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Critically discuss the extent to which the law allows for the wishes, feelings, beliefs, and values of adult patients without decision-making capacity to be considered when decisions are made about their medical treatment, and how this compares to the way it accommodates the same considerations in relation to those with capacity. (3500)

This essay will analyse the recent case law concerning the medical treatment of patients with anorexia nervosa, as an example of the inadequate extent to which the law takes into account wishes, feelings, beliefs and values of adult patients without decision-making capacity when making treatment decisions. Moreover, the principle is inconsistently applied across incapacitated adults, where in other instances it seems to be that wishes are taken into account more seriously. For adults with capacity, despite the fact that the law specifically requires that a so-perceived 'unwise' decision should not be used to doubt the capacity of an adult patient, the continued way in which the values of patients without capacity are often used as evidence for their lack of capacity, demonstrates that this still occurs and is a contradictory application of the law.

Although it cannot be doubted that patients with anorexia have a mental illness which precludes them from having capacity, it is unfair and inconsistent that the wishes of patients with capacity are taken seriously and yet often overlooked for those without. Although recent judgments clearly evidence a weighing up of these factors, they are not decisive and other considerations, such as the efficacy of treatment, form the actual basis of the judgments.

I will first analyse the best interests test, which provides for this assessment of feelings before a careful assessment of recent case law of anorexia patients. It will then turn to other instances of the best interests assessment applied to patients who are incapacitated for other reasons and to patients who retain capacity to demonstrate these inconsistencies. The analysis will point to suggestions of a fairer method of taking into account wishes and feelings for a range of patients with varying capacities. In every case, it is paramount that we consider a person's wishes, no matter their decision-making capacity.

The Best Interests Assessment

A fundamental facet of medical ethics and treatment concerns facilitating the enactment of a patient's autonomy. Consent to a proposed treatment option made by a medical practitioner is

necessary to make an act lawful when it would otherwise constitute a battery.[1] Although a patient can never demand a certain type of treatment which is not clinically indicated,[2] a fully capacitous adult has the right to refuse a recommended treatment for any reason.[3] An adult is considered competent and as having the legal capacity to make a decision about their treatment when they are capable of; understanding the information relevant to the decision, retaining, using and weighing said information to inform his decision, and able to communicate it. This is provided for under the Mental Capacity Act 2005.[4] The Act is formed on the fundamental principles that an adult is assumed to have capacity unless it can be established that this is not the case and,[5] where a lack of capacity is found, a decision can be made on that person's behalf but this must be done in their *best interests*.[6]

Although the Act does not define what the term 'best interests' means, it provides a list of considerations to be taken into account when determining which treatment decision will best promote that person's welfare.[7] This could mean taking a course of action which will preserve their life, as the principle of sanctity of life is used as a basis on which to make treatment decisions, although this is a rebuttable presumption.[8] Their best interests may also involve treatment which reduces their physical or mental suffering, improving their quality of life or providing palliative care. The best interests assessment includes considering the person's past and present wishes and feelings,[9] beliefs and values that would influence their decision if they had capacity.[10] In *Aintree* it was held that:

> "[I]n 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

[1] *Chatterton v Gerson* [1981] Q.B. 432
[2] *R (On the application of Burke v The General Medical Council)* [2005] EWCA Civ 1003
[3] *Re T (Adult: Refusal of Treatment)* [1993] Fam. 95
[4] Section. 3(1)
[5] Section. 1(1)
[6] Section. 4
[7] ibid
[8] *Airedale National Health Service Trust v Bland* [1993] AC 789
[9] Section. 4(6)(c)
[10] Section. 4(6)(d)

> 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…”[11]

Indeed, the best interest tests is inherently problematic before it is even applied to any case. It has been said that the House of Lords Select Committee opined that ‘especially in medical settings, the concept of best interests as defined by the Act was not well understood’,[12] and troublingly ‘[b]est interests decision-making is often not undertaken in the way set out in the Act: the wishes, thoughts and feelings of P are not routinely prioritised. Instead, clinical judgments or resource-led decision-making predominate’.[13] Although these factors are meant to form a vital part of the decision-making process, Jackson asserts that they are merely taken as ‘one relevant factor among many’.[14] Problematically, this could make the law non-compliant with Article 12(4) of the UN Convention on the Rights of Persons with Disabilities (CRPD) which requires that ‘measures relating to the exercise of legal capacity respect the rights, will and preferences of the person’ are taken into account.[15]

The case of Anorexia Nervosa

One particularly challenging scenario in the context of medical ethics concerns treating patients with anorexia. It has been stated in strong terms that a person who has a mental illness is not to be assumed to lack mental capacity.[16] Many individuals who struggle with a mental health issue are capable of fulfilling the requirements pertaining to their ability to use and apply the relevant information surrounding their healthcare decision. Many of these individuals are deeply concerned with treating and improving their condition to live a satisfying and fulfilling life. However, in the case of anorexia, it is nearly always assumed that the mental illness easily satisfies the requisite criteria of causing ‘an impairment of, or a disturbance of the functioning of, the mind or brain’, such that it renders the sufferer unable to make decision that is in their own best interests.[17]

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[11] *Aintree University Hospitals NHS Foundation Trust (Respondent) v James (AP)* (Appellant) [2013] UKSC 67, para 39
[12] House of Lords Select Committee on the Mental Capacity Act 2005, Report of Session 2013–14 Mental Capacity Act 2005: post-legislative scrutiny (Parliament, 2014), para 92
[13] ibid, para 104
[14] Emily Jackson, ‘From ‘doctor knows best’ to dignity: placing adults who lack capacity at the centre of decisions about their medical treatment’ (2017) Modern Law Review 1, 20
[15] UN Committee on the Rights of Persons with Disabilities, General comment No. 1 (2014) Article 12: Equal recognition before the law Eleventh session 31 March–11 April 2014, para 21
[16] *Re C (Adult: Refusal of Treatment)* [1994] 1 All ER 819
[17] Mental Capacity Act 2005, Section. 2(1)

Whether this is true or fair is a separate argument beyond the scope of this essay, but it has been said that; 'it is not obvious that a sweeping argument of this nature can hold with regard to capacity for any except the most moribund of patients'.[18] Often, these patients are highly intelligent, high achieving individuals. Indeed, the condition is often strongly correlated with traits such as perfectionism.[19] As a result, in many cases they are able to articulate to an impressive degree their thoughts and feelings and could conceivably appear to have capacity in most all other respects. Nonetheless, the NICE Guideline mentions that "some patients may have the intellectual ability to understand the treatment, but be unable to give valid consent because their capacity to consent is compromised by fears of obesity".[20] It also states that sufferers may have a good understanding of the risks of their condition and treatment, and yet still lack capacity.[21] It has been recognised that this puts them in a "Catch-22" situation,[22] and goes directly against the presumption that unwise decision-making is proof of lack of capacity.

Further complicating matters, the illness clearly manifests differently in different patients and to differing severities. Some anorexic patients are unable to recognise that their behaviour is damaging to their health and others are apathetic, placing a higher value on their desire to be thin than their life.[23] Thus, it is somewhat understandable that, even when considering an anorexic patient's wishes, feelings, beliefs and values, they may be so entrenched in their illness that their authentic values cannot be extricated and this may negate their ability to make reasonable decisions about their nutrition. Many anorexic patients also state that they wish to lead happy lives and have no wish to die, yet are unable or unwilling to manage their compulsions to limit their caloric intake and over-exercise.[24]

In a study, it has been demonstrated that psychiatrically ill patients often struggle to appreciate the relevance of their illness to themselves.[25] Although they might understand the information being given, and if they were deciding on the issue on someone else's behalf might decide positively for medical treatment using logical reasoning, they are unable to understand that

[18] Jacinta Tan and Lorna Richards, 'Legal and Ethical Issues in the Treatment of Really Sick Patients with Anorexia Nervosa' (2015) in *Critical Care for Anorexia Nervosa* 113, 117
[19] ibid
[20] British NICE Guideline for Eating disorders from 2017 (National Institute for Health and Care Excellence, May, 2017)
[21] ibid
[22] *Re E (Medical Treatment Anorexia)* [2012] EWHC 1639 (COP) para 53
[23] Isis F.F.M. Elzakkers et al, 'Assessment of mental capacity to consent to treatment in anorexia nervosa: A comparison of clinical judgment and MacCAT-T and consequences for clinical practice' (2018) 58 International Journal of Law and Psychiatry 27, 32
[24] *An NHS Foundation Trust v Ms X* [2014] EWCOP 35, [2014] MHLO 96, para 38
[25] Tan (n 18)

they are ill and in need of the treatment.[26] Tan et al, found in their qualitative studies that unlike other disorders such as anxiety or depression, anorexia sufferers often see their illness as part of their personal identity.[27] Hence, their wishes and values are a direct reflection of the illness itself and so cannot be considered authentic.

Anorexia in the case law

There have been a number of cases where appeals have been made to the court to determine whether or not it is in the best interests of patients with severe and enduring anorexia to be subjected to force-feeding treatment and admitted to treatment programmes against their will, or to allow for palliative care provision to be put into place. In every such case, the wishes, feelings, beliefs and values of the patients have been taken into consideration. However, in both the cases of *E* and *L*, it was said that it would be in the best interests of the patient to be subjected to non-consenting treatment.[28]

Most striking is the case of *E*, in which Justice Peter Jackson, despite stating that E's wishes and feelings were 'clear',[29] that her 'wishes for palliation have been consistent',[30] and that her 'views are entitled to high respect',[31] ruled that because her prospects of recovery were more than 20 per cent, this warranted overruling her wishes and made continued treatment in her best interests.[32] Evidently, significantly more weight was attributed to the less than likely recovery that E could have potentially made than her own knowledge of her suffering and wish to receive palliative care. This was an unjust outcome and although Justice Jackson took into account the right considerations, they were weighed wrongly. It has been stated that 'colloquialisms [such as] "you will thank me later" sometimes become the unwritten rules within which the merits of a patient's consent are assessed'.[33]

In all later cases, it has been ruled that treatment is not in the best interests of the anorexic patients, despite the fact that in nearly all cases such as in *X,* they '[retain] an interest in life,

[26] Elzakkers (n 18)
[27] J Tan et al, 'Competence to refuse treatment in anorexia nervosa' (2003) 26 International Journal of Law and Psychiatry' 697–707
[28] *Re E* (n 17), *Re L; The NHS Trust v L* [2012] EWHC 2741 (COP), [2012] MHLO 159
[29] ibid para 127
[30] ibid, para 104
[31] ibid, para 132
[32] ibid, para 90
[33] Jillian Craigie, 'Capacity, value neutrality and the ability to consider the future' (2013) 9(1) International Journal of the Law in Context 4, 6

and [have] plans for [their] future'.[34] In *Z*, the judge had taken into consideration earlier cases of *E* and *L*, and were distinguished on the basis that, 'the prognosis for successful treatment in that case was strikingly different to the facts presented in this case'.[35] Although there had been an analysis of Z's wishes, evidently the deciding factor was the futility of the treatment weighed against the suffering of the patient, rather than giving any real weight to the patient's wishes, which in every case consistently demonstrates a desire to be given supportive palliative care.

In *W*, it was stated that 'it is beyond the power of doctors or family members, and certainly beyond the power of the court, to bring about an improvement in W's circumstances or an extension of her life'.[36] Indeed, in many of the cases, reference has been made to what Sir Thomas Bingham said in the Court of Appeal in *Airedale NHS Trust v Bland*, that: 'a profound respect for sanctity of human life is embedded in our law and our moral philosophy.'[37] It has been said that in many of these cases, what drives the decision-making is the consideration that '[b]oth the condition and the death of people with anorexia are, instead, avoidable',[38] but this does not sufficiently address the fact that we lack adequate treatments for severe and enduring anorexia. Rather, we should consider it much like a terminal physical illness. Indeed, in *L*, despite quoting a doctor's report stating that 'there comes a point in the treatment of any patient where, regardless of the diagnosis, the slavish pursuit of life at any cost becomes unconscionable. I believe, sadly, that this point has been reached in Ms L's treatment,'[39] Justice Jackson still felt that it was possible to treat her illness. Although unlike in E's case, the chances of recovery were judged to be lower, and so force-feeding was not supported.

It is really rather difficult to argue that in any of these instances, it would be in the best interests of the patients who are utterly 'overwhelmed'[40] by their condition, to be forced to continue treatment against their wishes, where it 'would achieve nothing and would merely cause…further trauma, upset and psychological and emotional damage, whilst doing nothing significant to ameliorate [the] terrible anorexia nervosa'.[41] Although, excluding earlier cases, the correct decisions have been made to pursue palliative care, they have all given insufficient

[34] (n 19) para 38
[35] *Cheshire & Wirral Partnership NHS Foundation Trust v Z* [2016] EWCOP 56, para 18
[36] *W (Medical Treatment - Anorexia)* [2016] EWCOP 13, para 48
[37] *Airedale* (n 5) at 835
[38] Simona Giordano, 'Anorexia Nervosa and Refusal of Naso-Gastric Treatment: A Response To Heather Draper' (2003) 17(3) Bioethics ISSN 261, 269
[39] *Re L* (n 28) para 67
[40] *A Midlands NHS Trust v RD* [2021] EWCOP 35, para 33
[41] ibid

weight to the wishes of the patient. Arguably, had the chances of recovery in every instance been marginally more favourable, it is likely that forced treatment would be pursued.

Finally, Cave and Tan make an impactful argument that, 'whilst Anorexia Nervosa sometimes affects decision-making capacity in relation to nutrition, this does not preclude a finding that the patient has sufficient capacity regarding end of life decisions'.[42] It surely must be the case that a patient with such a condition is more qualified than any other person to evaluate how capable they are of recovery and how much suffering they can bear to stand. It truly seems odd that, even in the face of articulate, well-reasoned arguments to allow an end of life treatment plan, this is overshadowed by considerations of the very illness which has caused such suffering.

Other incapacitated adults

By looking at instances where other incapacitated adults have been treated, we can see the inconsistent valuation of wishes and feelings as compared to the cases of anorexia. In *Wye Valley*, a man without capacity refused to have his leg amputated where not doing so would likely lead to his death.[43] Peter Jackson J explained that, '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',[44] and allowed the refusal. In *Re M*, Jackson J acknowledged that 'the court must surely have regard to the person's own assessment of her quality of life',[45] 'rather than tirelessly striving to prolong life at all costs,'[46] and again gave way to the wishes of the patient.

Jackson J describes the process of balancing the competing factors as 'not mechanistic but intuitive'.[47] Kennedy has argued that this is essentially 'a form of ad hocery',[48] and though Series claims that this is unfairly reductionist and the actual assessment is much more formulated than a 'lottery', she states that judges should 'recognise and reflect on how their

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[42] Emma Cave and Jacinta Tan, 'Severe and Enduring Anorexia Nervosa in the Court of Protection in England and Wales' (2017) International Journal of Mental Health and Capacity Law 4, 5
[43] *Wye Valley NHS Trust v Mr B* [2015] EWCOP 60
[44] ibid, para
[45] *Re M (Best Interests: Deprivation of Liberty)* ([2013] EWHC 3456 (COP), [2014] COPLR 35, noted at [2014] Eld LJ 38,
[46] Alexander Ruck Keene and Cressida Auckland, 'More presumptions please? Wishes, feelings and best interests decision-making' (2015) Eld LJ 293, 297
[47] *Re E* (n 17) para 129
[48] Ian Kennedy, 'Patients, Doctors and Human Rights' in R. Blackburn and J. Taylor (eds), *Human Rights for the 1990s* (New York: Continuum International Publishing 1991) 90

own values and outlook shape the considerable discretion they exercise in best interests decisions'.[49] Indeed, Jackson J's judgments seem particularly inconsistent.

Adults with capacity

Unlike for patients that lack capacity, those who have it do not have to undergo a best interests assessment, and so their wishes, feelings, values and beliefs do not have to be assessed. No matter how unwise their decision seems to be in *Re CD*, Mostyn J warned that: 'it is vital that wishes and feelings are strictly confined to the best interests analysis and do not act subtly to undermine a capacity assessment'.[50] This is entrenched in the Mental Capacity Act under s. 1(3), where it is stated that 'a person is not to be treated as unable to make a decision merely because he makes an unwise decision', and s.1(1) lays out that 'a person must be assumed to have capacity unless it is established that he lacks capacity'.

However, in some circumstances, the law does seem to get this assessment backwards. For instance, in the case of Kerrie Wooltorton, although she had a diagnosed mental illness, after swallowing antifreeze, she was assessed as having capacity and so her refusal of treatment other than palliative was respected.[51] In this case, it does appear that her advanced refusal, though rendered unnecessary because of her capacity, was evidence of her wishes and feelings which were respected. As Mclean suggests; 'the Courts assess competence of patients on the basis of outcome of the choice'.[52] In other cases, such as with pregnant women who refuse to have an emergency caesarean section, despite otherwise having capacity, their reactions, and more broadly their wishes and feelings, are often used as evidence of a temporary incapacity, resulting in the lawful overriding of their decision. To take the example of *Rochdale Healthcare NHS Trust v C*, C was judged as unable to weigh up the information regarding a c-section due to being 'in the throes of labour with all that is involved in terms of pain and emotional stress'.[53] However, C changed her mind and was then deemed as able to consent, which Halliday points

[49] Lucy Series, 'The Place of Wishes and Feelings in Best Interests Decisions: Wye Valley NHS Trust v Mr B' (2016) 79(6) Modern Law Review 1101, 1111
[50] *A Hospital NHS Trust v (1) CD (2) A Mental Health Trust* [2015] EWCOP 74, para 28
[51] Sajid Muzaffar, ''To treat or not to treat'. Kerrie Wooltorton, lessons to learn' (2011) 28 Emerg Med J 741
[52] AR Mclean, 'Advance directives and the rocky waters of anticipatory decision making' (2008) 16 Med Law Rev
[53] [1997] 1 FCR 274, 275

out demonstrates the flexibility of forming capacity assessments based on the outcome of the patient's decision, informed by their wishes.[54]

It is perhaps a difficult argument to make, but some authors have raised parallels between the case of Jehovah's Witnesses refusing blood products and an anorexic patient refusing nutrition, 'the *Re E* decision indicates that less weight is given to the substantive reasoning of anorexic patients who refuse life-saving treatment compared to patients whose substantive reasoning is based, for example, on their religious values'.[55] Considering the suffering that forced treatment would inflict upon both an anorexic patient and a Jehovah's Witness against their will, it seems strange that a person's religious values, though they may seem alien to a person with secular views, are unquestioningly accepted when the result of a refusal of treatment is the same in both cases; namely death. In *Re E*, her parents poignantly stated, '[t]here is a logic to [overriding an anorexic's refusal of treatment], but not from the perspective of the sufferer who is not extended the same rights as any other person'.[56]

<u>Alternatives to the Best Interests Model</u>

Callaghan and Ryan have argued that a substituted decision-making model is a 'superior notion' to the best interests test, 'because it places the person's own views about treatment—however troubling they may appear to concerned onlookers—clearly ahead of any objective view of her best interests', and thus gives effect 'to the will and preferences of the person to the greatest extent possible and, in any case, be shown to be manifestly necessary to "promote the person's wellbeing, broadly conceived"'.[57] It has been correctly asserted by them that, 'if a substituted decision-maker were required to "promote the person's wellbeing, broadly conceived," that would in some circumstances, like those that prevailed in *Re E*, see the decision-maker opt for palliative treatment, rather than months of sedation, restraint, and forced feeding'.[58]

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[54] S Halliday, *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention* (Routledge 2016) 51
[55] Charlie Welman, 'Capacity and Patient Autonomy in Refusal of Treatment Cases: Paving the Way for a New Test' (2017) 7 Southampton Student L Rev 42, 43
[56] *Re E* (n 17) para 52
[57] Christopher James Ryan and Sascha Callaghan, 'Treatment Refusal in Anorexia Nervosa: The Hardest of Cases' (2014) Bioethical Inquiry
[58] ibid

On the other hand, Auckland raises an important point that, 'the more weight that is attached to the person's wishes in the determination of their best interests, the more important it is that the judge is sure about what those wishes are'.[59] In the case of severe and enduring anorexia, however, it is surely exceedingly clear that the majority of those patients find forced treatment intolerable and life-endangering, which should hold more weight than any consideration of how effective the treatment is speculated to be. Cave instead suggests that, 'a universal model of capacity would recognize that all individuals retain capacity, regardless of disability. Decisions would be supported to various (sometimes considerable) degrees so that everyone retains the right to make decisions according to their will and preferences'.[60] This seems much more preferable to the inconsistent application of the best interests assessments and the stress that incapacitated patients undoubtedly feel at the prospect of potentially having their wishes and feelings put to one side due to a overvaluation of the presumption in favour of life, and an underappreciation of the suffering that these patients endure.

Conclusion

Through the exploration of the case law concerning sufferers of severe and enduring anorexia, it is hopefully evident that there have been inconsistencies in the approach to weighing up wishes, feelings, beliefs and values of patients without capacity, and the determinative factor seems to be the value of the treatment. This is particularly difficult to reconcile with how fully capacitous adults may refuse treatment without a consideration of their wishes, even where their decision will lead to their own harm or death, and yet sometimes they are in fact used in order to support a determination of a lack of capacity.

We should be reconsidering how to give effect to a patient's desires, whether they have capacity or not. Arguably, this is through a substituted decision-making model, or potentially through another model of determining capacity so as to extend more respect to all decision-makers and facilitate every patients' autonomy to help them achieve ends which best align with their own values rather than the values of a judge.

[Wordcount excluding title, footnotes and bibliography: 3506]

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[59] Cressida Auckland, 'Barnsley Hospitals NHS Foundation Trust v MSP [2020] EWCOP 26: The Need for Caution When Establishing the Wishes of Incapacitated Patients' (2021) 29(2) Medical Law Review 347, 353
[60] Emma Cave, 'Determining Capacity to Make Treatment Decisions: Problems Implementing the Mental Capacity Act 2005' (2015) 36(1) Statute Law Review 86, 100

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