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THE RESPONSIBILITIES OF CONSCIENCE IN HEALTHCARE DECISIONS: MOVING TOWARDS A COLLABORATIVE FRAMEWORK

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ABSTRACT. *Claims of conscience are a substantial area of concern in relation to healthcare decisions but are often only considered in a limited context. Broadening our understanding of claims of conscience, however, might lead to claims that we are moving back towards a doctor-centred understanding of medical care. This article argues that we can allow claims of conscience without unduly penalising patients by focusing on the responsibilities that ought to attach to conscience claims. This article sets out three responsibilities – humility, universality and reciprocal respect – which ought to be part of any claim of conscience. The* Charlie Gard *case is then used as an example to explore the use of responsibilities. The article then moves to consider possible issues that arise from this view.*

KEYWORDS: *claims of conscience, conscientious objection, healthcare law, Charlie Gard, responsibilities of conscience.*

I. INTRODUCTION

Imagine you work as a healthcare practitioner (HCP) in a paediatrics ward. Parents have brought a newborn with a debilitating illness for treatment. After examination and tests, it becomes clear that none of the traditional therapies will be of any use in curing or treating the newborn. You offer palliative care to the parents to make sure that the child does not suffer pain or discomfort in the child's last few months, but the parents refuse. Instead, they want you to pursue an experimental treatment which they have found about on the Internet. After investigation, you find out that it has not previously been used for this condition, that it is likely to cause the newborn to be in additional pain and, you may feel, that the parents are being fed false hope. You are not completely sure about this and you would admit that it is possible that the experimental treatment might

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work in some way you do not understand. Nevertheless, you have deep moral objections to providing the treatment the parents want, but they are insistent. What options are available to you?

Your first option might be to convince the family that you are correct. You might sit them down and explain to them, either informally or in a formal mediation, why it is that you think the treatment would not be effective and would be detrimental to the newborn. You might explain how you think that the child would be in significant pain. You might explain how the treatment works and why that would not solve the newborn's problems. You might explain that the cases in which the treatment has worked are different in meaningful ways. You might conversely try to explain the benefits of the palliative care treatment you wish to provide instead and how it could help the newborn. Suppose, however, that these discussions do not change the parents' mind. Either they disbelieve the information you provide or are holding out hope or weigh up the interests differently from the way you do, but they continue to insist upon the experimental treatment. What then?

The hospital legal office suggest the Trust should petition the court for an order allowing you to withdraw all other forms of treatment and provide only palliative support. This, however, would require significant costs and hassle – legal representation needs to be secured, experts must be consulted, the case will need to be filed, and you will have to attend a hearing and give evidence. Moreover, you are worried this might make the relationship you have with the parents much more acrimonious. Furthermore, you have some objection to the legal test that would be applied. You know that the legal test is the "best interests" of the patient but you think that there are too many uncertain factors in order to be able to say conclusively that any treatment is "best" in the circumstances. You are worried you might have to admit in court that it is possible the treatment might help the patient even though you do not believe that to be the case. You have concerns that the court might side with the parents and you may have to provide treatment to which you have significant moral objections. What you really want is to be able to say that *you* object to the provision of this treatment and do not want to provide it.

What you might have, then, is a claim of conscience. Unfortunately, you would quickly find out that there is little you can do to protect your claim of conscience. While Article 9 of the European Convention on Human Rights (ECHR) provides protection for freedom of thought, conscience and religion, it has not been used much in relation to healthcare decisions. There are statutory grants within the UK which allow HCPs to claim conscientious objections but those are limited to abortion and in-vitro fertilisation (IVF). Conscience, as it currently stands, does not include the case being discussed here.

I have argued elsewhere, however, that we need to expand our understanding and analysis of conscience to include the kind of case we are

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considering.[1] Conscience is not limited to discrete areas of healthcare; so, our conception of it should likewise not be limited in scope. Instead, conscience permeates all healthcare decision-making because it is a fundamental part of all moral decisions about our own conduct.[2] It is not something which only applies to a specialised group of behaviours but applies across the board. It would not only apply to situations such as abortion, assisted conception or end of life decisions but would encompass any decisions a HCP made which had some moral import, including the one discussed above.[3] This not only broadens the types of cases in which conscience has a role but also sees the full diversity of the roles that conscience plays. It takes us beyond just conceptions of conscientious objection towards a more holistic approach to conscience.

Seeing conscience more broadly has significant benefits. It allows a greater discussion about the role of conscience in healthcare decision-making more generally. It also allows the part conscience plays in decision-making to be subject to greater transparency and oversight by those tasked with evaluating the decisions of HCPs. Considering the likelihood of conscience playing an important role in many controversial decisions, it would further let HCPs be more truthful about their process of making decisions rather than forcing their decisions to conform to legal or ethical buzzwords like "best interests".[4] This might permit HCPs to have more honest discussions with patients and families about the role that conscience has played in the decisions made about treatment. If HCPs were more truthful, their being so might alleviate difficulties which exist due to families or patients becoming upset about the use of legal categories like "best interests".[5] There is further some evidence from the case law that patients may be more accepting of sorts of moral reasons in discussion than they are of clinical judgements, although that they have been is merely anecdotal.[6] Also, since patients and families are more likely to have experience of moral claims than of technical legal ones, it may be easier for them to understand and appreciate them than claims like "best interests". The benefits of using a

1 S.W. Smith, "A Bridge Too Far: Individualised Claims of Conscience" (2015) 23 Med.L.R. 283.
2 S.W. Smith, "Individualised Claims of Conscience, Clinical Judgement and Best Interests" (2018) 26 Health Care Analysis 81.
3 See Smith, "A Bridge Too Far".
4 Ibid.
5 The "best interests" test applies in a number of healthcare situations. For example, section 4 of the Mental Capacity Act 2005 requires that all decisions about treatment for patients who lack capacity to be made in the "best interests" of the patient. The best interests test is discussed in more detail in Section V below.
6 For example, in the *Ms. B* case, the patient indicated that she understood a doctor's indicating that "I personally will not do it", *Re B (adult: refusal of medical treatment)* [2002] EWHC 429 (Fam), [2002] 2 All E.R. 449, at [50]. Reports from the *Re A (conjoined twins)* case also indicated that the parents and HCPs were able to continue to communicate despite their moral disagreement about what ought to happen to Jodie and Mary, *Re A (Children) (conjoined twins: surgical separation)* [2000] EWCA Civ 254, [2001] Fam. 147.

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more expansive version of conscience would be a substantial upgrade over the current focus on just conscientious objection.

There is a significant problem as well. If our conception of conscience is broader then it will also mean that it will be applicable in a greater number of cases than it has been previously. If we continue to see conscience as one way to create rights for HCPs to dictate, in some way, which treatment others might receive, then there is the crucial question of whether the broadening of conscience in healthcare will lead to reduced patient rights. In other words, are we sacrificing patient rights on the altar of greater respect for the conscience-based decisions by HCPs? If this is true, then it might provide a powerful reason against viewing conscience in the broader terms I have suggested.

This article will explore that question with a focus on finding a way to allow us to broaden our understanding of conscience without unduly restricting patient choices and rights. One possible avenue to explore is to determine what is necessary to make a claim of conscience. Conscience, being a moral claim, ought to require that those making it have some moral foundation on which to ground their claim. This might further require that individuals claiming conscience do not just have rights which might flow from their conscience-based decision, but attendant responsibilities as well.[7] In other words, a broader look at conscience provides reasons to argue that someone wishing to make a conscience-based claim must fulfil requirements necessary for that claim to have moral force, but it is important to determine what those attendant responsibilities might be and what role they ought to play in our evaluation of the conscience claims of others.

In order properly to analyse these claims, the article will take the following structure. First, it will characterise conscience, the underlying foundational ethical principles important to conscience, and how this applies to questions of healthcare. Next, it will explore how responsibilities might solve our central problem of conscience claims providing too much deference to HCPs at the expense of patient rights. To see how responsibilities might do this, the recent *Charlie Gard* case is used as an illustrative example. This case was chosen as the moral claims by the doctors and other members of the healthcare team about what they could be required to do in terms of treating Charlie Gard are central. Thus, while the case does not specifically reference conscience, there are claims made in the case which are significantly similar to claims of conscience. It is thus reasonable to presume that, had conscience claims been available, that is one

7 Fovargue and Neal also discuss duties which might arise from a claim of conscience in S. Fovargue and M. Neal, "'In Good Conscience': Conscience-Based Exemptions and Proper Medical Treatment" (2015) 23 Med.L.Rev. 221, at 233–41. However, the respective duties they endorse are different from the ones espoused here.

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legal angle the healthcare team would have pursued. Finally, the discussion will turn to concerns which would still arise even if we used responsibilities as part of claims of conscience.

II. What Is Conscience?

The first task is to provide a conception of what conscience is. This will include not only a general description of conscience but how it is different from conscientious objection. For the purposes of this article, conscientious objection, on the one hand, is defined as a legally enforceable right to object to providing treatment which goes against the conscience of the individual. Conscience, on the other hand, is defined as an internal mental process focused on an inward-looking choice to engage in particular behaviour on the basis of a moral value. The definition of conscience requires further unpacking.

The first part of the conception of conscience used in this article is that it is an internal mental process. This may seem to deviate from certain classic views of conscience which, instead of locating it within the individual, place conscience as directives from someone else, notably a god-like figure.[8] Conscience in these cases becomes a statement made by this powerful authority figure dictating what the correct moral actions are. There are two responses to such cases. First, noted Christian theologians such as Saint Augustine and Saint Thomas Aquinas both viewed conscience as an internal mental process even if they also saw it as where God spoke to human beings.[9] Secondly, and more importantly, conscience is not limited to only those individuals with specific religious views. Anyone is entitled to conscientiously object to the provision of abortion services whether it is based upon a religious viewpoint or not.[10] Additionally, freedom of conscience as enshrined in the ECHR is not limited to those from a particular religious tradition.[11] That it is not so limited would also be consistent with the use of conscientious objection in other situations. Conscientious objector status in armed conflict, for example, was at one time based upon a requirement of belonging to specific religious viewpoints.[12] Now most conscientious objector status claimants need merely to prove that the beliefs in question are strongly held and consistent with

8 Saint Thomas Aquinas, *Summa Theologica* I, q. 79 aa. 12–13; I–II, q. 19 aa. 5, 6; M. Svenson, "Augustine on Moral Conscience" (2010) The Heythrop Journal 42.

9 Ibid. A broader discussion of Christian theology as it relates to conscience and how it operates is beyond the scope of this article.

10 Abortion Act 1967, s. 4; *Greater Glasgow Health Board v Doogan & Anor* [2014] UKSC 68, [2015] A.C. 640.

11 European Convention on Human Rights and Fundamental Freedoms (1950), Art. 9.

12 H. LaFollette, "My Conscience May Be My Guide, but You May Not Need to Honor It" (2017) 26 Cambridge Quarterly of Healthcare Ethics 44, at 44; R.Y. Stahl and E.J. Emanuel, "Physicians, Not Conscripts – Conscientious Objection in Health Care" (2017) 376 New Eng.J.Med. 1380.

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a moral perspective.[13] So, the tendency has been for greater liberalisation of the basis for a conscientious decision.

Nor is conscience necessarily limited to particular substantive decisions. It is true that HCPs in the UK are only provided legislatively created abilities to conscientiously object in the limited scenarios of abortion and IVF provision. However, both the General Medical Council (GMC) and the British Medical Association (BMA) in official guidance have suggested that conscience ought to be allowed in a greater range of circumstances.[14] Moreover, courts have often indicated that HCPs and particularly doctors might have greater scope for conscientious decisions, stating in both *Burke v GMC*[15] and *Aintree v James*[16] that patients are not entitled to everything that they may want and that doctors may avoid providing treatment they deem inappropriate. While this was couched in terms of best interests in *Aintree v James*,[17] it also sounds in terms of conscience.[18]

Describing conscience as an internal mental process goes a long way towards avoiding the issues relating to the origins of conscience and its substantive content. It relies, to start with, only on the quantifiable facts that individuals experience a thing generally referred to as "conscience" and that those experiences are mental ones rather than dependent on any sensory input or particular substantive basis. Seeing it as an internal mental process also helps to deal with other questions of the creation of conscience. There is academic debate about whether conscience is an individual characteristic or socially constructed. Authors such as Baylis[19] and McLeod[20] argue that the standard view of conscience is too limited because it sees conscience as an individual trait rather than something which grows out of our social culture and upbringing. While it is not clear that there is as much difference between the two views as Baylis and McLeod argue there is,[21] focusing on the internal mental process of conscience rather than its development avoids the issue. Conscience might arise from anywhere, but it must be an internal mental process.

13 M.L. Rienzi, "The Constitutional Right Not to Kill" (2012–2013) 63 Emory L.J. 121, at 130; *United States v Seeger* (1965) 380 U.S. 163, 175.

14 General Medical Council, *Personal Beliefs and Medical Practice*, available at https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/personal-beliefs-and-medical-practice/personal-beliefs-and-medical-practice (accessed 14 August 2019); British Medical Association, *Expression of Doctors' Beliefs*, available at https://www.bma.org.uk/advice/employment/ethics/expressions-of-doctors-beliefs (accessed 14 August 2019).

15 *R. (Burke) v General Medical Council* [2005] EWCA Civ 1003, [2006] Q.B. 273.

16 *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [2014] 1 A.C. 591, at [45].

17 Ibid.

18 See Smith, "A Bridge Too Far".

19 F. Baylis, "A Relational View of Conscience and Physician Conscientious Action" (2015) 8 International Journal of Feminist Approaches to Bioethics 18.

20 C. McLeod, "Taking a Feminist Relational Perspective on Conscience" in J. Downie and J. Llewellyn (eds.), *Being Relational: Reflections on Relational Theory and Health Law* (Vancouver 2012), 161–81.

21 See Smith, "Conscience, Clinical Judgement and Best Interests".

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The second part of or requirement for conscience is that it is a choice relating to behaviour. This is a very content-thin description but there are two important aspects of the requirement. First, conscience requires a choice. For some, this might be controversial as conscience is sometimes stated to be an instance in which the individual "has no choice".[22] However, this statement is metaphorical rather than actual. Conscience does not directly control our actions. All it can reasonably do is to direct or cajole us into performing certain action. We must still listen to our consciences and act accordingly. If we do not, conscience can provide certain punishments (feelings of shame, for example) but it cannot force actions which we have not decided to do. So, there is always a choice involved in cases of conscience – we can either choose to follow our conscience or to do something else.[23] Secondly, conscience is about behaviours. Conscience concerns the rightness or wrongness of the things that we either do or that we fail to do. Conscience is not just about our actions but also about our inactions. We can feel pangs of conscience for failing to donate sufficiently to worthy charities as we can for actions that we perform. This provides one vital difference between conscience in general and conscientious objection in particular. Conscientious objection, by definition, only applies to situations where an individual wishes not to perform an action in which the individual might otherwise engage. Conscience applies also to cases in which an individual wants to perform an action the individual might otherwise avoid, which we might call conscientious provision.[24] Examples of these exercises of conscience might include doctors working in a Catholic hospital who wish to provide an abortion or doctors insisting on providing vaccines to the children of anti-vaccine parents. Both of those are instances of conscience but focus on the provision, rather than the avoidance, of treatment.

The third requirement for conscience is that the choice be based upon moral values. The crucial word is moral. Many decisions we make are based upon values. Basing a decision on values is insufficient for something to be considered a decision of conscience. Only those decisions which are based upon values which are at least partially moral constitute sufficient grounding for a claim of conscience.[25] A decision based upon aesthetic or cultural values is not a claim of conscience. A claim of

22 Individuals will often talk about being forced to do something because of their conscience or otherwise act as if conscience took away their ability to make a free choice.

23 Even if we actually did not have the ability to do anything other than act according to our conscience, there is an argument that it would still be the result of a choice. See J.M. Fischer, *My Way: Essays on Moral Responsibility* (New York 2006); J.M. Fischer and M. Ravizza, *Responsibility and Control: A Theory of Moral Responsibility* (New York 1998). However, that argument is beyond the scope of this article.

24 L.H. Harris, "Recognizing Conscience in Abortion Provision" (2012) 367 New Eng.J.Med. 981.

25 E.J. Sutton and R.E.G. Upshur, "Are There Different Spheres of Conscience?" (2016) 16 Journal of Evaluative Clinical Practice 338. See Smith, "Conscience, Clinical Judgement and Best Interests".

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conscience is based upon *some* set of moral values but does not require any specific set of moral values.[26] So, while a decision to remove treatment from a patient in a persistent vegetative state might be based upon a moral value, a decision not to remove treatment from the same patient might also be based upon a moral value. Both decisions might be decisions of conscience. What this requirement stipulates is that claims of conscience are process-based decisions rather than substantive ones. Decisions of conscience should be seen broadly and not simply as the purview of one particular moral tradition. All individuals who are capable of behaving according to moral values are capable of behaving consistently with their conscience.[27]

The final requirement for conscience is that it be inward-facing. This means that conscience is only capable of binding our own conduct and not the conduct of others. Conscience can only provide a reason for the individual to do or refrain from doing something. It is an insufficient reason for someone else to do or refrain from doing something. In other words, the sentence "I cannot do this because it violates my conscience" is a sentence which makes sense. "You cannot do this because it violates my conscience" is not a sentence which makes sense.[28] There are two important aspects of this requirement. First, just because a decision of conscience only applies to the individual's own conduct does not mean that it cannot arise based upon the conditional conduct of others. An individual who will participate in abortions only in cases for a few specified reasons such as that the pregnancy was the result of rape, incest or domestic violence is still making an inward-facing decision (it is *their* participation at issue) despite the fact that the conditions which determine that are dependent on the conduct of others. Secondly, the requirement that conscience be inward-facing is not a claim about where the morality which informs our conscience comes from. Again, there has been argument in academic literature that focusing on the individual in terms of conscience artificially reduces the role that social factors play in the creation of conscience.[29] The requirement that conscience be inward-facing might be subject to the same criticism. However, just because conscience claims are inward-facing does not mean that they cannot arise from socially constructed moral values. The inward-facing requirement is not about the development of morality necessary for conscience. It is instead about the way conscience operates after its

26 J.F. Childress, "Conscience and Conscientious Actions in the Context of MCOs" (1997) 7 Kennedy Institute of Ethics Journal 403; E. Sepper, "Taking Conscience Seriously" (2012) 98 Va.L.Rev. 1501; M. Neal and S. Fovargue, "Conscience and Agent-Integrity: A Defence of Conscience-Based Exemptions in the Health Care Context" (2016) 24 Med.L.Rev. 544.

27 See Childress, ibid.; Sepper, ibid.

28 See Smith, "A Bridge Too Far"; A.H.M. Antommaria, "Conscientious Objection in Clinical Practice: Notice, Informed Consent, Referral and Emergency Treatment" (2010–2011) 9 Ave Maria Law Review 81, at 84.

29 See Baylis, "A Relational View'; McLeod, "Taking a Feminist Relational Perspective".

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development. Nothing about its inward-facing nature denies that morality often arises from social context and culture.[30] Nothing about its inward-facing nature denies that morality often develops from the views espoused by parents or other important authority figures in an individual's life. What it instead acknowledges is that conscience, once developed, can only apply to the individual in question and not others.

This overall conception of conscience is very broad. It requires no substantive content and is instead largely process-based. It will cover a range of possible options both in terms of the moral principles which are necessary in order to claim conscience but also in how those principles apply in specific cases. Consequently, the scope of claims of conscience is very large. It can be contrasted with the scope of claims of conscientious objection, which is not large in the UK. As previously discussed, there are only two specific instances in the UK where an HCP can alter action on an explicit claim of conscientious objection. Those two instances are under the Abortion Act 1967[31] and the Human Fertilisation and Embryology Act 1990.[32] Courts have further argued that patients should not expect to be able to get anything they want[33] but have not explored the limits of the idea. Moreover, the courts discuss that idea only in the context of other broad legal rules such as "best interests".[34] The idea that doctors have some discretion in the provision of healthcare is not explicitly linked to claims of conscientious objection.[35] Conscientious objection, then, is limited and specific. Conscience, as defined here, is broad and pervasive. Additionally, conscientious objection only applies to an instance in which an individual objects to providing some behaviour that the individual would like to avoid. Conscience applies also in cases where the individual wishes to provide some behaviours that might otherwise be prohibited, such as the example previously of a doctor who wants to provide an abortion in a Catholic hospital which does not provide them. Conscience includes not just conscientious objections but also conscientious provisions. It would be wrong, however, to see conscientious objection as merely a subclass of claims of conscience. Conscientious objection does not always require proof of a moral claim.[36] Often, HCPs need simply to make a claim of conscientious objection but are not required to defend or even state that their objection is based upon moral reasons.[37] That they are not required is

30 See Smith, "Conscience, Clinical Judgement and Best Interests".
31 Section 4.
32 Section 38.
33 *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [2014] 1 A.C. 591, at [45], per Lady Hale; *R. (Burke) v General Medical Council* [2005] EWCA Civ 1003, [2006] Q.B. 273.
34 *Aintree* case, ibid.
35 *R. (Burke) v General Medical Council* [2005] EWCA Civ 1003, [2006] Q.B. 273.
36 See Stahl and Emanuel, "Physicians, Not Conscripts", p. 1380; C. Meyers and R.D. Woods, "An Obligation to Provide Abortion Services: What Happens When Physicians Refuse?" (1996) 22 Journal of Medical Ethics 115.
37 See Meyers and Woods, ibid.

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potentially based upon proof problems as well as other regulatory complications, but it is possible to claim a conscientious objection without having a moral objection. Finally, conscientious objection provides a legally enforceable right.[38] Conscience does not create an enforceable right as such. It may be that society decides to provide greater protection for conscience claims but, at the moment, HCPs cannot rely on a right of conscience to force medical treatment on patients or remove medical treatment which might otherwise be appropriate just on claims of conscience.[39]

Conscience should also be distinguished from clinical judgement. Clinical judgement involves claims by a doctor which are based on technical medical skill.[40] These are claims which rely on the expertise derived from medical knowledge, and we might therefore expect deference. Questions of clinical judgement are, for example, whether a drug will have a particular effect or whether a particular surgical method should be preferred over another in terms of effectiveness. Clinical judgement can be differentiated from conscience which involves claims based upon moral reasons for which doctors would not necessarily have any expertise.

The limits to conscientious objection are crucial. Conscientious objection can work in terms of healthcare regulation because its claims are limited. Since they only apply in very specific circumstances most healthcare decisions are not affected. For some, even these limited interferences with the healthcare of others is too much[41] but, for many, the limited nature of these claims is one of the reasons there are not significant objections.[42] Conscience since it is broad and pervasive could not be so limited. If claims of conscience created rights in the same way that conscientious objection has, then HCPs could use these claims to dictate treatment for patients in a much farther-ranging way. This has the potential to lead us back towards the days of physician rule over healthcare with patients' rights being quite limited. Even if we insist on patient autonomy, if doctors and other HCPs could simply refuse based on conscience, then patient choice could be limited to very few outcomes. Claims of conscience therefore cannot create

38 *Greater Glasgow Health Board v Doogan & Anor* [2014] UKSC 68, [2015] A.C. 640.

39 But see *R. (Burke) v General Medical Council* [2005] EWCA Civ 1003, [2006] Q.B. 273.

40 See Smith, "Conscience, Clinical Judgement and Best Interests".

41 J. Savulescu, "Conscientious Objection in Medicine" (2006) 332 British Medical Journal 294; J. Savulescu, "The Proper Place of Values in the Delivery of Medicine" (2007) 7 American Journal of Bioethics 21; U. Schuklenk and R. Smalling, "Why Medical Professionals Have No Moral Claim to Conscientious Objection Accommodation in Liberal Democracies" (2017) 43 Journal of Medical Ethics 234.

42 See e.g. M.R. Wicclair, "Conscientious Objection in Medicine" (2000) 14 Bioethics 205; D.P. Sulmasy, "What Is Conscience and Why Is Respect for it So Important?" (2008) 29 Theoretical Medicine and Bioethics 135; C. Cowley, "Conscientious Objection in Healthcare and the Duty to Refer" (2017) 43 Journal of Medical Ethics 207; J. Maclure and I. Dumont, "Selling Conscience Short: A Response to Schuklenk and Smalling on Conscientious Objections by Medical Professionals" (2017) 43 Journal of Medical Ethics 241; and X. Symons, "Two Conceptions of Conscience and the Problem of Conscientious Objection" (2017) 43 Journal of Medical Ethics 245. All of the above support claims of conscientious objection but only subject to limitations.

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rights in the way that conscientious objection does. The prime issue is deciding when the claims of conscience of the healthcare provider provide exclusionary reasons and when they do not. That is the focus of the next section.

III. Conscience and Responsibilities

Allowing a greater range for healthcare claims of conscience without unduly restricting patient choice is a fundamental issue for the regulation of conscience. If society wishes to allow conscience in healthcare decision-making, and protect it accordingly, then it needs to find a regulatory way of accommodating conscience while providing limitations and boundaries to the ways in which it might be used. This section will explore ways to do so.

Two possibilities which should be explored quickly but dismissed are limiting conscience claims either arbitrarily or by political lobbying. While both methods would provide a ready way to limit claims of conscience, neither would do so because of principle. Instead, decisions would be made based on either whim or which groups can muster sufficient political power to influence legislation. This is not to denigrate the use of politics and political lobbying within healthcare generally or over conscience. Conscientious objection exists in UK law at least partially because of political action. However, a lack of a principled basis would not allow for a comprehensive approach to conscience. Decisions on conscience would instead be piecemeal with little rhyme or reason to why practices were regulated in the ways they would be. A principled basis would allow for both a comprehensive as well as a coherent approach to conscience. This would have benefits not only for regulators but also for HCPs and patients, who would both be better able to determine in advance how conscience claims might relate to them.

Deciding on the principles to guide determination of conscience claims is difficult. One reasonable starting place is the definition of conscience and why it is worth protection. As discussed previously, conscience is an inward-looking moral choice about our behaviour. While this provides a rough and ready description of conscience, it does not provide us with much reason to accept claims of conscience as a reason for doing or not doing certain things, particularly when there is an external rule which specifies conduct. My own personal views do not provide a sufficient reason to allow me to engage in an action no matter how strongly I believe them. Simply because I believe, for example, that a specific group ought to be preferred over another is no reason to lend that view any credence. The reason that we support claims of conscience is because of their role in autonomy and personal integrity.[43] It is crucial to claims of moral responsibility that

43 See Neal and Fovargue, "Conscience and Agent-Integrity"; Maclure and Dumont, "Selling Conscience Short".

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we can claim authorship of decisions. They must be *our* decisions for us to be fully morally responsible for them.[44] One way we can be sure about this is to place a premium on autonomous decision-making. If our decisions are autonomous because they are made with sufficient information, without controlling influences and with capacity, then there is significant reason to believe we ought to be responsible for the consequences of those actions.[45] Autonomy allows us to claim the ownership necessary for responsibility to attach. Conscience is important in this process because of the role it plays (or at least can play) in our autonomous decisions.[46] Conscience provides the "inner voice" which helps us to determine whether the conduct in question is good or bad and whether we ought to do it.[47] It is effective only to the extent that we allow people to act consistently with their conscience-based decisions. If I cannot follow my conscience because an external force (as opposed to some internal failing) prohibits me from doing so, then the decision is less *mine* as a result. The same is true with personal integrity. Like autonomy, personal integrity is about our viewing ourselves as whole and consistent individuals. Integrity allows us to differentiate between those parts of us that we see as essentially *us* and those parts which are not. What integrity and autonomy do is to provide reasons to believe in the authenticity of ourselves. I am who I am because of the decisions I make, the actions I engage in (including those I fail to do) and especially those decisions and actions for which I claim authorship. Those are *me* in a way that not all decisions that I make may be.

Claims of conscience, consequently, are entitled to consideration based upon the idea of respect for persons. We show respect for the person *qua* individual when we allow them to make conscientious decisions in ethically difficult cases.[48] We are saying to them that they matter not just as entities with which we interact, but as thinking feeling beings in their own right. In Kantian terms, we treat them as capable of forming their own ends and not merely as means to our own ends.[49] This is why conscientious claims are allowed which are not widely held. It does not matter if others think that person wrong. What matters is that the *person claiming conscience* has a deeply felt belief. When we allow conscience claims, we tell those individuals that they matter, that we accept that their views might

44 See Smith, "A Bridge Too Far". We may still be legally responsible in certain cases even if we did not make an autonomous decision.

45 T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics*, 7th ed. (Oxford 2013), especially ch. 4.

46 The interaction between autonomy and conscience is beyond the scope of this article, but it is worth stressing that it is more complicated that it might initially appear. Not all claims of conscience would actually protect autonomy.

47 See Neal and Fovargue, "Conscience and Agent-Integrity", pp. 247–48 (discussing theories of conscience).

48 See Neal and Fovargue, ibid. See Maclure and Dumont, "Selling Conscience Short".

49 I. Kant, *Fundamental Principles of the Metaphysics of Morals*, tr. T.K. Abbot (Amherst, NY 1988), 56, 62.

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differ from ours, but that we nevertheless respect their decision and that they are entities worthy of respect.

A claim to respecting the worth of other persons must, however, be a universal claim. We must respect all persons not merely just some of them. To do otherwise is not to treat all individuals equally. If the respect that is due to all persons is given to some and not others, then it is not really persons as a philosophical class for whom we are having due regard. Instead, we are only showing the appropriate deference to those persons who have specific characteristics. Respect for persons as an ethical principle, however, is based upon the intrinsic worth of persons. This is where conscience claims without limitations begin to cause problems, as many of these claims necessitate a failure to be mindful of others. Others, patients for example, are treated not as individuals but as means to a conscientious end of the objecting practitioner. There is no acceptance that others might have different views and that those views are worthy of recognition. If an HCP decides that the view about a treatment the HCP takes is the only available view that matters, then the HCP is dismissing the views of patients and others as being unimportant. If not willing to accept that a patient might have different views and that their views ought to be considered, then the doctor in question is not respecting the other individuals. This, indeed, might be one of the concerns raised against the doctors in the *Glass v United Kingdom* case.[50] In that case, the medical team decided about the treatment of the patient without acknowledging the views of the patient's family or finding a way to resolve the dispute between the two parties which gave the family due respect.[51] They insisted upon their view of the nature of the treatment and insisted that the family comply. Had they found a more reasonable communication strategy and one that did consider the opinions and interests of the family, the case might have been avoided.

Moreover, there is also often no acceptance of responsibility for the person claiming conscience. The primary consequences fall not on them, but on other parties who have no responsibility for the claim of conscience[52] and ought not, therefore, to be responsible for it. This does not mean that HCPs might not see any consequences at all. However, the primary consequences of the action in question fall most heavily on the patient. For example, a doctor who refuses to treat same-sex couples may suffer backlash, either internally within their organisation or from members of the public. The primary consequence is the inability to receive healthcare and that primarily falls upon those within same-sex couples.

50 *Glass v United Kingdom* (Application no. 61827/00) (2004) 1 F.C.R. 553.

51 Ibid.

52 See Stahl and Emanuel, "Physicians, Not Conscripts", p. 1381. Stahl and Emanuel do not link the failure to accept consequences with a failure of respect for others although much of what they say would be consistent with that view.

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Those who wish to make conscience claims with primary consequences for others may object because the conscience claim is about them and not others. They may argue that any claim about what they can do is different from a claim that they do not respect others. In many cases, this is accurate. You do not need to abrogate your own moral reasoning to be mindful of other people. It is possible to argue that giving due deference to the rights and interests of others does not mean that you must abide by their moral reasons. You can reasonably disagree with someone while still showing regard for them. However, this will not always be accurate. In some cases, privileging one's own moral claims over the rights and interests and others does show a lack of respect. You must show due respect rather than just claiming to do so. If an individual is claiming that conscience's rights are prioritised over the rights of others in every case, if they insist that minimal or lesser harms to them are more important than more significant harms to others, or if they deny that their moral decisions have an impact at all upon others, then they are probably not showing adequate respect for other persons.

IV. What Conscientious Responsibility Might Look Like

If we accept that not all conscientious decisions ought to be approved, then we need to determine what the criteria should be for approval.[53] What should individuals do if they want their claims of conscience to be permitted? Presuming the claim of conscience is already sincere and deeply held, we should permit claims of conscience which correspond to the underlying principles of those claims. In other words, they need to show respect for others as moral actors. Furthermore, since a claim of conscience is focused on the conduct of the one making the claim, they ought to be willing to accept the consequences of that conduct. That provides us with three possible duties we might expect of those making a claim of conscience.

First, we ought to expect that those making a claim of conscience to exercise *humility* in their claims.[54] We ought to expect individuals making a claim of conscience to acknowledge that they may have made the wrong ethical decision and be willing to reconsider their claim in the light of further information. Additionally, humility would require that claimants accept that others may have different views. Humility requires that those seeking to

53 One important question that will not receive significant discussion in this article due to space limitations is the mechanism for determining societal approval. This article will presume that such approval would happen via a judicial determination after a full hearing, but there might be other methods which were as viable or even provide substantial benefits over a judicial model. A judicial model was chosen because it provides parallels to the actual *Charlie Gard* case which is the illustrative example. Nothing necessitates a judicial model as the only way society could assess whether claims of conscience ought to be approved.

54 Christopher Cowley makes a similar point, "Conscientious Objection in Healthcare", p. 211, although his view appears based on notions of moral pluralism rather than equal concern and respect.

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make a claim of conscience understand that their view is neither obviously correct nor accepted by everyone and, as such, can be subject to criticism. The importance of this as a duty is to increase the thoughtfulness of the claim of conscience. While a claim of conscience need not be based on thoughtful decision-making,[55] it ought to be subject to the possibility of deliberative thought. It does not require an argument that is reasonable to all, but it must be one which accepts our own moral limitations.

Acceptance of our own moral limitations may seem an unusual requirement since the point of conscience claims is to argue that one's moral code requires specific actions. Why should those who base their claim on the rightness of their own conduct need to accept the possibility that claim might be wrong? The reason this requirement is necessary is that it mirrors the one the person making a claim of conscience is asking others to make. Asking that one's claim of conscience ought to be respected is to claim, at least implicitly, that others ought to act with humility. If you are asking that I accept your claim of conscience in relation to withdrawing treatment from a terminally ill patient, you are asking me to accept that my own considered views about that practice might be incorrect or, at the very least, that there is scope for disagreement. Since I cannot guarantee that my own answer is correct, I ought to accept that others have different views and be willing to allow them the opportunity to live according to their own considered views. I am therefore being asked to accept humility in relation to my own views. If so, then those making a claim of conscience need to be willing likewise to accept the possibility that their views are incorrect.

One response to this requirement is that it disadvantages those with religious beliefs as those are less likely to be based upon provable facts. Indeed, it might be suggested that faith is the ability to believe despite reason and facts indicating the opposite. Those whose claims of conscience are based upon religious faith will not be able to satisfy this requirement as there is never any proof which could change their mind. There are two responses to such claims. The first is that the provision of further information need not be based only on empirical fact. Instead, further information could be the statements of a respected religious leader that modifies or changes statements of faith.[56] It could also be further religious study or some sort of divine sign. The question is whether there is any situation in which the individual's views would change. The second is that, for many, faith is not incompatible with reason or evidence.[57] Individuals

55 See e.g. J. Glover, "On Moral Nose" in J. Coggon, S. Chan, S. Holm and T. Kushner (eds.), *From Reason to Practice in Bioethics: An Anthology Dedicated to the Works of John Harris* (Manchester 2015).

56 See e.g. the encyclicals or apostolic constitutions which are written by the Pope in the Catholic faith.

57 See e.g. J. Locke, *An Essay Concerning Human Understanding*, bk. 4, ch. 18, where he indicates that even though faith comes from God, we should not believe things where the evidence indicates something else. See also John Paul II, *Fides Et Ratio* (1998) available at http://w2.vatican.va/content/john-paul-ii/en/encyclicals/documents/hf_jp-ii_enc_14091998_fides-et-ratio.html (accessed 15 August

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use reason when there is sufficient evidence to justify it but, when that is not available, issues became questions of faith. Faith is not a justification for overriding reason. That it is not provides an explanation for why we might be more sceptical of those claiming conscience not simply in the absence of evidence but in direct contradiction to it. This does not mean that the individuals in question must refrain from insisting that their decisions were based upon conscience. What it does mean is that these might be decisions of conscience society viewed to be due less deference because of their direct opposition to evidence and reason.

Secondly, in addition to humility we ought to require that claimants accept *universality* in their claims. This requirement is something close to the Kantian categorical imperative – claimants must be willing to accept that their claim of conscience is acceptable if it can be willed as a universal.[58] Additional clarity is required in what is meant "be willed as a universal". It does not mean claimants must be willing to accept that everyone could make the same decision. What it means instead is that claimants must be willing to accept detriments based on a similar-style claim. For example, let us presume that we have an HCP who wishes to continue to provide life-sustaining treatment to a patient even though that patient or their representative has requested that the HCP remove it. The universal claim is not that the HCP would be willing for all doctors to continue to provide treatments to patients in the same circumstances, a decision they might well accept. Instead, the claim is more general, as are the questions to be asked. Would the HCP agree with HCPs being able to override the decisions of patients or their representatives in relation to life-sustaining treatment? Would that HCP allow a doctor to remove a ventilator from a patient who continued to want one? Would the HCP be willing to allow a doctor to refuse to prescribe pain medication the patient wants because the doctor has a moral objection to those medications, believing that suffering is good for the soul? The purpose of the universality requirement is not to push a series of increasingly obscure hypotheticals on claimants, but to explore whether they are claiming their experience as special and not treating that of others similarly. It is to investigate whether they would be willing to extend the types of claims of conscience they wish to exercise to those with a different set of conscientious beliefs. In other words, are the claimants willing to grant to themselves a right they are not willing to grant to others? If so, that would provide sufficient reason to be wary of accepting the claim of conscience.

The universality requirement, as it is based on the Kantian categorical imperative, is subject to similar criticisms about how difficult "be willed

2019), which, although critical of certain philosophical approaches, does reiterate the use of philosophy along with faith in learning about the world.

58 See Kant, *Fundamental Principles*, p. 49.

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as a universal" can be to apply.[59] Even with the caveats listed above, the phrasing of the question is of crucial importance. Questions can be framed in narrow or expansive ways and differences in how the question is framed can have a substantial impact on the decision that is made.[60] For example, a question which asked "whether you would be willing to allow a medical expert to override a patient's family's views in relation to the removal of a ventilator" and one asking "whether you would be willing to allow a medical expert to override a patient's family's views in relation to the removal of life-sustaining treatment" may be referencing the same treatment option but the HCP may have very different answers to them. Parties may have concerns that how these hypothetical questions are worded gives too much leeway to judges or other decision-makers to shade or manipulate answers. While this is a problem for which there would need to be oversight, there are benefits to it as well. Using different questions can better focus what the actual controversy might be between parties. It may allow judges or other decision-makers better to flesh out both the disagreement and ways in which that disagreement can be resolved. So, while it is an issue that needs to be considered, it is not a bad thing.

Finally, we ought to expect individuals making a claim of conscience to exercise *reciprocal respect*.[61] By this what is meant is that the individual ought to take account not only of the possible effects of other individuals affected by the claim, but how those effects might be minimised, especially if others are likely to see those effects as detrimental. Questions to be asked include the following. Does the individual propose to offer an alternative service so that resources are freed for third parties to undertake the action the claimant wishes to avoid? For example, does the claimant HCP propose to take over some non-conscience raising duties of another practitioner so that the second practitioner can perform the objected-to treatment? What information does the claimant propose to provide the affected parties and when does the claimant propose to provide it? For example, when does the claimant propose telling the prospective patient the information about the availability of services that the claimant proposes to provide and how it will be provided (whether in writing or orally, and whether it will be

59 G.E.M. Anscombe, "Modern Moral Philosophy" (1958) 23 Philosophy 1, at 2.

60 Ibid. For a discussion of ways to avoid this problem in Kant's theory, see also I. Schumski, "The Problem of Relevant Descriptions and the Scope of Moral Principles" (2017) 25 European Journal of Philosophy 1588.

61 Fovargue and Neal have a similar expectation in relation to the duties owed by those making a claim of conscience as they indicate there should be a "general duty of respect", "In Good Conscience", pp. 233–34. While there is probably significant overlap between their general duty of respect and reciprocal respect as outlined here, there are probably also some significant differences in implication. Fovargue and Neal, for example, do not necessarily consider it appropriate for there to be a duty to refer or otherwise engage in actions which might seem to be "complicity", ibid., at pp. 239–41. However, under the view espoused here, it probably is contained within the duty of reciprocal respect. This is because the duty of reciprocal respect focuses on the other parties and what they should be entitled to receive rather than whether such entitlements interfere with the objecting person's integrity.

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presented in a neutral way)? The purpose of such questions is not to require that those making a claim of conscience have all the relevant answers, but to show they have given some thought to how they might protect the rights and interests of those affected by their claim of conscience. This is to make sure that claimants are willing to show others the kind of respect they are requesting of us. This requires persons making a claim to see others as persons and, as such, worthy of the same concern and respect that they are asking us to provide to them.

All of the above is more involved than what we currently require of those making a claim of conscience. That is by design. Making a claim of conscience should not be easy and should not be made lightly. It should be something which requires thought and reflection by the claimant not only of the claimant's own needs, wishes and desires, but of the needs, wishes and desires of those affected by the decision. It is not enough to claim that because the claimant is a person we ought to respect the claimant as such if the claimant is not willing to extend the same respect to others, especially those adversely affected by a decision not of their making. It should also require that a person making a claim of conscience be willing to accept that the inward-facing aspect of conscience means that any costs ought to fall, as much as possible, on the claimant rather than on others.

V. Application to the *Gard* Case

It is worth using an illustrative model case to explore whether the ideas above will be helpful in practice. The hypothetical used at the beginning of the article will not work because we do not have a definitive set of behaviours or intentions to examine. We will instead use the case on which the hypothetical is based. That case is the *Charlie Gard* case which reached the UK courts in 2017. It involved a young boy named Charlie Gard who was suffering from infantile onset encephalomyopathic mitochondrial DNA depletion syndrome (MDDS). Charlie was born at full term and at a "healthy weight" in August of 2016.[62] After the first few weeks, however, his parents noticed that he was less able to lift his head and support himself than newborns of a similar age. They then became concerned about his inability to gain weight. He then became lethargic and his breathing became shallow.[63] He was transferred from his GP to Great Ormond Street Hospital (GOSH) on 11 October where he remained throughout the proceedings. It was at GOSH where he was diagnosed with MDDS.

MDDS is a genetic disease which affects the gene necessary for the replication and maintenance of mitochondrial DNA and the repair of nuclear

62 *Great Ormond Street Hospital v Yates, et. al.* [2017] EWHC 972 (Fam), at [44].
63 Ibid., at para. [45].

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DNA.[64] As a result of the genetic mutations that he had, Charlie had "severe depletion of the amount of mitochondrial DNA in his tissues".[65] This meant that Charlie had congenital deafness, and a severe epilepsy disorder as well as progressive weakness of his muscles including his lungs, arms and legs.[66] He further had no signs of normal brain activity such as responsiveness, interaction or crying.[67] He was not able to open his eyes consistently enough to be able to see. He could not reach for things nor could he grasp them. He was dependent on a ventilator to breathe and had progressive respiratory failure. There does not appear to be a cure for MDDS nor did there appear to be any effective treatment for Charlie's condition.

Nevertheless, Charlie's parents attempted to find a way to help him. They found out about nucleoside treatment which has been used on patients with a less severe type of MDDS than Charlie suffered.[68] When contacted, a US doctor indicated that he thought it might "theoretically" have some benefit but that advice was based on only "scant evidence".[69] He further confirmed that nucleoside treatment had not been used on either mice or humans with Charlie's condition.[70] Further discussions among the experts confirmed that the treatment was very likely to have no effect at all and would not have an effect upon brain structures.[71] So, it would not help Charlie's brain damage and seizures and, according to the data was only likely to have a small effect on his life expectancy.[72] As a consequence, while the healthcare team at GOSH had initially been willing to try nucleoside treatment they decided that it would no longer be appropriate after Charlie's condition had deteriorated. They wished not to provide nucleoside treatment for Charlie, to be able to withdraw artificial ventilation and to provide only palliative care for him. Charlie's parents wanted the opportunity to take him to the US where he could have received nucleoside treatment.

The court case focused on the question of what treatment was in Charlie's best interests. Conscience plays no overt part of the discussion although there is some reference to ethics in the Supreme Court judgment.[73] Nevertheless, the judgment plays out entirely in terms of best interests and

64 Ibid., at para. [52].
65 Ibid.
66 Ibid., at paras. [53], [54], [58].
67 Ibid., at para. [58].
68 Ibid., at para. [71].
69 Ibid., at para. [74].
70 Ibid.
71 Ibid., at para. [90].
72 The High Court noted in the judgment that the experiments with mice with the less severe version of MDDS had only had an increase of "a little over 4% of normal lifespan", *Great Ormond Street Hospital v Yates, et. al.* [2017] EWHC 972 (Fam), at [102].
73 Judgment of the UK Supreme Court in the case of Charlie Gard, 19 June 2017, available at https://www.supremecourt.uk/cases/docs/charlie-gard-190617.pdf (accessed 15 August 2019). The statement about ethics, however, is simply in relation to continuing to treat Charlie after the judgments of the High Court and Court of Appeal that it was not in his best interests to do so.

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the Children Act 1989. However, it is possible to see the case in terms of conscience and to explore how the case might have developed if claims of conscience had been an option. To do so, it is first necessary to construct the argument for conscience and how it might be distinct from the best interests analysis. The best interests analysis centres on what treatment is best for the *patient* to *receive*. In Charlie Gard's case, the primary question was whether the nucleoside treatment that the parents wanted was something which would be in his best interests. Secondary questions involved whether it was in his best interests for medical treatment including ventilation to be withdrawn and whether he ought to be given only palliative care treatment. It involves weighing up the costs and the benefits of the proposed treatment and determining what, considering the alternatives available, is best for the patient under the circumstances. A claim of conscience, conversely, would have focused on what the *HCPs* felt able to *provide*. It thus would have focused on their moral reasons for why they thought the interventions were inappropriate. This would have likely centred on the questions about whether Charlie was in pain and thus the treatment violated their ethical duty of non-maleficence. They might also have noted that they did not believe that the treatment would cure or improve Charlie's condition and thus did not satisfy their duty of beneficence.[74] HCPs might also have stated that providing this treatment to Charlie would likely have resource implications, if not in actual financial costs but in terms of the healthcare team's time and hospital resources such as the continued use of the ventilator, hospital bed and other facilities. Those implications might have violated the ethical duty of justice as those resources were being spent in a way that did not provide sufficient benefits to relevant parties. If they were not principlists, the healthcare team might have argued on the basis of utility if they were utilitarians. Alternatively, they might have argued that providing treatment to Charlie which did not hold a chance of recovery did not allow them to care for Charlie in the way that complied with their ethical views.

It is also useful to distinguish how this claim of conscience would be different from a claim of clinical judgement.

Before exploring the role that responsibilities might play in the evaluation, it is worth highlighting one of the benefits of using conscience as an alternative for best interests as the central issue in the case. If the focus is on the "best interests" of the patient, then cases frequently involve an almost binary choice between the family and the healthcare team. As such, it is unlikely that the courts, as decision-maker, are ever likely to find a decision which pleases all of the parties. Instead, they are usually left to choose between two options presented by the parties with one decision specifically indicated as "best". Thus, there is a definite "loser" in the

74 Since the duty of beneficence is the duty to help others, including patients, it would not have violated that duty either. See Beauchamp and Childress, *Principles of Biomedical Ethics*, ch. 6.

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case. However, if the focus was on conscience, then the question becomes what is appropriate for this particular medical team to provide. It would not, however, forestall parties from finding another arrangement. For example, in the *Charlie Gard* case, if the decision was made that it was inappropriate for the medical team to participate in the treatment for Charlie Gard, this would not preclude the ability of Charlie's parents to find another doctor who did not have the moral problems with the treatment that the team at GOSH had. A "best interests" analysis could still have occurred at some point, but it might have involved a discussion that was not centred on diametrically opposed positions but instead focused on the parties working together with the court to decide upon a treatment plan which was acceptable to all of them – the healthcare team, his parents and Charlie himself.

Even if using conscience in this way reduces the possibility of acrimonious cases, that does not mean that those arguing conscience should not face real scrutiny in terms of the responsibilities outlined above. The *Charlie Gard* case provides an opportunity to see how the scrutiny might progress. While it is not possible to make firm determinations as to whether the hypothetical case for conscience would succeed on these grounds because of a lack of evidence,[75] using conscience in this way can show what kinds of questions will need to be addressed and how that might happen. The first requirement or responsibility is humility, and the healthcare team would have to show that they are willing to accept that there is the possibility that their position might be incorrect. We do have some evidence that the doctors would have been able to satisfy this requirement. They investigated the nucleoside treatment when it was brought up by the parents. This included what appear to be significant discussions with the US doctor involved. Moreover, these discussions continued during the case. While it is true that these discussions just seemed to have confirmed the opinion of the healthcare team that the treatment was not appropriate, their investigation is good evidence that, had the information they received been different, it is likely their decision would have been different as well. They also continued to do additional scans of Charlie which would indicate that they were at least open to the idea of new information. This new information could have opened several fronts in relation to Charlie. It could have shown that there might be some cause to believe improvement would have been possible. There might have been evidence to show that he was not in any pain – a question which is important but which no party really was able to answer in the case.

We can contrast the potential responses in the *Charlie Gard* case to the one presented to the court by the healthcare team in *Aintree v James*.[76] In

75 The evidence is not available because the questions that would need to be answered were not posed to the parties. It is not a case that they could not be answered, but they are not answered on the record which exists of the case.

76 *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [2014] 1 A.C. 591.

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this case, the patient was in declining health due to complications from a stoma. The patient, David James, lacked capacity and the healthcare team was worried about being required to provide certain treatments to him. These treatments included cardiopulmonary resuscitation (CPR), invasive circulatory support and renal replacement therapy.[77] The renal replacement therapy was of particular concern because it was possible that the patient was going to have to undergo this treatment for 24 hours a day seven days a week. Despite this, David appeared to be quite happy. He seemed to enjoy visits from family and friends, looking at the newspaper, listening to music and there is even testimony about jokes he made while in hospital.[78] The question was whether he ought to receive the specified treatments and, for our purposes, the crucial question involved the renal replacement therapy which the healthcare team did not want to provide. One of the doctors was asked in testimony if his decision would change if David James was able to tell them his preferences and specifically indicated he wanted to stay alive.[79] The doctor indicated that it would not.[80] This is evidence that no matter what further information they were provided, the healthcare team was unlikely to change their mind. Conversely, in the *Charlie Gard* case, the healthcare team appears to have continued to approach the case with an open mind. While further investigation would be required, from the evidence available, it looks likely that the healthcare team would have been able to show sufficient humility.

The second requirement is universality. As noted above, this is not a claim that the healthcare team would be willing to accept the same specific case on the other side, but that they would be willing to accept the general category of behaviour from everyone. There are two possible ways that the relevant issues in the case can be generalised: (1) by asking whether the doctors would be willing to let a healthcare team decide the treatment for their own child in a case where an experimental alternative option were available and in which they disagreed with the team's treatment preferences, or (2) by asking whether they would be willing to accept a general rule where healthcare teams are not required to act in situations where it violates strong moral principles they have. Again, as these questions were not posed to the healthcare team, we cannot know what their answers would have been. However, it is more likely that they would have agreed with the second formulation rather than the first. The second version, on the one hand, is, in some ways, simply a restatement of what a claim of conscience is. The first, on the other hand, requires an individual to turn over decision-making for their child to someone who might have expertise in

77 Ibid.
78 Ibid.
79 *Aintree Universal Hospitals NHS Foundation Trust v James* [2013] EWCA Civ 65, [2013] 4 All E.R. 67, at [19].
80 Ibid.

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certain areas but also has different views about treatment options from those the individual has. Putting these two questions to the healthcare team, however, can provide further specification as to what the conscience claim is. Taking the second question as being acceptable, it provides a reason to grant a claim of conscience in terms of being required to provide the nucleoside treatment to Charlie. It does not, however, provide a reason to grant a claim of conscience in relation to being able to prohibit Charlie's parents from seeking treatment elsewhere. In other words, the healthcare team could reasonably claim that they ought to be allowed to refuse to treat Charlie in the way that the parents wanted but they could not reasonably claim that Charlie could not be treated by anyone else. This further specification of the conscience claim might have afforded an opportunity to provide a reasonable accommodation of all sides. It does not resolve the entirety of the problem because there was the question of medical treatment of Charlie during the period of seeking help from the US doctor and any transfer of Charlie to the US for the treatment the US doctor might have provided. It does provide, though, a more limited disagreement to resolve.

The final requirement for a claim of conscience under the model presented here is reciprocal respect. This requires the individuals claiming conscience to be able to show they have thought about ways to minimise adverse effects on other individuals. The primary other individuals in question are Charlie himself and his parents. They are not the only ones, however, and the healthcare team would also need to consider other members of the team who do not want to make claims of conscience as well as other colleagues in the hospital who may have to cover Charlie's care if their claims are upheld.[81] Their doing so would increase the number of individuals the healthcare team should consider but there are some easy answers to at least the concerns related to their colleagues. If one of the concerns involved increased workload for those not claiming conscience, then those claiming conscience could agree to mechanisms which would redress the balance. This might include, for example, switching shifts or duties with those who would have to now cover the additional work that may be required as a result of the claim of conscience. Similarly, they could agree to take on additional tasks designed to make the jobs of those having to cover the responsibilities they otherwise would have had. This would be subject to hospital policies as well as general employment law but neither of these seems to pose an insurmountable initial problem. Taking account

81 An additional group which may need to be considered is that of other patients. Continuing to treat Charlie reduces the time available to treat other patients and limits the availability of existing physical resources (hospital bed, equipment, etc.). The extent to which this group would need to be considered would depend on how immediate such concerns are. If there is a patient immediately waiting for the bed, that would be a more pressing concern – and thus one that ought to be more central to the discussion – than if the next patient is only a theoretical possibility at the time of decision. In general, though, other patients are likely to have only a minimal impact upon the decisions made.

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of the parents' interests also may not initially seem that difficult. The healthcare team could simply agree that, while they will not provide the requested treatment to Charlie, neither will they stand in his way should the parents wish to seek treatment elsewhere. In the case at hand, there did appear to be a doctor willing at least to consider further treatment for Charlie; so, this would not have been a significant issue. Financial implications also would not be an issue as the parents had crowdfunded money sufficient to cover the cost of treatment. This would be more difficult if either there was not an available doctor or there was insufficient funding to make a potentially available doctor a viable option. If there is no available HCP willing to take over treatment (or provide the treatment patients or families request) then courts or other decision-makers will need to drill down to what might be reasonable to expect on the part of the family. If this were the standard treatment then HCPs might be expected to do more to ensure that the treatment is available than if the treatment option were experimental.

Charlie's situation, however, could pose problems in terms of reciprocal respect. To start with, it is not clear what reciprocal respect might mean in relation to Charlie. Because he cannot communicate and has never expressed any preferences, it is not possible to know what his beliefs or interests might be. We do have statements of his parents' preferences on his behalf, but neither we nor they can actually guarantee that these correspond with what Charlie himself would want. We do not know, for example, if Charlie would want to try the experimental treatment or not. Moreover, speculating about his likely interests is also difficult as some of the underlying facts were not clear. It was unclear whether he was in significant pain, for example. Consequently, it may be difficult for healthcare team members to be able to show the requisite amount of reciprocal respect for Charlie if they cannot be certain what that might entail. In response, reciprocal respect cannot require more of people than they can give. So, the healthcare team could only make decisions based on the best evidence that they have. If the best evidence they have, indicates that Charlie is in significant pain, then they ought to work on that premise even if, in reality, Charlie did not feel pain. What is to be done might require dispute resolution as to what the best evidence actually is and what it indicates, but the dispute is of a type that courts are able to resolve. Additionally, there is nothing to stop the healthcare team from acting on the basis of conditional statements. They might conclude that, for example, if Charlie is in significant pain, they will engage in X, whereas if he is not, then Y is a more appropriate response. Furthermore, the reciprocal respect requirement does not necessitate that individuals claiming conscience have detailed plans in place to cover every eventuality. It is designed instead to show that the individual wishing to claim conscience has given sufficient and serious thought to how that claim of conscience might negatively affect other people and

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how negative effects might be minimised. In this case, that may mean allowing Charlie to go the US for nucleoside treatment but, conversely, it may mean something else depending on the available evidence.

This illustrative example shows that there could be significant benefits from using claims of conscience in cases such as that of Charlie Gard. First, allowing claims of conscience may provide at least one way to reduce acrimony in these difficult moral cases. As noted above, there is some anecdotal evidence from the *Ms. B* and *Re A (conjoined twins)* cases that patients are sympathetic to moral objections HCPs might make to treatment. In *Ms. B*, she indicated that she understood a doctor not wanting to remove ventilation and was willing to allow a doctor to act on that position provided the doctor was willing to allow her to find a doctor who would satisfy her wishes. In *Re A*, reports indicate that the parties were able to keep open lines of communication despite their deep moral disagreement about what ought to happen to the twins.[82] These cases can be contrasted with cases like *Glass* where, despite using only the language of best interests and clinical judgement, the parties had an extremely acrimonious relationship based partially on the insistence of the HCPs as to what was "best" for the patient.[83] This does not mean that every case would align as these do. For some, the focus on the moral decisions of the doctors would not lead to less acrimony, but it does appear that there is at least some initial evidence that it would be of benefit to some patients. This is a substantial benefit as the relationship between patients and their families on one hand and doctors and other HCPs on the other is of prime importance. If HCPs can maintain good relationships with patients and their families, they can work towards common goals much more effectively. It would also reduce stress and friction in what is often a difficult time and may reduce the cases that come to court.[84] It could do this by providing ingrained reasons to use a more collaborative framework for decision-making between healthcare teams, patients and families. The responsibilities required for a claim of conscience not only seek to increase communication but empathy between the parties as well. HCPs, in exercising reciprocal respect, will need to have not only a good understanding of the interests of other individuals involved in the healthcare decision but be able to articulate how they can best protect those interests while maintaining their claim of conscience. The requirement for universality will require that the HCPs put themselves in the place of the patient or family not just in terms of medical benefits, but also in the way they react to the claims of conscience of others. Exercising humility will also have important benefits

82 *Re B (adult: refusal of medical treatment)* [2002] EWHC 429 (Fam), [2002] 2 All E.R. 449; *Re A (Children) (conjoined twins: surgical separation)* [2000] EWCA Civ 254, [2001] Fam. 147.

83 *Glass v United Kingdom* (Application no. 61827/00) (2004) 1 F.C.R. 553.

84 For example, a lack of communication and inability mutually to respect each other's viewpoints seems to be one of the prime reasons for the significant disagreements between the parties in *Glass*, ibid.

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of making sure that HCPs and others claiming conscience maintain an open mind about the available evidence. Using this version of claims of conscience and the attendant responsibilities could thus have a very beneficial effect of avoiding contested litigation in the first place. Additionally, it is possible to do this within the existing structures for medical decision-making. In other words, the necessary communication could take place within the informal discussions between parties which happen at the bedside, in the more formalised mediations which occur in difficult situations or in the courts if judicial recourse is necessary. The change required is not with the structures used to make these decisions but the questions which get asked when using these structures.

Secondly, allowing claims of conscience may allow us to reframe and focus the disagreements which continue to exist between parties. It may help the parties to note specifically where they disagree and to do so in language which may be less emotionally loaded. Here, the requirement for universality might be especially important as the ways to test the universality of the individual's claim of conscience help to narrow and refine discussions from the more general on "best interests" to those more focused on specific conduct. Thirdly, the reciprocal respect requirement allows for the creation of a more positive collaborative treatment. Since the party claiming conscience is required to provide evidence that they have thought about ways to minimise the adverse effects on the other parties, this provides an impetus for parties to work towards a shared mutually agreeable resolution. Even if it does not, it still provides an impetus for the HCP claiming conscience to attempt to understand the position of the other parties such as patients and the family to be better able to answer how they will minimise problems those parties may face as a result of the claim of conscience. Fourthly, it may provide an opportunity to broaden the scope of discussions to see the effects claims of conscience have on individuals who might be more tangentially related to the case in issue. They would include other colleagues or members of the healthcare team. Their inclusion's effect should not be overstated, however. While we ought to consider what effect claims of conscience might have on, say, the colleague forced to pick up additional duties because a doctor has made a claim of conscience, these are rarely going to be so substantial that they would override the concerns and issues of more central figures such as the patient. Even so, some consideration of the role more tangential people play is a good thing. Again, this can all be done using the existing structures for decision-making but changing the focus towards one which highlights and attempts to resolve the difficult issues in another way.

There are costs to allowing claims of conscience as well. First, allowing claims of conscience in the way envisioned in this article will not be easier than the current system if they do have to go to an external decision-maker like a court. Exploring different options to allow a claim of conscience and

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the number of additional elements would make for a more complex system. HCPs would have to think much more carefully about their moral reasoning and consider things they might not have previously (such as how to reduce adverse effects on other individuals). Complexity, however, is only a bad thing if it does not provide counter-balancing benefits. The benefits listed above, in addition to the fact that the use of claims of conscience will also be a more accurate reflection of the actual reasoning process, should counter-balance the complexity of the process. Secondly, the benefits of this process will only accrue if those engaged in the process actually participate in it fully. If, for example, doctors use the process merely to forestall arguments with patients about treatment decisions, or judges do not interrogate HCPs about the universality or humility of their claims but simply defer to them, then those benefits will not exist. Instead, the process would simply be another way in which doctors and HCPs could maintain power over patients. The problem can be overcome by reinforcing the role that judges and other gatekeepers should be taking and by emphasising their role in ensuring the rights and interests of all involved.

VI. Conclusion

While conscience is an important part of our decision-making process, we need not accept all claims of conscience made by individuals. Instead, we ought only to accept those claims made which enhance the underlying foundations of why we support conscience claims in the first place. Primarily, the reason to respect the claim of conscience of an individual is because it is an important part of showing respect for the individual as a person. We ought, therefore, to accept only claims of conscience which support those aims. This means that claims which do not adequately take account of the interests, wishes, desires and rights of others ought to be suspect and not supported either ethically or legally. In order to ensure individuals take adequate account of others when making a claim of conscience, we ought to require that claims be made with humility and universality and subject to reciprocal respect.[85] If individuals cannot show that they have acknowledged their own fallibility in making the claim, cannot show that they would be willing to accept the claim as universal, or cannot show that they have thought about ways to lessen the detrimental effects on others, then the claim is not one which ought to be considered worthy of respect.

Accept that responsibilities ought to be part of our analysis of claims of conscience will not make such claims easier to determine. The more complicated analysis detailed above will require more time and energy not just from HCPs but also from whoever is evaluating these determinations, including the courts. The benefits of such an analysis then are not

85 For a different list of possible duties, see Fovargue and Neal, "In Good Conscience".

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expediential. From the analysis, however, we will derive benefits in terms of its quality. It will benefit not only HCPs, who might now be able to make claims of conscience in broader circumstances than they could before. Additionally, it will provide more protection for patients and other members of society because these claims can be evaluated using the existing dispute resolution systems such as informal discussions, formal mediation or judicial recourse, with the result that, while their scope is broadened, we limit the use of claims of conscience to cases which are truly deserving. This analysis will further help to bring claims of conscience into the cold light of day, where their place within normal, everyday decision-making by HCPs can be subject to better scrutiny. This, in turn, might lead to more honest and fruitful conversations between HCPs and patients about when these claims arise, and attempts might be made to find suitable compromises without involving third-party decision-makers like the courts.

We can see the various benefits if we return to the hypothetical with which we started. If the case arose in a jurisdiction for which you could claim conscience under the model I have suggested, it may provide a way to resolve a dilemma. Instead of resorting to the crude legal determination of "best interests", you could have a discussion with the parents about your claim of conscience. This would involve you not only discussing why you had objections to the treatment the parents wished to provide to their child but how you might effectively deal with the disagreement. You could, for example, provide a clear steer to the parents what evidence was necessary to get you to change your mind. You could further discuss how you empathise with them and the situation in which they find themselves but that you could not, in good conscience, provide treatment in the current case. However, in your discussions, you could also highlight how you can minimise any adverse effect on them. Doing so might include, for example, allowing them to seek treatment elsewhere, or there may be other treatments on which you both can agree while you resolve the current controversy. The issue may not be resolved completely, and you may still have to go to court to have an official determination. But, even then, it may be that the further discussions which have happened with the parents reduce the animosity and allow the court to focus more directly on the specific disagreements. The more collaborative decision-making would then not only provide better results in terms of patient care, but also in terms of protecting the rights and interests of all involved in the treatment of individuals in these difficult moral cases.

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