

## Medical decision-making on behalf of a patient who lacks capacity when treatment is deemed to be “futile”: who ought to determine that a treatment is futile, and how ought this decision to be made?

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MEDICAL DECISION-MAKING ON BEHALF OF A PATIENT WHO LACKS CAPACITY WHEN TREATMENT IS DEEMED TO BE ‘FUTILE’: WHO OUGHT TO DETERMINE THAT A TREATMENT IS FUTILE, AND HOW OUGHT THIS DECISION TO BE MADE?

**ABSTRACT:** Recent case-law in England has considered the statutory guidelines in regards medical decision-making for patients who lack the capacity to make their own treatment decisions, and has tackled the further difficulty that arises when these interventions are described as being ‘futile’. The absence of absolute definitions of such concepts allows for disparate legal and moral interpretation, and it is understandable that the difficulty in reaching consensus on such theoretical issues has spilled over into everyday clinical practice. Who ought to decide that a treatment is futile? Is the ‘best interests’ standard appropriate for such end-of-life decision-making? As an objective professional, is the doctor not best positioned to decide what constitutes futile treatment? Respect for a patient’s autonomy suggests that the patient should make this decision. Other moral imperatives must be considered too: for example, when the harms of medical treatment outweigh its benefits, how should the doctor act in order to ‘do no harm’? Whatever solutions are proposed, unilateral decision-making of any kind (even with the best intentions) arguably cannot provide a sufficiently balanced assessment of such predicaments. When a patient is unable to decide for herself†, it seems appropriate to ask someone removed from the doctor-patient partnership to assist with decision-making. Are persons closest to the patient suitable for this role, or should we rely on a reasonable person in society, or perhaps even a specialist from any religious or secular, medico-legal or bioethical field? But value judgements pervade medical decision-making, and even the diligent application of legal and moral principles cannot guarantee impartial outcomes. All things considered then, the overall benefit to the patient may be achieved when experts in ‘the patient’, medicine, bioethics and law seek consensus on what constitutes the best interests of that particular patient at that particular time.

**KEYWORDS:** Futility; Capacity; Autonomy; Paternalism; Multidisciplinary Team

**SUMMARY:** 1. Introduction. – 2. Medical decision-making. – 3. The complication of futility. – 4. Finding solutions. – 5. Conclusion.

## 1. Introduction



There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery. In circumstances such as these, it may be that an assessment of best interests leads to the conclusion that it would be in the best interests of the patient to withdraw or withhold life-sustaining treatment, even if this may result in the person's death»<sup>1</sup>.

The Supreme Court in *Aintree v James* [2013]<sup>2</sup> had the challenging task of interpreting this paragraph from the Mental Capacity Act 2005<sup>3</sup> Code of Practice<sup>4</sup>. Given that it was the first review of the MCA (2005) by the highest court in England, it was hoped that Baroness Hale, presenting the judgment<sup>5</sup>, would provide an explanation of terms (including “best interests” and “futility”) that have been a source of confusion and consternation for many years. Although falling short of achieving this arguably impossible task, she provides a practical framework for approaching the decision-making process<sup>6</sup>, in regards a patient who lacks the capacity to make this decision for herself, when the benefits of a medical intervention are disputed.

Baroness Hale's declaration seeks not to change the law as previously understood<sup>7</sup>, but rather to clarify it. This is achieved to a point – her explanations of other concepts used in decision-making<sup>8</sup> are bound to spark vociferous debate. I will make reference to this Supreme Court judgment, and other relevant case-law, in my discussion of medical decision-making for incompetent patients when the issue of “futility” clouds this already challenging process. This essay aims to answer two questions: who ought to determine that a medical treatment is futile; and how ought this decision to be made? A cursory glance at this extract from Baroness Hale's judgment is bound to simplify the decision-making process; therefore it is desirable that a thoughtful review creates further discussion. Consider, for example, the potentially large number of people involved in decision-making, the medical unpredictability associated with end-of-life issues and the emotion that it elicits, as well as the interplay of legal and moral issues that shape decision-making. Hard and fast objective instructions may remain only an aspiration then, and ultimately it may be the explanations of these open-to-interpretation guidelines that determine outcomes. But the goal is not simply to reach decisions; it is

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<sup>1</sup> Mental Capacity Act 2005 Code of Practice, <https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>, paragraph 5.31 (last visited 19/04/2015)

<sup>2</sup> *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, hereafter *James*.

<sup>3</sup> The Mental Capacity Act 2005, hereafter the MCA (2005), came into force in England and Wales in 2007. It provides a statutory framework for decision-making when persons 16 years or older lack the mental capacity to make these themselves. <http://www.legislation.gov.uk/ukpga/2005/9/contents> (last visited 19/4/2015).

<sup>4</sup> The Code was issued in 2007 as per sections 42-43 of the MCA (2005).

<sup>5</sup> She was speaking for the majority.

<sup>6</sup> More so, arguably, than Sir Alan Ward's philosophically-heavy discussion in his Appeal Court judgment: *Aintree University Hospitals NHS Foundation Trust v David James* [2013] EWCA Civ 65.

<sup>7</sup> *James*, at 47.

<sup>8</sup> Such as substituted judgement and intolerability.

to reach appropriate and acceptable decisions. This is a hard task, but is (I argue) one that is achievable.

Such decisions should not be made unilaterally – they merit a joint discussion, based on consensus and compromise between patients and those close to the patient<sup>9</sup>, and the medical profession, assisted by legal and bioethical representatives. Such a specialist multidisciplinary team (MDT) would seek to overcome disputes in decision-making, avoiding the costly (in financial, emotional and time sense) recourse to the courts that should remain, appropriately, the final arbiter of unresolved disagreements. This multidisciplinary panel would recognise the importance of the objective decision-making process, while considering the subjectivity of the case under review. Thus I maintain that the current guiding principle of decision-making based on a patient’s best interests is correct.

To justify these conclusions, I begin with a discussion of the legal basis for current decision-making in regards patients who lack capacity, followed by a review of the moral concepts (autonomy and paternalism) that have shaped this evolution. I then apply these legal and moral concepts to a practical analysis of objectivity and subjectivity in decision-making. Paragraph Three introduces the notion of futility, leading to a deeper evaluation of this nebulous term in relation to the issues discussed in Paragraph Two and the questions proposed by this paper. In Chapter Four I consider how these theoretical concepts may be applied in practice. The final paragraph summarises my arguments for the claims made in this essay.

## 2. Medical decision-making

In this section I review medical decision-making in England<sup>10</sup> in regards patients who lack the capacity to make these decisions themselves. The evolution of the decision-making process is discussed, addressing firstly the legal considerations followed by the ethical. I then apply these concepts to practical decision-making, noting the significance of “subjectivity” and “objectivity” throughout this process.

Dispute over treatments considered futile may arise at any point in one’s life: cases discussed in this essay range from those involving extremely premature neonates to frail, elderly patients; while protracted terminal illnesses are mentioned in the same breath as acute catastrophic events; and the complexity of patients in an altered state of consciousness is also considered. Clearly, these situations are different, but owing to essay limitations, I will discuss all of these conditions generally – with specific reference to individual scenarios or interventions as required<sup>11</sup>. In addition, although “futile” treatment is not synonymous with end-of-life care, I treat these concepts as such here.

<sup>9</sup> I see the usefulness of this term used by the General Medical Council (GMC) in their 2010 guidance, *Treatment and care towards the end of life: good practice in decision making*. [http://www.gmc-uk.org/End\\_of\\_life.pdf\\_32486688.pdf](http://www.gmc-uk.org/End_of_life.pdf_32486688.pdf) (last visited 19/4/2015). «The term “those close to the patient” means anyone nominated by the patient, close relatives (including parents if the patient is a child), partners and close friends, paid or unpaid carers outside the healthcare team and independent advocates» (p. 17). I use this term interchangeably with proxy hereafter.

<sup>10</sup> In this essay, I refer almost exclusively to English case law (there are occasional references to declarations in other jurisdictions).

<sup>11</sup> See also n. 17 below.

## 2.1. Legal issues

### 2.1.1. Best Interests

In England, a mentally competent adult has the legal (and moral) right to refuse treatment, but is not able to demand it<sup>12</sup>. In regards the adult patient who lacks this mental capacity, the MCA 2005 and the Human Rights Act 1998 guide decision-making at the end of life<sup>13</sup>. Using the former statute, this process can be simplified to three steps. Firstly, does the patient have the capacity to make an informed decision<sup>14</sup>? If not, is there a valid and applicable advance decision<sup>15</sup>? If not, decisions are then to be made in a patient's best interests<sup>16</sup>.

The "best interests" standard is thus the tool for making decisions in regard patients who lack the mental capacity to make these themselves<sup>17</sup>. The concept, however, is nebulous, and the Courts acknowledge that it is potentially impossible to define precisely<sup>18</sup>. It has been suggested that the best interests standard amounts to guiding principles rather than a specific concept<sup>19</sup>; which is best utilised as a description, rather than a definition<sup>20</sup>.

In *James*<sup>21</sup>, Baroness Hale's guidance for determining how this standard is best achieved in clinical decision-making may be considered a summary of Section 4 of the MCA 2005: the decision-maker must consider, in a holistic way, the person as an individual<sup>22</sup>. The focus has always been, and remains, on the welfare (in the widest sense) of the specific patient at that specific time<sup>23</sup>.

### 2.1.2. Sanctity of life

An evaluation of life-worth is also enveloped within this best interests concept. The courts have made it clear, when considering complex medical decision-making, that

<sup>12</sup> Reasons for this exclusion may be both legal and moral (e.g. in respect public health and a patient's duty to others, respectively).

<sup>13</sup> See *Re E (Medical Treatment Anorexia)* [2012] EWHC 1639 (COP) [at 16-17] as a case in point.

<sup>14</sup> MCA (2005), ss. 2-3.

<sup>15</sup> MCA (2005), ss. 24-25.

<sup>16</sup> MCA (2005), s. 1(5).

<sup>17</sup> This is equally applicable to neonates and children: e.g. *Wyatt v Portsmouth Hospital NHS Trust* [2005] EWCA Civ 1181 provides a similar interpretation of «the child's welfare ... [as] paramount» as set out in statute (Children Act 1989 s.1(1)). While there are obvious significant differences in statute and case-law across the age spectrum, this essay focuses on the similarities – and considers best interests generally (with the adult position taken as the default).

<sup>18</sup> For example: Hedley J in *Portsmouth Hospitals NHS Trust v Wyatt* [2005] 1 FLR 21, at 23; Thorpe LJ in *Re S (Adult Patient: Sterilisation)* [2001] Fam 15, at 30.

<sup>19</sup> *R (Burke) v GMC* [2005] EWCA Civ 1003, at 63.

<sup>20</sup> R. HUXTABLE, *Law, Ethics and Compromise at the Limits of Life: To Treat or Not To Treat?*, London, 2013, 84-85 considers various differing opinions on this notion.

<sup>21</sup> David James, a previously reasonably healthy 68-year-old musician, and cancer survivor, had been dependent on intensive medical care for six months at the time of the first instance hearing. The hospital, believing further treatment to be "futile", sought a declaration that in the event of further deterioration in his condition it would be lawful to withhold cardiopulmonary resuscitation, inotropic support and renal replacement therapy.

<sup>22</sup> *James* [2013], at 39.

<sup>23</sup> See, e.g., the series of sterilisation cases: *Re S* [2001]; and *Re A (Male Sterilisation)* [2000] 1 FLR 549 (notably Butler-Sloss P at 555).

«the fundamental principle is the principle of the sanctity of human life ... But this principle, fundamental though it is, is not absolute ... the principle of the sanctity of human life must yield to the principle of self-determination ... and, for present purposes perhaps more important, the doctor's duty to act in the best interests of his patient must likewise be qualified...»<sup>24</sup>.

The case-law is reinforced by statute: Section 4(5) of the MCA 2005 does not imply that doctors are obliged to provide, or to maintain, life-sustaining treatment when it is not judged to serve that person's best interests, even if this may result in her death<sup>25</sup>.

### 2.1.3. The role of the doctor

What, then, are the obligations of the doctor in this decision-making process? It goes without saying that, apart from adherence to professional guidance, the doctor must obey the law. The Supreme Court in *James* clarified that «the focus is on whether it is in the patient's best interests to give the treatment rather than on whether it is in his best interests to withhold or withdraw it» and so a treatment by a doctor will only be lawful if provided in the patient's best interests<sup>26</sup>.

It is worth noting here the *Bolam* test: a doctor will not be seen as negligent if her actions are consistent with practices accepted as reasonable by a responsible professional body<sup>27</sup>. The courts, while generally respectful of professional medical opinion, affirm their own position as the final impartial arbiter of legality<sup>28</sup>. So although not decisive, the *Bolam* test provides a measure of objectivity that can be applied to individual cases<sup>29</sup>. The courts now demand a logical, but also more normative, review of expected practice<sup>30</sup> – which inevitably considers the reasonableness of the clinician.

### 2.1.4. Reasonableness

The concept of reasonableness pervades medico-legal decision-making, but its usefulness in relation to the individual is nevertheless contested. Proponents suggest that a standard of reasonableness, both in regards the individual and her standing in relation to others, better directs surrogate decision-making than best interests<sup>31</sup>. But this view is limited by the “reasonable test”<sup>32</sup> not necessarily providing an acceptable assessment of the individual<sup>33</sup>. Although still debated, both the legal<sup>34</sup> and the ethical<sup>35</sup> opinion is that the best interests test is not a “reasonable person” test.

<sup>24</sup> Lord Goff in *Airedale NHS Trust v Bland* [1993] AC 789, at 863; see also *James*, at 35; *Wyatt* [2005]; Donaldson LJ in *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33, at 42 and 46E.

<sup>25</sup> MCA (2005) Code of Practice, 5.33.

<sup>26</sup> Baroness Hale in *James*, referencing MCA (2005) s.5(1) & (2), at 22 see also Lord Browne-Wilkinson in *Bland* [1993], at 884.

<sup>27</sup> *Bolam v Friern Hospital Management Committee* [1957] 2 ALL ER 118.

<sup>28</sup> E.g. Mrs Justice King in *Re L* [2012] EWHC 2741, at 65.

<sup>29</sup> See Lord Mustill's concerns in *Bland* [1993], at 898H.

<sup>30</sup> The *Bolam* standard was reviewed in *Bolitho v City and Hackney Health Authority* [1997] 4 All ER 771.

<sup>31</sup> See e.g. J. MASON, G. LAURIE, *Mason and McCall Smith's Law and Medical Ethics*, Oxford, 2013, 548 for an interesting review.

<sup>32</sup> Simply, how a representative person ought to act/think if in that situation (ie. a comparative measure).

<sup>33</sup> See e.g. R. VEATCH, *Abandoning Informed Consent*, in *The Hastings Center Report*, 25, 1995, 6-10.

### 2.1.5 Substituted judgement

Baroness Hale (in *James*), while acknowledging that the best interests test remains the standard in English law, states that it «should also contain “a strong element of ‘substituted judgment’”»<sup>36</sup>. This type of judgement, utilised in several jurisdictions in North America, is applied when a proxy determines what the patient is likely to have wanted if the patient, herself, was deciding the outcome now. It is clear that best interests does not equate with substituted judgement in English case law and legislation<sup>37</sup>; what is unclear is the weight that the latter judgement should be given when reviewing the past and present wishes and feelings, beliefs and values and «any other factors» relevant to the patient<sup>38</sup>. As is customary with all decision-making now, the balancing process is sensibly guided by the particular case<sup>39</sup>. But the debate continues: certain commentators request further clarification of Baroness Hale’s declaration<sup>40</sup>, others favour substituted judgement over best interests given its consideration of consent issues<sup>41</sup>, while opponents are concerned with the accuracy<sup>42</sup> and applicability<sup>43</sup> of the test.

### 2.1.6. Considering the views of others

Legal cases following *James* have emphasised the importance of the decision making of significant others, but have nevertheless applied the best interests standard<sup>44</sup>. Case law has traditionally grappled with the question of what influence the opinions of significant others should exert in the decision-making process<sup>45</sup> and whose best interests is to be regarded<sup>46</sup>, usually placing greater weight on the patient’s views if available – but these are all subject to the balancing exercise mandated by the

<sup>34</sup> E.g. in *James*, Baroness Hale dismisses Lady Justice Arden’s Appeal Court endorsement of the reasonable person, at 45.

<sup>35</sup> E.g. J. STANLEY et al, *The Appleton Consensus*, in *JME*, 15, 1989, 131.

<sup>36</sup> *James* [at 24], quoting the Law Commission’s *Report on Mental Incapacity* (1995, No.231 at 3.25). Her words, at 45, highlight the respect for (and importance of) the patient’s view.

<sup>37</sup> See MCA (2005) Code of Practice, 5.38.

<sup>38</sup> MCA (2005), s.4(6).

<sup>39</sup> «Every patient, and every case, is different and must be decided on its own facts», *James*, at 35.

<sup>40</sup> See C. FOSTER, *Taking an interest in best interests*, in *New Law Journal*, 7588, 2013, 16; V. SACHDEVA, A RUCK KEEN, V BUTLER-COLE, *The MCA in the Supreme Court – reflections on Aintree v James in Elder Law Journal*, 1, 2014, 54-61-

<sup>41</sup> J. MASON, G. LAURIE, *op.cit.*, 547. They argue that «it eliminates many of the more obvious objections to [best interests] – “How can it be in the best interests of anyone to die?”; “How can a person with no interests have any best interests?”».

<sup>42</sup> E.g. «The view of the patient is, in effect, second-guessed» in S. PATTINSON, *Medical Law and Ethic*, London, 2011, 165 (nevertheless, the author champions substituted judgement).

<sup>43</sup> See Chapter IX in D. LAMB, *Therapy Abatement, Autonomy and Futility*, London, 1995.

<sup>44</sup> E.g. Cobb J in *County Durham and Darlington v PP* [2014] EWCOP 9, at 43: «In determining this application, I resolutely adhere to the best interests principles rather than applying a “substituted judgment” test». See also p. 24 for further discussion of this point.

<sup>45</sup> E.g. Coleridge J in *NHS Trust v Ms D* [2005] EWHC Civ 2439 (Fam) [at 45] «[M]y focus must be on the patient’s best interests and not on the family’s best interests».

<sup>46</sup> Although regarded as an aberrant declaration, *Re T* [1997] 1 All ER 906 [at 915] states that «the welfare of the child depends upon his mother».

MCA 2005<sup>47</sup>. So while the views of both patient and those close to the patient are of great significance, they are not determinative<sup>48</sup>.

### 2.1.7 The balance sheet

To assess best interests appropriately, the courts balance the interests of the individual to ensure an “in-the-round” welfare appraisal. The balance sheet approach involves weighing a number of factors<sup>49</sup> – on first glance this appears to be an objective exercise, but on closer review is inevitably influenced by personal value judgements<sup>50</sup>. For example, the values ascribed to various considerations by a patient or doctor may be very different from those assigned by a family member or judge. Perhaps, then, only when the patient’s views are clearly known can the balancing exercise take place appropriately<sup>51</sup>. This practice acknowledges that there is no single determining test, but rather a broad review of the case in question (where no factors are overlooked nor set one against another).

### 2.1.8. Human Rights

I will say no more about Convention rights<sup>52</sup> here besides that, in English case-law, it has been possible that certain patient human rights could be overruled by the best interests standard<sup>53</sup>. The courts now require that the principles guiding good medical practice are consistent with the terms and obligations of Convention rights<sup>54</sup>. However, the explanations used by certain judges, in their attempts to correlate the rights extended to certain patients (e.g. in a potentially-terminal condition or, perhaps more vexingly, in a vegetative state) with their best interests, have been questioned and are likely to be revisited<sup>55</sup>.

### 2.1.9. Challenging the doctor

The Courts have traditionally been unwilling to enforce the doctor to provide medical treatment which is at odds with her clinical judgement<sup>56</sup>. This is also true in regards life-sustaining treatment<sup>57</sup>. In addition, the Courts have avoided making declarations in respect hypothetically-available treat-

<sup>47</sup> See e.g. *NHS Trust v L* [2013] EWHC 4313 (Fam), at 118.

<sup>48</sup> *NHS Trust v (1) A and (2) SA* [2006] [2006] Lloyd Medical Reports 29, at 59; *An NHS Trust v VT* [2013] EWHC B26 (Fam); *Sheffield NHS Foundation Trust v TH* [2014] EWCOP 4; *United Lincolnshire NHS Trust v N* [2014] EWCOP 16.

<sup>49</sup> First applied to cases regarding infants, but is now ubiquitous. E.g. *W v M* [2011] EWHC 2443 (Fam).

<sup>50</sup> See e.g. *Re D* (1997) 38 BMLR 1.

<sup>51</sup> *Sheffield v TH* [2014], at 56.

<sup>52</sup> HRA (1998) and ECHR (1950).

<sup>53</sup> Articles 2 and 8 as qualified rights; 3 as absolute: see e.g. *W v M* [2011]; also *Burke* [2005]; *Glass v United Kingdom* [2004] 1 FLR 1019.

<sup>54</sup> See e.g. *NHS Trust A v M*, *NHS Trust B v H* [2001] 2 WLR 942.

<sup>55</sup> See J. MASON, G. LAURIE, *op.cit.*, 540-541; also S. MCLEAN, *Permanent Vegetative State and the Law in Journal of Neurology, Neurosurgery and Psychiatry*, 71, 2011, i26.

<sup>56</sup> See, e.g. *Re J* [1993], *op.cit.*, at 29E/F, 31A and 48D; *An NHS Trust v D & Ors* [2000] 2 FLR 677; *AVS v NHS Foundation Trust* [2011] EWCA Civ 7; *Burke* [2005], at 55.

<sup>57</sup> MCA (2005) Code of Practice, 5.33.

ments<sup>58</sup>, acknowledging that it is «right to be cautious about making declarations in circumstances which [are] not fully predictable or fluctuating»<sup>59</sup>.

While the Courts have challenged the medical decisions made in certain cases, and have stated their disagreement at times, they have not as yet specifically ordered that treatment be provided against medical opinion<sup>60</sup>. In the case of *MB*, an almost completely paralysed infant with severe Spinal Muscle Atrophy in whom, without ventilation, death would be inevitable by one year, Holman J decided that on balance the case for continued life outweighed the case for non-treatment (the unanimous opinion of the medical profession), stating that ventilation should continue<sup>61</sup>. He realised that anything more than a glancing statement «might appear to be an attempt to do what I have no power to do, namely to require doctors to carry out a positive medical intervention against their judgement and will» – and failed to make a declaration to that effect<sup>62</sup>. In *James*, the declaration of the first instance judge (whose opinion differed from that of several multidisciplinary medical professionals who had suggested that treatment was futile) was quickly overturned on appeal. Mr James had died by the time of the Supreme Court review, so the Courts did not oblige the doctors to provide treatment here, although this may have been different had he still been alive at the latter hearing<sup>63</sup>.

#### 2.1.10. Questions remain...

Despite the available comprehensive analyses of medico-legal decision-making, questions still abound. One certainty is that the best interests standard pervades this process, and cuts across the extremes of age<sup>64</sup>, focusing on the individual. It is this focus, applied against precedents, that allows outcomes in complex cases like persistent vegetative states<sup>65</sup> and minimally conscious states<sup>66</sup>. With the legal foundation now set, I turn to the moral factors that influence (a more normative assessment of) decision-making in regards complex end-of-life and “futile” conditions.

<sup>58</sup> E.g. *NHS Trust v L* [2013], at 113-116; also *AVS v NHS Foundation Trust* [2011], at 32, 38 and 39.

<sup>59</sup> Baroness Hale in *James*, at 41.

<sup>60</sup> Moylan J in *NHS Trust v L* [2013], at 116. *Cuthbertson v Rasouli* [2013] SCC 53, heard before the Canadian Supreme Court, is one high-profile case (of a man in a minimally conscious state/MCS) where doctors were required to continue treatment that they felt was medically futile. This stemmed from the fact that withdrawal of life-sustaining treatment requires consent (even if by proxy) under Canadian statute. But arguably the English courts would come to a similar verdict when considering the best interests of a patient in a MCS (rather than consent issues specifically), and they agree that treatment is not defined by medical benefit alone. Cases that are in any way evocative of assisted dying are likely to have similar outcomes. Chief-Justice Beverly McLachlin did note the dilemma of the healthcare professionals though, at 75: «Wherever one tries to draw the line, it is inevitable that physicians will face ethical conflicts... No legal principle can avoid every ethical dilemma».

<sup>61</sup> *NHS Trust v MB* [2006] 2 FLR 319. Treatment was to be continued with associated care, but if further intervention was required that resulted in pain, all intervention could be stopped.

<sup>62</sup> *NHS Trust v MB* [2006], 58.

<sup>63</sup> See Baroness Hale’s deliberation on potential treatments, at 42; however, she does declare the Court’s respect for clinical decision-making, at 18.

<sup>64</sup> Best interests guides the case law for children and legislation for adults.

<sup>65</sup> A standard exists that “quality of life” may allow removal of a feeding-tube so as not to prolong suffering.

<sup>66</sup> By considering sanctity of life, and utilising a balance sheet.



## 2.2. Ethical issues

In the following paragraphs I consider the challenges facing decision-makers given the tug-of-war between the moral concepts of autonomy and paternalism.

### 2.2.1. Autonomy

Respect for autonomy, as a self-determined value of life, has been buttressed in recent decades by changing social thought and legal practice<sup>67</sup>. The promotion of informed consent, as well as the development of measures to enshrine self-determination (such as advance decisions<sup>68</sup> and the appointment of proxy decision-makers<sup>69</sup>), has made these changes possible. While autonomy has significantly advanced its standing by steadily overcoming accusations that it unevenly balances professional medical authority, some commentators still caution that «[a]utonomy is not the last word; it is a valuable counter to oppression and professional paternalism, but a free decision is neither necessarily wise nor moral»<sup>70</sup>.

There is general consensus among philosophers, despite their use of differing terms and formulations, that respect for autonomy is a significant moral imperative. The challenge, however, is linking theory with practice. Kant's view of autonomy incorporating rationally-determined reason seems to find little support in English case-law<sup>71</sup>; while the utilitarian view of greatest good is also undermined by the legal deference for individual best interests<sup>72</sup>. As will become evident, the divide between concepts and custom can be difficult to bridge.

### 2.2.2. What, then, is autonomy in practice?

Critical review of the concept suggests it has strayed from its original foundations, now focusing on individual independence, and choosing or refusing treatment, rather than on (depending on philosophical persuasion) the nuances of duties towards others or self-discipline<sup>73</sup>. Autonomy is clearly a complex term, with Coggon proposing its separation into three classes: *current desire autonomy*, *best desire autonomy* and *ideal desire autonomy*<sup>74</sup>. These, respectively, incorporate the person's immediate wish (the «rational, irrational, unknown or even non-existent» desire of the patient in *Re T* is cit-

<sup>67</sup> S. SMITH, *End-of-Life Decisions in Medical Care: Principles and Policies for Regulating the Dying*, Cambridge, 2012, 94 explains that while autonomy is a philosophical principle, respect for autonomy is the ethical principle. He follows the conceptualisation of autonomy as proposed by T. BEAUCHAMP, J. CHILDRESS, *Principles of Biomedical Ethics*, Oxford, 2009, acknowledging that an autonomous decision is an intentional one, based on understanding, which is free from coercion. This fits neatly with the English law notions of competence and consent.

<sup>68</sup> MCA (2005), ss.24-26.

<sup>69</sup> The donee, through a Lasting Power of Attorney; MCA (2005), ss.9-10.

<sup>70</sup> D. LAMB, *op.cit.*, 113.

<sup>71</sup> Cf. Lord Donaldson's famous words in *Re T (Adult: refusal of treatment)* [1992] EWCA Civ 18: the patient has a right to make choices that are «rational or irrational, unknown or even non-existent», at 37(1).

<sup>72</sup> E.g. the courts' lack of commentary on resource issues, see *R v Cambridge Health Authority, ex parte B* [1995] 1 WLR 898.

<sup>73</sup> R. HUXTABLE, *op.cit.*, 117; O. O'NEILL, *Autonomy and Trust in Bioethics*, Cambridge, 2004, 39.

<sup>74</sup> J. COGGON, *Varied and principled understandings of autonomy in English law: justifiable inconsistency or blinkered moralism?* in *Health Care Analysis*, 15, 2007, 235-255.

ed as an example<sup>75</sup>); a more balanced view in which personal values temper the immediate wish (as evidenced in the choices of patients with a needle phobia); or a more ideal performance of an objective goal, in the manner of a Kantian duty (situations where patients are treated with blood transfusions or fed against their wishes)<sup>76</sup>.

Coggon favours the more middle-of-the-road *best desire autonomy*: *current desire autonomy* appears too subjective to receive approval as a moral theory, while the necessity of the *ideal desire autonomy* to create a universally accepted list of objective norms (laudable in terms of Kantian duty) is not unproblematic. O'Neill, guided by the view that «Kantian autonomy is manifested in a life in which duties are met, in which there is respect for others and their rights, rather than in a life liberated from all bonds»<sup>77</sup>, promotes the latter view of autonomy (which she calls *principled autonomy*), where more-universally-good outcomes are championed over individually-determined ones. Smith, while acknowledging the appeal of this approach, argues against it, noting that subjective bias inevitably infiltrates universal laws and that it is the appropriate treatment of others that is more important than the unfaltering allegiance to such a code<sup>78</sup>. In addition, the interests of the individual will remain personal, and so distinct from a universal norm<sup>79</sup>. As ever, outcomes are best determined by reviewing each individual case upon its facts<sup>80</sup>.

### 2.2.3. Protecting patient autonomy

The issue of advanced decisions aside<sup>81</sup>, the protection of a patient's autonomy is perhaps best assessed when considering different processes of decision-making. Many commentators argue that, in the absence of a competent or advance decision, the most autonomy-based means of achieving the wish of the patient is to apply substituted judgement<sup>82</sup>. However, as with advanced decisions, this standard tends to overlook the patient's current welfare in favour of the previous autonomous assertions. The latter, arguably, may not always provide what is desired now. By extension, such decisions would involve guesswork, and reinforces concerns that surrogates don't automatically use the substituted judgement standard when making decisions. Lamb argues that only when the views are beyond doubt that this process may be used to make life-and-death decisions<sup>83</sup>. A compromise, then, may involve a truly objective party acting as the facilitator of autonomous decision-making<sup>84</sup>.

<sup>75</sup> See note 71.

<sup>76</sup> The latter intimates a universal or social norm, suggestive of a reasonable person approach.

<sup>77</sup> O. O'NEILL, *op.cit.*, 83.

<sup>78</sup> S. SMITH, *End-of-Life Decisions in Medical Care: Principles and Policies for Regulating the Dying*, cit., 100.

<sup>79</sup> The same is true in regards individuals in the medical profession: e.g. R. LAWRENCE, F. CURLIN, *Autonomy, religion and clinical decisions: findings from a national physician survey* in *Journal of Medical Ethics*, 35, 2009, 216.

<sup>80</sup> See R. TRUOG, A. BRETT, J. FRADER, *The problem with futility* in *New England Journal of Medicine*, 326, 1992, 1563.

<sup>81</sup> See D. LAMB, *op.cit.*, 122ff for a thoughtful discussion.

<sup>82</sup> E.g. S. PATTINSON, *op.cit.*, 165; J. MASON, G. LAURIE, *op.cit.*, 547.

<sup>83</sup> D. LAMB, *op.cit.*, 135. «The introduction of a legal fiction that autonomous decisions can be made by others is incompatible with the principle of autonomy and could involve the reintroduction of paternalism».

<sup>84</sup> S. SMITH, *End-of-Life Decisions in Medical Care: Principles and Policies for Regulating the Dying*, cit., 108.

But the best interests standard is also difficult to apply consistently; for example, how can there be any argument between choosing life and choosing death? In such conditions personal preference should take precedence – in Dworkin’s terms, critical interests (such as how one dies) become more important than experiential interests (the situation one is in)<sup>85</sup>.

Pattinson considers a shift then towards a «wider test of overall interests», which would take the views of others (including society) into account: «[t]his would require *all* competing interests to be balanced»<sup>86</sup>. He notes that although not yet adopted, this wider test has not been ruled out<sup>87</sup>. But such a standard may threaten the safety of older and more vulnerable patients, especially if resource allocation is brought into the equation<sup>88</sup>. Here, utility and the value of individual life are also bound to clash.

#### 2.2.4. Limits to patient autonomy

The autonomy of the patient, therefore, may be seen to be suppressed by both surrogate decision-making and the best interests test. Autonomy is also tempered by the age of patient<sup>89</sup>, the requirements of the legal processes to increase autonomy<sup>90</sup>, and the differences between refusing and requesting treatment<sup>91</sup>. Autonomy may clash with the professional duty of the healthcare provider: the consideration of beneficence and non-maleficence springs to mind<sup>92</sup>. Courts limit autonomy when favouring preservation of life<sup>93</sup>, and it has been argued that outcomes at judicial review depend on the patient or proxy’s ability to engage with the judge<sup>94</sup>, and decisions may also be swayed by the rationality or even the social-standing of the decision-maker<sup>95</sup>.

Considering, then, the factors that both promote and limit autonomous decision-making, Baroness Hale’s support (in *James*) for decision-makers being more able to accept that decisions that seem

<sup>85</sup> R. DWORKIN, *Life’s Dominion*, New York, 1994, 208-217.

<sup>86</sup> S. PATTINSON, *op.cit.*, 166 (emphasis in original).

<sup>87</sup> *Re A* [2000], at 556-558.

<sup>88</sup> At this point, I must step aside to consider a significant issue in regards decision-making and “futility”. Futility is unfortunately associated with paternalism and rationing: society may be dubious of doctor’s decision-making in regards futility because it may feel that decisions are determined by resource issues. I will, for the sake of clarity and brevity, assume that such issues do not factor in “objective decision-making”. For a wider debate, see M. BAILY, *Futility, Autonomy and Cost in End-of-Life Care* in *Journal of Law, Medicine and Ethics* 39, 2011, 175 where she argues that «autonomy and individual self-interest provide strong ethical arguments for a system that limits the availability of care in an equitable manner» so cost is an ethical matter and the inevitable rationing of modern society can be justified if carried out equitably; for a review of cost and justice, see B. BRODY, A. HALEVY, *Is futility a futile concept?* in *The Journal of Medicine and Philosophy*, 20, 1995, 123-144; see also R. TRUOG, A. BRETT, J. FRADER, *op.cit.*

<sup>89</sup> A separate discussion in itself.

<sup>90</sup> E.g. the specificity and clear applicability of an Advance Decision; the cost and understanding of an LPA.

<sup>91</sup> See M. BAILY, *op.cit.*, 181.

<sup>92</sup> D. LAMB, *op.cit.*, 114 suggests that disagreements may be attributed to disputes with paternalistic authority rather than acknowledging the influence of opposing moral principles.

<sup>93</sup> *HE v A Hospital NHS Trust* [2003] EWHC 1017 [at 28]: «if there is doubt [about the patient’s wishes] that doubt falls to be resolved in favour of the preservation of life».

<sup>94</sup> R. HUXTABLE, *op.cit.*, 92; see also pp.97-98 in regards the “health professional” parents in *Re T* [1997], *op.cit.*

<sup>95</sup> J. COGGON, *op.cit.*, 246ff; he argues that the values of certain religions and members of society (especially prisoners) have been weighed differently.

unwise to professionals may still be in the patient's best interests is «whole-heartedly to be welcomed as a counterbalance to an excessive weight being placed upon keeping the individual safe at all costs»<sup>96</sup>.

### 2.2.5. The autonomy of the doctor

A doctor has medical, political, legal and moral obligations to act in a certain manner – and so is restrained in her autonomy by conscience (at an individual level) and duties (at a professional level)<sup>97</sup>. Her medical role also involves making decisions that may be value-laden. Brody argues that a prime example of this is a physician's decision to stop cardiopulmonary resuscitation (CPR)<sup>98</sup>. Professional guidance is provided in regards when, and how, to cease CPR, but the final decision is made by the physician who is experienced in such situations. There is no certainty that further resuscitation would not be beneficial after the point of stopping – but this remains a unilateral decision nevertheless. Brody argues that opponents of futility cannot argue convincingly against unilateral decision-making with such a reality in medicine<sup>99</sup>.

In his review of the extremes sheltered under the umbrella of autonomy, Huxtable concludes:

«In developing the logic of autonomy, we appear to be left with two choices: either we tend towards a wholly-individualistic stance in which 'I want' translates into 'I should get' or we arrive at a more objective position, where I will only get what I want if it features on a pre-approved list of what I should get. Neither extreme seems wholly satisfactory»<sup>100</sup>.

In this section, I hoped to introduce the idea that while respect for autonomy is a significant imperative, it does not translate into unquestioned deference for the patient's wishes (this idea will be developed in Chapter Two). The usefulness of Coggon's *best desire* model of autonomy stems perhaps from its almost-objective assessment of a subjective desire, and arguably this process holds great potential for reaching outcomes. Improved communication between decision-makers is essential to this end: simply being aware of the other's position and motivation (and understanding of autonomy, importantly) may help prevent the slide towards unilateral decision making.

### 2.2.6. Paternalism

Paternalism is interference in the rights of others, where its justification is said to come from its intention to promote good and prevent harm for those persons, rather than for others<sup>101</sup>. This concept

<sup>96</sup> V. SACHDEVA, A RUCK KEEN, V BUTLER-COLE, *op.cit.*, 51.

<sup>97</sup> GMC guidance (2010), *op.cit.*, para.79, notes that a doctor «can withdraw from providing care if [her] religious, moral or other personal beliefs about providing life prolonging treatment lead [her] to object to complying with ... a decision that providing such treatment is not of overall benefit to a patient», with the stipulation that a colleague is found to take over care.

<sup>98</sup> H. BRODY, *Medical futility: a useful concept?* in M. ZUCKER, H. ZUCKER (eds), *Medical Futility*, New York, 1997, 4ff.

<sup>99</sup> There is obvious potential for inappropriate unilateral decision-making, which should be addressed by procedural policy.

<sup>100</sup> R. HUXTABLE, *op.cit.*, 118.

<sup>101</sup> See S. SMITH, *End-of-Life Decisions in Medical Care: Principles and Policies for Regulating the Dying*, *cit.*, 111. He notes how this is at odds with John Stuart Mill's famous belief, expressed in *On Liberty*, that «the only

is perhaps best supported when considering the autonomy of the doctor in relation to her duties of beneficence and non-maleficence.

Buchanan deconstructs the «disarmingly simple» argument for paternalism, revealing the scale of its reliance on the doctors’ power of assessment<sup>102</sup>. In addition, the doctor’s obligation to make an assessment that is founded on an empathetic understanding of the most personal details of a patient’s life story is clearly nigh impossible and likely to involve guess work<sup>103</sup>.

Proponents may argue that paternalism is justified through the formation of a contract between patient and doctor, but this is easily rebutted in contemporary society given the partnership’s requirement for informed consent. Similarly, a reliance on “practices of the past” is unsatisfactory. Impairment in the cognitive and/or emotional state(s) of patients or proxies is viewed as another situation when paternalistic behaviour may be justified. Again this is easily overcome, with contemporary standards requiring greater attempts to overcome these deficits (also a legal requirement)<sup>104</sup>.

Another serious concern with paternalism, and particularly so here, is the ease with which a contentious moral decision may be construed to be an impartial scientific or clinical decision. Buchanan proposes that, more importantly, «to even suggest that a complex moral judgment is a clinical or technological judgment is to prejudice the issue of who has the right to decide whether life-sustaining measures are to be initiated or continued»<sup>105</sup>. While paternalistic decision-making is nigh obsolete (in regards adults, at least), still proponents resolutely refine and promote its altruistic intentions (with beneficence and non-maleficence inevitably and suitably lauded). As ever, a balanced assessment of the case under review should guide the most appropriate decision-making.

### 2.2.7. Paternalism of the courts

Briefly, there is concern that paternalism of the doctor may be replaced by paternalism of the courts. We have seen that the courts maintain their status as the ultimate arbiter of best interests, thereby diminishing the role of the doctor or those close to the patient. But learned unilateral decisions are not necessarily correct decisions, and sometimes educated intuition is also incorrect – despite its best intentions<sup>106</sup>. The courts, too, must take care not to miss opportunities to change practice, which may diminish family distress and financial burdens on the health services<sup>107</sup>.

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purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others». Mill held that those who are capable of exercising autonomy should have their decisions respected, suggesting that others (like children and incompetent persons) might be viewed with a more paternalistic eye.

<sup>102</sup> A. BUCHANAN, *Medical Paternalism* in M. COHEN, T. NAGEL, T. SCANLON (eds), *Medicine and Moral Philosophy: A Philosophy and Public Affairs reader*, Guildford, 1981, 221.

<sup>103</sup> A. BUCHANAN, *Medical Paternalism*, cit., 225-226; See also R. VEATCH, *op.cit.*, for an axiological exploration of this account.

<sup>104</sup> E.g. MCA (2005), s.3(10).

<sup>105</sup> A. BUCHANAN, *op.cit.*, 233-234.

<sup>106</sup> E.g. Jackson J in *Re E* [2012], *op.cit.*, on best interests assessments: «The balancing exercise is not mechanistic but intuitive...», at 129. See also *Re T* [1997], *op.cit.*

<sup>107</sup> P. LEWIS, *Withdrawal of treatment from a patient in a Permanent Vegetative State: Judicial involvement and innovative “treatment”*, in *Medical Law Review*, 15, 2007, 394-397.

### 2.3. Objectivity v subjectivity

Quite simply, all decision making in medicine involves some degree of value judgement<sup>108</sup>. The following paragraphs demonstrate that no matter who makes a decision, or how it is made, the issue of objectivity and subjectivity will arise. Recognising this can but only strengthen the decision-making process.

Huxtable notes that although «*Bolam* is written through medical law as if it were a stick of seaside rock»<sup>109</sup>, the “stranglehold” of the doctors’ views has been loosened over time. This is appropriate because, as we know all too well, science does not equate with objectivity. But practically, the majority of best interests decisions are made on the ward. The courts feel this is appropriate<sup>110</sup>: doctors are seen as the ones to decide about end of life decision-making, considering the patient in the round. They have also suggested that «[j]udges are neither qualified to make, nor required, nor entitled to make ethical judgments or decisions»<sup>111</sup>. But neither are doctors, especially not unilaterally. Holistic assessments are not necessarily objective assessments, and careless or naive decisions may undermine the portrayed objectivity of the clinician.

The Supreme Court, in *James*, dismissed the Court of Appeal’s explanation for decision-making based on supposed rationality, stating that the latter was wrong in describing the test of a patient’s wishes as an objective one<sup>112</sup>. The goals of treatment (the avoidance of treatment burdens, in this case) were easily influenced by subjectivity and could not be said to be objective<sup>113</sup>. So while the best interests test is an objective test, the assessment of a patient’s wishes is not – the objective test contains a specifically subjective element.

The balancing exercise of the courts is equally punctuated by personal value judgements. I conclude this chapter with reference to three recent cases of patients in minimally conscious states to highlight the differing weights applied in this balancing process (which also draws attention to a broader change in legal judgements).

In *W v M*, the Court, having reviewed its balance sheet, decided that «the importance of preserving life is the decisive factor in this matter»<sup>114</sup>. The assessment of M’s quality of life had been based mainly on the reports of carers who saw her on a daily basis<sup>115</sup>. In *TH*<sup>116</sup>, the assessment of quality of life appears to take place in a different time period: Hayden J is relying on TH’s past wishes rather than his present situation (where there may or may not be experiences of pleasure). Although awaiting an objective medical assessment<sup>117</sup> before deciding whether or not it is in the patient’s best in-

<sup>108</sup> E.g. Lord Browne-Wilkinson in *Bland* [1993], at 884C.

<sup>109</sup> R. HUXTABLE, *op.cit.*, 98.

<sup>110</sup> E.g. Wall LJ in *Wyatt* [2005] CA, *op.cit.*, at 86.

<sup>111</sup> *An NHS Trust v MB* [2006], at 24.

<sup>112</sup> Baroness Hale in *James*, at 45.

<sup>113</sup> See also S. SMITH, *End-of-Life Decisions in Medical Care: Principles and Policies for Regulating the Dying*, cit., 266-268, who argues that the CA judges, in failing to consider what David James wanted, were far from rational.

<sup>114</sup> *W v M* [2011], 249

<sup>115</sup> *W v M* [2011], 81. Baker J said that best interests is not substituted judgement.

<sup>116</sup> *Sheffield v TH* [2014].

<sup>117</sup> See discussion in chapter 2, note 190.

terests to continue receiving nutrition, hydration and medication, Hayden J’s provisional declaration appears to favour the past wishes of the patient and the substituted judgement of the significant others. Referencing Baroness Hale in *James*, he confirms that he is required to assess holistically TH’s wishes and best interests by paying close attention to «the subtlety, ambit and integrity of [all] the evidence»<sup>118</sup>. Will the objective medical review trump the subjective wish? Will the patient’s wishes override the demands of Section 24 of the MCA 2005? The judgment is eagerly awaited, especially in light of the recent decision in *United Lincolnshire Hospitals NHS Trust v N*<sup>119</sup>. In that case, Mrs Justice Pauffley determined that clinically assisted Nutrition and Hydration (cANH) could legally be withheld from a woman in a minimally conscious state. The judgment assesses best interests; but rather than focussing specifically on N’s wishes, it is more related to available treatment options in a patient who is potentially dying. Thus this case differs from those of minimally conscious patients where the concern is the weight ascribed to a type of substituted judgement<sup>120</sup> – so it remains that the views of the patient and family are significant, but are not determinative. Clearly the balance between the objective clinical evaluation and the more subjective, emotive wishes and feelings of the patient is simpler in theory than in practice.

The challenge, of course, is applying such reasoned decision-making to real life<sup>121</sup>. The English Courts have balanced autonomy against protectionism in their judgments of best interests, resulting in occasional judgments that appear inconsistent or irrational<sup>122</sup>. At certain times, more subjective wishes appear to triumph<sup>123</sup>; at others more objective wishes<sup>124</sup>. With this in mind, I now turn to an application of the legal and moral criteria discussed in this chapter – in regards treatment that is considered “futile”.

### 3. The complication of futility

#### 3.1. The theory

##### 3.1.1. What is futility?

Some common interpretations of “futile” medical treatment include intervention being inappropriate or non-beneficial, or not being medically indicated, with death being inevitable and imminent<sup>125</sup>. But, as with best interests, it has no clear definition – and debate continues concerning its meaning, utility and appropriateness. I will not attempt to summarise here the voluminous details of these debates,

<sup>118</sup> *Sheffield v TH* [2014], 53-55.

<sup>119</sup> *United Lincolnshire NHS Trust v N* [2014].

<sup>120</sup> This case is discussed further in the following chapter, in regards futility, at note 224.

<sup>121</sup> Lord Steyn: «The surest test of a new legal rule is not whether it satisfies a team of logicians but how it performs in the real world» in *R v G and Another* [2003] 1 AC 1034, at 57.

<sup>122</sup> J. COGGON, *op.cit.*, 235 suggests that the «equivocal nature of the concept [of autonomy] ... result[s in] the inconsistent application of the principle».

<sup>123</sup> E.g. *Re B* [2002] EWHC 429 (Fam); *Re T* [1992]; *United Lincolnshire v N* [2014].

<sup>124</sup> E.g. *Burke* [2005].

<sup>125</sup> In their discussion of futility, J. MASON, G. LAURIE, *op.cit.*, 505 view the connotation of “hopelessness” as unacceptable, and prefer to use “non-productive treatment”.

but rather provide an introduction to the term so as to allow a discussion of its key concepts in regards decision-making.

«The decision that some goals are not worth pursuing is best seen as involving a conflict of values rather than a question of futility»<sup>126</sup>. Truog's words highlight two major issues facing futility as a concept: firstly, what is the action's intent or goal?<sup>127</sup>; and secondly, how is its inherent value judgement best addressed? Perhaps these issues may be simplified into the *effect* and *benefit* of the supposedly-futile act. The *effect* is the physiological change or outcome produced, which tends to be measurable and hence more objective. The *benefit*, on the other hand, incorporates an evaluation of the person as a whole, which may involve a value judgement and so is more subjective. In the case of conflict between doctor and patient proxy, the *effect* perhaps represents quantitative or physiological futility, and is personified by the clinician; while the *benefit* perhaps represents qualitative or normative futility, and is personified by the patient's significant others<sup>128</sup>.

As such, one action can result in numerous outcomes – but *effects* and *benefits* don't necessarily correlate. In clinical decision-making, «[t]he real problem is with care that has an effect, but that clinicians believe has no benefit»<sup>129</sup>. Hence the concern is that decisions may be based on clinicians' individual values rather than medical science, and thus doctors' decisions should not be determinative. Understanding the difference between quantitative and qualitative futility may improve a clinician's approach to the dilemma. Schneiderman has been at the forefront of interpreting medical futility within the clinical context: I mention his opinion here because of the significant debate it has generated. Although far from perfect, his concept provides a helpful starting point in the quest to improve understanding of this complex subject.

### 3.1.2. Quantitative futility

Schneiderman (and various colleagues)<sup>130</sup> are well-known supporters of futility as a quantitative concept. Here the problem is determining where to draw the line in regards measurable outcomes<sup>131</sup>. Despite its self-promotion as an empirical concept, it cannot escape the reality that there are no absolutes in medicine – and this concept is challenged repeatedly by critics<sup>132</sup>. Case-differences and recall bias<sup>133</sup>, «questionable extrapolations from statistical data»<sup>134</sup> and variation in probabilities and prognostication<sup>135</sup> are some of the factors that weaken the scientific facade. So while there remains

<sup>126</sup> R. TRUOG, A. BRETT, J. FRADER, *op.cit.*, 1561.

<sup>127</sup> AMERICAN MEDICAL ASSOCIATION, *Medical Futility in End-of-Life Care*, in *Journal of the American Medical Association*, 281, 1999, 938; Ward LJ in *James* [2013] EWCA, 35, provides a review of possible interpretations.

<sup>128</sup> For an in-depth discussion, see R. VEATCH, C. SPICER, *Medically Futile Care: The Role of the Physician in Setting Limits*, in *American Journal of Law and Medicine*, 18, 1992, 15-36; also L. SCHNEIDERMAN, *Defining Medical Futility and Improving Medical Care in Bioethical Inquiry*, 8, 2011, 123–131.

<sup>129</sup> R. VEATCH, C. SPICER, *op.cit.*, 36.

<sup>130</sup> Amongst them Nancy Jecker and Albert Jonsen.

<sup>131</sup> At one percent or lower, or is a higher percentage acceptable? (for example, the 5% proposal of B. BRODY, A. HALEVY, *op.cit.*).

<sup>132</sup> For example, R. TRUOG, A. BRETT, J. FRADER, *op.cit.*.

<sup>133</sup> T. TOMLINSON, D. CZLONKA, *Futility and Hospital Policy in The Hastings Center Report*, 25, 1995, 31.

<sup>134</sup> B. BRODY, A. HALEVY, *op.cit.*, 138.

<sup>135</sup> R. VEATCH, C. SPICER, *op.cit.*, 12.



some potential for medical success in these cases, the professionals consider this too insignificant to justify pursuing the intervention. Rejecting such unilateral decision-making, the American Medical Association (AMA) holds that open-minded «[i]ndividuals do not judge the worth of an intervention by physiological outcomes alone»<sup>136</sup>, hence the quantitative approach may be strengthened when combined with a qualitative one.

### 3.1.3. Qualitative futility

This measure asks whether a benefit is worth the effort, and considers the value of the end result. I mention this concept only briefly (any real analysis would deserve at least a chapter of its own). Effects and benefits are easily blurred when considering this notion of futility. Consider, for example, patients with disordered consciousness: is decision-making simpler when the patient is permanently unconscious in comparison with critically ill patients who fall into the no man’s land between “alert competent” and “unconscious incompetent”<sup>137</sup>? A combination of both these types of futility may be helpful when considering such unanswerable questions.

### 3.1.4. A “hybrid” concept

Schneiderman’s original definition of futility states that it is reasonable to conclude that a medical treatment is futile if it has not worked in the last 100 cases (“quantitative”); in addition the treatment is to be considered futile if a patient lacks the ability to appreciate the benefit of an intervention, or if the patient remains dependent on intensive medical care (“qualitative”).<sup>138</sup> It is easy to see the flaws in this “hybrid” concept, including the inevitable qualitative analysis of the quantitative<sup>139</sup>, its confusion of effect with benefit<sup>140</sup> (e.g. its implications for patients in a vegetative state, and what counts as a “worthwhile life”?) and so its failure to respect patient autonomy<sup>141</sup>. While proponents of this concept of “futility” argue that it promotes safety by allowing decisions to be made using justifiable standards that balance the rights of the patients and their kin against those of the medical team and society, perhaps the concept’s greatest strength is its focus solely on the ill patient who may gain (in some manner) from the intervention.

### 3.1.5. Physiological futility

Here an intervention is futile if it fails to produce the expected physiological consequence. Almost every intervention can have a physiological effect, so physiological futility applies to very few pa-

<sup>136</sup> AMERICAN MEDICAL ASSOCIATION, *op.cit.*, 938.

<sup>137</sup> See e.g. E. GAMPEL, *Does professional autonomy protect medical futility judgments?* in *Bioethics*, 20, 2006, 92-104.

<sup>138</sup> L. SCHNEIDERMAN, N. JECKER, A. JONSEN, *Medical Futility: Its Meaning and Ethical Implication* in *Annals of Internal Medicine*, 112, 1990, 949.

<sup>139</sup> R. TRUOG, A. BRETT, J. FRADER, *op.cit.*, 1562; R. VEATCH, C. SPICER, *op.cit.*, 19 goes so far to say that «[t]here simply is no such thing as a value-free and concept-free fact».

<sup>140</sup> See e.g. W. HARPER, *Judging Who Should Live: Schneiderman and Jecker on the Duty Not to Treat* in *Journal of Medicine and Philosophy*, 23, 1998, 501ff.

<sup>141</sup> W. HARPER, *op.cit.*, 513. In regards keeping patients alive to say their goodbyes, this compassionate «exception on humanitarian grounds is just to admit that the position sans the exception is inhumane».

tients. Cardiopulmonary resuscitation (CPR) is one intervention which rouses vocal debate<sup>142</sup>: treatment cannot be considered futile if it is able to preserve the physiological function of the body or an organ system (e.g. respiration or circulation) – even in patients who are unconscious or have a terminal disease.

This more restrictive definition often champions the right of the medical team to determine treatment plans since its clear empirical basis is irrefutable (“the patient’s wish is simply not achievable”). Criticisms include its limited scope of applicability, its failure to resolve who ought to make decisions<sup>143</sup>, and its reduction of medicine to a crude science<sup>144</sup>. Schneiderman argues that it distorts the patient-centred approach to medicine, and endangers patients in the attempt to maintain the “physiological reference range”<sup>145</sup>. The ethical concerns are clear: patients become dehumanised, seen as machines with faulty parts<sup>146</sup>. While it is generally acknowledged that doctors’ professional experience and their clinical knowledge are legitimate factors that influence decision-making, these factors alone cannot be determinative of what is futile.

There has been noticeable change in the definition of “futility” over time, and there appears to be increasing disagreement with these definitions as they move away from (almost-universally accepted) physiological futility. Does futility still deserve a place at the decision-making table?

### 3.1.6. Is futility an outdated term?

For many years commentators have argued against the term “futile”, exposing it as a “trump card” against patient autonomy<sup>147</sup>, «fraught with ambiguity, complexity and potential aggravation»<sup>148</sup>. I argue to keep the term “futility” – it is a morally permissible concept however, and not an imperative one. Nevertheless, I accept that another word may be helpful given that futility has become a morally ambiguous term. But attempts to clarify its definition may have made it more indefinable. While some commentators argue for greater clarity of definition<sup>149</sup>, others claim that making it simpler holds greater benefit<sup>150</sup>.

In summary, I agree with the AMA’s view that «[f]utility is an essentially subjective but realistically indispensable judgment. A fully objective and concrete definition is unattainable»<sup>151</sup>. This term, however, is (appropriately) clearly amenable to helpful objective medical interpretation. Decision-makers are compelled to reach consensus despite these difficulties; fortunately they can turn to the existing legal and moral frameworks in this regard, which I discuss next.

<sup>142</sup> E.g. B. BRODY, A. HALEVY, *op.cit.*

<sup>143</sup> See E. GAMPEL, *op.cit.*, 95.

<sup>144</sup> L. SCHNEIDERMAN, N. JECKER, A. JONSEN, *Medical Futility: Its Meaning and Ethical Implication*, in *Annals of Internal Medicine*, cit., 953.

<sup>145</sup> L. SCHNEIDERMAN, *Defining Medical Futility and Improving Medical Care in Bioethical Inquiry*, cit., 127.

<sup>146</sup> H. BRODY, *op.cit.*, 4 makes a similar point; also AMERICAN MEDICAL ASSOCIATION, *op.cit.*, 938.

<sup>147</sup> C. WEIJER, C. ELLIOT, *Pulling the plug on futility*, in *British Medical Journal*, 310, 1995, 683; also B. BRODY, A. HALEVY, *op.cit.*, 123.

<sup>148</sup> R. GILLON, “Futility” – too ambiguous and pejorative a term?, in *Journal of Medical Ethics*, 23, 1997, 339.

<sup>149</sup> L. SCHNEIDERMAN, *Defining Medical Futility and Improving Medical Care in Bioethical Inquiry*, cit., 126.

<sup>150</sup> T. TOMLINSON, D. CZLONKA, *op.cit.*, 6 and 30.

<sup>151</sup> AMERICAN MEDICAL ASSOCIATION, *op.cit.*, 938.

### 3.2. Putting the theory into practice

#### 3.2.1. Legal interpretation

In *James*, Baroness Hale declares that a treatment would be futile if considered as «being ineffective or being of no benefit to the patient»<sup>152</sup>. In addition, she reasoned that «it is setting the goal too high to say that treatment is futile unless it has “a real prospect of curing or at least palliating the life-threatening disease or illness from which the patient is suffering” ... A treatment may bring some benefit to the patient even though it has no effect upon the underlying disease or disability»<sup>153</sup>. A medical definition accepted by the Courts is that «“futility” would normally be understood as meaning that the patient cannot benefit from a medical intervention because he or she will not survive with treatment»<sup>154</sup>. Baroness Hale notes that it is important to consider closely the effectiveness or benefit of the supposedly-futile act, given that the medical assessment is not the only factor to be weighed<sup>155</sup>. Her words make clear the importance of the patient’s subjective judgement.

#### 3.2.2. Legal change of futility

The 1981 decision in *Re B (a minor)*<sup>156</sup>, where Templeman LJ adjudicated that the life of a child with Down’s Syndrome who would die without an operation to relieve intestinal obstruction would not «be so awful that in effect the child must be condemned to die»<sup>157</sup> and so held that treatment must be directed by the interests of the patient rather than that of the parents, has been said to have «laid the [English Courts’] foundations for a quality of life therapeutic standard rather than one based on rigid adherence to the principle of the sanctity of human life»<sup>158</sup>. Lord Donaldson presided over a number of cases, in the 1990s, relating to selective non-treatment of infants<sup>159</sup>, in which the clinical autonomy of the doctor and the best interests standard were endorsed. The best interests standard has subsequently diminished the influence of the “touchstone of intolerability”<sup>160</sup>. The process of the Courts is clear – there is no one test to determine best interests, and intolerability is, at best, useful as one of many guides in decision-making<sup>161</sup>. Baroness Hale, in her description of patients’ welfare in broad terms, appears to support this view in *James*<sup>162</sup>.

Case judgments across the spectrum have acknowledged that medical treatment is not without its risks, and holds clear potential for both care and harm of a patient. Continuing treatment when justi-

<sup>152</sup> Baroness Hale in *James*, at 40.

<sup>153</sup> *James, op.cit.* 43. She also agreed with Jackson J, at first instance, who reasoned that «recovery does not mean a return to full health, but the resumption of a quality of life that DJ would regard as worthwhile».

<sup>154</sup> *James, op.cit.*, 43. Baroness Hale quotes the submission of The Intensive Care Society and Faculty of Intensive Medicine.

<sup>155</sup> Baroness Hale in *James*, 40.

<sup>156</sup> [1981] 1 WLR 1421.

<sup>157</sup> *Re B (a minor)* [1981], 1424.

<sup>158</sup> J. MASON, G. LAURIE, *op.cit.*, 509.

<sup>159</sup> Including the influential *Re J* [1991].

<sup>160</sup> Intolerability «should not be seen either as a gloss on or a supplementary guide to best interests»: *Wyatt* [2005], 91.

<sup>161</sup> *Wyatt* [2005], 76; also *Burke* [2005], 63.

<sup>162</sup> C. FOSTER, *op.cit.*, 16 argues that Baroness Hale is unclear on her position regarding intolerability.

fication for it no longer exists may be as wrong (and illegal) as continuing treatment without appropriate consent<sup>163</sup>. One such treatment that receives regular judicial review is clinically-assisted nutrition and hydration (cANH), as much a life-sustaining medical treatment as ventilation. There are a number of recent cases regarding patients with anorexia at the end of life that provide thoughtful (and yet opposing) views on decision-making in the context of futility, the limits of autonomy and the role of third parties<sup>164</sup>.

### 3.2.3. Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

It is appropriate to end this section with a discussion of one of the most contentious issues in futility decision-making: DNACPR orders. The Court of Appeal recently, in *Tracey v Cambridge University Hospitals NHS Foundation Trust*<sup>165</sup>, held that while decision-making in regards CPR is not an exclusive medical process, the ultimate decision remains in the domain of the clinicians. It also affirmed that doctors are legally bound to discuss DNACPR decisions with patients and/or those close to the patient – which is simply the legalisation of longstanding professional guidance<sup>166</sup>. A number of issues are raised by this judgment – firstly, the *Tracey* appeal was allowed owing to its focus on Article 8 rights alone<sup>167</sup> and so failure to involve the patient in this process of decision-making violates that right; secondly, it reiterates that full disclosure and information about medical conditions, prognoses and management is essential; and finally, a medical team should offer a second opinion if disagreement of opinions persists. Interestingly, the Court of Appeal in *Tracey* felt that if a multidisciplinary team (MDT) decision had concluded that DNACPR was not appropriate, it was not obliged to offer a second opinion<sup>168</sup>. This is quite different from the suggestion of the first instance ruling in *James*. There, the multidisciplinary team was overruled despite the concurring views of the (hospital and judicial) second-opinions. This judgment represents a greater acknowledgement of the patient's right to involvement in decision-making, balanced against an objective and professional medical review. But only time will tell how effectively these legal requirements are translated into practice<sup>169</sup>. Considering the *Tracey* judgment, it is good practice to encourage (when appropriate) early communication between doctor and patient on end-of-life issues. Knowledge of a patient's wishes prior to an event is certainly beneficial, and arguably many disputes could be avoided if advance decisions or advance care plans are created at an appropriate time<sup>170</sup>. However, this does require more openness

<sup>163</sup> See *Re B* [2002], for a caution regarding battery.

<sup>164</sup> See e.g. *Re L* [2012], and *Re E* [2012].

<sup>165</sup> [2014] EWCA Civ 33.

<sup>166</sup> Joint statement from the British Medical Association, Resuscitation Council (United Kingdom) and Royal College of Nursing *Decisions relating to cardiopulmonary resuscitation* (2007) London – subsequently updated in 2014. <https://www.resus.org.uk/pages/DecisionsRelatingToCPR.pdf> (last visited 19/4/2015).

<sup>167</sup> Rather than several others, as was the case at first instance.

<sup>168</sup> *Tracey* [2014], 63-65.

<sup>169</sup> The relatively-recent NCEPOD report (National Confidential Enquiry into Patient Outcome and Death) (2012) found that no discussion of end-of-life decision-making had been taken pre-CPR in the «overwhelming majority of cases» (p. 6) – suggesting a cultural rather than an individual case-by-case failing. <http://www.ncepod.org.uk/reports.htm> (last visited 19/4/2015).

<sup>170</sup> See discussion around note 205.

and a willingness to talk about death<sup>171</sup>. To promote a true doctor-patient/proxy partnership, both sides need to move away from the silence that is traditionally associated with issues of death. This is a challenge, but it is now a legal responsibility.

### 3.3. Separating the legal and the ethical

#### 3.3.1. Hearing the patient's voice

The doctors or those close to the patient are faced with a difficult task when a patient is unable to tell them her own opinions of a worthwhile life, or quality of life. I now consider briefly life's worthiness in the context of medically-futile treatment. In his discussions of English Law as «morally and intellectually misshapen»<sup>172</sup>, referencing *Bland* in particular<sup>173</sup>, Keown feels that it is more acceptable for the law to make judgements on futility than quality of life<sup>174</sup>. He says it is wrong to withdraw treatment based on assessment of worthiness of life; and separates life's intrinsic value into vitalism (absolute deference for life at all costs), sanctity of life and quality of life (or instrumental value of life). Few abide by the vitalist standpoint. Keown champions sanctity of life, and differentiates quality of life from quality of treatment. For Keown, there is little room for quality of life arguments when considering sanctity of life.

But while sanctity of life provides a possible middle-ground between vitalism and an extreme instrumental value of life, it is itself comprised of terms (like 'intention', 'burden' and futility) that are unclear and not easily applicable to real clinical scenarios<sup>175</sup>. It has been said this inviolability of life generally focuses on medical treatment (and so has been associated with life preservation); while quality of life focuses on the patient's wishes and goals (and has been associated ultimately with the ending of life)<sup>176</sup>. Considering the difficulty in unravelling the entanglement of quality of life and subjectivity/objectivity when considering futility, is it too simple then to say that the doctor should decide which treatment is futile, while the patient should decide which type of life is futile?

In *Burke* and *James* it was accepted that when death is imminent, it is appropriate that the focus shifts to the comfort and dignity of the patient rather than on attempts to prolong life by any means<sup>177</sup>. Quality of life then easily becomes confused with futility definitions. While the general consensus is that one should not judge whether the life of another is worthwhile or not<sup>178</sup>, quality of

<sup>171</sup> This includes a frank discussion about medical intervention. E.g. in regards CPR: «[t]he public believe that patients have a 50:50 chance of surviving, where the professionals accept that survival to discharge is less than 15%. Nor does public appreciation factor in the chance that survival will often involve disability». NCEPOD, *op.cit.*, 5.

<sup>172</sup> Lord Mustill in *Bland* [1993], 887.

<sup>173</sup> The instrumental value of life position having been approved in *Bland* [1993].

<sup>174</sup> J. KEOWN, *The Law and Ethics of Medicine: Essays on the Inviolability of Human Life*, Oxford, 2012, Chapter 13, p.i20; and J. KEOWN, *A Futile Defence of Bland: A Reply to Andrew McGee in Medical Law Review*, 13, 2005, 396; Cf. «...it is the futility of the treatment which justifies its termination» Lord Goff in *Bland* [1993], 870.

<sup>175</sup> R. HUXTABLE, *op.cit.*, 111.

<sup>176</sup> S. SMITH, *Commentary: Aintree University Hospital Foundation Trust V James* [2013] EWCA Civ 65, in *Medical Law Review*, 21, 628-630 argues that the latter's holistic assessment of wishes defies this misconception. He champions a combined approach.

<sup>177</sup> *Burke* [2005], 62-63 and *James* [2013], 38.

<sup>178</sup> See for example, Taylor LJ in *Re J* [1991], 55.

life considerations are still used in decision-making<sup>179</sup>. There has been much disquiet about the use of this concept in law<sup>180</sup>; and with its associated risk of a slide down slippery slopes<sup>181</sup>, the moral debate is unlikely ever to be settled. For the meantime, in law, we are guided by Baroness Hale's declaration that the patient's own view of the quality of her life must always be considered<sup>182</sup>.

### 3.3.2. Hearing the clinician's voice

It has been argued that doctors should refrain from providing treatment which they feel should not be given – otherwise medical issues risk becoming legal ones<sup>183</sup>. Other commentators argue that diagnostic assessments and prognostication remain medical, not ethical, issues<sup>184</sup>. Although decisions based on facts, experience and clinical judgement are grounded in objectivity, they will inevitably contain a degree of self-opinion. To ensure that the medical professional's voice is heard appropriately, the insightful doctor must advocate the move towards more objective assessments of medical conditions.

### 3.3.3. How do doctors determine what is futile?

This question is vital, since it is often the process of decision-making, rather than a proposed clinical plan, that becomes a source of dispute amongst decision-makers<sup>185</sup>. This process is also inevitably complicated by the influences of subjectivity and objectivity. Although evidence suggests that medically-trained personnel wish for less (rather than more) intervention at the end of their own lives<sup>186</sup>, a doctor's understanding of her duty at the end-of-life or even in regards futility management is understandably variable (and often the health-care providers' readiness for such decision-making is poor<sup>187</sup>). Whatever the cause may be<sup>188</sup>, a vast proportion of medical practitioners are clearly ill-equipped to deal with end-of-life issues. Do professionals whose occupation involves preserving or improving life automatically know enough about death to make such decisions?

<sup>179</sup> This is especially true for patients in a vegetative state, or in end-of-life considerations.

<sup>180</sup> E.g. *Re A (Conjoined Twins)* [2000] EWCA Civ 254; the differing opinions of quality of life in *Bland* [1993], see Lord Mustill's view, at 894.

<sup>181</sup> E.g. J. KEOWN, *The Law and Ethics of Medicine: Essays on the Inviolability of Human Life*, cit., note 174 argues that treatment should not be decided on quality of life, but on effectiveness of treatment.

<sup>182</sup> Baroness Hale in *James*, at 44.

<sup>183</sup> N. JECKER, L. SCHNEIDERMAN, *Families who want "everything done"*, in *Journal of Medicine and Philosophy*, 20, 1995, 145-163. This is especially true in light of the *Tracey* judgment, where doctors may over-treat in order to avoid any threat of legal complications.

<sup>184</sup> J. PARIS, E. CASSEM, W. DEC et al, *Use of a DNR Order Over Family Objections: The Case of Gilgunn v. MGH*, in *Journal of Intensive Care Medicine*, 14, 1999, 43.

<sup>185</sup> E.g. *Tracey* [2014], 43.

<sup>186</sup> E.g. J. GALLO, J. STRATON, M. KLAG et al, *Life-Sustaining Treatments: What Do Physicians Want and Do They Express Their Wishes to Others?*, in *Journal of the American Geriatrics Society*, 51, 2003, 966.

<sup>187</sup> See A. TEIXEIRA, E. FIGUEIREDO, J. MELO et al, *Medical Futility and End-of-Life Decisions in Critically-Ill-Patients: Perceptions of Physicians and Nurses in Central Portugal* in *Journal of Palliative Care Medicine*, 2, 2012, 110.

<sup>188</sup> Consider, for example, the super-specialisation of modern medicine that has all but eradicated the generalist.

Fortunately, voluminous guidance exists to help doctors make decisions. Even before a multidisciplinary team (MDT) review<sup>189</sup>, measures can be employed to provide a more objective assessment of outcomes (e.g. SMART<sup>190</sup>; APACHE<sup>191</sup>) or to structure decision-making (e.g. UFTO<sup>192</sup>, TEP<sup>193</sup>, AMBER care bundle<sup>194</sup>; the Gold standards framework<sup>195</sup>). I have chosen to discuss now the Universal Form of Treatment Options (UFTO), and review its compliance with ethical and legal practice.

### 3.3.4. The UFTO

The UFTO, formulated and initially implemented at Cambridge University Hospitals NHS Trust<sup>196</sup>, aims to provide an objective assessment of what constitutes appropriate management for an acutely-unwell hospitalised patient. Related studies have found, corroborated by various SUPPORT investigations<sup>197</sup>, that while enhanced communication may result in better care, the implementation of such guides is often poor – too often the physician would not broach the subject either timeously or for fear of distressing the patient/family. In such cases, it is important for the doctor to remember her professional<sup>198</sup> and legal<sup>199</sup> duty: “to work in partnership with patients”<sup>200</sup>.

Universal forms like UFTO help to remove the stigma associated with end-of-life discussions<sup>201</sup>. The UFTO is completed for all admitted patients, as opposed to the more traditional practice of selectively completing a DNACPR form. This creates consistency, with no discriminatory exclusions or “special cases”; it also normalises decision-making, even about end-of-life care. The result is a thought-through process rather than a knee-jerk reaction to complete a DNACPR order when a patient’s con-

<sup>189</sup> Guidance provided by a range of specialist opinions.

<sup>190</sup> A tool for the assessment of disorders of consciousness following brain injury; see H. GILL-THWAITES, R. MUNDAY, *The Sensory Modality Assessment and Rehabilitation Technique (SMART): a valid and reliable assessment for vegetative state and minimally conscious state patients in Brain Injury*, 18, 2004, 1255.

<sup>191</sup> Acute Physiology and Chronic Health Evaluation (APACHE) – a measure of critical care outcomes; W. KNAUS, E. DRAPER, D. WAGNER et al, *APACHE II: a severity of disease classification system in Critical Care Medicine*, 13, 1985, 818-829.

<sup>192</sup> Z. FRITZ, A. MALYON, J. FRANKAU et al, *The Universal Form of Treatment Options (UFTO) as an Alternative to Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Orders in PLoS ONE*, 8(9), 2013, e70977.

<sup>193</sup> The Treatment Escalation Plan (TEP): T. OBOLENSKY, T. CLARK, G. MATTHEW et al, *A patient and relative centred evaluation of treatment-escalation-plans: a replacement for the do-not-resuscitate process in Journal of Medical Ethics*, 36, 2010, 518.

<sup>194</sup> See [www.ambercarebundle.org](http://www.ambercarebundle.org) (last visited 19/04/2015).

<sup>195</sup> See [www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk) (last visited 19/04/2015).

<sup>196</sup> The respondent hospital trust in Tracey [2014].

<sup>197</sup> A. CONNORS, N. DAWSON, N. DESBIENS et al, *Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT)*, in *Journal of the American Medical Association*, 274, 1995, 1591-1598: a study of over 9000 critically-ill inpatients across five US hospitals advocating the use of advance directives in acutely unwell adults.

<sup>198</sup> To put into practice the shared decision-making ideal of the 2010 White Paper on the NHS (*Liberating the NHS*): “No decision about me without me”.

<sup>199</sup> E.g. Tracey [2014], *op.cit.*

<sup>200</sup> GENERAL MEDICAL COUNCIL, *Guidance for Doctors: Good Medical Practice*, 2014. [http://www.gmc-uk.org/Good\\_medical\\_practice\\_English\\_0414.pdf\\_51527435.pdf](http://www.gmc-uk.org/Good_medical_practice_English_0414.pdf_51527435.pdf) (last visited 19/04/2015).

<sup>201</sup> Z. FRITZ, J. FULD, *Ethical issues surrounding do-not-attempt-resuscitation orders: decisions, discussions and deleterious effects in Journal of Medical Ethics*, 36, 2010, 593.

dition deteriorates<sup>202</sup>: «[f]rom a predominant use of the word “futility” on the DNACPR forms, there was a shift to document diagnoses on the UFTO»<sup>203</sup>.

Apart from being in line with legal requirements, its focus on interventions to be provided rather than withheld (according to best interests) was found to lower the rate of harms to patients (by knowing when and how to act, with an earlier recognition of palliative care needs). Interestingly, Fritz et al found no increase in documented discussions with patients, while the number of patients “not-for-CPR” remained the same<sup>204</sup> – this suggests that while the “substantive” clinical acumen remains sound, the “procedural” aspects of application may be problematic. This highlights the age-old problem of communication; perhaps the recent legal declaration may improve this process.

### 3.3.5. What about autonomy in this process?

Advance decisions and community policies are well-known and well-studied, but these may not respect the patient’s autonomy for “that particular decision” at “that particular time”. While some studies demonstrate that patients with advance directives and advance care plans are more likely to receive the care that they prefer (which also tends to be less aggressive at the end of life), with greater family satisfaction of the care received<sup>205</sup>, other studies have found that health professionals did not better understand the wishes of critically-ill patients when relying on advance decisions or proxy decision-makers<sup>206</sup>. Programs encouraging patients to discuss their medical wishes with families have been of limited success<sup>207</sup>, as often this is felt to be “too medical” a task – here clinical intervention has been highlighted as the best alternative<sup>208</sup>. The physician may then have the opportunity to formulate an objective account of a subjective wish.

Advance Care Planning may provide great assistance in this quest, since a considered declaration provides more assistance than best guess alone – but its universality is some way off<sup>209</sup>. Its applicability is also limited: for example, acutely-unwell in-hospital patients lacking capacity would be ineligible for this intervention at that time, and predetermined wishes may not truly apply in a novel context. A cynical concern is that true medical change may only follow an incentive (for example, through legal necessity or a financial reward). For Advance Care Planning to become routine, it may require the review (by a general practitioner) of the wishes of at-risk patients to be listed as a Quality and Outcome

<sup>202</sup> Z. FRITZ, A. MALYON, J. FRANKAU et al, *op.cit.*, 4.

<sup>203</sup> Z. FRITZ, A. MALYON, J. FRANKAU et al, *op.cit.*, 9.

<sup>204</sup> Z. FRITZ, A. MALYON, J. FRANKAU et al, *op.cit.*, 9.

<sup>205</sup> J. TENO, A. GRUNIER, Z. SCHWARTZ et al, *Association between advance directives and quality of end-of-life care: a national study*, in *J American Geriatrics Society*, 55, 2007, 189-194.

<sup>206</sup> A. CONNORS, N. DAWSON, N. DESBIENS et al, *op.cit.*, 1591; Cf. P. LAYDE, C. BEAM, S. BROSTE et al, *Surrogates’ Predictions of Seriously-Ill Patients’ Resuscitation Preferences in Archives of Family Medicine*, 4, 1995, 518-524 and D. MOLLOY, G. GUYATT, R. RUSSO et al, *Systematic Implementation of an Advance Directive Program in Nursing Homes: A Randomized Controlled Trial in Journal of the American Medical Association*, 283, 2000, 1437.

<sup>207</sup> E.g. J. GALLO, J. STRATON, M. KLAG et al, Gallo, *op.cit.*, 966.

<sup>208</sup> A. CONNORS, N. DAWSON, N. DESBIENS et al, *op.cit.*, 1591.

<sup>209</sup> Just over ten percent of patients offered such a review accept this offer: ROYAL COLLEGE OF PHYSICIANS, *Advance Care Planning – National Guidelines*, London, 2009, 9.



Framework (QOF)<sup>210</sup>. Clearly, more open communication policies are essential for improved future care and decision-making.

What the patient wants matters morally, but this cannot be the only moral interest. What is to be done, for example, when a clinical condition reaches the point of physiological futility? We have seen that such futility involves failure to reach a physiological outcome, while subjective futility considers “worthiness” (“is there a point in carrying on regardless?”). The latter is a very individual decision, considering hopes (such as for a miracle)<sup>211</sup> and beliefs (including religious conviction)<sup>212</sup>. «The harsh reality, so harsh that it was understandably impossible for the family to accept it, was that his position was hopeless... We had to act on the real possibilities not those which were fanciful»<sup>213</sup>. Ward LJ’s words, in *James*, appear harsh, but there is arguably a ring of truth to them. There are facts, but there is also interpretation of those facts.

### 3.3.6. The doctor’s dilemma

The *initial* assessment of a patient at the end-of-life ought to be medical, and objective - to prognosticate physiological outcomes. Thus doctors assume, appropriately, an important role in decision-making – they are arguably in the best position to determine objective futility. Consider then, in such circumstances, a request from those close to the patient that «everything be done»<sup>214</sup>. The doctors, understandably, are now faced with a very difficult moral dilemma. If they do as the proxy wants, they may do harm to the patient (and «first, do no harm» is a primary moral imperative of the medical profession). Should doctors be forced to provide treatment that may prolong the suffering of a patient?

The legal answers<sup>215</sup> are perhaps simpler than the moral ones. The doctor here is in a difficult position, needing to balance significant moral imperatives. The doctor’s duty is always to act in the patient’s best interest, but in seeking to avoid harm there is a danger of acting in a paternalistic manner. It may then be too much to ask the individual doctor to balance all the possible harms to a patient, which ultimately prevents or impedes her interests<sup>216</sup>. Anything that promotes the patient’s interest will be benefit, while anything that stifles it will be harm<sup>217</sup>. These interests will determine the patient’s own wish to live or die; and may easily conflict with the doctor’s conscience, code of practice or objective decision-making.

<sup>210</sup> This measure of improved care is incentivised by rewards. See [www.hscic.gov.uk/qof](http://www.hscic.gov.uk/qof) (last visited 19/04/2015).

<sup>211</sup> For example, *NHS Trust v Ms D* [2005], at 45; *NHS Trust v A (a child)* [2008] 1 FLR 70.

<sup>212</sup> E.g. *VT* [2013], and *NHS Trust v L* [2013]; religious views traditionally hold little sway in English Courts.

<sup>213</sup> *James* [2013] EWCA, at 47.

<sup>214</sup> See e.g. *Re J* [1991]; *Burke* [2005]; *VT* [2013].; *NHS Trust v Ms D* [2005].

<sup>215</sup> As discussed above; also, the courts acknowledge the doctor’s dilemma: Sedley J in Wyatt EWHC, with reference to Lord Donaldson in *Re J*, at 27, recognises the difficulties faced by the doctor in such situations given that conscience is not a rigid concept. He states that the law would also appreciate this fact, provided the doctor took all appropriate, professional steps to analyse the dilemma. See also notes 60 and 97.

<sup>216</sup> S. SMITH, *End-of-Life Decisions in Medical Care: Principles and Policies for Regulating the Dying*, cit., 11; he later clarifies that interests may be *ultimate* (such as life goals) or *welfare* (those required to attain the ultimate interests), p.121.

<sup>217</sup> Translated into the principles of beneficence and non-maleficence.

While doctors have been criticised for being «too logical» (and so ignoring the emotional and less-logical reality of everyday life)<sup>218</sup>, those close to the patient have often been portrayed as equally hindered in decision-making for opposing reasons. Emotion and unbounded hope may misguide the kin to express their love by requesting that “everything is done”, rather than respecting the wishes of the patient. Medical professionals cannot be duty-bound to place hope above reality: this is unfair, involves withholding information, and distorts the balance of power.<sup>219</sup> Jackson J in *Re E* provides a legal opinion: «[i]f taken too far, the argument that everything that can be done must be done carries the risk of discrimination against incapacitated persons by depriving them of options that are available to the capacitous»<sup>220</sup>.

Undoubtedly, autonomy and individuals’ differing values come to the fore at the time of illness and death<sup>221</sup>. But in death, as in life, «we cannot always have what we want»<sup>222</sup> – but we can be listened to, and heard. Wishes and rights must be balanced against duties, and the rights of others; this need not be unnecessarily restrictive, though, if we consider the vein of Coggon’s *best desire autonomy*<sup>223</sup>. However, there is no one concept or interpretation that guarantees resolution in such predicaments; and a thoughtful review that balances the specifics of the individual case is perhaps the most morally-astute starting point.

On a practical note, futility should not equate with no treatment – it should ensure exemplary symptom-control and, when appropriate, end-of-life care that incorporates emotional, spiritual, communication and empathic support. In this way, defining futility is helpful in that it creates a standard of care that allows for the most appropriate treatment for an individual. This *has* been achieved by the courts.

### 3.3.7. Contemplating solutions

A recent case that draws significantly on the Supreme Court judgment in *James* is *United Lincolnshire Hospitals NHS Trust v N*<sup>224</sup>. The jointly instructed expert in this case, Dr Barry Jones, receives illustrious commendation from Mrs Justice Pauffley for his holistic assessment of N. The first mention of futility comes in his written statement, in which he argues that «continued attempts to feed would be futile»<sup>225</sup>. Pauffley J quotes Baroness Hale’s definition of futility in *James*<sup>226</sup>, but discusses this issue no further. If this case is considered as purely withdrawal of treatment in a minimally conscious patient, it will easily be criticised and misunderstood. But a deeper review is necessary here – if a patient is requiring therapeutic intervention, but for reasons owing to her underlying condition she is unable to endure any measures to improve her condition, the interventions may be regarded as fu-

<sup>218</sup> D. LAMB, *op.cit.*, 82

<sup>219</sup> L. SCHNEIDERMAN, N. JECKER, A. JONSEN, *Medical Futility: Response to Critiques*, in *Annals of Internal Medicine*, 125, 1996, 671.

<sup>220</sup> Jackson J in *Re E* [2012], at 134 (with reference to *Re B* [2002], where a patient, Ms B, chose to have ventilation withdrawn knowing that this would result in her death).

<sup>221</sup> See W. HARPER, *op.cit.*, 513.

<sup>222</sup> Baroness Hale in *James*, at 45.

<sup>223</sup> See note 74.

<sup>224</sup> *United Lincolnshire NHS Trust v N* [2014].

<sup>225</sup> *United Lincolnshire NHS Trust v N* [2014], 45.

<sup>226</sup> *United Lincolnshire NHS Trust v N* [2014], 56.

tile (as defined by Baroness Hale). With its incorporation of a cogent medical opinion and a consideration of substituted judgement, this declaration has demonstrated the best interests standard to be an exemplary model of medico-legal decision-making.

«[A]ny resolution of the debate about medical futility will require, at the least, determinations of the proper model of human health, the value of human life, the value of human autonomy, and the proper attitude toward suffering»<sup>227</sup>. Since a futility judgement is a combination of science, moral, political and economic issues, the decision should be made jointly by persons who understand this complexity. We are unlikely to always agree on futility, so the process of its decision-making, that balances professional empiricism against an individual patient’s wishes and values, must address its complexity appropriately. The following chapter will suggest practical means of achieving this goal.

#### 4. Finding solutions

We have seen that the courts are the final arbiter in disputes regarding treatment considered to be futile. This is far from an enviable task: there is no template for overcoming the unpredictability of even the most critical clinical situations<sup>228</sup> or for appeasing the most incompatible of opinions. Even if another procedural solution is found, the outcomes would be influenced by its substantive (legal) framework.

If best interests is championed, expect a more objective test – but not “objective” as originally formulated, since we have seen that this standard contains an element of substituted judgement. The objectivity, then, is required from a medical perspective: assessments like UFTO are helpful in overcoming the inherent value judgements that may cloud decision-making. The subjectivity is determined by the patient. The best interests evaluation, therefore, should balance these two components.

If substituted judgement is chosen, expect a more subjective test – although the medical personnel must still remain objective. Here, the doctor presents her quantitative assessment of futility and must explain why any evaluative conclusion should «override the patient’s or surrogate’s different judgment and values, given that it is the patient who will be most affected by the decision»<sup>229</sup>. It seems to follow that even when the probability of a successful outcome is low (but death is the alternative) and the patient wishes to receive treatment, that treatment should be offered.

Undoubtedly, the debate over decision-making is far from settled. I have promoted the use of the best interests standard since it has been formulated to provide a more balanced interpretation of the medical and personal situations. In this view, the doctor and patient are of equal standing – they are empowered to reach consensus even when *their opinions and beliefs cannot hold equal value*. When applied to an assessment of futility (that is patient-centred and takes professional medical and community standards into account), the best interests standard is shown to be a fair and truly in-the-

<sup>227</sup> W. HARPER, *op.cit.*, 514.

<sup>228</sup> E.g. the unexpected survival of baby David in *R v Portsmouth, ex parte Glass* [1999] All ER (D) 836.

<sup>229</sup> D. BROCK, *Medical Decisions at the End-of-Life* in H. KUHSE, P. SINGER (eds.) *A Companion to Bioethics*, Malden, 2009, 266.

round assessment, that can transcend ‘unattainable’ objectivity and ‘too-demanding’ subjectivity<sup>230</sup>. In this final chapter, I focus on measures that may address seemingly-irreconcilable differences in medical decision-making, and so help to avoid the significant costs (financial, emotional and time) involved otherwise with judicial review.

#### 4.1. Making decisions

Consider the following “truths”: “frank discussions about conditions, treatment options and prognoses are more helpful than reliance on ‘futility’”; “there will never be certainty, but there will be evidence”; “the aim is always to avoid harm and suffering”; “even if all judgements are made in court, there is no guarantee that these will correspond with a patient’s best interests – since none is fool-proof”. These few candours are useful as a starting point when formulating a policy to address what constitutes “futility” in medical decision-making. A fair process that allows negotiation and development of consensus in these sorts of cases must avoid a definition imposed from outside<sup>231</sup>. A workable policy should ensure a peer-reviewed, as-complete a discussion as possible, with a broad range of opinions including a biopsychosocial approach to futility, and education of health providers<sup>232</sup>. An acceptable policy, then, would include «distinguishable steps aimed at deliberation and resolution, ...steps aimed at securing alternatives in case of irreconcilable difference, and a final step aimed at closure when all other alternatives have been exhausted»<sup>233</sup>.

There are five groups of people who could potentially resolve the difficulty of decision-making in “futile” situations: I will consider each in turn, having noted in this essay their strengths and weaknesses:

- i. the doctor;
- ii. the patient/proxy;
- iii. society;
- iv. the courts;
- v. a special MDT.

The preceding reviews of the legal and moral issues involved in decision-making regarding “futile” medical treatment have essentially answered the questions of who ought to decide that a treatment is futile (and how this ought to be done). I will now raise some final points and present closing summaries, concluding that only through joint decision-making can the personal, medical, legal and moral concerns be addressed appropriately.

##### *i. Ought the doctor to decide?*

If a doctor “enforces” life-sustaining treatment on a patient, the patient and kin are left bearing any ensuing difficulties, which reinforces the justification that their views should be paramount. But the

<sup>230</sup> GENERAL MEDICAL COUNCIL GUIDANCE (2010), *op.cit.*, 47-49 states that the «aim is to reach consensus about what treatment and care would be of overall benefit to a patient...».

<sup>231</sup> T. TOMLINSON, D. CZLONKA, *op.cit.*, 33; AMERICAN MEDICAL ASSOCIATION, *op.cit.*, 939.

<sup>232</sup> T. TOMLINSON, D. CZLONKA, *op.cit.*, 28ff; AMERICAN MEDICAL ASSOCIATION, *op.cit.*, 939ff; L. SCHNEIDERMAN, A. CAPRON, *How Can Hospital Futility Policies Contribute to Establishing Standards of Practice?*, in *Cambridge Quarterly of Healthcare Ethic*, 9, 2000, 531.

<sup>233</sup> AMERICAN MEDICAL ASSOCIATION, *op.cit.*, 939.

tables are turned when a physician is left with that responsibility if a judge rules that a treatment is not futile<sup>234</sup>. The medical professional’s goals include healing disease and promoting health, as well as relieving suffering associated with illness. To provide care that fails to do any of these is to act contrary to set standards. The doctor, cognisant of known practice and scientific research, must balance benefits and harms of treatment to ensure appropriate management plans are established.

Doctors who provide evidence for the courts are generally lauded for their efforts<sup>235</sup>. In addition, medical opinions are typically measured, coherent and meticulous. Almost without exception, even in cases of supposedly-futile treatments, the judge will mention the dedication of carers on both sides of the argument. In *United Lincolnshire v N*, the medical opinion<sup>236</sup> convincingly assures Mrs Justice Pauffley: thus it is clear that an experienced doctor «of enormous compassion and great insight into the human condition»<sup>237</sup> is appropriate to lead a team in such decision-making.

But undoubtedly, not all doctors are capable of such a duty. The final word goes to Jackson J: «the assessment of best interests of course encompasses factors of all kinds, and not medical factors alone, and reaches into areas where doctors are not experts»<sup>238</sup>. Considering the issues raised in this essay, and the comments in this final analysis, it is not appropriate for the doctor to be the sole decision-maker in regards what constitutes futility.

#### *ii. Ought the patient’s proxy to decide?*

The answer may seem simple enough when those close to the patient want to make a decision: yes, when the decision does not infringe the moral or legal rights of others; no, when the decision does. The patient’s views, however, should remain of paramount importance. This cannot *always* be guaranteed, even when decisions are made by those closest to the patient. This is especially true when a proxy feels obliged to make a decision that she wishes not to; an enforced decision is potentially an untrue or artificial alternative. In such a case, helping the significant others understand the choice is more sensible than making the patient or proxy make the choice.<sup>239</sup> But the manner in which this is discussed is important: presenting a treatment as futile, and then asking about opinions and wishes is wrong. As we have seen, often the greatest concern in decision-making is the way it is executed, rather than the outcome. So while there must be checks and balances when addressing such complex issues, since non-judicial unilateral decision-making fails to match patient welfare safeguards, policies are required to be transparent and also applicable to circumstances. It is too simple, too unfair, and too illusory to expect the proxy, alone, to reach a decision that guarantees the patient’s overall benefit.

#### *iv. Ought society to decide?*

When, despite all attempts, consensus cannot be reached, the parties involved may wish to review their dispute within a public forum – with reference to public policy. A social conception of reasona-

<sup>234</sup> See L. SCHNEIDERMAN, A. CAPRON, *op.cit.*, 529.

<sup>235</sup> E.g. *NHS Trust v L* [2013], at 101.

<sup>236</sup> This opinion is essentially an objective review with a final subjective comment.

<sup>237</sup> *United Lincolnshire v N* [2014], at 62.

<sup>238</sup> At first instance in *James: An NHS Trust v DJ* [2012] EWHC 3524 (COP), at 82.

<sup>239</sup> T. TOMLINSON, D. CZLONKA, *op.cit.*, 29.

bleness may allow for a balancing of the different viewpoints<sup>240</sup>. Such a step removes the individual “reasonable person” test (rightly frowned upon, as discussed earlier), but maintains the safety of a reasonable body standard. Paris et al suggest that choices made in regard treatment options are «value assumptions about the nature and worth of life, and as such they belong to a broader community than medicine alone... It is not the personal predilections of the provider or the idiosyncratic views of the patient but the common social sense of what practices are to prevail»<sup>241</sup>.

In *James*, Baroness Hale suggests that she would have reached a different conclusion from Jackson J<sup>242</sup>. Thus the group decision may be argued to be more fair and encompassing than the individual decision (and may be helpful to families at the sharp end of a difficult choice). But, naturally, there is concern that there will never be societal consensus on certain issues; «population-wide, scenario-based preferences» generally represent the values of a particular group<sup>243</sup>, so are not necessarily population-wide – but they are wide enough that the individual is lost in the crowd.

Ultimately, society may hold greater influence than even the courts. Lord Mustill, in *Bland*, discussed the importance of Parliament (as representing society as a whole) in balancing ethics and custom through legislation<sup>244</sup>. This has been reiterated in a recent Supreme Court decision regarding assisted suicide<sup>245</sup>. But while there are certain decisions that “the people” must make, the blanket guidelines obtained in such a process cannot ever fully appreciate the individuality of a particular case in question. Once again, society plays an important role in assisting decision-making, but should not be responsible for deciding what constitutes futility.

#### *iv. Ought the courts to decide?*

«Deciding disputed matters of life and death is surely and pre-eminently a matter for a Court of Law to decide»<sup>246</sup>. The courts are empowered under the MCA (2005) section 15 to make declarations, and they carefully interpret the law to arrive at their learned, and usually respected, judgments. Although not in the habit of doing so, the courts do have the power to overrule doctors. Acknowledging this, Leggatt J notes that «[t]he court is not, or certainly should not be, in the habit of making orders unless it is prepared to enforce them»<sup>247</sup>.

The courts state that they cannot provide answers for every potential future scenario, instead calling on doctors to reassess the clinical situation when required<sup>248</sup>. The judgment in *W v M* makes interesting reading, acknowledging the most important role-players:

<sup>240</sup> E.g. R. TRUOG, A. BRETT, J. FRADER, *op.cit.*, 156

<sup>241</sup> J. PARIS, E. CASSEM, W. DEC et al, *op.cit.*, 41: this article is written by four members of the clinical and legal team of the defendant hospital in the American case of *Gilgunn v MGH* (1999), where the jury found that it was appropriate for a medical team to refuse intervention it felt futile despite a family’s fervent disapproval.

<sup>242</sup> Baroness Hale in *James*, at 42.

<sup>243</sup> L. EMMANUEL, K. GLASSER SCANDRETT, *Decisions at the end-of-life: have we come of age?*, in *BMC Medicine*, 8, 2010, i4.

<sup>244</sup> *Bland* [1993], at 896.

<sup>245</sup> *R (Nicklinson) v Ministry of Justice* [2014] UKSC 38.

<sup>246</sup> See e.g. Ward LJ in *Conjoined Twins* [2001], *op.cit.*, at II.14; also Butler-Sloss P in *Simms v Simms* [2003] Fam 83 [at 46].

<sup>247</sup> *Re J (minors)* [1992] WL 12678801, at 30A.

<sup>248</sup> See notes 58 and 59.

«...the court cannot say at this point whether a specific course of treatment ... would at some future date be in her best interests. Whether or not it is in her best interests will depend on the circumstances as they arise, and *it must be left to the clinicians to make that decision in consultation with family members having regard to all relevant circumstances*»<sup>249</sup>.

In the same vein, the courts also caution about asking for declarations prematurely<sup>250</sup>. Furthermore, the courts maintain that they are not an advice centre and insist that parties involved must look at issues practically<sup>251</sup>, and encourage the resolution of disputes at the bedside<sup>252</sup>.

Although a safe and established means of solving disputes, arbitration by the courts should remain the final option. The court is not a panacea: it is clearly afflicted by similar issues that aggrieve other decision-makers. And the significant human and financial costs here can be avoided with equally learned and esteemed resolution at an earlier stage.

*v. A special multidisciplinary team (MDT) should decide*

I promote a specialist MDT as a solution to the vexing question of who ought to decide that a medical treatment is futile. Such a team, acknowledged to understand the medical, legal and ethical obligations in this area, will achieve this outcome through communication and compromise. I agree with the view that decision-makers «can move beyond conflict by contemplating not consensus or conquest but, instead, compromise»<sup>253</sup>. Huxtable considers the morality of *principled compromise*, suggesting that participants should be reflective (considering the moral issue in dispute), reliable and trustworthy, and respectful towards others involved (in negotiation and compromise), concluding that the focus shifts to the process of the discussion rather than its product. To reiterate again, often the catalyst for legal recourse has been concern with the process of decision-making rather than the decision itself.

There are several reasons why such an MDT should make these decisions. Firstly, the panel possesses the required professional knowledge and skills, and is able to balance the individual expertise of its various members. Despite enjoying this specialist knowledge, the combined team does lack the esteemed and authoritative position of, say, the judiciary. The benefit of outsiders being less apprehensive as a result, and so more open to approach it, may outweigh the disadvantages. Secondly, no one person decides an outcome. There is no room for unilateral decision-making, power-struggles or a you-me/them-us divide, but ample opportunity for a return to partnership. Thirdly, such a process is likely to be less protracted, and far less costly, than a judicial alternative<sup>254</sup>. Finally, and perhaps most importantly, the focus returns to open discussion, in line with professional guidance and legal requirement, which may not always occur spontaneously in the clinical setting.

<sup>249</sup> *W v M* [2011], *op.cit.*, at 255 (emphasis added).

<sup>250</sup> Baroness Hale in *James*, at 41; Lord Woolf in *Glass* [1999], *op.cit.*, at 911A-B. See also V. SACHDEVA, A RUCK KEEN, V BUTLER-COLE, *op.cit.*, who note that such a recommendation risks increasing the need for emergency declarations.

<sup>251</sup> E.g. Lord Philips in *Burke* [2005], *op.cit.*, at 21.

<sup>252</sup> See note 110.

<sup>253</sup> R. HUXTABLE, *op.cit.*, 122. He discusses the concept of compromise at length in Chapter 6.

<sup>254</sup> Cost may be one of the reasons why such teams (and clinical ethicists particularly) are thin on the ground. See J. SAUNDERS, *Developing clinical ethics committees*, in *Clinical Medicine*, 4, 2004, 232.

The composition and views of such a team may vary greatly, but would generally be drawn from the local institution/hospital/trust (and the community it serves). The clinical team (doctors, nurses and allied healthcare professionals)<sup>255</sup> and the patient's proxy<sup>256</sup> are the fundamental participants – but it is the other participants that separate this specialist MDT process from the more usual clinical MDT family meeting. The role of “welfare experts”, such as social workers and psychologists, may be extended from their more customary role in cases regarding children to patients across the board. A hospital trust's legal representatives add official authority to the proceedings<sup>257</sup>. Finally, this MDT would incorporate the services of a local clinical ethics committee (CEC)<sup>258</sup>.

The CEC «is legitimized as an expression of certain themes of democratic liberalism, including especially the notion that moral controversies are best resolved through a process that takes into account multiple perspectives of the nature of the good life»<sup>259</sup>. Functions of CECs include case review, procedural advice, and education of staff<sup>260</sup>. Hence they aim to be practical, as well as considerate of those involved: these committees generally maintain that discussion of the case and the acceptance of the outcome are optional<sup>261</sup>. This is respectful, but also prone to failure when its processes are not actively integrated into everyday practice. It also recognises the risk of doctors feeling monitored, or the concern that they call for help merely to avoid litigation<sup>262</sup>. Only through experience and interaction will the practice develop, and the doctor and patient/proxy need to see this process as real and not a philosophical or legal exercise. What is the benefit of a clinical ethicist then? Lamb suggests that these professionals possess «... an ability to reason well, avoid errors in argument, and recognise them in the arguments of others»<sup>263</sup>. Sometimes the reality of a situation causes the parties involved to lose these abilities, and an external arbiter can provide a new perspective. In this way, the ethical values of the ‘ordinary person’ may also be represented.

This same decision-making process can be used for patients with capacity as for those without. It may be adapted to suit the specific circumstances of the particular patient at that particular time; and the process will remain near to the patient, both in site and in focus. The presence of such a multidisciplinary team does not guarantee resolution, but it is a practicable step that may diminish the need for a future judicial solution. By addressing the issues raised in this essay, the specialist MDT may provide certain answers to vexing questions.

<sup>255</sup> E.g. J. CURTIS, J. VINCENT, *Ethics and end-of-life care for adults in Intensive Care Unit in Lancet*, 375, 2010, 1349. Good interdisciplinary collaboration has been shown to result in improved outcomes not only for patients and families but also for intensivists (for whom poor teamwork is associated with burnout, stress and depression).

<sup>256</sup> By default the patient lacking capacity will usually not be able to engage in such a process.

<sup>257</sup> The proxy would naturally be entitled to similar representation.

<sup>258</sup> The CECs usually have a lay-delegate, representing the community-at-large.

<sup>259</sup> J. MORENO, *Ethics Committees and Ethics Consultants* in H. KUHSE, P. SINGER (eds.) *A Companion to Bioethics*, Malden, 2009, 576.

<sup>260</sup> UK CLINICAL ETHICS NETWORK (UKCEN), *Recognising, preventing and resolving ethical dilemmas in health-care*, 2014, 4. [www.ukcen.net](http://www.ukcen.net) (last visited 19/4/2015).

<sup>261</sup> UK CLINICAL ETHICS NETWORK (UKCEN), *op.cit.*, 4: «CECs are not decision-making bodies – they advise clinicians of the ethical implications of different courses of action».

<sup>262</sup> J. MORENO, *op.cit.*, 576-579.

<sup>263</sup> D. LAMB, *op.cit.*, 11.



## 5. Conclusion

The courts in England have grappled with the legal (and at times, moral) duties of those involved in medical decision-making: while certain concepts have been clarified, others remain debated. However, the Supreme Court has recently provided practical guidance to assist with decision-making, in regards treatment that has been described as futile, when that patient lacks the capacity to make a decision for herself.

I agree, and have argued, that the best interests standard provides an appropriate means of assessing the overall benefit of a suggested management plan. I have argued also that futility, even though a morally ambiguous term, has its merit as an essentially-subjective concept (which is amenable to objective medical interpretation) – when applied carefully in the decision-making process. Being aware of the means of reaching a decision is an imperative, since it is often the process of reaching the outcome, rather than the outcome itself, which is at the root of a dispute between decision-makers.

Finding sensible solutions that are in line with legal and moral guidance, as well as being practical, is a difficult (but not impossible) task. These solutions go some way to providing answers to the questions: who ought to decide that further treatment is considered futile; and how ought this decision to be made? I have concluded that only by respecting the individual can a decision that truly represents her best interests be made. This involves balancing the subjective opinions of the patient against the objective assessments of others. Reliance on a unilateral decision, made by any of these parties, fails to appreciate the complexity of the legal and moral issues that arise in such decision-making. When there is dispute regarding a treatment that is considered futile, the best interests standard should be applied by a specialist multidisciplinary team, whose focus remains on the patient. The fact that a patient cannot speak, does not mean that her voice should not be heard; quite the opposite, it should guide the decision-making process.

The swinging pendulum of authority associated with the doctor-patient partnership, as well as the legal change in recent years, suggests that we have not heard the last of this debate. But there is, currently, the opportunity to put into practice at the patient’s bedside the balancing exercise that may otherwise take place in a courtroom. Perhaps more than any other, this simple, practical step of being near the patient reminds the decision-makers that this process must focus not on their disputes, but solely on the patient.