A Façade of Futility

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I. INTRODUCTION

Since the courts first relied on the concept of "futility" in *Airedale NHS Trust v Bland*,[1] it has been widely invoked as a justification for the withholding or withdrawal of life-sustaining treatment, relieving doctors of any legal obligation to provide treatment even in the face of opposition from the patient or their family. Yet despite the widespread criticism the concept has received in the ethics literature, with calls for it to be "expunged" altogether from the "clinical lexicon",[2] it has received very little scrutiny in legal discourse. This is notwithstanding its varied and dubious application in a number of recent cases, in which the concept has operated as a façade, concealing broader value judgments about whether or not a person's quality of life is deemed sufficient to justify continued treatment. Given the deeply ethically contentious nature of such decisions, which touch on the value that we as a society place on human life, and when, if at all, we are prepared to regard death as preferable to continued life, it is imperative that the courts are transparent about the reasons underpinning such decisions. The concept of futility, at least as it is currently being understood and employed by the courts, militates against this.

While the Supreme Court attempted to give greater conceptual clarity to the term in *Aintree University Hospitals NHS Foundation Trust v James,*[3] defining futility broadly by reference to whether the treatment is "ineffective" *or* whether the patient will receive any "benefit" from the treatment, this conceptualisation of futility is deeply problematic. Deciding whether or not a person derives a benefit from life-sustaining treatment, particularly in circumstances where they are seriously disabled or brain damaged, inevitably involves value judgements about their perceived quality of life. By conflating these with questions about the efficacy of treatments under the broad umbrella of "futility", these value

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[1] [1993] A.C. 789; [1993] 1 All E.R. 821 at 869.

[2] M. Nair-Collins, "Laying Futility to Rest" (2015) 40 *J. Med. Philos.* 554-582.

[3] [2013] UKSC 67; [2014] A.C. 591 at [44].

judgements are being obscured, a problem exacerbated by a propensity for judges to move between talking about the *treatment* being futile and the patient's *life* being futile. While some value judgements may be unavoidable in cases such as these, it is crucially important that where a judge decides that a person's quality of life is sufficiently low that it ought not to be prolonged by further treatment, this assessment is made honestly and openly, and is capable of scrutiny and challenge. It should not be concealed behind statistics on therapeutic success.

In this paper, I will begin by exploring the significance of a finding that treatment is futile, both for individual patients and their families, but also more widely for universal healthcare systems, given the resource implications of relieving a doctor from any obligation to provide treatment to a patient. I will then consider how the courts have conceptualised futility, tracking its development from its origins in the House of Lords decision in *Bland*[4] to its restatement in *Aintree v James*,[5] arguing that the way that it is currently conceptualised has given rise to a number of problems, exemplified by the ways in which the courts have applied it in subsequent cases. Finally I will consider whether it would be possible for the courts to adopt a definition that would avoid these problems, through narrowing the concept to include only *therapeutic* considerations. However, I conclude that it is impossible to define futility in a way that is both value-neutral and broadly applicable. Far from helping to resolve disputes over when treatment ought to be withheld or withdrawn then, the language of futility serves only to obscure the value judgements which underpin these decisions. Given this, any legal significance attributed to futility as a justification for the withholding or withdrawing of treatment ought to be abandoned.

II. WHY IS THE CONCEPT OF FUTILITY IMPORTANT?

As early as 400 BC, Hippocrates was reported to have said that physicians should not treat patients who were "overmastered by their disease".[6] Now, as then, there will always be some cases in which a patient is so ill that treatment can offer no benefit to them, and may cause more harm than good. Yet despite this being long recognised in medical discourse, it was not until the early 1990s that the concept of "futility" gained prevalence in both the case law and

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[4] *Airedale NHS Trust v Bland* [1993] A.C. 789 at 869.

[5] *Aintree University Hospitals NHS Foundation Trust v James* [2014] A.C. 591.

[6] M. Whitmer *et al*, "Medical Futility: A Paradigm as Old as Hippocrates" [2009] *Dimens. Crit. Care. Nurs.* 28 at 67.

the ethical literature as a means of resolving disputes in which doctors and a patient's family disagree over whether or not further treatment ought to be provided to them.

The concept emerged in response to the growing importance attributed to patient autonomy during the mid-twentieth century, and the corresponding shift away from medical paternalism. As Michael Nair-Collins explains, by the 1980s and 1990s, concern arose that the "pendulum had swung too far", with patients and their families increasingly demanding treatments which doctors considered to be clinically inappropriate.[7] Futility was thus conceived as an antidote to this, "a corrective to the excesses of patient autonomy, providing a more suitable balance between professional integrity on the one hand, and patient autonomy rights on the other."[8] By determining that treatment was, as a matter of professional judgement, futile, the doctor had no duty to offer it. The function of invoking futility then, as now, is therefore to authorise physicians to "unilaterally limit" interventions in certain cases.[9] As Charles Weijer and Carl Elliott observe, it can be deployed as an "ethical trump card", permitting doctors to withhold or withdraw care deemed inappropriate without requiring the agreement of either the patient or their family.[10]

But futility serves not merely as an *ethical* justification for failing to provide treatment, but as a *legal* one. Where a doctor considers that treatment is not clinically indicated, namely where it is futile, they are under no obligation to provide it, even if a competent patient requests it.[11] While the doctor must determine what treatment to offer in accordance with their common law duty of care towards their patient[12] (and, if the patient lacks capacity, their statutory duty to act in their best interests[13]), an individual doctor cannot be required to provide treatment that they do not consider to be clinically justified as being in the patient's best interests. As Lord Donaldson M.R. made clear in *Re J* (endorsed by the Supreme Court in *Aintree v James*[14]), doctors owe a duty to their patient to treat them in accordance with their best clinical judgement, and so it would be "abuse of power" for the court to require them to "adopt a course of treatment which in the bona fide clinical judgment

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[7] M. Nair-Collins, "Laying Futility to Rest" (2015) 40 *J. Med. Philos.* 554 at 555.

[8] Nair-Collins, "Laying Futility to Rest" (2015) 40 *J. Med. Philos.* 554 at 556.

[9] B. Brody and A. Halvery, "Is futility a futile concept?" (1995) 20 *J. Med. Philos.* 123 at 125.

[10] C. Weijer and C. Elliott, 'Pulling the Plug on Futility: Futility Is Not the Ethical Trump Card that Some Would Like It to Be' (1995) 310 *B.M.J.* 683 at 683.

[11] *R (Burke) v General Medical Council* [2005] EWCA Civ 1003; [2006] Q.B. 273 at [50].

[12] Which must be exercised in accordance with a "responsible body of medical opinion": *Bolam v Friern Hospital Management Committee* [1957] 1 W.L.R. 582; [1957] 2 All E.R. 116 at 587.

[13] Mental Capacity Act 2005, s1(5).

[14] *Aintree University Hospitals NHS Foundation Trust v James* [2014] A.C. 591 at [18].

of the practitioner concerned is contra-indicated as not being in the best interests of the patient", even if other doctors or the court may disagree.[15]

There is, of course, a strong presumption that a person's best interests will be served by giving them life-sustaining treatment. As Sir Thomas Bingham noted in *Bland*, "a profound respect for the sanctity of human life is embedded in our law and our moral philosophy."[16] However this will not always be the case, and while the courts have been reluctant to lay down general principles on when life-sustaining treatment will not be in a patient's best interests, three legally-established bases for withholding treatment can be derived from the case law.[17] These are now found within the Mental Capacity Act 2005 (MCA) Code of Practice, according to which:

> "There will 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."[18]

A determination that treatment is "futile" is therefore one justification for deeming it not to be in the patient's best interests to provide it. The concept of futility here derives from the case of *Bland.*[19] In that case, considered in more detail below, the House of Lords held that the withdrawal of treatment was properly regarded as an omission, and that an omission would only give rise to liability *if* the doctor had a duty to act. As treatment in that case was futile, it could not be in the patient's best interests to continue to give it to him. And given that the treatment was not in the patient's best interests, there could be no legal obligation on the doctor to provide it.

Such a view has been reiterated in a number of subsequent cases. In *NHS Trust A v M* for example, Dame Elizabeth Butler-Sloss conducted a full review of the European authorities before concluding that the article 2 right to life does not impose an "absolute" obligation to offer life-sustaining treatment "if such treatment would be futile."[20] She also applied it in the context of children in *Re L*, noting that:

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[15] *Re J (A Minor) (Child in Care: Medical Treatment)* [1993] Fam 15; [1992] 4 All E.R. 614 at 26-27.

[16] *Airedale NHS Trust v Bland* [1993] A.C. 789 at 808.

[17] *Aintree University Hospitals NHS Foundation Trust v James* [2014] A.C. 591 at [29].

[18] Department for Constitutional Affairs, Mental Capacity Act 2005 Code of Practice (London: T.S.O., 2007) at 5.31.

[19] *Airedale NHS Trust v Bland* [1993] A.C. 789 at 869.

[20] [2001] Fam 348; [2001] 1 All E.R. 801 at [37].

> "There is a strong presumption in favour of preserving life, but not where treatment would be futile, and there is no obligation on the medical profession to give treatment which would be futile."[21]

Professional guidance for clinicians also reflects this, with both the General Medical Council[22] and the Royal College of Physicians[23] explicitly noting that doctors are under no obligation to offer treatment which they regard as futile.

If the patient or their families object to this determination, NHS Trusts are advised to apply to the court for authorisation that the withholding or withdrawal of treatment would be lawful.[24] The court must then determine whether treatment is in the best interests of the patient. If the court decides that it is and thus refuses to issue the declaration sought, then while it cannot order an individual doctor to treat the patient,[25] in practice, many doctors will continue to treat (or their NHS Trusts will find another doctor who will), for fear of the legal or insurance ramifications of failing to do so. Alternatively, the patient or their families can seek judicial review of the decision by the NHS Trust not to offer the treatment, although given the high bar that must be met for any judicial review challenge to succeed, very few cases of this kind arise.

Most cases, however, never make it to court. Given the evidence therefore, that most deaths in emergency departments and intensive care units now result from a decision by medical staff to withhold or withdraw treatment,[26] and that the perceived futility of the treatment is one of the most commonly cited justifications given by doctors for withdrawing treatment,[27] the concept of futility is hugely important. Indeed this has never been more acutely relevant than during the coronavirus pandemic, which saw ventilation being withheld or withdrawn from thousands of patients on the basis of its perceived futility. It is imperative therefore, that we are clear about how the concept is being understood and applied.

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[21] *Re L (Medical Treatment: Benefit)* [2004] EWHC 2713 (Fam); [2005] 1 F.L.R. 491 at [12].

[22] General Medical Council, "Treatment and care towards the end of life: good practice in decision-making" (G.M.C., 2010) at 76.

[23] Royal College of Physicians, "Prolonged disorders of consciousness following sudden onset brain injury: National clinical guidelines" (London: R.C.P., 2020) at 4.2.1.

[24] *An NHS Trust & Others v Y* [2018] UKSC 46; [2019] A.C. 978 at [125].

[25] For a detailed discussion, see J. Youngs, "Can the courts force the doctor's hand? *St George's Healthcare NHS Trust v P* [2015] EWCOP 42" (2015) 24(1) *Medical Law Review* 99-111.

[26] C.L. Sprung *et al*, "End-of-life practices in European intensive care units" (2003) 290 The ETHICUS Study *J.A.M.A.* 790-797; M. Braganza *et al*, "Treatment withdrawal and end-of-life care in the intensive care unit" (2017) 17(2) *B.J.A. Education* 396–400; P. Le Conte *et al*, "Death in emergency departments: a multicenter cross-sectional survey with analysis of withholding and withdrawing life support" (2010) 36 *Intensive Care Med.* 765–772.

[27] C. Seale, "Hastening death in end-of-life care: a survey of doctors" (2009) 69 *Soc. Sci. Med.* 1659 at 1664.

The concept also has wider implications for the patient and their family. Firstly, doctors have never been under a legal obligation to discuss treatments with the patient which are not clinically indicated, and so by deeming a treatment futile, this may relieve doctors of the need to involve the patient or their family in the decision. For patients who lack capacity, this position has been eroded to some extent by the MCA's requirement that when determining their best interests, the decision-maker must take into account their current "wishes and feelings"[28] and the views of those involved in their care, or interested in their welfare.[29] Even for competent patients, the courts have carved out a (somewhat incoherent) exception for "do not attempt cardiopulmonary resuscitation" orders,[30] in respect of which the doctor must consult with the patient or their family even if resuscitation is deemed futile. It is therefore questionable how far this position survives the general trend towards empowering patients through greater information disclosure and dialogue, culminating in the Supreme Court's decision in *Montgomery v Lanarkshire Health Board.*[31] Nonetheless without a clear legal duty to bolster this, it is easy to see why doctors may be reluctant to engage in such difficult conversations with patients and their families, with the result that their ability to participate in the decision may, as John Lantos *et al* have argued, be diminished.[32] A finding of futility may therefore determine not only what treatment is offered, but also what information is provided to patients and their families about why these life-changing and life-ending decisions are being made.

Secondly, a decision that further life-sustaining treatment is futile and so ought not to be provided may be very hard for families to challenge. Futility is a question of fact, concerning the efficacy of a particular treatment in achieving a certain physiological outcome. Understood thus, it is inherently a medical or scientific question, over which doctors may justifiably claim expertise and thus authority. It will therefore be very difficult for families to dispute such a determination, except through obtaining a second medical opinion which contradicts the view of the treating doctors.

But it is not just the patient and their family who are affected by the way in which the concept of futility is defined and applied. If deeming life-sustaining treatment futile can remove the obligation to provide it, then it also defines when and in what circumstances

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[28] Mental Capacity Act 2005, s4(6).

[29] Mental Capacity Act 2005, s4(7).

[30] *Tracey v Cambridge University Hospitals NHS Foundation Trust & Ors* [2014] EWCA Civ 822; [2015] Q.B. 543.

[31] [2015] UKSC 11; [2015] A.C. 1430.

[32] J. Lantos *et al*, "The Illusion of Futility in Clinical Practice" (1989) 87 *Am. J. Med.* 81 at 81.

doctors can legally stop providing treatment, with huge resource implications. In their submissions as intervenors in the *Aintree* case for example, the Intensive Care Society and Faculty of Intensive Medicine estimated (albeit with some caution) what impact the legal definition of futility might have. As figures suggest that up to 20,000 patients die each year in intensive care units following the withdrawal of treatment, they suggested that if each of these were to receive an extra three days of treatment which would currently be considered futile, a further 60,000 critical care bed days would be required. Absent increased resources, "this could delay admission to intensive care of up to 50,000 patients per year."[33] The definition and deployment of "futility" thus has a significant impact on care more generally, given its implications for the provision of services and the allocation of resources.

The very fact that futility is relied on so widely in law and policy may, as Robert Truog *et al* point out, "seem to indicate that it is clearly understood and widely accepted."[34] In fact, the opposite is true. While the futility of a given treatment must be judged relative to some goal or outcome,[35] substantial debate remains in both the case law, and in the clinical ethics literature, about what that goal or purpose of treatment ought to be, and when treatment ought to be deemed incapable of achieving this outcome. Julian Savulescu and Dominic Wilkinson, for example, summarise a number of different possible meanings of futility:[36] where the treatment cannot achieve its physiological aim ("physiological futility"); where it has a very low (but not zero) chance of working ("quantitative futility"); where it cannot restore the patient to an acceptable quality of life ("qualitative futility"); and where it cannot prevent the person from dying imminently. While these will be considered in more detail below, it is clear that there are a number of possible meanings of futility that the law might adopt, which have each been picked up on in different cases. Far from there being a coherent and defensible definition of the term then, "the notion of futility hides many deep and serious ambiguities that threaten its legitimacy as a rationale for limiting treatment."[37]

Given the legal significance of deeming treatment to be futile, it is important to scrutinise the way in which it has been understood and applied, both in clinical practice and in the courts. As Lawrence Schneiderman notes, "physicians should not be free to invoke medical futility unless they can justify it before their peers with good evidence-based data

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[33] A. Ruck Keene and V. Butler-Cole, "Case for the Intensive Care Society and the Faculty of Intensive Medicine in *James v Aintree University Hospitals NHS Trust* UKSC 2013/01234" (skeleton) at 18.

[34] R. Truog, AS. Brett, J. Frader, "The Problem with Futility" (1992) 326 *N. Engl. J. Med.* 1560 at 1560.

[35] D. Kasman, "When is medical treatment futile?" (2004) 19 *J. Gen. Intern. Med.* 1053 at 1053.

[36] D. Wilkinson and J. Savulescu, "Knowing When to Stop: Futility in the Intensive Care Unit" (2011) 24 *Curr. Opin. Anaesthesio.* 160 at 161.

[37] R. Truog *et al*, "The Problem with Futility" (1992) 326 *N. Engl. J. Med.* 1560 at 1560.

and before society with professional standards of practice." This "requires that we examine the notion, not hide from it."[38]

III. THE LEGAL CONCEPTION OF FUTILITY

The courts first invoked the concept of futility to justify the withdrawal of treatment in *Bland* in 1993. Anthony Bland was seventeen when he suffered catastrophic injuries in the Hillsborough disaster, leaving him in a persistent vegetative state (PVS). By the time the case came to court, he had been unconscious for three years, and in the view of the medical professionals, had no hope of recovering. With the consent of his parents, the hospital wished to withdraw the clinically assisted nutrition and hydration (CANH) which was keeping him alive, and they applied to the court for a declaration that doing so would be lawful. The House of Lords issued the declaration sought. The treatment was futile, since "the patient [was] unconscious and there [was] no prospect of any improvement of his condition."[39] Consequently, it was not in his best interests to receive CANH and so there was no duty on the doctors to provide it.

Much of the confusion that now surrounds the legal significance of futility and its relationship with the broader notion of best interests derives from this case. Lord Goff of Chieveley distinguished between two categories of cases. The first were those in which having regard to all of the circumstances (including the invasiveness and risks associated with the treatment, and the patients quality of life), it was thought not to be in the patient's best interests to offer life-prolonging treatment.[40] In these cases (which I will call "category one" cases), the decision of whether to withhold or withdraw treatment had to be made by weighing up *all* the relevant considerations. The second category, by contrast, were situations like that in *Bland,* where the treatment was thought to be of no benefit to him whatsoever as he was totally unconscious and there was no prospect of him improving.[41] Here there was "in reality no weighing operation to be performed" since the treatment is "properly regarded as being, in medical terms, useless."[42] While it was reasonable to take account of the invasiveness of the treatment and the indignity it caused to the patient, "in the end, in a case such as the present, it is the *futility* of the treatment which justifies its termination."[43] The

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[38] L. Schneiderman, "Defining Medical Futility and Improving Medical Care" (2011) 8 *J. Bioethical Inq.* 123 at 126.

[39] *Airedale NHS Trust v Bland* [1993] A.C. 789 at 869.

[40] *Bland* [1993] A.C. 789 at 868.

[41] *Bland* [1993] A.C. 789 at 868.

[42] *Bland* [1993] A.C. 789 at 869.

[43] *Bland* [1993] A.C. 789 at 869.

court's determination that treatment was futile was thus portrayed as a trump card: it could not be in the person's best interests to be given futile treatment and so there was no obligation on doctors to provide it.

The context of this case is crucial, as all of the parties were agreed that in its current condition, Bland's life was not worth sustaining. His father gave evidence that his son "certainly wouldn't want to be left like he is",[44] and that he and the rest of the family felt treatment should be removed. Given this, everyone was in agreement that any further treatment would only be worthwhile *if* it was able to bring about a meaningful improvement to his quality of life. The goal by which any treatment's utility was to be judged was thus clear: it must be able to improve Bland's quality of life, not merely to sustain him as he was. Given the undisputed clinical evidence that Bland had "suffered irreparable damage to the cortex" and there was "no hope whatsoever of recovery or improvement of *any* kind",[45] the parties also agreed that this goal could not be met. Invoking the concept of futility in this context was therefore uncontroversial, as there was consensus between the family and doctors over both whether or not the patient's quality of life was worth sustaining in its current state, and over what impact, if any, the treatment was likely to have on that. In the cases that have followed, however, difficulties have arisen precisely because there is disagreement over what the goal of the treatment ought to be and therefore what it is futile in achieving.

1. Diverging definitions of futility

Despite its narrow origins in *Bland*, in the years that followed, futility was invoked more widely. Later cases saw it applied in the context of a more clinically diverse category of patients that merely those in a persistent vegetative state, and the courts also began to rely on it in cases in which the families opposed the withholding or withdrawal of treatment. With this, notions of when treatment would be deemed futile began to diverge.

In *Simms v Simms & Another* for example,[46] concerning whether an experimental treatment could be trialled on two teenagers with a neurodegenerative disorder, Dame Elizabeth Butler-Sloss appeared to define futility by reference to whether or not it was able to produce "a benefit" for the patient. She explained three possible "benefits" that patients might derive from the treatment: an improvement to their condition, their condition not

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[44] *Bland* [1993] A.C. 789 at 807.

[45] *Bland* [1993] A.C. 789 at 869.

[46] (2002) EWHC 2734 (Fam); [2003] Fam. 83.

deteriorating any further, or the prolongation of their life.[47] As the medical evidence in the case "provided for the possibility of one of those three benefits occurring", she concluded that "it does not seem to me… that it can be said in principle this is treatment which is clearly futile".[48] Unlike in *Bland* then, prolongation of life, even if it did not lead to improvement in the patient's quality of life or the condition itself, was considered to be a "benefit" which militated against regarding treatment as futile.

In *W v M*[49] a decade later, the court questioned whether the concept of futility ought to have any application whatsoever outside of the context of a persistent vegetative state. The court was called upon to determine for the first time whether it could authorise the withdrawal of life-sustaining treatment from a patient in a minimally conscious state. Mr Justice Baker acknowledged that the effect of Lord Goff's speech in *Bland* was that while "there was a category of case in which the decision whether to withhold treatment would be made by weighing up relevant and competing considerations", such an approach "was inappropriate in the case of Anthony Bland as the treatment had no therapeutic purpose and was "futile" because he was unconscious and had no prospects of recovery."[50] The question was which of Lord Goff's two categories *this* case was to fall into it. Both the Applicant and the Primary Care Trust argued that this was, in effect, a "category one" case and so the courts should apply a balance sheet approach to decide whether the treatment was, in light of all the relevant considerations, in the patient's best interests. They argued that the second, "*Bland"* category of cases ought to be limited to those in which the patient is in a PVS, "where the futility of treatment means that treatment had no benefit at all."[51] Mr Justice Baker agreed, holding that there was "no rationale" for extending the approach in *Bland* to non-PVS cases, as this would undermine "the clear requirement laid down in s.4 of the MCA to consider all the relevant circumstances when determining best interests."[52]

Given the requirements of section 4 MCA, which came into force after *Bland,* it is doubtful that the futility of treatment should *ever* been conceived of as a trump card in best interests determinations, negating the need to weigh up relevant considerations. However, there was also a lack of clarity in the judgment about whether the effect of confining *Bland* to PVS cases was to limit the application of the concept of futility entirely to such cases, or

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[47] *Simms v Simms & Another* [2003] Fam. 83 at [57].
[48] *Simms* [2003] Fam. 83 at [58].
[49] *W v M & Others* [2011] EWHC 2443 (Fam); [2012] 1 W.L.R. 1653.
[50] *W v M* [2012] 1 W.L.R. 1653 at [65].
[51] *W v M* [2012] 1 W.L.R. 1653 at [100].
[52] *W v M* [2012] 1 W.L.R. 1653 at [102].

whether futility could still be used in non-PVS cases, but not employed as a trump card. Notably, however, he did not rely on futility when reaching his conclusion that treatment could be withdrawn.

Notwithstanding this, only a year later Mr Justice Hedley invoked the concept of futility to justify the withdrawal of ventilation from a child with profound and irreversible brain damage which fell far short of a PVS.[53] Despite the fact that the treatment would undoubtedly have prolonged the child's life, which Dame Elizabeth Butler-Sloss had thought militated against treatment being futile in *Simms*, the judge in this case instead returned to the characterisation of futility put forward in *Bland*, suggesting that "as there will be no improvement, it could from X's point of view, all be described as futile: no chance of recovery and no purpose in treatment."[54]

It was against the backdrop of these seemingly conflicting decisions that *Aintree University Hospitals NHS Foundation Trust v James* came before the courts,[55] in which the court was asked to authorise the withholding of various life-sustaining treatments in the event that they became necessary in the future. This resulted in the most detailed judicial consideration of the concept of futility to date, which, while useful in clarifying the definition and application of futility, nonetheless gives rise to a number of problems.

2. *Clarifying the legal conception of futility in Aintree v James*

Aintree v James saw a disagreement between the appellate courts over how "futility" ought to be defined. Mr James had suffered from numerous infections resulting in multiple organ failure, a stroke and on one occasion, cardiac arrest requiring resuscitation. By the time the case came to court, he was not on medication and was well enough to tolerate twelve hours a day on a lesser supported breathing system. However his level of consciousness was described as "limited", with his awareness varying considerably depending on his physical condition. In the view of the doctors, further treatment would be futile, being of "extremely limited" benefit to him, given that his condition, while not a PVS, was "progressive and irreversible".[56] His family disagreed, believing that he still gained *some* benefit from his life, and would not wish for treatment to be withheld. In particular, his wife felt that gained considerable enjoyment from seeing his family and friends, and that his previous experiences

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[53] *NHS Trust v Baby X* [2012] EWHC 2188 (Fam); [2013] 1 F.L.R. 225.

[54] *Baby X* [2013] 1 F.L.R. 225 at [20].

[55] [2012] EWHC 3524 (COP); [2012] 12 W.L.U.K. 155.

[56] *Aintree University Hospitals NHS Foundation Trust v James* [2012] 12 W.L.U.K. 155 at [75].

of cancer had cast light on what he would want in this situation.[57] Treatment could not therefore be said to be futile or of no benefit to him.

At first instance, Mr Justice Peter Jackson refused to issue the declaration sought. This was because firstly, he was "not persuaded that treatment would be futile or overly burdensome, or that there is no prospect of recovery",[58] and secondly, this would undervalue "the non-medical aspects" of Mr James' situation, most particularly his close and meaningful family life.[59] In relation to the former, he explained that:

> "(a) In Mr James's case, the treatments in question cannot be said to be futile, based upon the evidence of their effect so far. (b) Nor can they be said to be futile in the sense that they could only return Mr James to a quality of life that is not worth living."[60]

He therefore acknowledged two dimensions to futility: whether the treatment was effective in achieving its physiological aim; and whether or not it was capable of sustaining a quality of life that was worth living. In doing so, he followed the MCA Code of Practice in separating the question of whether the treatment was "futile" from that of whether the patient had any "prospect of recovery" with the treatment, which he defined as being the resumption of a quality of life that *the patient* would regard as worthwhile.[61] However given the clear overlap between treatment being unable to "return the patient to a quality of life worth living" and the patient being unable to "resume a quality of life that they would regard as worthwhile", the latter might be better thought of as a dimension of the former, with the question of whether or not the treatment will enable the person to return to a quality of life "worth living" being judged from the patient's perspective rather than objectively (as a "life that is not worth living" might suggest). Certainly any distinction between futility and the prospect of recovery was absent from *Bland*, where the prospect of recovery was encompassed within the assessment of futility, defined as "no prospect of any improvement of his condition".[62]

In the Court of Appeal, Sir Alan Ward was critical of this conceptualisation of futility. In his view, futility must be judged relative to a goal, even if deciding what that goal would be was "ethically controversial".[63] He suggested a number of possible 'goals' that could be identified for life-sustaining treatment: (1) to prevent imminent death; (2) to prolong life albeit for a limited time; (3) to delay death even if it would not alleviate suffering; (4) to

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[57] *Aintree* [2012] 12 W.L.U.K. 155 at [66]–[67].
[58] *Aintree* [2012] 12 W.L.U.K. 155 at [84].
[59] *Aintree* [2012] 12 W.L.U.K. 155 at [84].
[60] *Aintree* [2012] 12 W.L.U.K. 155 at [84].
[61] *Aintree* [2012] 12 W.L.U.K. 155 at [84].
[62] *Airedale NHS Trust v Bland* [1993] A.C. 789 at 869.
[63] [2013] EWCA Civ 65; [2013] 4 All E.R. 67 at [34]–[35].

provide the patient with a minimum quality of life; (5) to allow the patient to achieve a goal which they had set for themselves; or (6) to have a real prospect of curing or palliating the life-threatening disease from which the patient was suffering.[64] Futility could not, in this view, be judged "simply by the ability to score goals (1)–(3)" because "there is no duty to maintain the life of a patient at all costs" nor to "needlessly prolong dying".[65] It should also not be defined by reference to whether it could achieve a minimally acceptable quality of life for the patient, even though "there was implicit in every judgment about whether treatment was futile or worthwhile a judgment about the quality of life the patient would have with or without that treatment."[66] He likewise dismissed the fifth "goal", as while the patient's wishes were important to determining their overall best interests, they did not dictate the patient's "*medical* interests".[67] In his view then, futility should be judged by the sixth goal: whether or not it secures a "therapeutic benefit for the patient", in the sense that it (either standing alone or with other medical care) has a "real prospect of curing or at least palliating the life threatening disease or illness from which the patient was suffering."[68] Although not defined in his judgment, a treatment which "palliates" is commonly defined as one which makes a disease or its symptoms less severe without curing it, such as pain management.

The impact of Sir Alan Ward's judgment in confining futility to the medical sphere and avoiding judgements about the patient's quality of life was, however, short-lived. In the Supreme Court, Lady Hale dismissed this conceptualisation of futility as "setting the goal too high",[69] favouring the approach of Mr Justice Peter Jackson in the High Court instead. Given the genesis of futility in the *Bland* case, she held that he had been "correct to consider whether the proposed treatments would be futile in the sense of being ineffective or being of no benefit to the patient".[70]

Regrettably, Lady Hale did not set out explicitly whether she was intending to refer only to therapeutic benefits here, or to non-medical benefits more broadly construed. She noted that "a treatment may bring some benefit to the patient even though it has no effect upon the underlying disease or disability".[71] However it is not clear whether she was referring to other *therapeutic* benefits that a person can receive from treatments but which do not affect

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[64] *Aintree University Hospitals NHS Foundation Trust v James* [2013] 4 All E.R. 67 at [35].

[65] *Aintree* [2013] 4 All E.R. 67 at [36].

[66] *Aintree* [2013] 4 All E.R. 67 at [36].

[67] *Aintree* [2013] 4 All E.R. 67 at [36].

[68] *Aintree* [2013] 4 All E.R. 67 at [35].

[69] [2014] A.C. 591 at [43].

[70] *Aintree* [2014] A.C. 591 at [40].

[71] *Aintree* [2014] A.C. 591 at [43].

the underlying disease — such as the palliation of symptoms or sustaining their life while other treatments work on them — or to non-therapeutic benefits, for example living in accordance with one's religious beliefs or gaining pleasure from the company of one's friends and family. Nor was she explicit about exactly how "benefit" is to be assessed: is it an objective question to be determined by the judge, or is the question whether the patient *themselves* would regard treatment as providing a benefit?

Although Lady Hale did not engage with these issues directly, she stresses throughout her judgment the importance of considering matters from the *patient's* point of view, noting that decision-makers must, when determining best interests, "try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be."[72] Furthermore immediately after the discussion of futility, Lady Hale emulated Mr Justice Peter Jackson in explaining that the meaning of "no prospect of recovery" is not whether it allows the person to recover to a state of good health, but to resume "a quality of life *which the patient would regard as worthwhile*".[73] Against this backdrop, and given her endorsement of both Peter Jackson J's judgment and the decision in *Bland* (which did not treat prospect of recovery and futility as separate questions), whether a "benefit" is derived from a treatment might be thought to be assessed from the patient's perspective and will therefore include non-therapeutic considerations. Certainly subsequent judgments have understood it in this way. In *United Lincolnshire Hospital NHS Trust v N* for example, Mrs Justice Pauffley noted that when considering whether treatment was futile,

> "the treatment does not have to be likely to cure or palliate the underlying condition or return the patient to full or reasonable health, rather it should be capable of allowing the resumption of a quality of life which the patient would regard as worthwhile."[74]

This passage was cited with approval by Mr Justice Hayden in *Abertawe Bro Morgannwg University Local Health Board v RY*.[75] Likewise in *Re A*, Lady Justice King approved the trial judge's finding that treatment for a severely disabled child was futile, accepting her conclusion that "A would [not] want this life for himself".[76] This lends support to the idea that benefit ought to be considered from the patient's perspective, even in cases involving children. In their guidance on "futility", the Royal College of Physicians also stress that according to the "English courts", treatment for a dying patent

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[72] *Aintree* [2014] A.C. 591 at [39].

[73] *Aintree* [2014] A.C. 591 at [44].

[74] [2014] EWCOP 16; [2014] C.O.P.L.R. 660 at [56].

[75] [2017] EWCOP 2; [2017] C.O.P.L.R. 143.

[76] *Re A* [2016] Med.L.R. 427 at [58].

> "could not be considered futile merely because it would not be able to reverse the course of the illness, so long as it was able to restore the patient to a condition that they themselves would find acceptable."[77]

Following the decision in *Aintree* then, it would seem, at least in the way it has subsequently been interpreted, that there are two aspects to determining whether or not a treatment is futile: whether the treatment is *ineffective*; and whether the person derives any *benefit* from it, defined as whether it enables them to enjoy a quality of life that they themselves would regard as worthwhile. While none of the judges discussed the consequences of conceptualising futility in this way, whether defined in terms of efficacy or benefit, the concept of futility cannot withstand closer scrutiny.

IV. DEFINING FUTILITY AS THE TREATMENT BEING "INEFFECTIVE"

Despite holding that treatment would be futile if it was "ineffective", Lady Hale did not elaborate on *what* exactly the treatment was supposed to be "ineffective" in achieving or *when* it would be deemed so. While she did not set out the goal against which the effectiveness of a treatment was to be judged, efficacy was clearly intended to be considered separately to "benefit" (futility meant "ineffective *or* being of no benefit", not, for example, "ineffective in achieving a benefit"). Given this, and Lady Hale's approval of Mr Peter Jackson's decision that the treatment was not futile in Mr James' case "based upon the evidence of their effect so far",[78] it would seem that "ineffective" was intended to capture futility in a physiological sense, that is, treatment which is ineffective in achieving its physiological aim. Subsequent case law certainly interprets it thus. In *RY* for example, after quoting from a summary of *Aintree*, Mr Justice Hayden held that as the trascheotomy served "its immediate function" of substituting for RY's "compromised cough reflex" and clearing secretions, it "cannot be described as futile."[79]

As Truog *et al* explain, conceptualising futility in a physiological sense offers the "most promising candidate" for a "value-free understanding of the concept",[80] since the goal is defined merely by what physiological purpose of any given treatment is. It is this perceived value-neutrality that has led to it gaining the support of a number of professional medical bodies in the United States of America. In a joint policy statement by them, a distinction is

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[77] Royal College of Physicians, "Prolonged disorders of consciousness following sudden onset brain injury: National clinical guidelines" (London: R.C.P., 2020) at 4.2.1.

[78] *Aintree University Hospitals NHS Foundation Trust v James* [2012] 12 W.L.U.K. 155 at [84].

[79] [2017] C.O.P.L.R. 143 at [53].

[80] R. Truog *et al*, "The Problem with Futility" (1992) 326 *N. Engl. J. Med.* 1560 at 1561.

made between “futile treatments” and “potentially inappropriate treatments”. The term “futile” is “restricted to the rare situations in which the patient or surrogate decision-maker requests interventions that simply cannot accomplish their intended physiologic goal.” By contrast, “potentially inappropriate” treatment is that which has “at least some chance of accomplishing the effect sought by the patient, but clinicians believe that competing ethical considerations justify not providing them.”[81]

Understanding the concept in this way also helps to justify why futility remains a matter of professional medical judgement, and accordingly why doctors should be relieved of the obligation to provide treatment which they regard as clinically futile. Whether or not a treatment will work to achieve a given outcome for an individual is a question of medical or scientific fact, on which doctors have expertise based on years of training and experience of similar situations. As Nair-Collins explains, this “*epistemic* authority rooted in specialized knowledge and experience” makes them “presumptively the best source of information” for determining the likelihood that a particular treatment will achieve a particular goal for a given patient.[82] Not only does this justify a degree of deference to medical opinion when cases come before the courts, but it also provides a clearer role for medical evidence in such cases. If the question is whether or not the treatment can achieve its physiological aim, then medical expertise and evidence is highly relevant *in so far* as it casts light on that complex factual question, albeit that as this is an issue that tests the limits of our medical knowledge, it is right that the evidence and theoretical assumptions on which such predictions are made are fully interrogated.

However despite its apparent value-neutrality, problems remain with this conceptualisation of futility. Lady Hale did not set out anywhere in her judgment *when* she would consider a treatment to be ineffective. This poses the question: does the treatment have to actually be incapable of achieving an outcome, or merely unlikely to do so? As Truog *et al* note, “in most medical situations, there is no such thing as never. Futility is almost always a matter of probability.”[83] Situations in which treatment is truly futile (that is, *incapable* of achieving its physiological goal) will thus be extremely rare. Even in *Great Ormond Street Hospital v Yates and Gard*,[84] which concerned a highly experimental treatment which had not

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[81] G.T. Bosslet *et al,* ‘An Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units’ (2015) *Am. J. Resp. Crit. Car. Med.* 191(11):1318-1330 at 1318.

[82] M. Nair-Collins, “Laying Futility to Rest” (2015) 40 *J. Med. Philos.* 554 at 565.

[83] R. Truog *et al*, “The Problem with Futility” (1992) 326 *N. Engl. J. Med.* 1560 at 1561.

[84] [2017] EWHC 972 (Fam); [2017] 4 WLUK 260.

been trialed on an animal model, let alone a human with the patient's particular type of mitochondrial condition, and for which there were good theoretical reasons for thinking it could not work, the chance of it working was extremely low, but not zero. The trial judge described its prospect of having any benefit as "as close to zero as makes no difference",[85] but he was still reluctant to describe it as impossible. Therefore while a zero percent chance of the treatment working may be the only value that represents "pure futility",[86] given that "prognostic ability could rarely achieve a level of certainty to determine an intervention truly futile in an individual case",[87] requiring treatment to be completely ineffectual (in the sense of a zero percent chance of working) would effectively define the concept out of existence. The effect, as Dominic Wilkinson notes, is that the "clarity of this form of futility comes at the cost of its applicability — it applies to very few of the actual cases where treatment is disputed".[88]

Therefore in order for futility thus defined to have any application in future cases, a statistical cut-off point must be established as part of its legal definition which sets out when the likelihood of treatment working, while not zero, is deemed to be sufficiently low as to be deemed "ineffective". Lady Hale did not discuss what this cut-off point should be, and no case since has engaged with this question explicitly. However this question has been grappled with in the clinical ethics literature, with Nancy Jecker and Lawrence Schneiderman proposing that a treatment should be regarded as futile if it "can be shown not to have worked in the last 100 cases."[89] Although some have been critical of this suggestion as setting an arbitrary threshold,[90] Schneiderman himself acknowledges that this is "not an 'objective' or 'value-free' definition, but rather one that seeks reasonable consensus where absolute certainty is impossible."[91] He points out that while "the medical community, or society at large, may prefer longer (or shorter) odds… in the end we all will have to accept some empirical notion of medical futility or else throw all commonsense to the wind."[92] This may

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[85] *Great Ormond Street Hospital v Yates and Gard* [2017] EWHC 972 (Fam) at [119].

[86] M. Nair-Collins, "Laying Futility to Rest" (2015) 40 *J. Med. Philos.* 554 at 557.

[87] L. Francis *et al*, "Decision-Making on Behalf of Children in the Research and Clinical Context: A US Perspective" in I. Goold et al, *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* [forthcoming, Hart Publishing 2020].

[88] D. Wilkinson, "Medical Futility", *International Encyclopaedia of Ethics* (Wiley Blackwell, 2013) at 3.

[89] N. Jecker and L. Schneiderman, "Medical Futility: The Duty Not to Treat" (1993) 2 *Camb. Q. Healthc. Ethics* 151-159.

[90] M. Nair-Collins, "Laying Futility to Rest" (2015) 40 *J. Med. Philos.* 554 at 557.

[91] L. Schneiderman, "Defining Medical Futility and Improving Medical Care" (2011) 8 *J. Bioethical Inq.* 123 at 125.

[92] Schneiderman, "Defining Medical Futility and Improving Medical Care" (2011) 8 *J. Bioethical Inq.* 123 at 125.

be right, but reaching agreement on what these odds are will be very difficult, especially as they may mean different things to different parties. For a doctor, attempting a treatment on a patient that has a one percent chance of working means subjecting ninety-nine patients to a treatment which may be burdensome and distressing, in the hope that each will be the one patient on which the treatment proves successful. This is a very different perspective from that of the family who might well consider a one percent chance of their loved one living good enough odds to warrant a trial. Indeed in one study, thirty-two percent of family members suggested they would continue treating their critically ill family member even if the chance of them surviving was *less* than one percent.[93]

Even within the medical profession there may be different perspectives on this question. In a study into how physicians applied futility in the context of cardiopulmonary resuscitation for example, Curtis *et al* found that amongst patients for whom treatment had been deemed futile based on its low prospect of success, the probability that they would survive to hospital discharge if given the treatment varied from zero to seventy-five percent. Thirty-two percent of these patients had a predicted survival rate of five percent or more.[94] This suggests that different doctors are willing to accept very different statistical odds of success within a determination that treatment is futile. It may also depend on the clinical context and the specific treatment in question. While a doctor or court might be willing to accept a very low prospect of success if the treatment is non-invasive and has negligible side effects, much greater odds might be required if the treatment was very burdensome or had harmful side effects. The "acceptable" statistical cut-off for treatment being deemed futile will therefore depend on the circumstances of the individual case.

The result is that except in an extremely narrow category of cases where the chance can actually be said to be zero, the determination that treatment is physiologically futile denotes two separate judgements. The first is a factual finding that the chance of the treatment working is negligible or very low. The second is a value judgment that this chance is *sufficiently low* that it is not worth trialling, even if the alternative might be that the person dies. The doctor may have expertise which warrants some deference in relation to the first of these findings but there is no reason to defer to them over the second question, which concerns what chances are worth taking and at what costs. Dealing with both of these

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[93] L.S. Zier *et al*, "Surrogate decision makers' responses to physicians' predictions of medical futility" (2009) 136(1) *Chest* 110-117.

[94] J.R. Curtis *et al*, "Use of the medical futility rationale in do-not-attempt-resuscitation orders" (1995) 273(2) *J.A.M.A.* 124-8.

questions under the umbrella of futility therefore risks doctors "giving opinions disguised as data", allowing doctors to substitute their values for those of their patient "under the guise of medical expertise".[95] However it also serves to obscure what the real nature of the disagreement is between the parties in these cases: is it that they disagree over what the statistical chance of the treatment working is; or are they really disagreeing over whether or not that statistical chance is a chance worth taking? In doing so, it creates confusion about how the medical evidence ought to be used in the determination of best interests. Furthermore, where the disagreement is over whether or not the chance of success is sufficient to justify its application, it risks concealing ethically salient reasons that doctors might have for *not* wishing to trial the treatment on the patient. As Nair-Collins explains, "futility *qua* ineffectiveness" is rarely what has "generated much of the moral concern in the first place",[96] rather it is concerns about the potential burdens or harm of treatment, questions about resource allocation and concerns over whether the surrogate decision-maker is acting in the patient's best interests.

Even if a statistical cut-off point could be agreed, it would then fall to doctors and the courts to determine whether or not the treatment meets it in each individual case. In reality, however, "physicians are often highly unreliable in estimating the likelihood of success of a therapeutic intervention".[97] If it cannot be said with any degree of certainty whether a treatment falls above or below the statistical cut-off, it is deeply questionable whether this cut-off point ought to carry such legal and ethical significance. As Nair-Collins explains, given that the function of invoking futility is to enable the doctor to make a unilateral decision to limit life-sustaining treatments, "the confidence rating in the professional's factual claims ought to be quite high."[98] Baruch Brody and Amir Halevy make a similar point. They argue that if futility is to justify withholding or withdrawing treatment without the patient or their family's consent, it must satisfy certain conditions. In reality however, as examples of "physiologically futile treatment" given in the literature show, "it is very difficult to define a concept of physiological futility that is precise, prospective, and applies to a significant number of cases".[99] The greater the certainty of prognosis that is required before treatment is deemed futile, the fewer cases will be able to meet that standard.

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[95] S.J. Younger, "Who defines futility?" (1988) 260 *J.A.M.A.* 2094-5.

[96] M. Nair-Collins, "Laying Futility to Rest" (2015) 40 *J. Med. Philos.* 554 at 574.

[97] R. Truog *et al*, "The Problem with Futility" (1992) 326 *N. Engl. J. Med.* 1560 at 1561.

[98] M. Nair-Collins, "Laying Futility to Rest" (2015) 40 *J. Med. Philos.* 554 at 570.

[99] B. Brody and A. Halvery, "Is futility a futile concept?" (1995) 20 *J. Med. Philos.* 123 at 137.

Indeed even if one accepted Jecker and Schneiderman's suggestion to look at whether treatment has worked in the prior 100 cases, the question would still remain of how similar the prior 100 patients would have to be to the current patient in order to for them to be sufficiently useful in predicting this individual's prognosis (do they have to be alike in terms of age, ethnicity and comorbidities?) and of what to do where there are not 100 previous cases on which to base the assessment. In *Gard* for example, the therapy had never been trialled on a patient with his exact condition, but had been found to have some success on a less severe mitochondrial condition, giving the doctor some hope that it might also work for his mitochondrial condition. Could this evidence be used in support of the treatment's efficacy, in the absence of any evidence concerning the specific condition?

Lady Hale did not engage with any of these issues when she defined futility in terms of the ineffectiveness of a treatment. Yet at the heart of this conceptualisation of futility is a tension between value-neutrality and applicability. In order to be applicable to a wide range of cases, doctors and courts must accept a higher statistical cut-off point for when treatment will be deemed futile. In doing so, however, the definition of physiological futility inevitably becomes value-laden. The effect, therefore, is that both doctors and the courts are making value judgements about what statistical chances are worth taking and at what costs, which are being concealed by the language of futility.

V. DEFINING FUTILITY AS THE TREATMENT BEING OF NO "BENEFIT"

The second aspect of Lady Hale's conceptualisation of futility, where treatment is of no "benefit" to the patient, is even more problematic. As this section will explain, deciding whether a person derives a benefit from life-sustaining treatment inevitably involves value judgements being made about the person's quality of life, which are being obscured by the language of futility, and thus insulated from scrutiny and challenge.

In evaluating this conception of futility, it is helpful to distinguish between two different types of cases in which the concept has been invoked. The first involves a disagreement between the doctors and the patient or family over whether or not the patient's life ought to be preserved in its current form (and thus whether life sustaining treatment ought to continue to be provided). This involves both cases such as *Alder Hey Children's NHS*

Foundation Trust v Evans & Others[100] and *Raqeeb v Barts NHS Foundation Trust & Anors*,[101] which concern whether life-sustaining treatment should be withdrawn, and those such as *Aintree*[102] and *Portsmouth Hospitals NHS Trust v Wyatt*,[103] which concern whether treatment should be offered in the future if it becomes necessary to preserve life. In both sets of circumstances, the issue is whether the person's current quality of life justifies continued treatment to keep them alive. There is therefore no real question about the efficacy of the treatment (it will undoubtedly work to prolong life), the real question is whether the person derives a "benefit" from continued life. The second category of cases are those in which the doctors and patient or family agree that the patient's current life is not worth sustaining, but *disagree* over whether or not an alternative treatment ought to be provided which *may* offer some improvement to their condition, such as in *Gard.*[104] Here the issue may be about the medical efficacy of the treatment, but it may also be about whether the patient will derive a benefit from the treatment if it does prove to be successful.

When a case concerns whether or not a person will derive a "benefit" from treatment which is necessary to sustain life, this must involve an assessment of whether or not the person would benefit from continuing to be kept alive. It is a trite point that if the person benefits in some way from his continued life, and further treatment is necessary to sustain that life, then treatment cannot be said to be of no benefit to them. Therefore life-saving treatment can only be said to be of no benefit (and thus futile) *if* it can be established that continued existence does not bring about any benefit to the person. This, of course, is a deeply personal question that engages not only a person's medical interests, but their psychological, relational and spiritual interests. To reach a conclusion on this, the decision-maker must weigh all of these different interests or factors against each other, in order to determine which, overall, ought to take precedence. This process, which involves attaching greater importance to some factors and less to others, will inevitably be influenced to some extent by the decision-maker's own values, beliefs and priorities: the inherent value they attach to human life, and their own views on when a person's quality of life becomes so compromised that it might be better to end their life. This is not then a question of objective fact, but a value-laden assessment over which people might — and do — legitimately disagree. As Alexander Kon explains, "deciding when the outcome of care will be a fate

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[100] [2018] EWHC 308 (Fam); [2018] 2 F.L.R. 1223.

[101] [2019] EWHC 2531 (Admin); [2019] 1 C.M.L.R. 28.

[102] *Aintree University Hospitals NHS Foundation Trust v James* [2012] 12 W.L.U.K. 155.

[103] [2005] EWCA Civ 1181; [2005] 1 W.L.R. 3995.

[104] *Great Ormond Street Hospital v Yates and Gard* [2017] 4 W.L.U.K. 260.

worse than death" is a deeply personal matter: "there is no right or wrong answer".[105] While Anthony Bland may not have derived a benefit from prolonged life without any prospect of improvement, others may well do. In *Aintree,* for example, Mr James was still able to enjoy his family life, which was "of the closest and most meaningful kind";[106] while in *Raqeeb*, Mr Justice MacDonald recognised that continued life-sustaining treatment would enable the child to live in "accordance with the tenets of the religion in which she was being raised and for which she had begun to demonstrate a basic affinity."[107] These "benefits" militated against withdrawing treatment in these cases.

It was in recognition of the deeply subjective nature of these questions that Lady Hale sought to move away from objective notions of benefit in *Aintree,* focussing instead on whether or not treatment could enable the person to resume a quality of life which *they* would regard as worthwhile. Clearly given this, it would be extremely difficult for either the doctors or the court to argue that treatment provided no benefit to someone, if the patient was able to express a capacitious wish to receive it. Indeed the British Medical Association has been clear that it is "highly questionable" that treatment could be considered to be "of no 'benefit' to the patient" if the patient "knows, and has accepted, the chance, level and length of expected recovery and wishes to accept treatment on that basis."[108] Similarly, the Court of Appeal in *Burke v G.M.C.* noted in *obiter* that it was "extremely unlikely" for a scenario to arise in which a doctor regarded artificial nutrition and hydration as futile where a competent patient wished to receive it.[109] This may explain the lack of cases on futility involving people who have capacity.

However even for those who lack capacity (for whom decisions must be made on their behalf in their best interests), it is difficult to justify a finding that treatment offers no benefit to them whatsoever in cases where this conclusion is opposed by their family. It is useful here to distinguish the position of incapacitated adults from that of very young children. In the case of adults, evidence about what the patient would want will invariably come from their family members or friends, based either on evidence from past discussions or their intimate knowledge of the patient's values and preferences. It is uncontroversial that family members and friends will usually be best placed to relay information about what the

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[105] A. Kon, "When Parents Refuse Treatment for Their Child" (2006) 8(1) *JONAS Healthc. Law Ethics Regul.* 5 at 7.

[106] *Aintree University Hospitals NHS Foundation Trust v James* [2012] 12 W.L.U.K. 155 at [84].

[107] *Raqeeb v Barts NHS Foundation Trust & Anors* [2019] 1 C.M.L.R. 28 at [173].

[108] British Medical Association, *Withholding and Withdrawing Life-prolonging Medical Treatment: Guidance for decision-making* (3rd Edition, BMJ Books, 2007) at 15.

[109] *R (Burke) v G.M.C.* [2006] Q.B. 273 at [55].

patient's perspective would be and so where they consider that the patient would gain some kind of "benefit" from continued existence in their condition and the treatment is clearly capable of prolonging their life, then absent contradictory evidence from other friends or family members, it is difficult to see how doctors or the courts could conclude that life-sustaining treatment did not benefit them (and so was futile), *except* through imposing their *own* values about what constitutes a minimally acceptable quality of life onto the case. In other words, to deem treatment futile, the judge must be making an implicit assumption that contrary to the evidence of the family, the patient does not benefit from continuing to be kept alive. This was exactly the kind of value judgement that Sir Alan Ward cautioned against making in the Court of Appeal in *Aintree.*

The position is more complex in relation to very young children, as they will not have expressed any views on what they would want in such a situation. This leaves room for debate over who is best placed to decide this: the parents, doctors or the courts. While there is not space to engage with this question in detail here,[110] suffice to say that where doctors or the court decide *not* to accept the parents' perspective on whether or not the child will derive a benefit from continued life, this must involve them imposing their own view of whether or not the child's life is worth living onto the case. This is readily apparent from the case law. In *Re A* for example, in deeming further life-sustaining treatment to be futile for a severely brain-damaged two-year-old, Lady Justice King accepted the judge's conclusion that she did not think "A would want this life for himself."[111] Given the position of the child's parents in this case — that it *was* in A's interests to continue ventilation — it is difficult to see on what basis the judge could have reached this conclusion *except* through applying her own assessment of what constitutes a minimally acceptable quality of life to the case.

This is even clearer in *Evans,*[112] which concerned whether or not a tracheotomy and continued ventilation ought to be given to a baby suffering from a progressive neurodegenerative condition that had left him in a "semi-vegetative state". While the treatment would undoubtedly have achieved its aim of keeping him alive (and so could not be said to be futile in the sense of being "ineffective"), what it could not do was improve his condition. Accordingly his treating hospital sought a declaration from the courts that life-sustaining treatment could be withdrawn, a position strongly opposed by his parents. Giving

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[110] For a longer discussion, see C. Auckland and I. Goold, 'Parental Rights, Best Interests and Significant Harms' (2019) *C.L.J.* 78(2), 287-323.

[111] *Re A* [2016] Med.L.R. 427 at [58].

[112] *Alder Hey Children's NHS Trust v Evans* [2018] 2 F.L.R. 1223.

judgment, Mr Justice Hayden "accept[ed] entirely the conclusion of the medical evidence that treatment for Alfie [was] futile."[113] He acknowledged that it did not follow "axiomatically" from this that treatment should be withdrawn immediately, but concluded that continued ventilation in circumstances that were futile, "compromises Alfie's future dignity and fails to respect his autonomy".[114] It was not therefore, in his best interests and he issued the declaration authorising its withdrawal.

There are many things which may be criticised about this statement, but given the clear evidence of Alfie Evan's parents that he *would* derive a benefit from being kept alive, it is unclear on what basis the judge "accepted" the evidence that treatment was futile, *except* through making his own value judgement (or accepting that of the doctors) that the patient was not benefited by continued existence given the severity of his disability. In fact both in this judgment, and in later judgments in the same dispute (it came back to court twice more), Mr Justice Hayden switched between talking about the *treatment* being futile, Alfie's *situation* being futile, and his *life* being futile. In two of his later judgments, he stated first that in the original hearing he had come to the conclusion "that his *life* was futile";[115] and later "that Alfie's *situation* is now futile",[116] adding credence to the view that his assessment of was based on a judgement about whether Alfie Evans had any prospect of recovering to a quality of life deemed acceptable. There are a number of examples from other cases of the courts similarly referring to the patient's "life" being futile as opposed to the treatment.[117]

The *Evans* case aptly demonstrates the problem with relying on the concept of futility in cases such as this, as it obscures those value judgements. Mr Justice Hayden accepted "entirely" the medical evidence that treatment would be futile, however he did not set out anywhere what the treatment was futile in achieving. Given that it was not in doubt that the treatment could work to prolong the child's life (the outcome sought by his parents), the doctors and judge must have judged its utility by reference to a different goal, namely whether it could return the child to a quality of life that they considered acceptable. The crux of the disagreement between the parties was not therefore over a matter of medical fact, but over whether or not merely prolonging the child's life in its current condition was a goal

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[113] *Evans* [2018] 2 F.L.R. 1223 at [51].

[114] *Evans* [2018] 2 F.L.R. 1223 at [66].

[115] *Alder Hey Children's NHS Trust v Evans* [2018] EWHC 818 (Fam); [2018] 4 WLUK 93.

[116] *Alder Hey Children's NHS Trust v Evans* [2018] EWHC 953 (Fam); [2018] 2 F.L.R. 1246.

[117] In *Gloucestershire Clinical Commissioning Group v AB* [2014] EWCOP 49; [2014] 11 W.L.U.K. 799 for example, Mr Justice Baker said at [18]: 'All parties are now agreed that AB's life is futile, in the sense of that word used by Lord Goff in the *Bland* case.' See also *CWM TAF University v F* [2015] EWHC 2533 (Fam); [2015] 5 W.L.U.K. 395 AT [22] and *SS v CCG & Anor* [2018] EWCOP 40; [2018] 10 W.L.U.K. 488 at [29].

worth pursuing. Only if it was *not* a worthwhile goal, could treatment be said to be futile. However as Truog *et al* note, "the decision that certain goals are not worth pursuing is best seen as involving a conflict of values rather than a question of futility."[118] As this is not a medical question, and thus not "within the professional expertise of the physician", [119] it is difficult to see why medical opinion on it should be "accepted" in its entirety or given any special weight in the determination at all. This, as Nair-Collins explains, is to commit "the fallacy of the generalization of expertise": "knowledge about physiology and pathophysiology does not generalize to 'moral expertise' or to the moral authority to determine what is *good* for another."[120]

This is particularly so, when such value judgements involve questions as fundamental as when a life no longer has value. Indeed, a tendency to focus on medical considerations at the expense of the patient's other interests might be a good reason *not* to give too greater weight to the views of doctors in such determinations. Empirical evidence suggests, for example, that doctors may assess quality of life differently to families when deciding whether to withdraw treatment. A study by Paul Muirhead found that while healthcare professionals and parents "viewed the mild to moderately disabled states similarly", "parents were more accepting of the severely disabled health state than health care professionals".[121] A doctors view of when treatment no longer benefits a patient in these cases may then reflect little more than a different perspective about when a person's quality of life becomes so low that it does not justify further treatment. Too greater deference to medical "evidence" of futility is thus unwarranted.

This problem is exacerbated by the fact that post-*Aintree,* there is arguably a divergence between the legal definition of futility and its understanding in clinical practice, which in the view of the Intensive Care Society and the Faculty of Intensive Medicine, aligns more closely with that of Sir Alan Ward in the Court of Appeal in *Aintree.*[122] Parties in such disputes may therefore be talking past each other: while doctors regard the treatment as "futile" because it will not cure or palliate a condition, families do not consider it so because the patient will derive some other non-therapeutic "benefit" from it. By accepting "entirely"

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[118] R. Truog *et al*, "The Problem with Futility" (1992) 326 *N. Engl. J. Med.* 1560 at 1561.

[119] H. Brody, "Bringing Clarity to the Futility Debate: Don't Use the Wrong Cases" (1998) 7 *Camb. Q. Healthc. Ethics* 269 at 270.

[120] M. Nair-Collins, "Laying Futility to Rest" (2015) 40 *J. Med. Philos.* 554 at 563.

[121] P. Muirhead, "When parents and physicians disagree: What is the ethical pathway?" (2004) 9(2) *Paediatr. Child Health* 85 at 85

[122] A. Ruck Keene and V. Butler-Cole, 'Case for the Intensive Care Society and the Faculty of Intensive Medicine in *James v Aintree University Hospitals NHS Trust* UKSC 2013/01234' at [30].

the doctor's evidence of futility in *Evans,* Mr Justice Hayden thus failed to distinguish between the different claims being made by the parties. In doing so, not only are the value judgements that underpinned the doctors' decisions left unchallenged, but the judge's own evaluations can be concealed within discussions of the medical evidence.

As Truog *et al* note, "judgements cast in the language of futility falsely assume that there is an objective and dispassionate standard for determining benefits and burdens".[123] In reality, no such objective standard exists and underlying all of these judgments are value-laden claims about the patient's quality of life. While these may be important to determining whether treatment is, overall, in the patient's best interests, they should not be being made by doctors in isolation or presented as medical facts.

Given that there can scarcely be a more important (or controversial) question than whether a person's quality of life is so low that it ought to be brought to an end, especially when this is against the wishes of the patient's family, it is essential that the reasons for such decisions are made openly and explicitly, rather than being hidden behind the façade of the "treatment" being "futile". These questions go to the heart of how we, as a society, view life, death and disability. It is crucial, therefore, that they are open to scrutiny and challenge, not just by the families in the decisions, but also by the wider public.

VI. INCLUDING BOTH "EFFECTIVENESS" AND "BENEFIT" WITHIN THE DEFINITION OF FUTILITY

Problems therefore afflict futility, conceived either as efficacy or as benefit. However by encompassing *both* efficacy and benefit within the legal definition of futility, the effect of the *Aintree* decision is to conflate clinical assessments about whether as an objective fact the treatment will be successful in achieving a certain physiological goal, with non-clinical subjective evaluations about whether or not the patient will derive a benefit from it, given their priorities, values and beliefs. This exacerbates the concerns raised above, making it even harder to scrutinise the assumptions which underpin such decisions.

This problem arises in particular in cases where the patient's family and doctors agree on whether or not the current life is worth sustaining, but the family hope to obtain treatment which could improve his or her condition, which doctors regard as futile. In such cases, treatment might be deemed futile because the statistical chance of it working is so low that it

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[123] R. Truog *et al*, "The Problem with Futility" (1992) 326 *N. Engl. J. Med.* 1560 at 1562.

is effectively incapable of working. Or it may be futile because even if it does work, it will not restore the person to a quality of life worth sustaining, so they will not derive any benefit from it. By failing to distinguish between these two different claims, concerns about presenting opinions as objective medical fact are heightened.

Gard[124] is illustrative of this problem. Charlie Gard suffered from an inherited mitochondrial condition, which had left him substantially brain damaged, and unable to move or to breathe unaided. The hospital decided that further treatment would be futile, and sought a declaration that ventilation could be withdrawn from him. This was objected to by his parents who wished to take him to the United States to trial an experimental treatment which they hoped would improve his condition. In the High Court, Mr Justice Francis concluded that nucleoside therapy would be futile, clarifying that "for the avoidance of any doubt, the word "futile" in this context means pointless or of no effective benefit."[125] Although this is subtly different from the definition of futility put forward in *Aintree,* it is substantially the same in terms of its effect. Gard's parents challenged this determination before the Court of Appeal, arguing that following *Aintree,* there was a distinction between the medical and legal definitions of futility. Legally, whether treatment was futile ought to be judged not by reference to whether it could cure or palliate their son's condition, but by whether it could bring *some* benefit to him. Since in this case, his parents argued it could benefit him in some way, the treatment could not be said to be futile.

Giving judgment, Lord Justice Macfarlane did not dispute the existence of this distinction, but felt it was a "distinction without difference" in the present case, as the trial judge had considered the benefit of nucleoside therapy to be "zero" and therefore further treatment *was* "pointless, or of no effective benefit".[126] However neither he, nor the trial judge, was explicit about exactly why Charlie would gain no benefit from the treatment: was it because the treatment had "zero" chance of being successful, or was it because even if it was successful, his quality of life would remain so low that he would gain no benefit from continued existence? Although it is not made explicit in the case, it seems that at the heart of the judgment was a concern that even if the therapy proved to be successful, the improvement to his condition would be so limited that it could not justify the potential risks involved in the treatment. Mr Justice Francis noted for example, that even if the treatment was to work, the "*highest* point of evidence" was that he would "be able to interact with others, to smile, to

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[124] *Great Ormond Street Hospital v Yates & Gard* [2017] 4 W.L.U.K. 260.
[125] *Gard* [2017] 4 W.L.U.K. 260 at [93].
[126] *Great Ormond Street Hospital v Yates & Gard* [2017] EWCA. Civ. 410; [2018] 4 W.L.R. 5 at [44].

look at objects and to use his hands to grab objects."[127] Moreover the fact that the hospital had been willing to trial the treatment, despite its low chance of working, until the patient suffered from epileptic seizures causing irreversible brain damage,[128] suggests that they would have taken the chance *if* it could have provided a meaningful improvement for him. What changed was not that the treatment could no longer work, but that as it would not be possible to reverse the structural brain damage, the treatment was no longer thought to be worth it, as it could not improve his brain function. This suggests that the key issue was not whether the treatment was capable of working but whether the very small chance of improvement in his condition was worth the risks involved in trialling the treatment, given that his quality of life would remain limited. For the parents, the potential to extend his life by a few years and provide for some improvement was sufficient to justify trialling the treatment, even if its chance of working was low. For the treating team meanwhile, and ultimately Mr Justice Francis, given that the patient would only live for a few more years in a position where he was still profoundly brain damaged and deaf, this was not a risk worth taking. By relying on the concept of futility, the courts once again avoided engaging explicitly with this question, placing the emphasis on the efficacy of treatment and not on the foreseeable quality of life of the child. The value judgements on which the decision rested thus remained implicit, and the assumptions which underpinned them went unchallenged.

VII. A FUTURE FOR FUTILITY?

Given the many problems with the conceptualisation of futility in *Aintree,* one might ask whether the concept has any useful application in disputes about what medical treatment ought to be offered to a seriously ill patient. In order to answer this, it is necessary to consider whether there might be other ways of defining futility which give rise to fewer problems.

As noted above, treatment can only be futile if it is incapable of achieving a desired goal or outcome. If, as in *Gard* and *Evans,* the very nature of the disagreement is over what goal ought to be pursued by treatment (in particular whether prolongation of life is an appropriate goal), then merely describing the treatment as "futile" will do little to help resolve the dispute, and may in fact obscure what it is really about. For futility to be useful as a descriptive term which can be employed by doctors to explain why treatment would not be in a patient's best interests, some kind of consensus must therefore be reached over what goal

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[127] *Gard* [2017] 4 W.L.U.K. 260 at [120].

[128] *Gard* [2017] 4 W.L.U.K. 260 at [76]–[79].

or purpose the treatment ought to be assessed against; and when the treatment will be judged to be incapable of achieving that goal.

In *Aintree,* Lady Hale sought to define futility by reference to two goals: would the treatment achieve its physiological aim, and would it provide any benefit for the patient. For the reasons given above, assessing whether the person derives a "benefit" from treatment is deeply problematic and so any chosen "goal" must therefore seek to avoid these kinds of value judgements about whether the person's quality of life is acceptable. However even attempts to restrict the definition to whether it achieves certain readily definable therapeutic goals cannot avoid making some value judgement, albeit about what the appropriate goals of medical intervention are rather than what constitutes a minimally acceptable quality of life. These will still inevitably give rise to disagreement within the medical profession and the broader public.

For example, in defining futile treatment as that which does not have a "real prospect of curing or at least palliating the life threatening disease or illness",[129] the Court of Appeal in *Aintree* expressly excluded treatments which do not cure or palliate an illness, but merely sustain or prolong life. In support of this, Schneiderman argues that "the obligation of physicians to support life is not supported by the classic tradition of medicine",[130] a point with which Lord Bingham concurred in *Bland,* when he suggested that the "objects of medical care" have traditionally been to prevent the occurrence of an illness; to cure that illness when it occurs; to prevent deterioration of the patient's condition and to relieve pain and suffering. He continued:

> "I doubt if it has ever been an object of medical care merely to prolong the life of an insensate patient with no hope of recovery where nothing can be done to promote any of these objects. But until relatively recently the question could scarcely have arisen since the medical technology to prolong life in this way did not exist."[131]

The practice of medicine has changed immeasurably since its origins in the classical period, not just because new treatments enhance our ability to prolong life, but also because of changing societal attitudes towards death and disability, an ever-evolving relationship between doctor and patient, and changing funding structures. Medical practice, and the law and professional ethics that constrains this, must adapt to these changes. As Nair-Collins explains, determining what the appropriate aims of healthcare are is therefore "not solely a

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[129] *Aintree University Hospitals NHS Foundation Trust v James* [2013] 4 All E.R. 67 at [35].

[130] L. Schneiderman, "Defining Medical Futility and Improving Medical Care" (2011) 8 *J. Bioethical Inq.* 123 at 126.

[131] *Airedale NHS Trust v Bland* [1993] A.C. 789 at 809.

matter of the allopathic medical profession attending to its historical roots". Rather the question is "what are the acceptable aims of *contemporary health care*, which includes the practices of multiple professions and occupations, and is *largely publicly funded*?"[132] This must be answered by reference to what can achieve consensus in a democratic country, with widely-divergent value and belief systems, which include for example, Judeo-Christian-Islamic commitment to sanctity of life.

Reaching consensus across society over what the appropriate goals of medicine are is therefore likely to prove impossible. Moreover the broader that these "goals" are conceived in order to achieve consensus, the narrower the category of cases that fall within them are. It would be rare, for example, for a treatment to be unable to cure or palliate a disease *or* maintain or prolong life for any period of time, and in the extreme situations where this is the case, it will be unusual for the refusal to offer treatment to give rise to disputes in the first place. As Brody and Halevy explain, the "social acceptability" of definitions of futility is thus "inversely correlated with the extent of their applicability".[133]

While physiological futility avoids this problem by defining the goal in a value-neutral way (which is more likely to garner consensus), this still faces the further problem which afflicts all definitions of futility, namely that a statistical cut-off point must be established for when the chance is considered low enough to render a treatment futile. This is similarly unlikely to give rise to agreement, given different perspectives on what chances are worth taking and at what costs, and thus faces the same problem that while setting the statistical cut-off point low might achieve greater consensus, in doing so it becomes inapplicable to the vast majority of cases.

It is this impossibility of establishing a robust, widely applicable and value-neutral definition of futility which has led to calls by a number of commentators in the ethics literature to avoid reliance on the notion of futility altogether. Truog *et al* for example have argued that "the rapid advance of the language of futility into the jargon of bioethics should be followed by an equally rapid retreat."[134] Nair-Collins meanwhile, has urged "that the word 'futility' be finally and permanently excised from the clinical lexicon."[135] Its fate as a legal concept should be similarly short-lived.

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[132] M. Nair-Collins, "Laying Futility to Rest" (2015) 40 *J. Med. Philos.* 554 at 561.
[133] B. Brody and A. Halvery, "Is futility a futile concept?" (1995) 20 *J. Med. Philos.* 123 at 125.
[134] R. Truog *et al*, "The Problem with Futility" (1992) 326 *N. Engl. J. Med.* 1560 at 1563.
[135] M. Nair-Collins, "Laying Futility to Rest" (2015) 40 *J. Med. Philos.* 554 at 578.

While it is right that in disputes of this kind there should be robust discussion over whether or not treatment can properly be regarded as ineffective and how low the statistical chance of treatment working would have to be to render it no longer worth trialling, there is no need to rely on the concept of futility in order to do this. Instead, by simply separating out the question of fact (what is the chance of the treatment working) and of value (is this chance worth trialling the treatment, taking into account the prospect of success *and* the burdens of treatment) and dealing with each in turn, the courts could employ a transparent framework which did not require recourse to the notion of futility. This would introduce greater clarity about what the nature of the disagreement is between the parties in these cases and about how the medical evidence should be used by the court. Evidence about what is *therapeutically* in the patient's interests should then be weighed against their other non-medical interests as part of a broader assessment of whether the treatment is, overall, in their best interests as required by the Mental Capacity Act 2005 and the Children Act 1989. While Lady Hale was right to note in *Aintree* that the assessment of the medical effects of the treatment is "only part of the equation", with regard also needing to be had "to the patient's welfare in the widest sense",[136] these broader non-therapeutic considerations should be considered within the well-established structure of best interests, and not as part of the determination of whether treatment is futile or not.

While assessing whether treatment is in the best interests of the patient will inevitably require the judge to make value judgements about whether or not the quality of life of the patient warrants further treatment, or about what chances are worth taking and at what cost, these ought to be made explicit, so that they can be scrutinised and, if necessary, challenged. By placing the onus on the treatment and not on the person, and relying in support on medical evidence and not evidence of the person's subjective values, the language of futility obscures these. The judgments of Mr Justice MacDonald in *Kings College Hospital NHS Foundation Trust v Hastruup & Others*[137] and *Raqeeb*[138] are good examples of a more transparent approach, in which the judge addresses explicitly the values which underpin each decision without any invocation of the concept of futility. Both cases involved parents wishing for a tracheotomy to be performed and for artificial ventilation to be continued on their severely brain damaged child. In *Haastrup*, although Mr Justice MacDonald held that further treatment would not be in the child's best interests, unlike in *Evans,* he was explicit that "to

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[136] *Aintree University Hospitals NHS Foundation Trust v James* [2014] A.C. 591 at [40].

[137] [2018] EWHC 127 (Fam); [2018] 2 F.L.R. 1028.

[138] *Raqeeb v Barts NHS Foundation Trust & Anors* [2019] 1 C.M.L.R. 28.

continue life sustaining treatment for the child will not result in his recovery and will condemn him to a life of profoundly limited quality."[139] In *Raqeeb* meanwhile, he decided the opposite. In doing so, he noted that the determination of her best interests rested on "subjective" and "highly value laden ethical, moral or religious factors" which "mean different things to different people in a diverse, multicultural, multifaith society".[140] Because of the religious and cultural tradition in which this child was raised, she would derive benefit from continued life, even if others in her position would not. While the decision for the court in these cases was therefore similar to that in *Evans* and *Gard*, by addressing the conflict of values at the heart of the decision head on and not hiding behind the concept of futility, the judge was able to engage with the ethically salient features of these cases in a sensitive and transparent manner.

VIII. CONCLUSION

Given the difficulties that afflict the concept of futility, it cannot perform a useful function in disputes of this kind. Wherever a treatment is deemed futile, underpinning this will be a series of value judgements about what the appropriate goals for treatment are, and what chances are worth taking at what cost. While such judgements are inevitable when deciding whether or not treatment should be withheld or withdrawn, the language of futility places the emphasis on the treatment, and not on the quality of life of the person, and in doing so obscures both these underlying assumptions and judgements, and who the appropriate decision-maker is. Given the importance of such decisions, especially where the patient or their family objects and even more so where there are other doctors who are willing to offer the treatment in question, it is essential that the reasons underpinning such decisions are made clear and explicit, so that the families can challenge these, and the broader public can scrutinise them. Judges should no longer be able to hide behind a façade of futility.

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[139] *Kings College Hospital NHS Foundation Trust v Hastruup & Others* [2018] 2 F.L.R. 1028 at [110].

[140] *Raqeeb v Barts NHS Foundation Trust & Anors* [2019] 1 C.M.L.R. 28. at [191].