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Can ‘Medical Futility’ Conflicts be Mediated?

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Abstract

*Mr Justice Francis ended his judgment in *Great Ormond Street Hospital v. Yates, Gard and Gard* with the recommendation that ‘mediation should be attempted in all cases such as this one’. Although this gave the impression that mediation would be unquestionably beneficial in the *Gard* case and other ‘medical futility’ cases where the patient is incompetent, this paper contends that this is not as straightforward as it might at first appear. With the general absence of a middle ground and with the law in such cases frequently on the doctors’ side, the mediation’s potential for a satisfactory resolution of medical futility conflicts is arguably limited.*

1. Introduction

The high-profile case of Charlie Gard¹ journeyed through several courtrooms in the first half of 2017. From the High Court² to the Court of Appeal,³ then the Supreme Court⁴ and the European Court of Human Rights,⁵ the case returned to the High Court in July 2017.⁶ All agreed that it was not in Charlie’s best interests for life-sustaining treatment (LST) to be continued and that his doctors’ application for an order for LST to be withdrawn was granted. As the case progressed through the court system, it triggered an unprecedented degree of public attention not just in the UK but also from abroad, thus turning the case into ‘a global

¹ Hereinafter referred to as ‘Charlie, the way he was referred to in the law reports.

² *Great Ormond Street Hospital v Yates, Gard and Gard* [2017] EWHC 972 (Fam).

³ *Yates and Gard v Great Ormond Street Hospital and Gard* [2017] EWCA Civ 410.

⁴ Judgement of the UK Supreme Court in the Case of Charlie Gard, 19 June 2017.

⁵ *Gard and Others v The United Kingdom* [Application number 39793/17], 27 June 2017.

⁶ *Great Ormond Street Hospital v Yates, Gard and Gard* [2017] EWHC 1909 (Fam).

phenomenon’.⁷ The public opinion was deeply divided. Some were in support of the judicial rulings and Charlie’s doctors and others sided with Charlie’s parents who took a radically different view of Charlie’s best interests. Over £1 million were raised through crowdfunding to enable Charlie to be treated abroad,⁸ and there were also offers of free treatment received from hospitals in the USA⁹ and Italy.¹⁰ Several of the parents’ supporters, however, showed little restraint in their condemnation of the medical team. In addition to public demonstrations outside the courts and the Great Ormond Street Hospital (GOSH) where Charlie was treated, abuse and even death threats have reportedly been hurled at the hospital staff.¹¹ Against this background, it is hardly surprising that an alternative method of resolving the dispute was suggested. Hence when the case went back to the High Court for the second time, Mr Justice Francis repeated the advice he gave when the case first arrived at the High Court¹² that ‘mediation should be attempted in all cases such as this one’.¹³

⁷ A. Mostrous, ‘Charlie Gard: Publicity That Was Not Always in the Family’s Interests’, *The Times*, 29 July 2017.

⁸ N. Khomami, ‘Charlie Gard Parents Set Up Foundation with £1.3m of Donations’, *The Guardian*, 15 August 2017.

⁹ B. Kentish, ‘Charlie Gard: US Hospital “Offers Free Treatment” to Terminally Ill Baby After Donald Trump Intervenes’, *The Independent*, 4 July 2017.

¹⁰ H. Horton, ‘Pope’s Hospital Offers to Take Care of Charlie Gard’, *The Telegraph*, 4 July 2017.

¹¹ Whilst death threats and violence towards doctors are not unknown in some parts of the world, it has hitherto been rare in this country – see e.g. P. Ambesh, ‘Violence Against Doctors in the Indian Subcontinent: A Rising Bane’ (2016) 68(5) *Indian Heart Journal* 749; T. Hesketh, ‘Violence Against Doctors in China’ (2012) 345 *British Medical Journal* e5730; K. Sidika *et. al.*, ‘Violence Against Doctors and Nurses in Hospitals in Turkey’ (2016) 12(1) *Journal of Forensic Nursing* 26. Yet, this case seemed to have unleashed a dangerous precedent when the same abuses were subsequently seen in the case of Alfie Evans – A. Griffin, ‘Alfie Evans: Medical Experts Speak Out About “Guerrilla Warfare Tactics” Being Used Against Family and Doctors’, *The Independent*, 26 April 2018.

¹² See *Great Ormond Street Hospital v Yates, Gard and Gard* [2017] EWHC 972 (Fam) at para. 130.

¹³ *Great Ormond Street Hospital v Yates, Gard and Gard* [2017] EWHC 1909 (Fam) at para. 20.

The favouring of mediation over litigation is not difficult to see. It is widely credited with offering disputants a positive and constructive conflict resolution experience.¹⁴ This stands in sharp contrast to the distressing experience of most litigants. As is commonly known, the rights-based approach to dispute analysis polarises claimants and defendants.¹⁵ The courtroom becomes a gladiatorial arena where their legal representatives focus on securing a victorious verdict for their clients, often by discrediting and attacking the other side.¹⁶ At the end of what can be a costly, distressing and protracted process, one party will be adjudged the winner. The consequence of this defeat is that the loser would usually be asked to pay compensation to the winner.¹⁷ After such an acrimonious and divisive process, the parties could find it difficult to maintain a relationship with one another. Mediation, on the other hand, focuses on both sides' underlying interests and needs.¹⁸ It has a collaborative ethos which encourages the parties to identify common ground and work towards a mutually satisfactory outcome.¹⁹ The mediation forum has drawn praise for its ability to help the parties generate creative and flexible solutions to their dispute, rather than merely monetary compensation.²⁰ It is far less expensive than litigation and is also less time-consuming.²¹ Given its amicable and harmonious character, parties are more likely to preserve and sustain their relationship after the conflict is resolved.²²

¹⁴ See e.g. S.F. Ali, *Civil Mediation Reform: Efficiency, Confidence and Perceptions of Justice* (Cheltenham: Edward Elgar Publishing Ltd., 2018); J.M. Haynes, G.L. Haynes & L.S. Fong, *Mediation: Positive Conflict Management* (Albany: State University of New York Press, 2004).

¹⁵ M. King, *et. al.*, *Non-Adversarial Justice* (New South Wales: The Federation Press, 2014) p. 1.

¹⁶ R. Aldave, 'Mediation Training: Turning Gladiators into Peacemakers' (2000-2001) *Experience* 12.

¹⁷ *Ibid.*

¹⁸ S. Hardy & O. Rundle, *Mediation for Lawyers* (Sydney: Wolters Kluwer, 2010) p. 9.

¹⁹ J.M. Haynes, *et. al.*, *Mediation: Positive Conflict Management* (Albany: State University of New York Press, 2004) p. 15.

²⁰ B. Clark, *Lawyers and Mediation* (Berlin: Springer-Verlag, 2012) pp. 57-58.

²¹ *Ibid.*

²² D. Kolkey, *et. al.* (eds.), *Practitioner's Handbook on International Arbitration and Mediation* (New York: JurisNet, LLC, 2012) p. 482.

As interesting as Mr Justice Francis' recommendation is, he was by no means the first member of the judiciary to advocate the wider use of mediation in lieu of or as an adjunct to litigation. Indeed, three of the most prominent advocates of mediation in recent times include Lord Woolf,²³ Lord Justice Jackson²⁴ and Lord Neuberger.²⁵ Further, neither is this the first time that its usage in the healthcare context has been encouraged, with high numbers of medical negligence claims channelled into mediation the last few decades.²⁶ What is particularly intriguing and noteworthy about Mr Justice Francis' statement is his recommendation for its usage in all cases like Charlie Gard's, which can be interpreted broadly as medical futility conflicts involving patients who are incompetent either by reason of age and/or lack of consciousness or mental capacity. Be this to avoid the rift which the courtroom battle helped widen between family members and the medical team, and/or to prevent the spillage of the antagonism into the public sphere, the deployment of a less combative and more private setting like mediation seems sensible and even desirable. However, is mediation's framework sufficiently capacious and elastic to embrace this subset of end of life dispute?

To address the question, Part 2 will highlight the kinds of cases which fall within the umbrella term 'medical futility'. It then identifies the unique characteristics which distinguish this setting from other civil and commercial cases. Part 3 will explore the two main challenges likely to be encountered in attempts to mediate these cases, namely the absence of a middle ground and having to negotiate in the shadow of the current law that is frequently on the side of doctors. Part 4 by assesses the viability of mediation as a useful and effective method for resolving conflicts in this context, by balancing some perceived benefits against those limitations.

²³ Lord Woolf, *Access to Justice: Final Report* (London: The Stationery Office, 1996).

²⁴ Lord Justice Jackson, *Review of Civil Litigation Costs: Final Report* (Norwich: The Stationery Office, 2010).

²⁵ Lord Neuberger, 'Keynote Address: A View From On High', Civil Mediation Conference, 12 May 2015.

²⁶ For discussion, see e.g. L. Mulcahy, 'Can Leopards Change Their Spots? An Evaluation of the Role of Lawyers in Medical Negligence Mediation' (2001) 8(3) *International Journal of the Legal Profession* 203; L. Mulcahy *et. al.*, *Mediating Medical Negligence Claims: An Option for the Future?* (London: The Stationery Office, 2000); NHS Resolution, *Delivering Fair Resolution and Learning from Harm: Our Strategy to 2022* (April 2017).

2. Medical Futility

From the Latin word '*futilis*' meaning 'leaky',²⁷ futility refers to actions which produce no useful result.²⁸ In the medical context, further treatment is regarded as futile and should not be attempted when, as a consequence of irretrievable illness or injury, it is clinically assessed as not being able to improve the patient's condition.²⁹ The concept itself is as old as medicine.³⁰ According to the Hippocratic corpus, '[w]henever the illness is too strong for the available remedies, the physician surely must not expect that it can be overcome by medicine... To attempt futile treatment is to display an ignorance that is allied to madness'.³¹ This idea that 'enough is enough'³² regained significance in the last few decades. With the increasing availability of sophisticated medical technology and treatment options in modern hospitals, failing organs either through trauma, disease or old age no longer spell the end of one's life. These have enabled corporeal existence to be sustained even when the patients may have lost relational ability and conscious appreciation of their surroundings.³³ In some of these circumstances, the medical team may be of the opinion that LST should be withdrawn and the patient be allowed to die. Or that extraordinary life-saving interventions should not be attempted. This, they believe, would prevent the prolongation of the dying process or causing undue pain and suffering prior to death.³⁴ The resources sustaining the patient's life can then be used to benefit other patients.³⁵

²⁷ D. Sokol, 'The Slipperiness of Futility: When Clinicians Deem an Intervention to be Futile, What Do They Actually Mean?' (2009) 338 *British Medical Journal* b2222.

²⁸ Scanlon, A. & Murphy, M., 'Medical Futility in the Care of Non-Competent Terminally Ill Patient: Nursing Perspectives and Responsibilities' (2014) 27(2) *Australian Critical Care* 99.

²⁹ J. L. Bernat, 'Definition, Determination, Disputes in Critical Care' (2005) 2 *Neurocritical Care* 198.

³⁰ L. J. Schneiderman, 'Defining Medical Futility and Improving Medical Care' (2011) 8 *Bioethical Inquiry* 123 at 124.

³¹ *Ibid.*

³² E.D. Pellegrino, 'Decisions at the End of Life – The Abuse of the Concept of Futility' (2005) 1(3) *Practical Bioethics* 3 at 4.

³³ N. Dubler, 'Conflict and Consensus at the End of Life' (2005) *Hastings Center Report* S19.

³⁴ A. Scanlon & M. Murphy, *op. cit.*, p. 99.

³⁵ A. Bagheri, *Medical Futility: A Cross-National Study* (London: Imperial College Press, 2013) p. 210.

Medical futility cases that have courted the most attention in this country are those that relate to disorders of consciousness. This is mainly because those cases have, up until August 2018,³⁶ required court approval whether or not family members agree with the doctors' decision regarding the removal of LST from patients in a permanent vegetative state (PVS) and a minimally conscious state (MCS).³⁷ But medical futility cases are not, of course, confined to these instances. These are situations where doctors may consider it medically inappropriate or inadvisable for terminally ill patients or those in intensive care to be given interventions like chemotherapy, radiotherapy, cardiopulmonary resuscitation (CPR), dialysis, transfusions, transplant or surgery.³⁸ There are also situations, like the Gard case, where experimental treatments are assessed as not likely to be successful for such patients. And presumably the ultimate in medical futility is the continued ventilation and treatment of those diagnosed as brain stem dead.³⁹ Suffice it to say that there are numerous scenarios which can come under the category of medical futility.

³⁶ Following *an NHS Trust and Others v Y (by his Litigation Friend, the Official Solicitor) and Another* [2018] UKSC 46, withdrawal of LST can now proceed without application to the court if family members and medical team agree on the best interests of the patient. The Supreme Court nevertheless made clear that where doubt exists as to the way forward, or where there is a difference of medical opinion or where those with an interest in the patient's welfare disagree with a proposed course of action, a court application can and should indeed be made – *per* Lady Black at para. 125.

³⁷ See 'Practice Direction E – Applications Relating to Serious Medical Treatment' para. 5(a)(which supplements Part 9 of the Court of Protection Rules 2007).

³⁸ V.M. da Cruz, *et. al.*, Factors Associated with Futile End-of-Life Intensive Care in a Cancer Hospital (2014) 32(3) *American Journal of Hospice and Palliative Medicine* 329; J.M. Steiner, *et. al.*, 'Moral Distress at the End of a Life: When Family and Clinician Do Not Agree on Implantable Cardioverter-Defibrillator Deactivation' (2018) 55(2) *Journal of Pain and Symptom Management* 530; M. Linecker, *et. al.*, 'Potentially Inappropriate Liver Transplantation in the Era of the "Sickest First" Policy – A Search for the Upper Limits' (2018) 68(4) *Journal of Hepatology* 798; A.C. Kidd, *et. al.*, 'Does Medical Futility Matter in "Do Not Attempt CPR" Decision-Making?' (2014) 68(10) *International Journal of Clinical Practice* 1190; M. Cardona-Morrell, *et. al.*, 'Non-Beneficial Treatments in Hospital at the End of Life: A Systematic Review on Extent of the Problem' (2016) 28(4) *International Journal for Quality in Health Care* 456.

³⁹ F.G. Miller, 'Medical Futility and "Brain Death"' (2017) 60(3) *Perspectives in Biology and Medicine* 400.

Conflicts arise when family members disagree with the doctors' decision to withdraw LST or to abandon life-saving or life-prolonging interventions. There are many underlying factors of their objection. These include their feelings of helplessness; refusal to give up or to abandon the patient; a strong belief in the potential of modern medicine; and concerns about incorrect diagnosis and prognosis or with the medical assessments that those procedures would be unsuccessful or worthless.⁴⁰ Further, they could be immobilised by fear, denial, mistrust of the medical team or even grief, to the point where they are unable to accept the patient's terminal condition.⁴¹ Their opposition could also be on the grounds of religion whereby they may believe that death is the prerogative of God rather than doctors; and/or that religion dictates that all efforts should be expended to honour the sanctity of life.⁴² Hence, continuation of treatment which doctors deemed unwarranted may be significant for the family's religious commitment and observance.⁴³ They may also try to be respectful to the patient's known or previously expressed beliefs, wishes and values about treatment limitation.⁴⁴ These, which may align with their own culturally-held perspective on what would be acceptable, beneficial or valuable, may be at variance with those of the medical team. Aggressive measures which the doctors consider medically inappropriate may be acceptable to the patient or his/her family.⁴⁵ Likewise, a final curative procedure which doctors regard as unnecessary may be deemed as a worthy effort to prolong life.⁴⁶ Some

⁴⁰ D.J.C. Wilkinson & J. Savulescu, 'Knowing When to Stop: Futility in the Intensive Care Unit' (2011) 24(2)

Current Opinion in Anesthesiology 160; A. Scanlon & M. Murphy, *op. cit.*, p. 102.

⁴¹ E. Waldman, 'Bioethics Mediation at the End of Life: Opportunities and Limitations' (2014) 15 *Cardozo Journal of Conflict Resolution* 448 at 450.

⁴² R.A. Ankeny, *et. al.*, 'Religious Perspectives on Withdrawal of Treatment from Patients with Multiple Organ Failure', (2005) 183(11) *Medical Journal of Australia* 616.

⁴³ H. Akah, 'Expanding the Scope of Bioethics Mediation: New Opportunities to Protect the Autonomy of Terminally Ill Patients' (2016) *Ohio State Journal on Dispute Resolution* 73 at 74 & 97.

⁴⁴ Heland, M., 'Fruitful or Futile: Intensive Care Nurses' Experiences and Perceptions of Medical Futility' (2006) 19(1) *Australian Critical Care* 25 at 27.

⁴⁵ *Ibid.*, p. 29.

⁴⁶ S. Mohammed & E. Peter, 'Rituals, Death and the Moral Practice of Medical Futility' (2009) 16(3) *Nursing Ethics* 292 at 293.

families even come to the decision that chances of less than 1% are worth taking and life in a vegetative state is still worth living.⁴⁷ Indeed, as expressed by one family member, her unconscious father would have taken the view that ‘any life is better than no life’.⁴⁸ Thus for patients and their families, the choice of which medical options to follow is not always directed exclusively by medical determinants. Importantly, within the context of the NHS, they would also not have to be directly responsible for the cost of the continued care,⁴⁹ i.e. for the result of their insistence that the medical team ‘pursue every avenue for extending life’⁵⁰ or their willingness to ‘try anything’.⁵¹ These conflicts over the future care of a loved one can easily escalate.⁵² But can they be successfully mediated?

Mediation has been described in different ways by various parties. For purposes of this article, the description offered by the Civil Mediation Council (CMC) will be used.

According to the Council, mediation ‘involves an independent third party – a mediator – who helps both sides come to an *agreement*’.⁵³ As for the role of the mediator, this is to ‘help parties reach a *solution to their problem* and to arrive at an outcome that *both parties are happy to accept*’. The focus of a mediation meeting is therefore, the Council adds, ‘to reach a *common sense settlement agreeable to both parties in a case*’. The aim is to push disputants away from the courtroom unless the parties ‘are unable to reach agreement’.⁵⁴

⁴⁷ C. M. Bowser, ‘Exploring Nurses’ Attitudes About the Value of a Hospital Based Medical Futility Policy’ (2016) Master’s Theses, Dissertations, Graduate Research and Major Papers Overview, Rhodes Island College p. 7.

⁴⁸ *Abertawe Bro Morgannwg University Local Health Board v RY & CP* [2017] EWCOP 2, para. 5.

⁴⁹ H. McKenna, ‘Are We Expecting Too Much from the NHS?’, Joint Report by The Health Foundation; Institute for Fiscal Studies; The King’s Fund and The Nuffield Trust, 2018, p. 5.

⁵⁰ H. Akah, *op. cit.*, p. 74.

⁵¹ *Yates and Gard v Great Ormond Street Hospital and Gard* [2017] EWCA Civ 410, para. 112.

⁵² K. Knickle, *et. al.*, ‘Beyond Winning: Mediation, Conflict Resolution, and Non-Rational Sources of Conflict in the ICU’ (2012) 16 *Critical Care* 308.

⁵³ Civil Mediation Council, ‘What is Mediation?’ at <http://www.civilmediation.org> (accessed on 5th September 2018).

⁵⁴ Emphasis added.

It is necessary to note that mediation of medical futility cases would hold a number of unique characteristics. First, since the patient is incompetent by reason of age and/or lack of consciousness or mental capacity,⁵⁵ the mediation triad would be made up of the mediator, doctors and the patients' parents or family members. Secondly, we are here dealing with time-sensitive decisions.⁵⁶ From the families' perspective, for a procedure or experimental treatment to have the best chance of helping their loved ones, it needs to be carried out as soon as possible.⁵⁷ From the medical team's point of view, the longer LST continues, the more the patient is subjected to preventable pain and suffering.⁵⁸ Thirdly, it is also potentially far more emotionally charged than other civil and commercial cases including medical negligence conflicts, since the parties are 'locked in a life or death struggle'.⁵⁹ Family members may be embroiled in a wide range of strong emotions like grief, fear, anger, defiance and denial.⁶⁰ Although they may have more invested in the outcome, the medical team too has strong feelings about providing care which they now believe is futile. They are known to be distressed and offended by the idea of providing inappropriate care,⁶¹ as they may not believe that medical practice should include the provision of measures which do nothing other than to maintain corporeal existence and mere biologic functioning.⁶² They may consequently find such practices wrong, gruesome, demoralising, inhumane, cruel, burdensome, abusive, degrading and obscene.⁶³ With this in mind, the discussion now proceeds to the question of whether mediation can successfully be used to resolve such disputes.

⁵⁵ Medical futility conflicts involving competent patients do not seem to be directly or indirectly addressed in Mr Justice Francis' recommendation. It is therefore not within the scope of this paper.

⁵⁶ N. Dubler, *op. cit.*, p. S25.

⁵⁷ D. Noll, 'Bioethical Mediation: Peacemaking and End of Life Conflicts' (2014), available at <https://www.mediate.com/pfriendly.cfm?id=1549> (accessed 1 September 2018).

⁵⁸ M. Cardona-Morrell, *et. al.*, *op. cit.*, pp. 456-469.

⁵⁹ E. Waldman, *op. cit.*, p. 469.

⁶⁰ A. Scanlon & M. Murphy, *op. cit.*, p. 101.

⁶¹ *Ibid.*, p. 102.

⁶² T.M. Pope & E.A. Waldman, *op. cit.*, pp. 185 and 188.

⁶³ *Ibid.*, pp. 188-189.

3. Challenges and Limitations

Recent literature indicates that there are two main characteristics of medical futility cases which could impede mediation efforts: the absence of a middle ground; and having to negotiate in the shadow of current law that is frequently on the side of one party. These will be explored in turn.

3.1 *The Absence of a Middle Ground*

If mediation is supposed to be a conducive environment for the generation of creative options that will help the parties reach a solution they are happy to accept, this is not easily achievable in the futility context. The choices present themselves in stark terms: e.g., to continue or withdraw LST including artificial ventilation; attempt life-sustaining or life-saving procedures or forego aggressive treatment options; allow the patient to be taken abroad for further care or to not allow the patient to be removed from hospital; and to undergo an experimental procedure or be prevented from doing so. How do they meet each other half way in those circumstances? After all, ‘extremism does not, in the crucible of conversation, give way to moderation’.⁶⁴ It has been pointed out that the parties will instead cling on to their initial starting points and new creative options are not forthcoming.⁶⁵ This is especially so where religion is at the heart of the conflict since these religious issues are often deemed as non-negotiable.⁶⁶ As families have more at stake in the outcome yet they do not have to bear the cost of the LST should it be continued or the cost of life-saving or life-prolonging interventions should these be attempted, these may breed intransigence on their part. At the same time, the medical team find it difficult to justify the continuation of medical care where it is not obvious that these can lead to any benefit for the patient. In the case of brainstem dead patients, doctors even view the provision of LST as merely to mechanically sustain a corpse.⁶⁷

⁶⁴ T.M. Pope & E.A. Waldman, *op. cit.*, p. 158.

⁶⁵ *Ibid.*, p. 155.

⁶⁶ G. Baeke, *et. al.*, ‘Orthodox Jewish Perspectives on Withholding and Withdrawing Life-Sustaining Treatment’ (2011) 18(6) *Nursing Ethics* 835.

⁶⁷ J.M.A. Swinburn & S.M. Ali, ‘Discontinuation of Ventilation After Brain Stem Death: To Whom is Our Duty of Care?’ (1999) 318 *British Medical Journal* 1753.

As there is no movement to middle ground, the outcome is predictable rather than creative. So, rather than having, as the CMC described, a mutually consensual agreement or solution which both parties are pleased to accept, one side will eventually have to acquiesce to the standpoint of the other, leading to a binary win-lose resolution just as in litigation. As to which party will usually have to give in, this is linked to the next point below concerning the impact of the existing legal framework on the bargaining power and behaviours of the parties.

3.2. *Negotiating in the Shadow of the Law*

Although mediation is a non-legal process, it is important to remember that it takes place ‘in the shadow of the law’.⁶⁸ In other words, the parties negotiate against a backdrop of the likely outcomes if the dispute is litigated.⁶⁹ This inevitably means that the party who anticipates a better outcome in court will have stronger bargaining power in the mediation.⁷⁰ In the case of medical futility disputes, case law has shown that this is consistently the medical team rather than the patients’ family.

Disorders of consciousness, where the patient is ‘dangling by a filament of consciousness’,⁷¹ is clearly one such instance. When a patient is confirmed as being in a PVS, it has always been held that LST is ‘useless’.⁷² In other words, a diagnosis of PVS routinely leads to the conclusion that the continuation of LST is not in their best interests and can legally be withdrawn.⁷³ Even for those who received a diagnosis of MCS, where withdrawal of LST is

⁶⁸ R.H. Mnookin & L. Kornhauser, ‘Bargaining in the Shadow of the Law: The Case of Divorce’ (1979) 88(5) *Yale Law Journal* 950.

⁶⁹ *Ibid.*

⁷⁰ *Ibid.*, p. 997.

⁷¹ J. Samanta & A. Samanta, ‘Awake and (Only Just) Aware? A Typology, Taxonomy, and Holistic Framework for Withdrawing Clinically Assisted Nutrition and Hydration in the Minimally Conscious State’ (2017) *Medical Law Review*, available at <https://doi.org/10.1093/medlaw/fwx058> (accessed 1 October 2018).

⁷² *Airedale NHS Trust v Bland* [1993] 1 All ER 821 *per* Lord Goff at 870. See also *A NHS Trust v D* [2006] 1 FLR 638; *Gloucestershire Clinical Commissioning Group v AB (by his Litigation Friend, the Official Solicitor)*, CD [2014] EWCOP 49; *Cumbria NHS Clinical Commissioning Group v Miss S, Mrs D, Miss T* [2016] EWCOP 32.

⁷³ R.W.M. Law & K. Choong, ‘Disorders of Consciousness: Is A Dichotomous Legal Approach Justified?’ (2018) 25 *European Journal of Health Law* 1 at 19.

not automatically countenanced,⁷⁴ cessation of care would be legally approved when LST is expected to cause intolerable suffering, with the matter determined from a medical perspective.⁷⁵ There is statutory support for this position too. According to the Code of Practice of the Mental Capacity Act, ‘where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery... 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’.⁷⁶

Further, as is well known, in the case of Charlie Gard itself, where medical evidence indicates that there is no benefit to be attributed to an experimental treatment abroad that may even cause pain, suffering and distress to the patient, this was held to be tantamount to prolonging his existence in a manner which is no longer justified as being in his best interests.⁷⁷ This was confirmed in the more recent case of Alfie Evans where the courts took the view that it was not in his best interests for LST to be continued for him to be taken abroad for this purpose, when the medical consensus was that his prognosis is futile.⁷⁸ Importantly, just as in the case of disorders of consciousness and other futility cases, once an intervention is no longer in the patient’s best interests, doctors would not be in breach of a legal duty of care if they remove or withhold it from the patient.⁷⁹ This is similarly the case in disputes relating to the diagnosis of death. This can be illustrated through the case of *Re A (A Child)*,⁸⁰ which despite its complex facts, did not receive any media coverage. This concerned a 19-month old boy who choked on a tiny piece of fruit and rushed to hospital where he was operated on and put on a ventilator. When he was subsequently confirmed to be brainstem dead, his doctors wanted to switch off the ventilator as they deemed the patient already medically and legally dead. The

⁷⁴ Where a balance sheet exercise of the advantages and disadvantages of the continuation of LST would firstly be undertaken – see *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67.

⁷⁵ *Ibid.*, para. 22.

⁷⁶ Department for Constitutional Affairs, *Mental Capacity Act 2005: Code of Practice* (London: The Stationery Office, 2007) para. 5.31.

⁷⁷ Judgement of the UK Supreme Court in the Case of Charlie Gard, 19 June 2017, para. 15.

⁷⁸ *In the Matter of Alfie Evans No. 2*, Supreme Court 20 April 2018.

⁷⁹ GMC, *Treatment and Care Towards the End of Life: Good Practice in Decision Making* (2010) p. 76.

⁸⁰ [2015] EWHC 443.

father protested as he disagreed that brainstem death equates the death of the person in Islam. He is originally from Saudi Arabia and wanted ventilation continued until at least the child can be repatriated to Saudi where he said ventilation would be continued. The court nevertheless held that the child was dead and doctors were allowed to remove the ventilation. If the case was mediated, as Mr Justice Francis' statement seems to suggest that it can, it is important to remember that the law is on the doctors' side as brainstem death has long been recognised as the legal definition of death.⁸¹ The case is also a reminder that to date, courts have never been willing to accommodate objections made to the withdrawal or withholding of LST on religious grounds.⁸²

The fact that the law relating to medical futility is frequently on the doctors' side means that they can negotiate in the full knowledge that if no settlement or resolution is reached in the mediation, their standpoint is most likely to be supported by the courts based on past cases. The determinacy or predictability of court outcome thus gives doctors greater bargaining power. This does not create a mediation-friendly environment since mediation usually thrives in an environment where the legal outcome for both parties cannot be predicted with any degree of certainty.⁸³ It is the uncertainty that would then lead them towards compromise in the hope of avoiding an unwelcome outcome or loss in litigation.⁸⁴ Whereas in futility cases, doctors can effectively direct the outcome of the dispute as they do not need to make significant, or indeed any concessions.⁸⁵ Given doctors' strength of feeling on the provision of inappropriate care, they are likely to stand their ground and succeed. Thus, the LST is likely to be withdrawn or life-saving or -prolonging procedures not carried out. Even in

⁸¹ Brainstem death has been recognised as the medical and legal definitions of death in British ICUs for the last few decades – see e.g. 'Diagnosis of Death: Memorandum Issued by the Honorary Secretary of the Conference of Medical Royal Colleges and Their Faculties in the United Kingdom on 15 January 1979' (1979) 1 *British Medical Journal* 332; *R v Malcherek and R v Steel* [1981] 1 WLR 690; *Re A (A Minor)* [1992] 3 *Medical Law Review* 303.

⁸² See e.g. *An NHS Foundation Trust v VT & A* [2013] EWHC B26 (Fam); *Abertawe Bro Morgannwg University Local Health Board v RY & CP* [2017] EWCOP 2.

⁸³ T.M. Pope & E.A. Waldman, *op. cit.*, p. 180.

⁸⁴ *Ibid.*

⁸⁵ *Ibid.*, p. 163.

situations where doctors continue with treatments as a consequence of acceding to the request of the family members or in compliance with a stay of a declaration for the withdrawal of LST, they do so not because they believe that the treatment is useful, but in order to stave off legal actions or to avoid media scrutiny⁸⁶ whilst at all times considering it professionally wrong.⁸⁷

Thus, if the mediation process should, as the CMC claims, help both sides reach a common sense settlement agreeable to both parties, the discussion above has shown that this is difficult to attain in the futility context. In addition to having predictable and inflexible outcomes rather than creative ones which both parties are happy to accept, the process will also lead to a win-lose situation just as in litigation.

4. Conclusion

Mediation's potential to resolve a wide range of disputes may have given the impression that it can be equally beneficial for the resolution of medical futility disputes. However, as discussed, this may be hindered by two main challenges: the absence of a middle ground; and having to operate against a backdrop where the law is firmly on the side of one party.

This does not mean, however, that mediation is completely devoid of any positive value in this context. Significantly, it can provide the parties an opportunity to engage in a face-to-face facilitated discussion.⁸⁸ One clear benefit of this is that family members are given a chance to ventilate their emotions⁸⁹ and express more fully their concerns to those who they actually feel need to hear it, especially the anger at what they may perceive as a premature abandonment of their loved ones.⁹⁰ The process allows the doctors to express empathy for

⁸⁶ A. Scanlon & M., Murphy, *op. cit.*, p. 100. One healthcare practitioner described the challenge as follows:

'It's really hard to even look at the patient half the time, and sometimes you even have to take a break from the patient, because you just can't continue, it's like a form of torture really'- see M. Heland, *op. cit.*, p. 27.

⁸⁷ Judgement of the UK Supreme Court in the Case of Charlie Gard, 19 June 2017, para. 15.

⁸⁸ E.G. Howe, 'Mediation Approaches at the Beginning or End of Life' (2015) 26(4) *Journal of Clinical Ethics* 275 at 277.

⁸⁹ E. Waldman, *op. cit.*, p. 463.

⁹⁰ E.G. Howe, *op. cit.*, p. 276.

their predicament and clarify the rationale⁹¹ for their own divergent views on the prolongation of life and the relief of suffering.⁹² Here, the doctors can learn how culture and faith inform the family's worldview. Family members may seek clarifications and simplification of the medical situation so as to enable them to better understand the patient's condition, situation and options.⁹³ As insightfully observed by Dubler, '[a]t the end of life, short answers are inappropriate, only essays will do'.⁹⁴ Not only can the process disperse any misperceptions, it can help decrease the asymmetry of knowledge, skill and experience between the two parties.⁹⁵ As such interactions can help improve trust, they may be able to prevent the situation from disintegrating into an outbreak of hostilities.⁹⁶ Mediation should not, however, be asked 'to do more than it is structurally equipped to handle'.⁹⁷ It is not psychotherapy and cannot therefore rationalise magical thinking or overcome firmly maintained defences.⁹⁸ Neither can, nor should, it be tasked with breaking through denials.⁹⁹ When coupled with the two major limitations explored in Part 3 above, namely the absence of a middle ground and the presence of unequal bargaining power between the medical team and family members, could it be that Mr Justice Francis was overly optimistic about mediation's potential when recommending its usage in this context?

⁹¹ For example, to explain that the provision of nutrients via a feeding tube can cause serious complications like skin breakdown, pneumonia, swelling of the arms and legs, constipation or loss of bladder control – see E.

Waldman, *op. cit.*, p. 464.

⁹² D. Noll, *op. cit.*

⁹³ *Ibid.* This is particularly useful for concepts like brainstem death, for instance, which can be particularly difficult for non-medically trained people to grapple with – see A. Moorkamp, 'Don't Pull the Plug on Bioethics Mediation: The Use of Mediation in Health care Settings and End of Life Situations' (2017) *Journal of Dispute Resolution* 219 at 235.

⁹⁴ N. Dubler, *op. cit.*, p. S24.

⁹⁵ *Ibid.*, p. S25.

⁹⁶ *Ibid.*, p. S24.

⁹⁷ T.M. Pope & E.A. Waldman, *op. cit.*, p. 151.

⁹⁸ Waldman, E., *op. cit.*, p. 467.

⁹⁹ *Ibid.*