general anaesthetic as opposed to an epidural.

To summarise, this Court feels as though this application ignores the necessary supported decision making in favour of an overtly paternalistic approach to best interests. On these grounds, the Court refuses the anticipatory declaration and instead requests CD receives the appropriate help to formulate an advance decision. The guidance of which is as follows:

11.17 An advance decision to refuse treatment:

• must state precisely what treatment is to be refused – a statement giving a general desire not to be treated is not enough.

• may set out the circumstances when the refusal should apply – it is helpful to include as much detail as possible.

• will only apply at a time when the person lacks capacity to consent to or refuse the specific treatment.

⁸³⁰ Department of Health and Social Care, 'Deprivation of liberty safeguards resources' (31/03/2015).

⁸³¹ NHS Trust & Ors v FG [2014] EWCOP 30 [107].

⁸³² ibid [110].

• should include a statement of values, for example an individual might want to state whether it is more important to them that they be kept pain free rather than kept alive.⁸³³

Thus, the advance decision for CD would detail her refusal of an epidural should she lose capacity during labour, we ask that CD is assisted in completing her statement of values. An advance decision is a far more appropriate way to manage a potential loss of capacity as opposed to evoke the Court to approve an invasive and draconian order. Such an approach safeguards the woman's autonomy, in a way that an anticipatory declaration fails to do so. Finally, following Lieven J in *Shrewsbury and Telford Hospital NHS Trust v T & Another*, the court acknowledges that if true emergency were to arise, then the clinicians can use the doctrine of necessity to protect the mother.⁸³⁴

5.11.2.3 Re Z

Re Z has already featured a case commentary in subsection 4.5.2. Therefore, only the re-imagined judgment will be provided in this section.

5.11.2.3.1 Re-imagined ReZ case

The application before us concerns a young women aged 22, from now on referred to as Z, who is currently in the late stages of her pregnancy. This is her fifth pregnancy. Sadly, we have been informed that of her four children, one died aged just 6 days old and her other three children have been taken into care. Concerning her current pregnancy, Z is deemed as medically high risk; she suffers from a bicornate uterus and is at risk of preterm birth and foetal malpresentation. For these reasons Z has been booked to deliver her baby by caesarean section on 3rd April 2020. Note, there is no indication to suggest that Z objects to the proposed

 ⁸³³ Mental Capacity Act 2005 Code of Practice, 11.17 available at <u>https://assets.publishing.service.gov.uk/media/5f6cc6138fa8f541f6763295/Mental-capacity-act-code-of-practice.pdf</u> [Accessed 20/09/2023].
 ⁸³⁴ Observational Tafford Upperite LNU/COD 20.

⁸³⁴ Shrewsbury and Telford Hospital NHS Trust v T + Anor [2023] EWCOP 20.

caesarean section, it can be inferred that Z was involved in the decision-making process regarding this matter.

In addition to the diagnosis of a bicornate uterus, we have been informed of the following regarding Z's health. Z has a mild learning disability with an IQ in the range of 60-69. However, she has been assessed to have capacity about her antenatal care generally and her mode of delivery specifically. Further, Z has poorly controlled gestational diabetes, anaemia and a severe vitamin D deficiency.

The court acknowledges these mitigating factors and echoes the concerns expressed for Z's individual well-being both aside from and for the duration of her pregnancy and childbirth. However, this application on behalf of the trust is not concerned with Z's current pregnancy. Rather, it is in relation to potential future pregnancies and seems somewhat reminiscent of a risk-management strategy.⁸³⁵ The trust are seeking approval for an intrauterine contraceptive device to be inserted at the time of Z's caesarean section on the basis that Z lacks the capacity to make decisions about her contraception and to safeguard against additional pregnancies in order to allow for what is termed as "family spacing",

What strikes the Court as somewhat peculiar is that Z has been deemed to have the requisite capacity to decide upon matters relating to her birth plan; yet this does not extend to matters concerning other intrinsic parts of her fertility. Whilst we do not dispute that capacity is task specific and must be decided upon on the basis of the relevant circumstances;⁸³⁶ if a person is able to decide upon their care and delivery of a pregnancy, deciding upon their contraceptive treatment presents as a matter which should go hand in hand.

We are aware that an interview took place between Dr Camden Smith and Z, from which a report was generated. It was explained that Z was struggling to understand several issues including why the court might be involved with her decision about

⁸³⁵ Judith A Lothian, 'Risk, Safety and Choice in Childbirth' 21 (1) (2012) *Journal Perinatal Education* 45.

⁸³⁶ Social care institute for excellence, 'Mental Capacity Act, Assessing capacity' available at <u>https://www.scie.org.uk/mca/practice/assessing-capacity</u> [Accessed 20/09/2023].

contraception, why the doctors might be worried about her understanding of the issue, or that she had a solicitor to advocate on her behalf. The Court notes that the only apparent attempt made to help aid Z's understanding was when Dr Smith tried to draw parallels with Z's prior court experience, which similarly, Z failed to understand. After that attempt, there is no evidence to suggest further steps were advanced to encourage Z's participation. Owing to the lack of information presented to the Court, it is difficult to ascertain whether Z was intentionally excluded. The Court can only adjudicate on what has been made available to us and on that basis, it would seem that the appropriate steps set out in the MCA to maximise patient participation have not been fully adhered to.

To re-iterate, according to the Mental Capacity Act 2005, patients should be supported, wherever possible, to take part in the decision-making process. Further the Code of Practice stipulates that, "The Act also states that people must be given all appropriate help and support to enable them to make their own decisions or to maximise their participation in any decision-making process."837 Moreover, that "People with an illness or disability affecting their ability to make a decision should receive support to help them make as many decisions as they can."838 The Code of Practice goes on to expand that such support could include using a different form of communication, providing information in a more accessible form or having a structured programme to improve a person's capacity to make particular decisions.⁸³⁹ Most significantly, Section 3 of the Code of Practice states, "could anyone else help with communication (for example, a family member, support worker, interpreter, speech and language therapist or advocate)?"⁸⁴⁰ Further, it questions whether help is available from people the person trusts.⁸⁴¹ The court finds it troublesome that none of the above was enacted in terms of Z's participation in the relevant medical dialogues. We have been made aware that Z has a good relationship with a nurse practitioner who has expressed a willingness to help Z attend the necessary appointments to retain the effectiveness of the contraceptive

⁸³⁷ Mental Capacity Act Code of Practice (2007), Section 1.2.

⁸³⁸ ibid [2.1].

⁸³⁹ ibid [2.7].

⁸⁴⁰ Mental Capacity Act Code of Practice, Section 3.

⁸⁴¹ ibid.

injection. This relationship requires further due diligence to determine the practicalities of such an arrangement. The court understands that time is sparse within the NHS and so we would need to determine whether the support is both available and viable. From consulting our own medical expertise, we have been informed that Depo-Provera injections should be given every three months. Further, that if Z were to start injections on or before day 21 after giving birth, she would be immediately protected against becoming pregnant.⁸⁴² Therefore, for the desired intents and purposes of contraception, the injection appears to be a suitable option.

From reviewing the medical evidence provided, the reluctance of the Trust to endorse such a treatment appears to rest on Z's lack of ability to expand upon her refusal of the IUD. However, we have been provided no evidence to indicate whether any aids or resources were provided which would have helped Z articulate her decision. According to the NICE guidelines on supported decision making, it is specified that in accordance with the Mental Capacity Act Code of Practice, principle 2, the patient should be asked how they want to be supported and who they would like to have involved in the decision-making process.⁸⁴³ Additionally, there is an obligation to "support people to communicate so that they can take part in decision-making. Use strategies to support the patient's understanding and ability to express themselves".⁸⁴⁴ On review of the discussions regarding Z's capacity preceding this judgment, it appears that Z was judged on her inabilities, rather than being helped to express her wishes.

Most importantly, the NICE guidelines state that in cases where "the consequences of the decision would be significant" health and social care practitioners should refer to other services that could help support decision-making when the persons' level of need requires specialist input.⁸⁴⁵ As already stated, the potential consequences of having a child are significant. Rather than enlist such support, it was simply

⁸⁴² NHS, 'The contraceptive injection, Your contraception guide' (Last reviewed 07/02/2018) available at <u>https://www.nhs.uk/conditions/contraception/contraceptive-injection/</u> [Accessed 01/10/2023].

⁸⁴³ National Institute for Health and Care Excellence, 'Decision-making and mental capacity' (December 2017) 233, 1.2.3

⁸⁴⁴ ibid [1.29].

⁸⁴⁵ ibid [1.2.16].

considered that Z lacked any understanding relating to her compliance with the injection.

Both the MCA and Code of Practice dictate that the circumstances surrounding the individual patient be considered, however, it appears that there was a failure to do so in the case of Z. Her obstetric history has been presented purely from a medical perspective. Thus, the Court would like to reflect on the potential emotional strains that could be impacting Z's ability to articulate her reasoning sufficiently. Z's rebuttal of "it's my body" when probed on why she preferred the contraceptive injection to the IUD was deemed to be insufficient and unsubstantiated. From a humanistic viewpoint, the Court feels as though this sentiment merited further consideration and believes that this emotional response was Z's attempts to reclaim her reproductive autonomy.

We implore a consideration of the issue from the patient's perspective which would remove some of the concerns that are surrounding the somewhat exclusive approach that encompasses this case and the sheer lack of regard for making time and allowances for Z's participation. Once again, it would seem that paternalism has reared its head and resulted in the application before us. Inserting an IUD without patient consent is an act of unwarranted aggression and on that basis, the Court refuses the application. Nonetheless, our refusal of the application does not equate to a suggestion that Z has the capacity to have fully autonomous reign over her contraception. However, we believe there is a compromise which balances Z's individual wishes and that of the Trusts to achieve an outcome that satisfies Z's best interests.

The Court would now like to consider the potential human rights implications regarding the non-consensual insertion of the IUD. Following the insightful observations of Peter Jackson J in *Wye Valley NHS Trust v Mr B* [2015] EWCOP, the following must be re-stated. At paragraph 6 of his judgment, Jackson explained that whether or not a person has the capacity to make decisions for himself, he is

entitled to the protection of the European Convention on Human Rights.⁸⁴⁶ He continued, "Where a patient lacks capacity it is accordingly of great importance to give proper weight to his wishes and feelings and to his beliefs and values",⁸⁴⁷ further that, "as the Act and the European Convention make clear, a conclusion that a person lacks decision-making capacity is not an "off-switch" for his rights and freedoms. To state the obvious, the wishes and feelings, beliefs and values of people with a mental disability are as important to them as they are to anyone else, and may even be more important. It would therefore be wrong in principle to apply any automatic discount to their point of view."⁸⁴⁸ Most importantly, Jackson also asserted that, "...It is, I think, important to ensure that people with a disability are not – by the very fact of their disability – deprived of the range of reasonable outcomes that are available to others. For people with disabilities, the removal of such freedom of action as they have to control their own lives may be experienced as an even greater affront than it would be by others who are more fortunate."⁸⁴⁹

To apply Jackson's reasoning to the case at hand, it would seem that the Trust's application would result in a removal of freedom of action through the exclusion of the wishes, feelings, beliefs and values of Z to the disregard of her autonomy. It is not uncommon for paternalistic themes to emerge in such cases, there is an instinctive desire to protect patients from potential harms. However, this is a risk that needs to be management.

As per Munby J in Re MM (An Adult) [2007] EWHC 2003 (Fam):

"A great judge once said, 'all life is an experiment', adding that 'every year if not every day we have to wager our salvation upon some prophecy based upon imperfect knowledge' (see Holmes J in <u>Abrams v United States</u> (1919) 250 US 616 at 630). The fact is that all life involves risk, and the young, the elderly and the

⁸⁴⁶ Wye Valley NHS Trust v Mr B [2015] EWCOP [6]

⁸⁴⁷ ibid [10].

⁸⁴⁸ ibid.

⁸⁴⁹ ibid [12].

vulnerable are exposed to additional risks and to risks they are less well equipped than others to cope with. But just as wise parents resist the temptation to keep their children metaphorically wrapped up in cotton wool, so too we must avoid the temptation always to put the physical health and safety of the elderly and the vulnerable before everything else. Often it will be appropriate to do so, but not always. Physical health and safety can sometimes be brought at too high a price in happiness and emotional welfare. The emphasis must be on sensible risk appraisal, not striving to avoid all risk, whatever the price, but instead seeking a proper balance and being willing to tolerate manageable or acceptable risks as the price appropriately to be paid in order to achieve some other good – in particular to achieve the vital good of the elderly or vulnerable person's happiness. What good is it making someone safer if it merely makes them miserable?"⁸⁵⁰

Forcing the IUD upon Z would certainly result in emotional distress. Additionally, such action would run the risk of contravening Article 8 of the ECHR.⁸⁵¹ The Trust laments that the IUD would be in Z's best interests, but such an interference can only be justified if the court is satisfied that it adheres to the law and is required for the protection of Z's health. Health must receive a wide interpretation, to encompass not only physical health, but mental health, emotional wellbeing and all other aspects of Z's life. An insertion of the IUD without consent would amount to a clear infringement of P's human rights and freedoms.

The Court therefore orders that Z receive the contraceptive injection to be administered after Z has given birth which will achieve effective contraception for the following 3 months. The Court then mandates that Z attend a follow up appointment at that stage where her compliance will be assessed to determine whether continued injections are appropriate. Such a measure will attach greater weight to Z's wishes, feelings and sense of autonomy. This balance of rights and risks must be kept under regular review as it will change with age, maturity, education, advice and social circumstances. Owing to the nature of these circumstances, the Court concludes

⁸⁵⁰ *Re MM (An Adult)* [2007] EWHC 2003 (Fam).

⁸⁵¹ European Convention on Human Rights, 'Right to respect for private and family life, home and correspondence (1953).

there will be a stay of proceedings to be re-visited in 3 months. In that time frame, the Court asks the Trust to propose a care-plan detailing proposed methods to assist Z in the maintenance of the required contraceptive injections.

5.11.2.4 NHS Trust v JP

The final case is *NHS Trust v JP*,⁸⁵² which involves an application for a covert csection on a young woman. The facts are as follows. Williams J was asked to endorse the covert carrying out (under general anaesthetic) of a Caesarean section on a young woman, JP. JP, who had learning disabilities, was seen by the community midwife in February 2019 and was pregnant. She was in a relationship, but at that time was living at home with her mother and spending time at her boyfriend's family home. Her due date was 14 July 2019. Over the next 4 months, the community midwifery team, clinicians from the relevant NHS Trust, a learning disabilities team, and local authority adult and her children's social workers had been involved with JP and her pregnancy. By 11 May, she had moved out of her mother's home into a supported living placement. Over the following months those around JP had been seeking to support her through the pregnancy and to reach a decision as to how the delivery was to be managed.

The team at the applicant Trust eventually concluded that the only safe way to manage the labour for JP was for her to have a caesarean section under general anaesthetic. That was contrary to JP's wishes. JP had expressed a wish to have a natural birth therefore the care plan involved deception to carry out the caesarean section. The plan also envisaged that the local authority would take steps to remove JP's baby from her after birth (whether temporarily or permanently was not clear from the judgment).

The case opens with a consideration of best interests, stating whether it was in JP's best interests to:

(i) Deliver her baby via a caesarean section under general anaesthetic.

⁸⁵² NHS Trust v JP [2019] EWCOP 23.

- To be transferred to hospital from her home in accordance with the transfer plan by 24th June.
- (iii) Not to inform her of the outcome of these proceedings.

The third factor is the most troubling, as it completely disregards any autonomous right of JP to choose her birthing plan. The application is seeking to not only remove JP from the decision-making process, but to hide the decision from her. The second point to make regarding supported decision making follows in para 4 of the judgment, whereby it states, "JP's family and the father of the baby are not respondents to the application and have not participated in these proceedings".⁸⁵³ Had the court employed a relational approach to supported decision making, it would have been logical to include the support network surrounding JP.

The issue of JP's wishes becomes apparent in para. 11 of the judgment where it is stated;

" The team at the applicant Trust eventually concluded that the only safe way to manage the labour for JP was for her to have a caesarean section under general anaesthetic. This is contrary to JP's wishes; she had expressed a wish to have a natural birth. However, as the Trust considered JP lacked capacity to make the decision for herself this application was issued".⁸⁵⁴

Thus, it is abundantly clear that the outcome of the best interests assessment both contradicted and excluded JP's wishes. Section 4 (6) of the MCA explains that the person's past and present wishes and feelings should be taken into consideration whenever reasonably practicable. It appears that the Trust approached JP's participation with a negative presumption, looking for reasons to justify exclusion rather than methods to promote inclusion. Again, we are presented with a scenario where the patient's wishes contradict that of the doctors and once more, the disagreement of opinion has resulted in a finding of incapacity. Such an outlook

⁸⁵³ ibid [4].

⁸⁵⁴ ibid [11].

becomes more apparent in para 30 of the judgment where JP's character and demeanour are discussed. It reads:

"ix) On 22 May JP attended the Trust for a scan. She was aggressive and rude. She allowed the scan to take place and appeared to be happy to see her unborn child. She would not engage in any conversation with Dr Sullivan now including over labour, burying her head in her hands, banging her hat on the table and shouting and swearing at staff. She calmed down but when Dr Sullivan attempted to speak about childbirth she again disengaged and when a caesarean section was mentioned she said she did not want to be cut open. She appeared to understand the simple outline but could not understand or explain anything beyond that. She said that as it was her baby, she would do what she wanted." ⁸⁵⁵

This extract evidences that the Trust viewed JP as aggressive and rude. Despite her apparent attitude, JP allows the scan to take place and is happy to see her unborn child. What follows, seems like a natural response considering JP did suffer from learning disabilities and was obviously distressed at the situation as she was aware the hospital wanted to carry out a caesarean section against her wishes. No thought is given to what emotions JP might have been experiencing at the prospect of having such a procedure. The Trust acknowledges that JP had clearly expressed that "she did not want to be cut open" and that she understood the "simple outline", however, it seems that her engagement was unwelcome as it was noncompliant with the plan of the hospital. The MCA details all "practicable steps" should be taken to aid the patient in their decision-making process and the language in this judgment clearly acknowledges behaviour which strongly indicates JP required assistance. For example, the above extract states JP buried her head in her hands and banged her hat on the table, which indicates that she was frustrated and attempting to communicate this frustration to the Trust.⁸⁵⁶ As a result of this frustration and perceived behavioural issues, the medical team looking after JP decided it would be in her best interests to undergo a caesarean section.⁸⁵⁷

⁸⁵⁵ ibid [30].

⁸⁵⁶ ibid [9].

⁸⁵⁷ ibid [X].

The MCA 2005 guidance dictates that should a patient even blink or squeeze a carer's hand it be counted as attempting to communicate a decision; it does not seem fair or just that JP's behaviour was disregarded as "rude" as opposed to being considered as a means of communicating her feelings. The most egregious of the Trust's report is the statement that JP would not engage in any conversation. This statement completely overlooks any learning needs faced by JP which could have made it extremely challenging for her to communicate effectively without assistance. The following is slightly speculative as the detail is missing from the judgment. However, under a supported decision model JP should have been provided with visual aids or the option to write down words in order to answer the questions of the Trust. However, as revealed by Series et al, the participation of the patient in proceedings is often dictated by the availability of resources.⁸⁵⁸ In order to enable the patient's direct participation in proceedings sometimes special measures or reasonable adjustments are required, for example, funding for intermediaries to assist with putting questions to the patient during a hearing.⁸⁵⁹ Therefore, it could be the case that financial constraints provided barriers to JP's participation.

The remainder of the judgment discusses, at quite some length, reasons why it was necessary to sedate JP and carry out the caesarean section. The whole application is dedicated to advocating reasons against JP's wishes and even that of her family. Para 43 of the judgment explains that:

"The following matters weigh against the approval of the proposed treatment plan:

i) It is against JP's expressed wishes. She is likely to experience distress, distrust, anger, frustration at both the deception that may be necessary and the carrying out of a surgical procedure against her will in respect of such a profoundly important matter. This is likely to be all the greater because it is proposed that the baby will be removed from her care.

 ⁸⁵⁸ Lucy Series, Phil Fennell, Julie Doughty, The Participation of P in Welfare Cases in the Court of Protection (Nuffield Foundation 2017)
 <u>https://sites.cardiff.ac.uk/wccop/files/2017/09/Series-Fennell-Doughty-2017-Statistical-overview-of-CoP.pdf</u> [Accessed 22/08/2022].
 ⁸⁵⁹ ibid.

ii) It appears likely to be against the expressed wishes of some family members close to her, including the putative father of the baby.

iii) There are risks associated with the administration of general anaesthetic in the hospital environment.

iv) There are far higher risks associated with the administration of anaesthetics outside the hospital environment if that became necessary."⁸⁶⁰

However, the judgment still concludes with the determination that "The overall balance in the evaluation of JP's best interests is thus in favour of the proposed treatment plan provided it is supplemented to address the psychological or psychiatric consequences of giving birth in this way."⁸⁶¹ Yet again, the greatest irony in this case, as was the situation in CD, is that following these proceedings, JP gave birth naturally. This outcome evidences an emerging pattern, time and resources are employed on a continual basis against pregnant women who are deemed incapable, only for the applications to have been unnecessary. A more pragmatic and beneficial approach would be to dedicate time and resources into creating a patient centred supported decision-making process, whereby the role of the patient is included throughout. This would work by ensuring the patient was provided with the appropriate tools to aid communication. I believe this would result in a more inclusive patient centred approach, for the patients involved in such cases as it has been revealed, often, patients are seemingly discriminated against and excluded for being unable to express themselves in the matter required by the Court.

When re-imagining this case from a model of supported decision making there are clear opportunities to utilise. Undoubtedly JP suffered from learning difficulties which posed as barriers to her understanding and engagement. However, the judgment does reveal that there were times when JP attempted to communicate her opinions and preferences. There are several instances in which JP makes her feelings towards childbirth apparent. These start at para 11 where it is stated, "She had expressed a wish to have a natural birth."⁸⁶² This is followed at paragraph 23 where

⁸⁶⁰ ibid [43].

⁸⁶¹ ibid [45].

⁸⁶² ibid [11].

it is stipulated, "JP has said she did not want a caesarean".⁸⁶³ Again, at paragraph 30 where it is explained that "JP understood some basic information about her pregnancy",⁸⁶⁴ that "she would like to push the baby out"⁸⁶⁵ and that "when a caesarean section was mentioned she said she did not want to be cut open". 866 Rather than considering these preferences, a blanket assumption of incapacity was made which excluded JP's participation from all of the proceedings. Granted, I am not arguing that full weight should have been given to JP's wishes, rather, that under a supported model, there would have been some consideration of her preferences, rather than disregarding them owing to her learning disability. It is her learning disability, not her behaviour, that was highlighted as the reason for her nonparticipation. In the judgment Dr Sullivan states, "JP's lack of engagement in the decision-making process arose from her learning disability rather than from her simply being obstructive.", further that "due to the combination of her limited intellect being exacerbated by her stress level and the behaviour this brings about". JP's disability should have been accounted for in the decision-making process and not been the reason for her exclusion.

5.11.2.4.1 Re-imagined case of JP

This case is concerned with an application for a covert caesarean section on a young woman.

It is widely accepted that pregnancy is often accompanied by an increase of anxieties. Whether it is the expectant mother worried over the health and well-being of her unborn child, the surrounding family and friends wishing for a safe and uncomplicated pregnancy, or in some cases, such as the one to which this judgment is concerned, the healthcare professionals over the welfare of both the unborn child and expectant mother in terms of obstetric care and subsequent delivery.

⁸⁶³ ibid [23].

⁸⁶⁴ ibid [30]. 865 ibid.

⁸⁶⁶ ibid.

Central to all these scenarios is that of the mother and child. It must never be overlooked that it is indeed the mother's pregnancy and as such, her concerns, wishes or beliefs must always be given due consideration, whether it be during the pregnancy, during the delivery or post pregnancy.⁸⁶⁷ Note, if it is believed that the mother poses a risk to the unborn child, it is undisputed that such circumstances could warrant an intervention.⁸⁶⁸ However, should this be the case and there is an application by healthcare professionals to override the mother's autonomous choices in favour of an alternative obstetric plan, such a request must be firmly evaluated and must at all times try to accommodate the mother's wishes and preferences.⁸⁶⁹ If it is not possible to do so, the process must be clearly articulated to the expectant mother by whatever means possible as to avoid any further stress in what is undoubtedly already a highly emotional period.⁸⁷⁰ It must be stressed that it is imperative that every attempt should be made to include the mother within the decision-making process.⁸⁷¹

Today, we are concerned with questions over how to help manage a sensitive situation regarding a 25-year-old expectant mother, JP, and her delivery plan. The

⁸⁶⁷ Jennifer M Torres, Raymond G De Vries, 'Birthing Ethics: What Mothers, Families, Childbirth Educators, Nurses and Physicians Should Know About the Ethics of Childbirth' 18 (1) (2009) *Journal Perinatal Education* 12; NHS England, National Maternity Review, Better Births, Improving Outcomes of Maternity Services in England, A Five Year Forward View for Maternity Care' (2016) available at https://www.england.nhs.uk/publication/better-birthsimproving-outcomes-of-maternity-services-in-england-a-five-year-forward-view-for-maternitycare/ [Accessed 10/09/2023].

⁸⁶⁸ National Institute for Health and Care Excellence, 'Antenatal and postnatal mental health: clinical management and service guidance' Clinical Guidance [CG192] (2014) [Last updated: 11/02/2020] Available at: <u>https://www.nice.org.uk/guidance/cg192</u> [Accessed 14/10/2023]. ⁸⁶⁹ Sue Kruske, Kate Young, Beck Jenkinson, Ann Catchlove, 'Maternity care providers' perceptions of women's autonomy and the law' 13 84 (2013) *BMC Pregnancy Childbirth* 1; Keith Begley, Deidre Daly, Sunita Panda et al, 'Shared decision-making in maternity care: Acknowledging and overcoming epistemic defeats' 25(6) (2019) *Journal Evaluation Clinical Practice* 1213.

⁸⁷⁰ Katie Cook, Colleen Loomis, 'The Impact of Choice and Control on Women's Childbirth Experiences' 21 (3) (2012) *Journal Perinatal Education* 158; Sue Kruske, Kate Young, Bec Jenkinson, Ann Catchlove, 'Maternity care providers' perceptions of women's autonomy and the law' 13 (84) (2013) *BMC Pregnancy Childbirth* 1; National Institute for Health and Care Excellence, 'Intrapartum care: existing medical conditions and obstetric complications' Quality standard [QS192] (28/02/2020).

⁸⁷¹ Katie Cook, Colleen Loomis, 'The Impact of Choice and Control on Women's Childbirth Experiences' 21 (3) (2012) *Journal Perinatal Education* 158; Helen J Taylor, 'What are 'Best Interests'? A Critical Evaluation of 'Best Interests' decision-making in clinical practice' 24(2) (2016) *Medical Law Review* 176.

Trust has asserted that JP lacks the relevant capacity to participate in the decisionmaking process. It is the court's duty to ensure that s4 MCA has been adequately applied in the respect of reviewing JP's life holistically. Thus, the primary issue before the Court is how we can help support the expectant mother and assess factors such as her surrounding network and home life, to determine the appropriate steps forward. We have been informed of the following by the applicant Trust; JP has learning disabilities; she is in a relationship with the expectant father and is currently residing in a supported living placement after having moved out of her mother's house. JP has expressly stated she wishes to have a natural birth; however, the Trust believes JP lacks the capacity to make such a decision herself, which brings us to the application before us.

The Trust submits that it is in JP's best interests to:

- i) Deliver her baby via a caesarean section under general anaesthetic
- ii) To be transferred from her home in accordance with the transfer plan
- iii) Not to inform her of the outcome of these proceedings

Prior to examining each of these asserted interests in turn, it is important to re-visit the definition of best interests as set by Baroness Hale in *Aintree v James* to provide sufficient context to the judicial reasoning.

"The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must

consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be."⁸⁷²

Thus, it is clear that best interests such be approached from a holistic viewpoint, however, it would appear that the assessment of JP has been conducted from a purely medical perspective.

As the Court is aware a caesarean section is against JP's wishes, it is necessary to determine whether a fair assessment has been conducted and has accounted for the following:

- i) JP's emotional well-being and support
- ii) That information has been disseminated effectively to JP
- iii) That there were reasonable steps taken to ensure appropriate communication and understanding
- iv) Whether there was support regarding JP's sense of control to enable her to build trusting relationships with the relevant healthcare providers.

This case provides us with an opportunity to challenge the stigma that continues to exist regarding disabled mothers and their caregiving and mothering capabilities. Disabled people and their families frequently experience inequalities in accessing health services, facing poor communication and challenging attitudes amongst some healthcare providers.⁸⁷³ This case can serve to remedy some of these difficulties and illustrate that by effectively employing supported decision-making helps mitigate such discrimination.

⁸⁷² Aintree University Hospitals NHS Foundation Trust (Respondent) v James (Appellant) [2013] UKSC 67 [26].

⁸⁷³ Afia Ali, Katrina Scior, Victoria Ratti, Andre Strydom, Michael King, angel Hassions, 'Discrimination and Other Barriers to Accessing Healthcare: Perspectives of Patients with Mild and Moderate Intellectual Disability and Their Carers' 8(8) (2013) *PLoS One* 1; Reem Malonf, Jane Henderson, Maggie Redshaw, 'Access and quality of maternity care for disabled women during pregnancy, birth and the postnatal period in England: data from a national survey' 7(7) (2017) *BMJ Open* 1, Karen McBride-Henry, Solmaz Nazari Orakani, Gretchen Good et al, 'Disabled people's experiences accessing healthcare services during the COVID-19 pandemic: a scoping review' 23(346) (2023) *BMC Health Services Research* 1.

As with the Trust seeking this application, it is accepted that concerns regarding disabled women's abilities to cope with pregnancy and motherhood exist beyond this case. However, according to the social model of disability, it is suggested that disability is a social construction resulting from structural and attitudinal barriers encountered by people with impairments.⁸⁷⁴ Further, the model views people as socially oppressed and argues for policies and practices that facilitate full inclusion. It is abundantly clear from the information supplied to the court today that the inclusion of JP in the relevant proceedings was absent. That being said, this Court does not believe the exclusion of JP was a result of ill intent; we assert it has resulted from an omission which has occurred due to a lack of knowledge and experience in planning and providing care for pregnant, disabled women. We do not doubt that the trust has acted in what they honestly believe to be in JP's best interests, nevertheless, their assessments have not adequately provided opportunities for JP to articulate her wishes and preferences. Communication has obviously failed at some stages which has resulted in a loss of dignity for JP.

Prior to seeking approval for the application of not only a forced caesarean section, but a covert one, the court must consider whether the trust and relevant healthcare professionals fulfilled the following steps set out by the Code of Practice:

- i) "Communication"⁸⁷⁵ has the Trust taken sufficient measures to ensure JP was provided with the required support to articulate her preferences? (Section 3.10)
- ii) Further, upon realising and determining the extent of JP's learningdisabilities did the Trust and relevant healthcare professionals abide by

⁸⁷⁴ Stephen Bunbury, 'Unconscious bias and the medical model: How the social model may hold the key to transformative thinking about disability discrimination' 19 (1) (2019) *International Journal of Discrimination and the Law* 26; Iryna Babik and Elena S. Gardener, 'Factors Affecting the Perception of Disability: A Developmental Perspective' 12 (2021) *Frontiers in Psychology* 1.

⁸⁷⁵ Mental Capacity Act 2005 Code of Practice s3.10.

Section 3.11, "Helping people with specific communication or cognitive problems"? ⁸⁷⁶

- Did the Trust and relevant healthcare professionals consider section 3.15
 of the Code of Practice? (Support from other people)⁸⁷⁷
- iv) Finally, did the Trust seek if there were any other ways to enable decisionmaking?

A statement has been provided to the Court from Dr Sullivan, consultant obstetrician and gynaecologist:

"She would not engage in any conversation with Dr Sullivan now including over labour, burying her head in her hands, banging her hat on the table and shouting and swearing at staff. She calmed down but when Dr Sullivan attempted to speak about childbirth she again disengaged and when a caesarean section was mentioned she said she did not want to be cut open. She appeared to understand the simple outline but could not understand or explain anything beyond that. She said that as it was her baby she would do what she wanted."⁸⁷⁸

At no point during the evidence submitted to the Court has it been made apparent whether any consultation took place between the healthcare professionals and any people who know JP well in order to ascertain what the best form of communication would be for speaking with JP. Whilst we have been informed that the "boyfriend"⁸⁷⁹ and "several individuals"⁸⁸⁰ attended the appointment with JP, it is not explicit who the "several individuals" were, whether the boyfriend – or perhaps more appropriately referred to as the expectant father, was able to communicate to the professionals on behalf of JP. In fact, it is not mentioned in what capacity any of the

⁸⁷⁶ ibid [3.11].

⁸⁷⁷ ibid [3.15].

⁸⁷⁸ NHS Trust v JP [2019] EWCOP 23 [ix].

⁸⁷⁹ ibid [9].

⁸⁸⁰ ibid [ii].

third parties attended. The crux of the Trust's application appears to rest on JP not being able to expand upon her reasoning of:

- "She had expressed a wish to have a natural birth".⁸⁸¹
- "JP has said she did not want a caesarean".882
- "JP understood some basic information about her pregnancy, that she would like to push the baby out".⁸⁸³
- "When a caesarean section was mentioned she said she did not want to be cut open".⁸⁸⁴

On consideration of the above and in the absence of an explanation of the role of the aforementioned third parties, the court is confused as to why an advocate (someone who can support and represent JP) was not employed to improve JD's communication in this situation.

An additional concern of the Court is the apparent failure of the professionals to recognise the non-verbal methods of communication expressed by JP. The code of practice states that changes in behaviour can provide an indication of the patient's feelings. The above extract for example, shows that when talking about childbirth, JP appeared to engage and that engagement faltered when talk of the caesarean section was reprised. It appears to the court that the professionals failed to acknowledge JP's physical responses as a means of articulating her feelings.

Building upon the above, it is clear to all parties concerned that JP was visibly distressed. The Court is not satisfied that steps were taken to put JP at ease. As the healthcare professionals were aware of JP's disability prior to the consultation with Dr Sullivan, the Court believes that in order to provide JP with the best chance of participation an alternative location should have been identified where JP could have felt more comfortable.

⁸⁸³ ibid [iv].

⁸⁸¹ ibid [11].

⁸⁸² ibid [vi].

⁸⁸⁴ ibid [ix].

Finally, it appears another area of the code of practice has been neglected. Section 3.16 refers to additional means to improve the communication of the patient. As it has been submitted that the main barrier to JP's participation was her learning disability, a designated support worker should have been employed to help. For example, in the evidence submitted by Dr Sullivan, it is stated that "JP's lack of engagement in the decision-making process arose from her learning disability rather than from her simply being obstructive",⁸⁸⁵ further that "due to the combination of her limited intellect being exacerbated by her stress level and the behaviour this brings about".⁸⁸⁶

From the limited information presented before the Court it easily discernible that the patient had familial support available to her. Further that the patient was able to communicate – albeit not up to the standard expected by the trust. It is at this stage of the judgment that a correction must be issued to the trust for failing to comply fully with the supported decision-making regime advocated for by the MCA and adjoining code of practice and instead operating on what appears to be an interpretation of individualistic autonomy.

Owing to the above discrepancies and failings of the trust and healthcare professionals to implement the required steps to facilitate supported decisionmaking, the court is left with quite the conundrum. Unfortunately, owing to the nature of pregnancy (that time is inevitably of the essence), it is not plausible, or even ethical, to submit JP to further consultations even with the above support enlisted. The aim of the court is to minimise any further distress to JP and her unborn child. Our present worry is that owing to the manner in which previous proceedings have been conducted, is that JP may be too distressed to sustain a natural birth, and taking guidance from medical expertise, our priority is to reduce harm to both the mother and baby. However, the court is not sufficiently satisfied that such a procedure needs to be carried out covertly. As such, the Court orders that a designated support worker be employed and that a further meeting is carried out at JP's place of residence, which is to be attended by both the expectant father and

⁸⁸⁵ ibid [24].

⁸⁸⁶ ibid.

JP's mother. During this meeting it should be explained that it is medically necessary for a caesarean section to take place and that it is in JP's best medical interests to be sedated for the procedure.

The Court therefore rejects the third ground of the application.

Prior to the closing of the session, the Court would like to strongly emphasis the unfortunate manner of these proceedings and that there has been a failing of due diligence for allowing the pregnancy to advance to such a late stage without employing the necessary models of support for JP.

5.11.2.5 Comment

These four cases have each presented a different set of facts, all based around issues of a pregnant woman whose capacity is doubted. In each of the cases, the priority is given to a best interests assessment which seemingly disregards the wishes and feelings of the patient. Further, that when a female patient disagrees with the prevailing medical opinions, concerns are often raised regarding their capacity to participate within the medical decision-making process. Significantly, the final case JP evidenced that even when supported by family and the child's father, a declaration of incapacity eradicates any form of autonomy, whether it be individual or relational. Had these cases been approached from an alternative perspective, one of supported decision making and relational autonomy, it is probable that the women in these cases would have benefited from retaining a greater sense of selfdetermination. Had relational autonomy been employed it would have meant that the women and their abilities would not have been judged in isolation, but instead, alongside their support networks (whether that be family members or healthcare workers). In both X and JP, the pregnancies occurred naturally, and the women gave birth to healthy babies. There seems to be an overarching attitude that rather than going through the process of engaging with the individual, the Trusts are more likely to refer to the Court for a declaration that permits them to act without the consent of the patient to streamline the process of managing a potentially difficult pregnancy.

Owing to the biological differences, it is impossible to complete a "like for like" comparison with a male patient within the CoP. However, comparisons can be made

more generally regarding assessments of capacity on male patients within the CoP. As demonstrated in the cases of CD & JP, their refusal to comply with the recommended treatment resulted in them being labelled as "disengaged", "aggressive" and "rude". Therefore, it is interesting to consider the differences in judicial tone when it is a male patient who is refusing treatment. The recent case of KG (by his Litigation Friend) X Local Authority involved a 68-year-old inpatient at Kingsgate Hospital who had been an inpatient since 2016.887 KG was clinically fit for discharge; however, he did not want to leave the hospital. However, rather than his personal character being subject to review, focus was instead given to his condition and how "difficult" it was to treat.⁸⁸⁸ Further para 33 of the judgment reveals "It is relevant for me to point out that when I spoke with KG on the telephone, he told me that it was "all right" speaking with Dr S. For my part, I find that reassuring, for it indicates that KG was probably relaxed in submitting to the capacity assessment rather than resistant to the same". KG's compliance with speaking to the doctor resulted in Mr Justice Cobb feeling "relaxed" which draws connotations from the earlier survey results that so long as a patient agrees with the clinical opinion, capacity is less likely to be doubted.

Another recent case concerning a male P provides an alternative insight relating to the role of gender within the CoP, particularly Gilligan's feminist theory concerning the influence of shared experiences.⁸⁸⁹ The case, *Pennine Acute Hospitals NHS Trust and TM (by his litigation friend, the Official Solicitor)*⁸⁹⁰ is incredibly tragic and involves a man who was found collapsed at a bus shelter in Manchester. P was discovered to be suffering from acute kidney injury, secondary muscle damage and accompanying anaemia⁸⁹¹ and was requiring a bilateral below- knee amputation.⁸⁹² The medical professionals dealing with P described him as lacking in

⁸⁸⁷ KG (by his Litigation Friend) X Local Authority [2021] EWCOP 30.

⁸⁸⁸ ibid [22].

⁸⁸⁹ Carol Gilligan, Feminist Legal Theory and the Ninth Circuit' (1993) 8 *Wisconsin Women's Law Journal* 143.

⁸⁹⁰ Pennine Acute Hospitals NHS Trust and TM (by his litigation friend, the Official Solicitor) [2021] EWCOP 8.

⁸⁹¹ ibid [2].

⁸⁹² ibid [1].

engagement,⁸⁹³ not "forthcoming" ⁸⁹⁴ and generally "challenging".⁸⁹⁵ However, these comments are in stark contrast to those provided by Mr Justice Hayden, who stated:

"In the light of all I had heard, it came as something of a surprise to me, that he engaged with me easily, openly and with great courtesy. I found him to be an intelligent man and an articulate one. He and I discussed football, discovering we supported the same team. He had obvious enthusiasm for it and up to date knowledge."⁸⁹⁶

The stand-out point from Justice Hayden's observations is the discovery of a shared passion between the two. This "common-ground" is reminiscent of what Derbyshire identified much earlier on in this chapter. Derbyshire stated: "Judges used their own experiences as reference points"⁸⁹⁷ This difference of opinion between the judiciary and the medical professionals is rare, as usually the judiciary relies upon the medical expertise. However, the connection formed over football seems to prevail. Hayden continued that. "His enthusiasm for his football team and for nature (as described above) also signalled to me a man who was interested in and engaged with life."898 This suggests that shared experiences can have an influential impact on the discourse of judgments. Whilst this case does not necessarily indicate a gender imbalance, it does give some credence to the claim that gender stereotypes (in this case men and football) can have some bearing on the capacity proceedings. Almost more importantly, this case provides legitimate grounding for the basis of my proposed model of supported decision making, as this is evidence that the kind of empathy required is possible and does lead to good outcomes for patients. Furthermore, the tools/frameworks already exist, for example, MCAs, litigant friends, s 4(6) and the checklist in the CoP. The approach would work as evidenced in the case of KG, at times the Courts will express empathy, they just do not apply it consistently.

⁸⁹³ ibid [4].

⁸⁹⁴ ibid [9].

⁸⁹⁵ ibid [10].

⁸⁹⁶ ibid [23].

⁸⁹⁷ Penny Darbyshire, *Sitting in Judgment: The Working Lives of Judges* (Hart Publishing 2012) 237.

⁸⁹⁸ Pennine Acute Hospitals NHS Trust and TM (by his litigation friend, the Official Solicitor) [2021] EWCOP 8 [24].

5.12 Do capacity assessments need to be reformed?

Gibson argues that the concept of capacity as defined in the Mental Capacity Act (2005) is conceptually flawed and places practitioners in an impossible situation regarding its application.⁸⁹⁹ Gibson asserts that the Act claims a distinction between capacity/incapacity is natural and that incapacity is an intrapsychic feature of an individual. I am of the opinion that Gibson touches on an incredibly important point, we are all individuals, with different sets of beliefs and cultures and attitudes. Therefore, it seems somewhat inappropriate to limit the application of "capacity" to those who are capable and those who are not. This line of thinking is supported by the CRPD, notably Article 12, which dictates that all individuals are entitled to legal capacity. Thus, it is fitting that academics such as Williamson, Graham and Cowley believe that the framework of the MCA should be understood in a much broader context and as part of the movement in health and social care for greater protection of those experiencing vulnerability, whilst also empowering individuals to act with self-determination.⁹⁰⁰ It is incredibly important that the MCA is understood to adopt a more inclusive approach in order to become more accessible to people who may experience issues with capacity. It is important to recognise that CRPD proponents would argue that we need to dismantle the MCA all together, to re-iterate, that is not what this model asserts, instead the model asserts the MCA required re-framing to create an approach which will maximise autonomy and capacity.

The MCA outlines the conditions under which an individuals' actions are to be respected, but also outlines the conditions under which an intervention can be made. Where the individual is found to have capacity, their actions are to be respected and therefore capacity is thought of as the "gatekeeper to the right of autonomy".⁹⁰¹

⁸⁹⁹ David Gibson, 'Negotiating Relationality: Mental Capacity as a narrative congruence' 23 (2017) *International Journal of Mental Health and Capacity Law* 1.

⁹⁰⁰ Toby Williamson, 'Capacity to Protect – The Mental Capacity Act explained' (2007) 9 (1) *Journal of Adult Protection* 25, 31; Matthew Graham, Jackie Cowley, *A Practical Guide to the Mental Capacity Act 2005: Putting the Principles of the Act Into Pract*ice (Jessica Kingsley Publishers 2015) 16.

⁹⁰¹ Mary Donnelly, Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism (CUP 2010) 2.

Gibson believes that whilst the Act has "received political praise and support" ... "considerable difficulties remain".⁹⁰² Such difficulties focus on the non-binding status of the Code of Practice and the lack of a definitive guide for compliance with the MCA.⁹⁰³ Gibson believes that it is questionable "whether a capacity assessment in accordance with the Act can be performed".⁹⁰⁴ Further critique has been identified by Heywood et al who state, "the context of research, the MCA (2005) has been criticised for lacking an appropriate balance between protection from exploitation and empowerment, with emphasis placed on the former. Indeed, the MCA postlegislative scrutiny criticised the implementation of the Act in care contexts, noting a culture of protection and paternalism amongst professionals working with people who may lack capacity".⁹⁰⁵ As established through the review of the CRPD and the subsequent issues involved with the Act's compliance with unequivocal legal capacity, there are obvious issues with capacity assessments. Through reviewing a range of cases from the Court of Protection, it is clear that at times, not all possible resources are employed in order to enhance patient capacity and provide opportunities to exercise autonomy.

When the MCA introduced a statutory definition of capacity in medical law it was heralded as a triumph for personal autonomy, as it recognised that as far as possible, people should be able to play an active role in decisions concerning their welfare.⁹⁰⁶ Alghrani et al explain that "the law, therefore, assumes that everyone has the ability to act and take decision in accordance with their own interests and affords primacy to individual priorities over paternalistic imperatives".⁹⁰⁷ However, as previously alluded to through the work of Gibson, the Act has attracted a great deal of criticism. This in part was due to the ambitious scope of the MCA's application.

⁹⁰² David Gibson, 'Negotiating Relationality: Mental Capacity as a narrative congruence' (2017) *International Journal of Mental Health and Capacity Law* 49.

⁹⁰³ Department for Constitutional Affairs, Mental Capacity Act 2005: Code of Practice (TSO, 2007).

⁹⁰⁴ David Gibson, 'Negotiating Relationality: Mental Capacity as a narrative congruence' (2017) *International Journal of Mental Health and Capacity Law* 49, 50.

⁹⁰⁵ Harley Ryan, Rob Heywood, Olyseyi Jimoh et al, 'Inclusion under the Mental Capacity Act (2005) A Review of research, policy guidance and governance structures in England and Wales' 24 (2020) *Health Expectations* 152, 153.

 ⁹⁰⁶ Amel Alghrani, Paula Case and John Fanning, 'Editorial: The Mental Capacity Act 2005 – Ten Years On; (2015) 24 *Medical Law Review* 311.
 ⁹⁰⁷ ibid.

Alghrani et al expand that "A major challenge for its drafters was to devise a coherent framework through which decision makers could determine whether P lacks capacity to make her own decisions and what to do when she is found to lack that capacity".⁹⁰⁸

Undoubtedly, there have been some successes to claim from the Act, such as the decision in *Aintree University Hospitals NHS Foundation Trust v James*,⁹⁰⁹ in which the Supreme Court were heralded for insisting that the perspective of incapacitated patients should be central to the MCA best interests test. The case illustrated judicial acceptance of the fundamental principle that the patients' interests should take primary position as opposed to practical expediency or any form of paternalistic measures. This case evidences that inroads have been made, but the problem remaining is that such an approach is not universal. Problems still remain, particularly so with the application of the law for women, thus change still needs to be implemented as the problems associated with the MCA outweigh the positives. Substituted decision making remains dominant, the criteria surrounding patient participation is far too vague and as a result is easily excluded owing to the prevalence of paternalism.

5.13 Conclusion

This chapter set out to establish that a relational approach to capacity assessments and the implementation of a supported decision-making regime would result in fairer and more consistent outcomes for exercising a patient's autonomy. Through an extensive review of both the theoretical elements of the legislation and how the legislation operates in practice it has become evident that at present, the MCA and its assessments of both capacity and best interests are insufficient to safeguard and protect everyone's equal right to legal capacity. A supported decision-making regime would be compatible with a relational approach which would require that the patient's social setting be considered when making judgments concerning the appropriate treatment and course of action.

⁹⁰⁸ ibid [312].

⁹⁰⁹ Aintree university Hospitals NHS Foundation Trust v James [2013] UKSC 67.

At present, the procedural approach is too narrow to deal with the highly charged, often emotionally disturbing cases that come before the Court of Protection.⁹¹⁰ If the approach were to evolve to consider the patient's lifestyle and support structure, it is inevitable that different outcomes would occur as a result. Whilst it cannot be guaranteed if the outcomes would be "better", it is probable that the outcomes would be greater aligned with the personal beliefs of the patient, enabling them to exercise their right to self-determination. According to the CRPD, an individual's views should take primacy wherever possible (the exception is explained for those who physically are unable to make decisions about their lives). I agree with the ethos of the CRPD and that the process of increased supported decision making, would come hand in hand with a move towards a relational model. From a patient perspective, it would save a great deal of unnecessary emotional distress, evidenced in the cases of both X and JP who delivered healthy babies naturally. From comparing the judicial language in the Court of Protection to assess if any differences existed between female P's and male P's two findings were evident; that the character of a male P attracted less attention in the court proceedings and further that can the Justice draw on shared experiences with the P to create an empathetic narrative.

Incapable patients should not be excluded from the decision-making process for the sake of convenience, incapable patients cannot be viewed from a binary perspective of "yes" they can do this or "no" they can't do that. A relational approach would provide the system with a far more inclusive regime, where the goal is to include, not exclude.

⁹¹⁰ Cases concerning best interests are not exclusive to the Court of Protection, best interests decisions are made daily. The approach of supported decision making, and relational autonomy would apply to all best interests' decisions.

6 Thesis Conclusion

"This isn't a trivial issue about who wears pink or blue, gender stereotypes are harmful. But the evidence is clear, the wiring in our brains is soft not hard. We can challenge attitudes and change lives, but we must wake up to the harm that gender stereotypes are doing to all of us and the price that we are paying for it."⁹¹¹

This thesis has explored the impact of gender stereotypes on medical decision making. The original and core contribution of knowledge has been uncovering the effects of such stereotypes and implicit biases and suggesting these can be mitigated through the adoption of supported decision-making which embodies the ethos of the CRPD whilst maintaining the MCA. This aspect differentiates the argument from existing literature which views the instruments in a decidedly more binary nature; from the proponents who believe the MCA is effective and those who believe it should be abandoned in favour of the approach offered by the CRPD. It is important to note that such an adoption will not eradicate gender stereotypes. As extensively discussed within the thesis, gender stereotypes have become part of society through social constructionism. Rather, supported decision making will recognise the impact these stereotypes can have on both the depiction and treatment of female patients. Further, this is not to say that patient empowered supported decision making will result in a series of judgments that fully accord with the patients' wishes and prefers; rather, it will reduce the marginalisation faced by those with impaired capacity, by moving away from functional and cognitive conceptions of capacity and instead, including and "supporting" the emotions of the patient within the wider web of their social context.

⁹¹¹ Sam Smethers, 'Fawcett Research Shows Exposure to gender stereotypes as a child causes harm in later life' (07/03/19) *Fawcett Society* available at <u>https://www.fawcettsociety.org.uk/news/fawcett-research-exposure-gender-stereotypes-child-causes-harm-later-life</u> [Accessed 10/08/2023].

6.1 Summary of Research Questions

(1) What gender stereotypes exist in relation to women?

This thesis has revealed that the stereotypes faced by women are manifold. Women are consistently doubted of being able to determine the course of their own actions. Sadly, as demonstrated throughout the thesis, these attitudes have culminated in practical consequences for women, who are now more statistically likely to require support from third parties owing to issues such as a lower socio-economic status and other responsibilities such as being the primary carer. Thus, highlighting the need for an adoption of a relational approach to supported decision making.

From birth, girls are expected to be "pretty" and "cute". On reaching adolescence, teenagers have faced wrongful discrimination based on sexual activity. The case of Gillick illustrated viewpoints that inferred if an adolescent girl received contraception, it would result in her becoming promiscuous. Note, no such language or treatment is had in respect of adolescent teenage boys, for whom sexual activity is considered as a rite of passage, with a more "slap on the back" approach.

Further discrimination results should a woman become pregnant; even in cases when the pregnancy is a result of a sexual assault. There are many conceptions that purport pregnancy reduces a woman's ability to act and think cognitively; aka, that women suffer from "baby brain", so cannot possibly formulate a reasoned conclusion regarding their own treatment. Note: not all such opinion comes from a place of ill intent; some cases illustrate a desire of professionals to preserve and protect the alleged "maternal instinct" and the health of both mother and baby. However, decisions are often made in such a manner that actively excludes the mother to be from the relevant discourse. However, it would be wrong to form a blanket assumption in this regard, as some of the cases discussed in the course of the thesis displayed a pure disregard for the mother's own personal welfare because such societies expect the welfare of the foetus to be prioritised.

Another significant area where women face the consequences of harmful stereotypes relates to healthcare more generally, namely, the treatment and management of pain, where women often face responses that they are too emotional and complain too much.

All in all, even in 2023, society remains very much, a male dominated world. This can even be recognised in the professional gender disparities which extends to both the judicial and medical sectors where there is an overwhelming under representation of women.

(2) How do judicial constructions of women engage with such stereotypes to the detriment of women's autonomy?

A theme exists across judgments that information is often withheld from women on the basis that it would affect their emotional stability which would result in negative consequences for the patient's health. The consequence of this approach results in barriers to women being able to exercise their autonomy as they are prevented from effectively participating in the relevant discussions. Sometimes, cases have even illustrated a complete disregard for any "emotional" impact for the woman, instead basing decisions on their medical expertise which is believed to be too complicated for the lay person to understand, therefore, attempting to explain such information would result in patient confusion.

(3) What is relational autonomy and how can it counteract the detrimental effect of such stereotypes on women's autonomy?

Relational autonomy acknowledges the potential emotional consequences and elements of such decisions, but as opposed to individual autonomy which prioritises the atomistic agent, it requires and encourages collective action. It provides a mechanism whereby the patient is helped by third parties to participate in decision making processes regarding her health, by recognising her individual, wider context. Whilst this argument may be subject to rebuttals that the inclusion of an emotional element serves to reinforce the previously articulated stereotypes, a counter exists. It is futile to deny the existence and impact of stereotypes and it would be both completely unfeasible and ignorant to assume that, for example, a change in legislation or guidance would magically result in a universal dismissal of such stereotypes. Rather, the question needs to be how can we work with such stereotypes in order to promote patient autonomy? The answer lies in a relational approach to supported decision-making; offering a holistic view of the patient which actively seeks to include, rather than exclude on the basis of marginalisation.

6.2 Summary of recommended changes

"All the legislative frameworks, obligations and guidance in the world means nothing if the principles and ways of putting them into practice are not shared or communicated properly. Ambiguity can only undermine the confidence of those who wish to service the best interests of others and may delay or degrade a positive outcome".⁹¹²

This section will summarise the suggested changes that have been discussed throughout the thesis. As per its title, the aim of this research has been to illustrate how a relational approach to best interests can mitigate the influence of gender stereotypes on the participation of a patient during the decision-making process. In order to achieve a relational approach, changes are required to the Mental Capacity Act and its adjoining Code of Practice, as well as the GMC guidance. By altering each of the instruments individually, the effect will be cumulative, resulting in less ambiguity and an increased level of consistency with regard to patient participation. As evidenced, there is prima facie assumption of relational autonomy within the MCA and there is some guidance regarding supported decision-making. However, the theory is not translating effectively to practice. I assert these failings can be attributed to the vagueness of the legislation and guidance, absence of statutory definitions and the binary nature in which capacity is currently viewed. Therefore, this

⁹¹² Baroness Finlay, 'Dignity, safety, liberty – watchwords for the Mental Capacity Act' *Gov.uk* (22/07/2016) available at <u>https://socialcare.blog.gov.uk/2016/07/22/dignity-safety-liberty-watchwords-for-the-mental-capacity-act/</u> [Accessed 20/09/2023].

section of the conclusion will re-iterate a series of suggestions for amendments to improve medical interactions and the subsequent patient experience. Change is needed to articulate the focus of the MCA in terms of promoting capacity to enable decision-making for those within the ambit of its protection.

6.2.1 Suggested changes for the MCA 2005

"The principles of the Act must be spelt out more clearly"913

As demonstrated throughout this thesis, one of the fundamental flaws of the MCA rests on its inherent vagueness. As demonstrated through the various case analysis' application of the provisions can result in subjectivity. Whilst there will always be a degree of subjectivity owing to individual circumstances, all individuals should be provided with the same opportunities to allow for patient participation.

6.2.1.1 "So far as reasonably practicable"

A central tent of concern is found within s4(4) of the MCA. It dictates that the healthcare professionals should encourage the patient to participate or improve his ability to participate as fully as possible – but only so far as it is reasonably practicable. The inclusion of "reasonably practicable" reinforces the inherent power imbalance within medical dialogues. It is for the healthcare professional to judge whether it is feasible to promote patient participation, rather than the MCA discharging an automatic obligation to do so. Therefore, this caveat introduces a great deal of subjectivity. This thesis has not sought to deny subjectivity. However, in terms of opportunities and assistance provided to patients, there should be a standardised approach, as every patient should be offered a full and fair chance to participate in the decision-making process. Just as patients differ, so do health care

⁹¹³ ibid.

professionals and any deviations can result in differing levels of encouragement and assistance. What must be recognised is that autonomy is not an absolute concept; there are ways to infer autonomy as opposed to conceptualising it as an all or nothing approach. Emotions and feelings are a means of communication for many patients and rather than being discounted and regarded as a failure to articulate and express an opinion, through the correct and proper support, these emotions can be interpreted as a patient attempting to express their opinions on whatever treatment or decision is being proposed. At present, there is a lack of security in terms of safeguarding such expressions. As explained, assessments are not fully determined by a procedural criterion, thus allowing for the potential permeation of stereotypes and pre-cast assumptions to impact upon judgments of a patient's potential abilities. The practicable standard results in further risks for prejudice impeding upon the opportunities afforded to the patient's involvement.

6.2.1.2 "Reasonably ascertainable"

Another aspect of the MCA which poses a challenge to the involvement of the patient is found within s6 which refers to the patient's wishes and feelings. Similarly to the issues embedded within the caveat of reasonably practicable, in absence of a clear criteria or definition of what standard "reasonably ascertainable" sets, further ambiguity is introduced to the decision-making process. Section 6 is designed to account for the patient's wishes (be they past or present), yet again though, owing to the vagueness of what is practically required, the standard remains open to interpretation. This poses the risk of reverting the narrative to one of "doctor knows best", retaining an "in-control" model of autonomy where best interests are interpreted as best medical interests. When this section is compared with Article 12 of the CRPD, it is abundantly clear that the MCA is lacking in its ability to provide for the will and preferences of an incapacitated patient within the decision-making process.

6.2.1.3 "If it is practicable and appropriate to consult them".

The third critique of the MCA is in relation to the role of third parties. Section 4(7) of the MCA explains that the views of third parties who have a proximate relationship with the patient should be taken into consideration. However, once more, this requirement is negated if it is not deemed to be "practicable". This does not go far enough to ensure a relational approach is applied. Whilst it can be said that this section does provide a degree of acknowledgement concerning the importance of third parties, the way in which it is constructed continues to harbour the potential to exclude the patient from the process. The section would be improved by providing for a universal dialogue, whereby the patient is present and the third party is able to provide assistance, whether that is by helping the patient articulate their opinions, or even just to provide emotional support during the decision-making process. Practicable is too subjective a requirement as it can result in the support system surrounding the patient to be ignored. A decidedly more stringent criteria is required, for example, setting out an assumption that the third party will be consulted alongside the patient unless there is a track record of abuse or undue influence. This opinion is shared by academics such as Herring who calls for part of the capacity assessment to evaluate the extent to which the designated third party can provide support for the person who is alleged to lack the capacity to make the requisite decision. Baroness Finlay has stated that, "unpaid or informal carers have spoken to me of their frustration at not being consulted by health and care professionals as a matter of course. As the people arguably closest to the individuals being cared for, their insights and concerns must always be considered"⁹¹⁴ and "when it comes to matters of mental capacity, carers should feel that their voice is being properly heard in decisions about those they care for. What they know about their loved ones' needs and wants should be taken into account".915

This thesis builds upon this suggestion to call for a collaborative process to mandate third party support to aid the patient's understanding and articulation of the decision-

 ⁹¹⁴ Baroness Finlay, 'Dignity, safety, liberty – watchwords for the Mental Capacity Act' *Gov.uk* (22/07/2016) available at <u>https://socialcare.blog.gov.uk/2016/07/22/dignity-safety-liberty-watchwords-for-the-mental-capacity-act/</u> [Accessed 20/09/2023].
 ⁹¹⁵ ibid.

making process.⁹¹⁶ Should the approach evolve holistically, encompassing the patient's lifestyle and support structure, it is inevitable that outcomes would differ as a result. This does not necessarily mean the outcomes would guarantee the patient's wishes are adhered to, but it is highly probable that the preceding process would greater enable the exercise of a patient's right to self-determination. Following the ethos of the CRPD, that the process of increased supported decision making would compliment a move towards a relational model.

6.2.1.4 No statutory definition of best interests

"Best interests" are not defined in the MCA. This was a deliberate decision by those drafting the act. It would be impossible to specify in advance what would be in every individual's best interests, and such decisions will be taken by a range of professionals, in a variety of settings and circumstances. However, whilst the ambiguity of the best interests standard allows for flexibility, it fails in offering protection from biases and prejudices.⁹¹⁷

Best interests are meant to encompass more than just medical interests and were intended to follow the statutory checklist set out within section 4 of the act. However, as established, due to vagueness of the adjoining principles, there is a lack of security surrounding the interpretation of an individual's best interests and in practice the ideal of a holistic approach often fails to take shape.

6.2.1.5 Binary nature of capacity

Further, the binary nature of capacity needs to be addressed. For example, if you have mental capacity, you are entitled to make decisions that other people may think are unwise. If you are classed as lacking capacity, anything done for you must be in your best interests. A person is considered as lacking capacity if it is believed that

⁹¹⁶ Note, if a person is without friends or family, an independent advocate should be automatically appointed.

⁹¹⁷ Helen Taylor, 'What are best interests? A critical evaluation of best interests decisionmaking in clinical practice' 24 (2) (2016) *Medical Law Review* 175.

their mind is impaired or disturbed in some way which results in them being unable to make a decision at that time. However, this thesis has asserted that mental capacity is too complex to be divided into those who a) have capacity or b) lack capacity. There needs to be some allowance for those who need extra help and support to articulate themselves to meet the capacity requirements. Thus, creating a finding of supported capacity which acknowledges the patient holistically.

Further, there are intrinsic problems within the assessment process which have yet to be formally recognised. As stated in the main body, there is a considerable amount of literature which demonstrates that "aspects of behaviour" are considered when forming the basis of medical opinion. Despite the obvious prevalence of gender in medical settings, the MCA fails to reference gender as a means by which incapacity cannot be inferred.

6.2.2 Changes to the Code of Practice

The Code of Practice appears to offer a more inclusive approach to best interests than that of the MCA. It builds upon the role emotion can play in the decision-making process and further still, acknowledges the importance of emotional support. However, the guidance is lacking as to how an emotional approach can effectively be implemented consistently within the patient-practitioner dialogue to create a standard that offers patients a consistent level of care. The difficulties of implementing such guidance is exemplified by the non-binding status of the Code of Practice and the lack of a definitive guide for compliance with the MCA.

6.2.3 GMC Guidance

The GMC guidance is similarly vague and echoes sentiments such as reasonability. Section 88 states that with patients lacking capacity "reasonable steps" should be taken to determine whether there is evidence of the patients previously expressed values and preferences, that "may be legally binding".⁹¹⁸ Whether legality is attached to a value or preference should be irrelevant. Patient's wishes should command universal consideration.

6.3 Summary of chapters

My first chapter on methodology sought to answer whether relational autonomy could resolve the gender imbalance? It found that women are currently faced with a double faceted problem; an individualistic approach to autonomy which reinforces gender stereotypes. From which another question was drawn out, if gendered stereotypes were producing prejudiced outcomes for women, how exactly would the employment of relational autonomy overcome those stereotypes? Research suggested that a major problem in the construction of such outcomes is as that informed consent currently adopts an individualistic approach which fails to do enough to balance gender bias. A relational approach can do more to bridge this gap as it could help create a broader framework which would support women through the decision-making process, particularly so in relation to reproductive rights. The reason women might require further support was made evident in the discourse; women are pre-disposed to require support throughout their lives, by encompassing that realisation within the medical decision-making process and encompassing the broader social context, women would retain a greater sense of autonomy within the decision-making process. All in all, a holistic approach is required as opposed to one of a clinical nature. A proposition to remedy this situation would be a comprehensive doctor-patient consultation that embodies a relational nature. This chapter asserted that the goal of relational autonomy should be used to transform the informed consent process into a more balanced and comprehensive consultation that better supports women's autonomy, not only in the context of reproductive choices, but their whole health. This chapter revealed many flaws within the individualistic approach, particular so its framework. It is too narrow within the medical context

⁹¹⁸ GMC, 'Guidance on professional standards and ethics for doctors' (2020) s88, available at: <u>https://www.gmc-uk.org/-/media/documents/gmc-guidance-for-doctors---decision-making-and-consent-english_pdf-84191055.pdf</u> [Accessed 26/01/2023].

which results in a process which is fundamentally flawed as it fails to take into account the broader social context which would help minimise the influence of gender stereotypes. Furthermore, in the context of reproductive choices, where two beings are integrally intertwined, relational framework for informed consent should be instituted. The interrelated nature of women and foetus has no equal outside of pregnancy, which reinforces that an approach of individuality is incompatible when issues such as pregnancy involve at least two parties.

The chapter established an over-reliance on stereotypes by the medical profession, illustrating that stereotypical assumptions can impact upon the recommended treatments, the available procedures and the information provided. For example, in the US case Gonzalez vs Carhart, it was stated, "While we find no reliable data to measure the phenomenon, it seems unexceptionable to conclude some women come to regret their choice to abort the infant life they once created and sustained severe depression and loss of self-esteem can follow"919 Major et al have commented on such statements arguing that to make such assumptions about a woman's regret, are potentially overbroad and stereotypical, vitiates the woman's autonomy – it does not assist her or protect her".⁹²⁰ The chapter further advocated for supported decision-making to replace the substituted regime as it advocates and promotes a more interactive dialogue between the doctor and patients, thereby creating a collaborative decision-making process.⁹²¹ It argues that relational autonomy provides an alternative understanding that acknowledge the many social and contextual constraints and pressures that may be placed on choices while simultaneously recognising that there is value of self-determination. Relational autonomy can help practitioners understand the competing interests, influences and social pressures involved. Such dialogue will not only allow a patient to learn from doctors, but also allow a doctor to learn about the interests of particular patients and therefore not have to rely on stereotype when making recommendations. As previously stated, should patient participation increase; so, will patient autonomy.

⁹¹⁹ Gonzalez vs Carhart 550 U.S 158-59.

⁹²⁰ Brenda Major et al, Report of the APA Task Force on Mental Health and abortion (Psychological Association) available at

http:///www.apa.org/women/prgorams/abortion/mental-health.pdf.

⁹²¹ Jessica Berg et al, *Informed Consent: Legal Theory and Clinical Practice* (OUP 2001);Jay Katz, *The silent world of the doctor and patient* (JHUP 2001).

The following chapter concerning feminism supported the findings asserted by methodology. This reviewed many different factors that can impact on the existence of gendered differences and how those gendered differences place women at a disadvantage in terms of being able to access adequate and appropriate healthcare. It demonstrated that there are clear links between women being of a lower socioeconomic rank, having less power to act autonomously and as a result, often struggle to receive medical attention. Furthermore, it has been evidenced that when women are able to access medical attention, the treatment they receive is often substandard. Women are subjected to demeaning attitudes, which often paint women as hysterical, overly emotional people who cannot tolerate pain. A consequence of such dismissive attitudes has been an increased mortality rate for women, demonstrated for example, by recent studies conducted by The British Heart Foundation.⁹²² Research demonstrated throughout the chapter has revealed that women are more likely to have their physical symptoms ignored and are more likely to have pain ascribed to a supposed mental health problem and as a result are at a higher chance of severe misdiagnosis of conditions such as heart disease and as such are more likely to suffer strokes.⁹²³

The chapter revealed an overwhelming theme that women are penalised for being women. The medical profession bases itself on a male standard patient.⁹²⁴ The dictum demonstrated throughout the courts, the information presented in medical

⁹²² British Heart Foundation, *Bias and biology: how the gender gap in heart disease is costing women's live* (2019) available at <u>https://www.bhf.org.uk/what-we-do/news-from-the-bhf/news-archive/2019/september/heart-attack-gender-gap-is-costing-womens-lives</u> [Accessed 11/11/23].

⁹²³ Jennie Popay, Mel Bartley, Charlie Owen, 'Gender inequalities in health: social position, affective disorders and minor physical morbidity' 36 (1993) *Social Science Med*icine 21; Carol Vlassoff, 'Gender Differences in Determinants and Consequences of Health and Illness' 25 (1) (2007) *Journal of Health Population Nutrition* 47; Gabrielle Jackson 'I'm not a hypochondriac. I have a disease. All these things that are wrong with me are real, they are endometriosis.' *The Guardian* (28/09/2015) Available

at: <u>https://www.theguardian.com/society/2015/sep/28/im-not-a-hypochondriac-i...</u> [Accessed 10/05/20].

⁹²⁴ Geordan Shannon, Melanie Jansen, Kate Williams et al, 'Gender equality in science, medicine and global health: where are we at and why does it matter?' (2019) *The Lancet* 560.

textbooks and the teaching carried out by universities, are all displays of male-centric attitudes.⁹²⁵ The prevalence of such attitudes has meant that women, for the most part, are still regarded as an inferior sex. Whilst it is true that advances have been made in the fight for equality, for example, with regards to period poverty, huge discrepancies remain.⁹²⁶ The research revealed prevailing attitudes which expect women to conform to the stereotypical gender roles as being the caregiver. It demonstrated that women still tend to undertake the majority of the responsibilities for running the home and childcare and expected to prioritise the needs of others above their own. As a result of the pressure for women to place increased value on social relationships, particularly those with men, they have less independence.⁹²⁷ Such a pattern creates a cycle where women gradually become more and more reliant on the benevolence of others. A consequence of the intense social pressure leads to further health difficulties and problems for women. Research indicates that issues of low esteem, anxiety and depression are higher in females than males.⁹²⁸ Overall, the chapter illustrated the need of feminist theory in analysing medical cases involving women and their treatment and further supported the rationale provided in the methodology chapter which advocates for a change to relational autonomy.

The chapter on autonomy followed, which undoubtedly is a central concept to the thesis. If autonomy is constrained, the right to self-determination is lost. As we are aware, autonomy and self-determination relate to a person's capability of dictating the course of their own life. Without an autonomous individual, any subsequent questions of whether the relevant information is understood, or if the individual

 ⁹²⁵ Mel Bartley, Amanda Sacker, David Firth et al, 'Dimensions of inequality and the health of women' in Hilary Graham, *Understanding Health Inequalities* (OUP 2000) 58 ;Lesley Doyal, 'Gender equity in health: debates and dilemma' 51 (2000) *Social Science Medicine*, 931-9
 ⁹²⁶ Jo Waters, 'Just why do women face a fight for equal health' *Community Practitioner* (November 7th 2019) Available at

https://www.communitypractitioner.co.uk/features/2019/11/just-why-do-women-face-fightequal-health [Accessed 11/05/20]

Diane E Hoffmann, Anita J Tarzian, 'The Girl Who Cried Pain: A Bias Against Women in the Treatment of Pain' 29 (2003) *Journal of Law, Medicine and Ethics* 13.

⁹²⁷ Jennie Popay, Mel Bartley, Charlie Owen, 'Gender inequalities in health: social position, affective disorders and minor physical morbidity' 36 (1993) *Social Science Medicine* 21; Lesley Doyal *What makes women sick: gender and the political economy of health* (Macmillan Press Ltd 1995).

wishes to proceed with treatment, lose meaning. As the previous chapters have illustrated, a move is required to relational autonomy. However, as of yet, relational autonomy has not been successfully implemented throughout medical practice.929 Despite publications from authorities such as The General Medical Council which dictates clear and coherent rules to professionals for allowing patients to be part of the decision-making process, such guidance does not clearly translate into practice. Much of the medical and healthcare profession is still premised on the basis of individualism, which views any support from a third party as a threat of interference.⁹³⁰ This leads to the "undue influence" aspect of the question. It cannot be denied that undue influence remains a risk in clinical practice. However, undue influence can quite clearly be distinguished from relational autonomy; one input is invited, the other, forced. The chapter reveals that there are many practical measures that can be taken by medical professionals to minimise, if not eradicate, the threat of undue influence.⁹³¹ Although, the management of this process is conducted by healthcare professionals, this leads back to concerns over paternalistic interventions. Importantly, this chapter has revealed that the threat of paternalism is not limited to models of relational autonomy. Paternalism is inherent within medical practice and exists no matter what form of autonomy is applied. Doctor knows best, while is most definitely outdated, still exists within clinical practice. It was established that medical knowledge is often infiltrated with a gender bias that assumes males as the standard patient. It has been accepted that women are predisposed to a weaker conception of autonomy owing to their gender. However, this disposition is strengthened by paternalism, which continues to follow stereotypical assumptions that believe women to be irrational and incapable. This was demonstrated most clearly when considering maternal autonomy and the cases of forced caesarean sections.⁹³² Therefore, it can be deduced that a relational approach to autonomy is likely to be more successful in creating an adequate dialogue between the patient

⁹²⁹ Roy Gilbar, José Miola, 'One size fits all? On patient autonomy, medical decision-making and the impact of culture' (2015) 23 *Medical Law Review* 375.

⁹³⁰ Francis X Baker, Colleen M Gallagher, 'Identifying and Managing Undue Influence From Family Members in End-of-life Decisions for Patients with Advanced Cancer' 13 (2017) *Journal of Oncology Practice* 702.

⁹³¹ ibid.

⁹³² Heather Cahill, 'An Orwellian Scenario: Court Ordered Caesarean section and women's autonomy'6 (1999) *Nursing Ethics* 494.

and practitioner which secures the patient's involvement, the benefits of which outweigh the risks of undue influence.

The patient-practitioner dialogue was the focus of the following chapter, capacity, to establish how a relational approach to assessments would result in more inclusive opportunities for exercising a patient's autonomy. Through an extensive review of both the theoretical elements of the legislation and how the legislation operates in practice it became evident that at present, the MCA and its assessments of both capacity and best interests are insufficient to safeguard and protect everyone's equal right to legal capacity. A supported decision-making regime would be compatible with a relational approach which would require that the patient's social setting be considered when making judgments concerning the appropriate treatment and course of action. It was concluded that the procedural approach was too narrow to deal with the emotional elements which are implicit within decision making. If the approach were to evolve to consider the patient's lifestyle and support structure, it is inevitable that different outcomes would occur as a result. Whilst it cannot be guaranteed if the outcomes would be "better", it is probable that the outcomes would be greater aligned with the personal beliefs of the patient, enabling them to exercise their right to self-determination. The chapter did not conclude that an abolishment of the MCA was necessary, rather, it required reform. From comparing the judicial language in the Court of Protection to assess if any differences existed between female P's and male P's two findings were evident; that the character of a male P attracted less attention in the court proceedings and further that can the Justice draw on shared experiences with the P in order to create an empathetic narrative. This illustrates that the courts are capable of an empathetic approach, and this should be applied consistently. The other problem this chapter identified that despite capacity being deemed task specific, in reality, there often seems to be blanket assumptions of incapacity. Incapable patients should not be excluded from the decision-making process for the sake of convenience, incapable patients cannot be viewed from a binary perspective of "yes" they can do this or "no" they can't do that. A relational approach would provide the system with a far more inclusive regime, where the goal is to include, not exclude.

The major output from this thesis is that the system and framework surrounding best interests decision making needs significant reform. Currently it operates from an individualistic viewpoint, focussing too much on the patient's independent abilities to communicate their decisions, with only substandard clauses to aid participation. The requirements provided in the MCA 2005 under section 4 are superficial. The wording is far too vague, which reduces any level of commitment to the provisions. For example, "He must, so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him." By not defining reasonably practicable, this requirement can "reasonably" be avoided. Further, my thesis disagrees with the objective standard set by this legislation. The individual should be considered and the wider context of the individual's life, it should follow a subjective standard. I appreciate this may seem contradictory as on one hand I am claiming the statute lacks clarity, then on the other I am asserting a need for subjectivity. I don't believe it needs to be a choice of clarity or subjectivity. I think all professionals should have to include the individual, the extent of inclusion to be determined subjectively dependent on the individual's abilities. Further, under subsection 7 it is stated "He must take into account, if it is practicable and appropriate to consult them, the views of (a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind, (b)anyone engaged in caring for the person or interested in his welfare, (c) any donee of a lasting power of attorney granted by the person, and (d)any deputy appointed for the person by the court." My problem with this provision is two-fold. Once again with the "practicable and appropriate" caveat, but also with the terminology "consult them". To enhance patient autonomy, the consultation needs to include the patient. The third-party member should be introduced to the proceedings for emotional support, not in lieu of the patient's preferences, not for the doctor to consult, but for the patient. Without these changes, the system remains to be one of paternalism and substituted decisionmaking masquerading under the guise of patient participation. It is true, the seeds of my proposed model already exist, but as of yet, they are not flourishing. An ideological change is needed to capacity and best interests assessments where empathy is introduced. We know this is possible as sometimes the courts do engage in an empathetic dialogue with patients, whereby they relate to their experiences and account for that within their findings. The meaningful dialogue in the patient-

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practitioner relationship desperately needs developing and I believe this is possible through ideological change to relational autonomy alongside supported decision making.

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