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Consequentialism and the Law in Medicine

Professor Julian Savulescu and Professor Dominic Wilkinson

Overview

There are two broad schools of ethical theory: consequentialism and non-consequentialism.

According to consequentialism, the right act is that act which has the best consequences. According to non-consequentialism, the rightness of an action is not solely determined by its consequences. (Though, most versions of non-consequentialism allow some ethical relevance of consequences). The most famous version of non-consequentialism is deontology, which holds that one has an absolute duty to obey certain rules. “Never kill an innocent person” or “never lie” are examples of such rules. Christianity is one form of deontology and the Ten Commandments represent one set of rules.

Medical law exists at the intersection between consequentialism and deontology. Much of medical law is consequentialist in nature. However, having evolved from a set of Christian values and principles, it retains certain deontological characteristics. In particular, it retains a commitment in many jurisdictions to the Sanctity of Life Doctrine, though this is being shed or modified as assisted dying becomes legalised.

In this chapter, we will begin by defining consequentialism, and contrasting it with deontology. We will describe some examples of the influence of consequentialism over current medical law. We will close by outlining the areas where consequentialism is at odds with current medical law and how medical law should evolve according to consequentialism.

Consequentialism

Consequentialism is a theory of right action. It instructs the agent to outline all the possible actions, including doing nothing at all. One must then assign a value to the possible outcomes of each action, and a probability for each of these outcomes occurring. The expected value of each action is the sum of the value of the outcomes of each action, where each value is multiplied by the probability of it eventuating. The agent should choose that act with the greatest expected value.

There are two key components to consequentialism:

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1. **probability** of outcomes occurring. These should be based on the best evidence available. Thus, consequentialism sits naturally with scientific approaches to medicine and evidence-based medicine.
2. the **value** of the outcomes. This is a distinctively ethical evaluation of the good.

Consequentialism is a broad school of ethical theory. There are many different forms of consequentialism depending on how one values outcomes. For example, welfare consequentialism, or welfarism, maintains that all that matters or is good is welfare, or well-being. The right act is the act which maximises well-being.

Utilitarianism is a version of welfare consequentialism. It instructs the agent to choose the action which maximises utility. Utility has traditionally been defined in terms of either happiness or preference satisfaction (though there are other versions).

According to Hedonistic Utilitarianism, the right act is the act which maximises happiness or pleasure. According to Preference Utilitarianism, the right act is the one which maximises preference satisfaction.

The goal of medicine has traditionally been the promotion of health. The goals of medicine are thus consequentialist: maximising health. But this has evolved over the last decades to include well-being. The goal of medicine is to promote the best interests of the patient. For example, in a recent judgement, Justice Francis said, "The term "best interests" encompasses medical, emotional, and all other welfare issues."¹

The "best interests" principle of medicine is essentially a part of welfare consequentialism. And when it comes to groups of patients - resource allocation or public health - medicine is explicitly welfare consequentialist. It aims to bring about the greatest improvement well-being for the whole population, as we shall see.

Act and Rule Consequentialism

There are two different ways of evaluating consequences. According to act consequentialism, the right act is the act which produces the best consequences. According to rule consequentialism, the right rule is the rule which produces the best consequences. The law is in many instances an instantiation of rule consequentialism: laws are chosen because they bring about the best consequences. When governments are contemplating whether or not to change the law, evidence about the potential impact of the law (in terms of risks and harms) is highly important. This is clearly consequentialist.

These versions of consequentialism can come apart. Sometime an act will clearly have better consequences, or no adverse consequences but a rule proscribes that act. As an example, in 2017, a transplant surgeon was found guilty of "assault by beating" for using an argon beam laser to draw his initials in two cases on the under-surface of a liver that he was transplanting². In this case, there was clear evidence that marking the initials had no medical effect on the patients whatsoever. The surgeon's actions had not caused any harm to the patients concerned. Nevertheless, there may be good reasons to, in general, prohibit doctors from taking advantage of their patients while unconscious to make personal markings on the inside of their bodies. That could lead to harm in other cases, or could lead to patients losing trust in health professionals. Principles or laws around non-discrimination are other examples. For example, one example would be not considering social worth criteria (eg whether someone is a criminal, or has dependents, etc) in the allocation of resources, including doctors' time. Some have argued, for example, that in a disaster setting, victims of a terrorist attack should be prioritized over the perpetrators³. It might be clear that in a particular case, deprioritising a terrorist in the emergency room will

1 *Re A (Medical Treatment: Male Sterilisation)* [2000] 1 FLR 549, (2000) 1 FCR 193

2 Clare Dyer, "'Arrogant" surgeon fined for writing his initials on patients' livers' (2018) *BMJ*360:k200 < Available at: <https://www.bmj.com/content/360/bmj.k200>> accessed 24 April 2018 PubMed PMID: 29335240.

3 A Gold, RD Straus, 'Second thoughts about who is first: the medical triage of violent perpetrators and their victims' (2016) *JME*43(5):293-300

maximise short term utility, but such a practice may well lead to worse consequences in the long term (see slippery slope arguments).

Two Level Consequentialism

The two different schools of consequentialism can be combined. Famous utilitarian Richard Hare described a two-level approach⁴. Hare argued that moral thinking occurs at two levels: intuitive and critical. At the intuitive level, we have many rough rules of thumb that can be rapidly deployed without protracted and demanding reflection: don't kill, don't steal, be honest, etc these enable us to act efficiently in everyday life.

However, at times these conflict or situations are more complex and we must rise to the more reflective and deliberative critical level and ask what kinds of rules or principles should we endorse? What really is the right answer. Here, he argues, we should employ act utilitarianism (this corresponds to system 1 and 2 thinking in psychology⁵).

If medical law were to adopt this approach, that might allow a more coherent response to exceptional cases – see, for example, the case of Jodie and Mary below.

Autonomy

Besides aiming to promote the best interests of the patient (maximizing welfare or well-being), modern medicine aims to respect the autonomy of the patient. This is encapsulated in the need to obtain valid consent for any medical procedure. In the precedent-setting case of *Schloendorff v New York Hospital*,⁶ Justice Cardozo observed that '[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body.'⁷

This might appear to be a deontological, non-consequentialist element to the law. The very strong emphasis on the importance of consent, seems to conflict with welfare consequentialism. For example, occasionally during an operation surgeons may find something unrelated to the procedure, perhaps a tumour or a blood vessel aneurysm. In those circumstances, there may be good reason to think that it would be best for the patient to address the incidental finding (eg by biopsying a tumour or clipping an aneurysm); this would be in the patient's best interests. It would save the patient having to have a separate operation. However, if the surgeon hasn't discussed this possibility with the patient beforehand (and if it isn't urgent to intervene), additional procedures would appear to be a breach of patient autonomy. In other situations, patients refuse medical treatment that would be in their best interests. A patient might, for example, refuse a blood transfusion because they have a fear of needles, or refuse antibiotics because they believe in the power of prayer to heal them. Doctors are legally obliged to respect those decisions, as long as the patient has capacity, even if withholding treatment would lead to serious harm, even the death of the patient.

A rule consequentialist might endorse patient autonomy for epistemic reasons. In general, people know their own circumstances better than others do. It might be thought that the patient is better placed than the doctor to know what would be best for them. However, there are going to be situations (for example, those described above) where there is good reason to believe that the patient is mistaken about their own interests. Surely, the consequentialist should then believe that the patient's decision should not be respected?

4 RM Hare, 'Moral Thinking: Its Levels, Method and Point' (Clarendon Press 1981)

5 Daniel Kahneman, *Thinking fast and slow* (Farrar, Straus and Giroux 2011)

6 *SCHLOENDORFF V. NEW YORK HOSPITAL* [1914] 211 NY 125 [1914]

7 *SCHLOENDORFF V. NEW YORK HOSPITAL* (n6)[129-30]

Perhaps surprisingly, respect for patient autonomy in medical law sits very comfortably with the arguments of one famous utilitarian, John Stuart Mill.

Mill was a hedonistic utilitarian. Mill claimed that "...pleasure, and freedom from pain, are the only things desirable as ends"⁸.

However, Mill accorded great importance to individuality and originality.

"He who lets the world, or his own portion of it, choose his plan of life for him, has no need of any other faculty than the ape-like one of imitation. He who chooses his plan for himself, employs all his faculties. He must use observation to see, reasoning and judgement to foresee, activity to gather materials for decision, discrimination to decide, and when he has decided, firmness and self-control to hold to his deliberate decision ... It is possible that he might be guided in some good path, and kept out of harm's way, without any of these things. But what will be his comparative worth as a human being? It really is of importance, not only what men do, but what manner of men they are that do it. Among the works of man, which human life is rightly employed in perfecting and beautifying, the first in importance is surely man himself."⁹

"... individuality is the same thing with development, and ... it is only the cultivation of individuality which produces, or can produce, well-developed humans ..."¹⁰

This quote comes from the chapter from *On Liberty* entitled, "Of Individuality, as One of the Elements of Well-Being." Mill clearly believes that individuality is one of the goods of life. The value of individuality for Mill is intrinsic. For although a person may "be guided in some good path", that is, achieve good, something very important will be lacking: that life will not be his own.

*"If a person possesses any tolerable amount of common sense and experience, his own mode of laying out his existence is the best, not because it is the best in itself, but because it is his own mode."*¹¹ (Italics ours.)

Mill calls "individuality" what we call "autonomy." He attaches such importance to it that he believes it ought only be obstructed in a few very special circumstances (when it results in harm to others - harm to self is not sufficient).

While Mill did not write on either medical law or ethics, it would seem that giving priority to autonomy in promoting well-being would be entirely consistent with his influential approach to utilitarianism.

Such an approach also supports modern changes to the doctor patient relationship. While the old paternalistic model involved doctors imposing their value judgement of what is in the best interests of the patient, modern conceptions such as shared decision making [cite] or liberal rationalism (cite) take seriously the patient's own values in arriving at what is best for the patient.

The law has gradually come adopt this Millian perspective. In recent years, medical law has moved away from the paternalistic Bolam standard¹², which involved disclosing risks to patients according what a reasonable body

8 JS Mill, *On Liberty*. (J. M. Dent and Sons; 1910.) 6.

9 Ibid, 117

10 Ibid, 121

11 Ibid, 125

12 *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 583

of medical practitioners would disclose, to a more person-centred approach. The Supreme Court in the UK in its 'Montgomery' judgment¹³ ruled that clinicians must enter into 'dialogue' with their patient to achieve sufficient understanding of the advantages and disadvantages of the options available to make a choice that '...take(s) into account her own values...'¹⁴. This follows similar decisions in Australia¹⁵

This Millian approach, which might be called liberal welfarist consequentialism, has two values or two factors: liberty and well-being. It is important to enable the patient to both make their own decision and to promote their well-being. It is consistent with the strong emphasis on the principles of autonomy and beneficence in medical ethics. (The principle of distributive justice, which also features in the oft-cited 'four principles' of medical ethics¹⁶, might be partly understood to incorporate Mill's concept of harm to others as limiting individual freedom to choose).

Importantly, sometimes there might be large discrepancies in the values of liberty and wellbeing. For example, some intervention may minimally promote well-being but significantly promote freedom and autonomy. Some cases of sterilisation or contraception or abortion may fit this category (though clearly in many cases such procedures do promote the interests of the patient). They would still be justified on a liberal welfarist consequentialist approach.¹⁷

In some cases, freedom or autonomy are not significantly at issue - such as when patients have impaired decision making capacity. In those cases, the patient's best interests (welfare) should purely be promoted. However, courts in recent decisions have emphasized that the patient's prior wishes should be given considerable weight in a best interests determination.¹⁸

Acts and Omissions

Consequentialist care only about the consequences, not how they were brought about. This often caricatured by the phrase "The end justifies the means".

Importantly consequentialists see no morally relevant differences between acting and omitting to act, if that would result in the same outcome. James Rachels famously provided the case of Smith and Jones:

Smith stands to inherit a lot of money if his four-year-old cousin dies. He sneaks into the bathroom of his cousin and drowns him, arranging things so that it will look like an accident.

Jones also stands to gain a similar large inheritance from the death of his four-year-old cousin. Like Smith, Jones sneaks into the bathroom with the intention of drowning his cousin. The cousin, however, accidentally slips and knocks his head. He falls face down into the bath, struggles but drowns all by himself in the bath. Jones could easily have saved his cousin, but far from trying to save him, he stands ready to push the child's head back under if this becomes necessary. However, it is not necessary¹⁹.

13 *Montgomery v Lanarkshire Health Board* [2015] UKSC 11

14 *Montgomery v Lanarkshire Health Board* (n13) 115

15 *Rogers v Whitaker* [1992] HCA 58; 175 CLR 479

16 Tom Beachamp. and James Childress. *Principles of Biomedical Ethics*. (Oxford University Press; 1979.)

17 J Savulescu, 'Autonomy, the Good Life, and Controversial Choices' in R.Rhodes, L.P.Francis, and A.Silvers (eds) *The Blackwell Guide to Medical Ethics* eds. (Blackwell Publishing 2007) 17 – 37

18 *Briggs v Briggs* [2016] EWCOP 48

19 James Rachels. 'Active and Passive Euthanasia.' (1975;) *NEJM*.292:78–80. PubMed PMID: 1109443.

Smith acted; Jones omitted to act. From a moral point of view, Rachels argues that Smith and Jones are equally blameworthy. From a consequentialist point of view, their act or omission is equally wrong. However, the law would not necessarily see it that way.

In medicine, the difference between acts and omissions appears to have strong relevance to decisions about either withholding (not starting) or withdrawing (stopping) treatment. Doctors frequently believe there is a moral difference between withholding and withdrawing life prolonging medical treatment²⁰. Withholding is seen as an omission, while withdrawing is more of an action. It is seen by doctors and by some families to be more acceptable to withhold than to withdraw. This has the consequence that trials of treatment are not started and sometimes patients are not given a chance to benefit, when the chances are small. It also means that sometimes treatment is prolonged for a long period of time, because once started it cannot be stopped.

Consequentialists reject any distinction between withholding and withdrawing treatment. If it would be ethical to withhold treatment, all other things being equal it must be ethical to withdraw treatment (if that treatment had already been started. Conversely, if it would be wrong to withdraw treatment, it would be equally wrong to withhold that treatment.

Here, medical law has adopted an approach that sometimes appears compatible with consequentialism, and in some ways incompatible. The courts have explicitly endorsed the idea that withholding and withdrawing are equivalent. In the case of Tony Bland, where the court debated whether it was acceptable to withdraw artificial feeding from a man in a persistent vegetative state, Lord Goff noted that “discontinuation of life support is, for present purposes, no different from not initiating life support in the first place”²¹. However, the judges in that case were not supporting the wider consequentialist view that actions and omissions are equivalent. Lord Mustill stated that “For the time being all are agreed that the distinction between acts exists, and we must give effect to it”. Rather, they appeared (perhaps implausibly) to accept the view that since withholding treatment is obviously an omission, and withholding and withdrawing were equivalent, that withdrawing life-sustaining treatment should also be categorized as an omission. (The law lords mentioned, but dismissed the counter-argument that if, in a parallel case, an interloper had crept into a hospital and disconnected a mechanical ventilator, or pulled out a feeding tube, that no one would have any doubt that the interloper had “acted”).

Intention-Foresight and Doctrine of Double Effect

In deontological ethics and law, intentions play a significant role. For example, murder is distinguished from manslaughter on the basis of whether killing was intentional. This distinction also plays a role in medical law - it is legal to administer potentially life shortening doses or types of medication (such as large doses of morphine) in the care of a terminal patient provided that the intention is to relieve pain and not shorten life. One is permitted to foresee the action might shorten life, but provided it is not intentional, it can be permissible.

The doctrine of double effect captures this: it is permissible to act in a way which brings about harm (that would ordinarily be impermissible, such as leading to the death of an innocent person) provided that one merely foresees the harm and does not intend it, that the positive effects of the act do not occur via the negative effects, and provided that the benefits of the act outweigh the harm.

Consequentialists reject any distinction between intended and foreseen effects. What matters is the predicted outcome of an action, and whether that is justified, not the intent. Accordingly, consequentialists are typically skeptical of the doctrine of double effect.

20 D Wilkinson and JSavulescu ‘A Costly Separation Between Withdrawing and Withholding Treatment in Intensive Care’ (2014) B28: 127–137

21 *Airedale N.H.S. Trust v Bland* [1993] A.C. 789

In some situations, medical law does take a more consequentialist approach. In the case of Tony Bland, the judges rejected the significance of intention. Lord Browne-Wilkinson stated “there can be no doubt that ... the whole purpose of stopping artificial feeding is to bring about the death of Anthony Bland”, while Lord Lowry stated “even though the intention to bring about the patient’s death is there, there is no proposed guilty act”.²² It seems that intentions are not deemed to be relevant to omissions – rather the issue is whether the doctor has a duty to act.

Applications of Consequentialism: Cases

1. Killing and Conjoined twins: Jodie and Mary²³

In 2000, Rina Attard gave birth to conjoined twins known as Jodie and Mary. They joined at the pelvis and spine. Lord Justice Ward described their plight this way:

“Jodie and Mary are conjoined twins. They each have their own brain, heart and lungs and other vital organs and they each have arms and legs. They are joined at the lower abdomen. ... [T]hey can be successfully separated. But the operation will kill the weaker twin, Mary. That is because her lungs and heart are too deficient to oxygenate and pump blood through her body. Had she been born a singleton, she would not have been viable and resuscitation would have been abandoned. She would have died shortly after her birth. She is alive only because a common artery enables her sister, who is stronger, to circulate life sustaining oxygenated blood for both of them. Separation would require the clamping and then the severing of that common artery. Within minutes of doing so Mary will die. Yet if the operation does not take place, both will die within three to six months, or perhaps a little longer, because Jodie’s heart will eventually fail.”²⁴

The High Court authorised surgical separation, knowing it would kill Mary. “Mary may have a right to life, but she has little right to be alive. She is alive because and only because, to put it bluntly, but nonetheless accurately, she sucks the lifeblood of Jodie and she sucks the lifeblood out of Jodie. She will survive only so long as Jodie survives. Jodie will not survive long because constitutionally she will not be able to cope. Mary’s parasitic living will be the cause of Jodie’s ceasing to live. If Jodie could speak, she would surely protest, ‘Stop it, Mary, you’re killing me’. Mary would have no answer to that. Into my scales of fairness and justice between the children goes the fact that nobody but the doctors can help Jodie. Mary is beyond help.

“Hence I am in no doubt at all that the scales come down heavily in Jodie’s favour. The best interests of the twins is to give the chance of life to the child whose actual bodily condition is capable of accepting the chance to her advantage even if that has to be at the cost of the sacrifice of the life which is so unnaturally supported. I am wholly satisfied that the least detrimental choice, balancing the interests of Mary against Jodie and Jodie against Mary, is to permit the operation to be performed.”²⁵

This was a consequentialist decision. There were two courses of action: do nothing, and both would die. Or, “separate”, which would kill Mary, and Jodie would survive.

In this case, the judges were unable to pretend that the surgical procedure to separate the twins was an omission. It was, moreover, a fiction to describe Mary as a parasite and to couch this in terms of justifiable self defense. Mary and Jodie arose from the same original embryo. Neither had a greater claim to shared body parts. It is not accurate to describe Mary as killing Jodie. They were both dying because their body could not support both of

22 *Airedale N.H.S. Trust v Bland* (n21)

23 Julian Savulescu, ‘Abortion, infanticide and allowing babies to die, 40 years on’, (2013) *JME*39;5, 257–259

24 *In Re A (Children) (Conjoined Twins: Surgical Separation)* [2001] *Fam.* 147, 155

25 *In Re A (Children) (Conjoined Twins: Surgical Separation)* (n23) 147, 197

their lives. The common artery was the property as much of Mary as it was of Jodie. Mary was killed to save Jodie.

The ethics of separating conjoined twins is complex²⁶. From a consequentialist point of view, one must consider the length and quality of life, and probability of achieving these, with and without separation for both twins. Importantly when separation risks death, and continued existence is possible without separation, one must carefully evaluate the quality of life with and without separation. The improvement in quality of life with separation may not be sufficient to justify the risks of separation for a consequentialist perspective. In contrast, those who hold a deontological view about the value of normality may be prepared to accept much higher risks of surgery.

There is no question that the court made the right decision in the case of Jodie and Mary. However, their attempt to reconcile that decision with the existing deontological framework of the law appears incoherent.

2. The Case of Charlie Gard²⁷

In 2017, the courts heard the case of Charlie Gard. This was a young infant with a rare severe mitochondrial disorder – infantile onset encephalomyopathic mitochondrial DNA depletion syndrome (MDDS). This resulted in failure of mitochondria to make DNA necessary for energy supply to all cells. The result was that all cells being starved of energy. There were only a handful of patients who had ever been described with Charlie's illness. He was profoundly weak, unable to move, or breathe, and experienced seizures.

In December 2016, Charlie's parents identified an experimental treatment after contacting other parents on the internet. This had been used in a related but less severe form of MDDS. The clinicians treating Charlie had become convinced that treatment, both continued intensive care and the nucleoside therapy, would be futile. In contrast, a US expert offered to provide the nucleoside replacement therapy if Charlie were transferred to the US. The parents began crowd sourcing funds to take Charlie overseas.

However, doctors in the UK applied to the Family Division of the High Court on 28th February for permission to withdraw life support and to provide palliative care. On the 11th April, Justice Francis ruled in favour of the hospital. A series of legal appeals were unsuccessful, and after a further court hearing, and new tests, his parents accepted that further treatment could not help him. He died after withdrawal of life support.

This case illustrates the strengths and challenges of consequentialism.

It was clearly a welfare consequentialist decision. As Charlie's own wishes were unknown, the decision was reached on the basis of consideration of his best interests.

Justice Francis concluded:

“It is with the heaviest of hearts, but with complete conviction for Charlie's best interests, that I find it is in Charlie's best interests that I accede to these applications and rule that GOSH may lawfully withdraw all treatment save for palliative care to permit Charlie to die with dignity.”²⁸

26 J Savulescu and IPersson, 'Conjoined Twins – Philosophical Problems and Ethical Challenges' (2016) JPM41(1):41–55;

26 I Persson and JSavulescu, 'Conjoined Twins' in H.LaFollette (Ed), *International Encyclopedia of Ethics* (Wiley, forthcoming, Online in 2017. 2nd print edition, 2021)

27 Material for this section on Charlie Gard is drawn from DWilkinson and JSavulescu, *Ethics, conflict and medical treatment for children: from disagreement to dissensus* (Elsevier2018) (Forthcoming)

28 *Great Ormond Street Hospital v Yates Gard and Gard* [2017] EWHC 972 (Fam) 23

The gesture to dignity is not an essential part of the judgement. Indeed, consequentialists typically eschew discussions of dignity (which are rarely cashed out or operationalisable) except where this is defined as either a subjective or objective value to be considered in the consequentialist calculus.

One of the challenges of consequentialism is that it is heavily dependent on the facts to decide what has the best consequences. In medicine, there is often great uncertainty as to what the effects of medical interventions will be. Because of that uncertainty, assessment of the consequences may be heavily influenced by individual's prior beliefs as well as by their values. This is nowhere more apparent than in judgements of medical futility.

The most common argument that further treatment is not in the interests of the patient is on grounds of "futility".²⁹ This can be for two reasons.

a. Treatment Itself Has No Relevant Biological Activity

One early consideration in *Gard* was whether nucleoside replacement would cross the blood brain barrier. If it didn't, it would be futile. However, it was accepted later in the case it would cross.

The dominant ground for a judgment of futility in the High Court Decision was that there was no direct evidence that such therapy would have any effect in Charlie's condition because it had never been tried in humans or animal models.

The only evidence produced by the US expert (Dr Hirano) was from patients with a related disorder. These studies were small with modest results, and no blinded controlled trials had been conducted. However, there was a physiological rationale and the US expert stated the chances of improvement in Charlie's condition were "low, but not zero."³⁰

Despite this, Judge Francis concluded that

"that there is no scientific evidence of any prospect of any improvement in a human with RRM2B strain of MDDS..."³¹

It is a value judgement whether there was any evidence of any prospect of improvement. According to some, Hirano did present such (albeit weak and indirect) evidence.

In the late stages of the case, several experts wrote with new evidence of activity in "cultured human cells with RRM2B mutations."³² They also urged reconsideration of scientific plausibility. It supported the US doctors' claim earlier that the chances of it working were non-zero and thus it was not futile.

b. Irreversible Damage

Indeed, argument shifted after this to the second ground for futility. Although an agent might have biological utility, features about this particular patient mean it will not work. In particular, it was the alleged fact that Charlie had suffered irreversible brain damage that led the Court to find that treatment would be futile.

However, the assessment that someone's condition is irreversible, implies that it cannot be reversed (ie that there is no chance of this outcome occurring). Yet, this is an extremely difficult conclusion to reach for a condition

29 D Wilkinson and JSavulescu, 'Knowing when to stop: futility in the intensive care unit' (2011) COA, 24(2):160–165

30 *Great Ormond Street Hospital v Yates, Gard and Gard* (n27)104

31 *Great Ormond Street Hospital v Yates, Gard and Gard* (n27)106

32 http://www.charliesfight.org/home/421c34c100000578-4673276-image-a-13_1499432432453/

that is rare or unique, and for a treatment that has never been tried. (Absence of evidence is not the same thing as “evidence of absence”).

The crux of the matter for consequentialists was how reversible was Charlie’s brain damage. His initial brain scans did not appear to show loss of actual brain tissue. Recordings of electrical brain activity showed seizures, however, even if it was thought unlikely that nucleoside treatment would improve these, that could not be known with certainty unless it was tried.

Consequentialism thus faces at least three challenges:

1. to define what is of value
2. to determine what the probability is of various outcomes occurring.
3. to compare the expected value of different courses of action.

This requires the most up to date science but also normative interpretation of that science.

The second version of the interests argument is that the chance, although non-zero, of improvement was too low to justify the suffering which would occur in trying to realise a beneficial outcome. At very least, a three month trial of intensive care seemed necessary, with the painful procedures and suffering associated with that.

But what is too low? 1%, or 1/1000? The harms of intensive care are also debatable. Some patients with severe brain damage may be so severely affected that they are unaware of everything, even pain. Some of the evidence in Charlie’s case appeared to indicate that professionals believed that this applied to him,³³ in which case he would not suffer if subjected to a trial. Alternatively, if he was capable of experiencing pain, this could, in theory, be controlled with careful analgesia and sedation.³⁴

This argument is ethical, necessarily involving value judgments about probability and value, and what risks are worth taking. The challenge for the consequentialist is epistemic: how to evaluate the probability of different harms (or benefits) and how much value to place on them.

The third way in which the treatment could be against Charlie’s interests is that, even if it were “successful”, the best outcome that could be achieved is still not one worth aiming for either in terms of length or quality of life. This brings us to the hardest challenge of consequentialism: deciding what constitutes well-being and a life worth living.

The parents’ own medical expert, said, elaborated on quality of life that Charlie would face (assuming no improvement):

“The nature of Charlie’s condition means that he is likely to continue to deteriorate, that he is likely to remain immobile, that he will exhibit severe cognitive impairment, that he will remain dependent on ventilatory support to maintain respiration, will continue to need to be tube fed and that he will always be dependent on mechanical ventilation to maintain life.”³⁵

Elsewhere it was said that Charlie was deaf.³⁶

33 J Savulescu, ‘Is it in Charlie Gard’s best interest to die?’ (2017); TL389:1868–1869.

34 RD Truog RD, ‘The United Kingdom Sets Limits on Experimental Treatments: The Case of Charlie Gard (2017) JAMA; JSavulescu. and PSinger, ‘Charlie Gard: Why Donald Trump and the Pope are Right.’, (ABC Online, 14 July 2017.) < Available at: <http://www.abc.net.au/news/2017-07-13/charlie-gard-donald-trump-and-the-pope-are-right/8706390>> accessed 28 July 2017.

35 *Great Ormond Street Hospital v Yates, Gard and Gard* (n27) 91

36 *Great Ormond Street Hospital v Yates, Gard and Gard* (n27) 58

So a life with severe cognitive impairment, paralysis, deafness and dependent on artificial nutrition and ventilation is a life not worth living. That is a life of severe disability and dependency on life support. Walter Sinnott-Armstrong and Frank Miller argue that what makes killing wrong is that it inflicts total disability, or removes all abilities.³⁷

There are three challenges for this welfarist account of the worth of life based on dependency and disability. Firstly, it seems to suggest that at some point disability makes life not worth living. The severely disabled would be better off dead, from their own perspective. Disability groups may well disagree. Indeed, Miller and Sinnott-Armstrong received considerable opposition to their proposal relating worth of life to disability. Some people who are quadriplegic on a ventilator with spinal muscular atrophy find their lives worth living. Many severely disabled people find their own lives worth living.³⁸ It runs the risk of being accused of being “ableist”, discriminating against those with disability. Perhaps for this reason, where the line lies on this account has been left fuzzy.

Secondly, disability is instrumentally bad: it is not, in itself, what matters. Rather, as Judge Francis acknowledged, it is well-being or welfare that is intrinsically good. As one of us has argued elsewhere³⁹ whether deafness or paralysis reduces well-being is context dependent. How bad functional disabilities are will depend on the social context and state of technology.

Indeed, Justice Hedley, in another case of Charlotte Wyatt cited as the basis of the Gard decision, said that ‘Best interests must be given a generous interpretation’⁴⁰ but although he referred to the broader concept of best interests as including non-medical interests, he did not go further, saying simply that, ‘The infinite variety of the human condition never ceases to surprise and it is that fact that defeats any attempt to be more precise in a definition of best interests.’⁴¹

Thirdly, the bar of a life worth living has elsewhere been set very low - even at minimal consciousness as the case of M illustrates.

M was an adult who contracted viral encephalitis, leaving her in minimally conscious state over a period of many years. Her family petitioned a court to remove artificial nutrition and hydration on the basis of her previously expressed wishes. However the judge, using the “balance sheet” approach used in Gard and other cases, came up with the view:

“M does experience pain and discomfort, and her disability severely restricts what she can do. Having considered all the evidence, however, I find that she does have some positive experiences and importantly that there is a reasonable prospect that those experiences can be extended by a planned programme of increased stimulation.”⁴²

M was profoundly disabled. Despite her family’s evidence that she would not want to live in such a state, the judge decided that it was in her best interests to live with such profound disability.

37 W Sinnott-Armstrong and FGMiller, ‘What makes killing wrong?’ (2012) JME39:3–7

38 Not Dead Yet <<http://notdeadyetuk.org/about/>>; YvonneNewbold, ‘ Why severely disabled lives matter too.’ (World Health Innovation Summit, 26 July 2016.) < Available at: <http://www.worldhealthinnovationsummit.com/blog/2016/07/26/health-why-severely-disabled-lives-matter-too/>>

39 J Savulescu and GKahane, ‘Disability: A Welfarist Approach’ (2011) CE6:45–51.

40 *Wyatt v. Portsmouth NHS Trust* [2006] 1 FLR 554

41 *Wyatt v. Portsmouth NHS Trust* (n38) 87

42 *W v M and others* [2011] EWHC 2443 (Fam) 8

Consequentialism needs to tether the line of a life more closely to well-being, and specify more what constitutes well-being, rather than the vague, open-ended accounts employed so far in law. Philosophers Derek Parfit and James Griffin describe 3 theories of well-being: Hedonistic, Desire Fulfilment and Objective list theories.⁴³ According to Hedonistic Theories, what makes life go well is pleasure and happiness, and what makes life go badly is pain and unhappiness. According to Desire Fulfilment Theories, what makes life go well is being able to satisfy desires, and what makes it go badly are frustrated desires.

Parfit explains Objective List Theories in the following way:

“[C]ertain things are good or bad for people, whether or not these people want to have the good things or avoid the bad things. The good things might include moral goodness, rational activity, the development of one’s abilities, having children and being a good parent, knowledge and the awareness of true beauty. The bad things might include being betrayed, manipulated, slandered, deceived, being deprived of liberty and dignity, and enjoying either sadistic pleasure, or aesthetic pleasure in what is in fact ugly.”⁴⁴

Objective list theories can be extended⁴⁵. Other items might include love, deep and varied personal relationship, originality, creativity, autonomy, engagement with nature, sex and soon.

Each of the three accounts of well-being - Hedonistic, Desire-Fulfilment and Objective List theories - has some plausibility. Parfit concludes that an adequate account of well-being must accord weight to all of valuable mental states, desire-satisfaction and objectively valuable activity.⁴⁶ It may be best not only to engage in activities that possess objective value, but to also want to engage in such activities, and to derive pleasure from them.

Given the wide disagreement about what constitutes a good life and a life worth living, the least controversial account of a life not worth living is one in which is not worth living on all 3 accounts:

1. balance of pain over a pleasure
2. greater desire frustration than fulfilment
3. lack of any objective goods or objectively valuable activity in life

Disability will be relevant to these 3 criteria but we cannot say what its precise effect will be on welfare or well-being, out of the specific context, and especially the social and technological context. A life with loving and devoted parents may tip the balance of pleasure over pain.

The pervading presence of pain in such an account is important. It is on the basis of unrelenting pain that some people believe life with severe dystrophic epidermolysis bullosa (where the skin peels off and death occurs very early in life) and Lesch-Nyhan disease (characterised by intellectual disability and painful self-mutilation) are lives which are not worth living.

So whether Charlie Gard’s life could have been worth living is dependent on the substantive account of the value of life which one holds. On the most conservative view, it is dependent on happiness, desire satisfaction and ability to engage in objectively valuable activity. A judgement of the value of life will be heavily influenced by pain and suffering. The degree to which Charlie Gard was suffering from pain was the subject of considerable disagreement and unclarity.⁴⁷

43 D Parfit *Reasons and Persons* (Oxford University Press, 1984);

43 J Griffin ‘Well-being: Its meaning, measurement, and moral importance’ (Clarendon Press, 1986)

44 D Parfit *Reasons and Persons* (n 41)

45 M Nussbaum, *Creating Capabilities: The Human Development Approach*. (Harvard University Press; 2011.) 33–34.

46 D Parfit *Reasons and Persons* (n41) 502

Although, the central question in the Gard case can be understood to be consequentialist, there are several features of the case that were not part of the legal decision, but which would be relevant from the perspective of consequentialism.

In the Gard case, and other cases relating to medical treatment for children, decisions focus almost exclusively on the interests of the child. However, that might be unjustified.

In cases like this, where parents have very strong desires for treatment to be provided, but that treatment is (potentially) not in the child's interests, there is a potential clash. It may be better for the parents to provide the desired treatment (that may mitigate their grief and distress if they know that experimental treatment has been tried). A consequentialist would potentially need to weigh up the parents interests against those of the child. Even if treatment were contrary to the child's interests, if the harm were slight, it might be that the best outcome overall would be to provide it.

Second, faced with a situation of conflict, the consequentialist would need to take into account not simply which treatment would be best, but also which way of resolving a dispute would be best. In the Gard case (and in the subsequent Alfie Evans case), the high profile court cases (with multiple subsequent legal appeals) were costly, and involved investments of huge amounts of time by the health professionals and legal teams. They led to extremely negative publicity for the health system and for the hospitals involved. It might have been better overall, in retrospect, to have allowed the parents' request rather than embarking on a potentially prolonged, painful and costly legal dispute.

Third, in the Gard case, the judge specifically set aside the question of the cost of treatment (in part because Charlie's parents had raised funds to pay for it). However, concern about the impact of providing treatment is a crucial consequentialist consideration.

3. Resource Allocation and Distributive Justice: Jaymee Bowen

In 1995 Cambridge Health Authority was taken to court. The Authority had refused to make NHS money available for a second bone marrow transplant, following an unsuccessful bone marrow transplant for a 10-year-old girl ("Child B" or Jaymee Bowen), suffering from leukaemia. The estimated cost of the treatment was £75,000. In the view of the Health Authority, the treatment had little chance of success. This view was based on her own doctor's opinion backed up by specialists from the Royal Marsden Hospital in London. The initial justification was that treatment was not in the child's best interests. Her doctor said, "it would not be right to subject her to all this trauma."⁴⁸ The Health Authority wrote to B's parents that the decision was taken with "B's best interests in mind" and not "on financial grounds."⁴⁹

However, a specialist from the Hammersmith Hospital in London believed that a further course of treatment was worth attempting. The chances of inducing a remission were put at 5%, and the chance of cure less. Her father objected to the Trust's decision. He believed that a 5 % chance was worth taking. Cambridge Health Authority refused to fund the treatment.

When the case came to court, the Health Authority changed its tune. It said that treatment would not be "an effective use of resources", that its funds were "not limitless" and that it had to consider the interests "of other patients."⁵⁰ On the basis of guidance from the Department of Health in relation to funding unproven treatment,

47 D Wilkinson and J Savulescu, *Ethics, conflict and medical treatment for children: from disagreement to dissensus* (n26)

48 *R v. Cambridge Health Authority, ex p. B* [1995] 2 All ER 129, 133 (CA)

49 *R v. Cambridge Health Authority* (n 47)

50 *Ibid*

the Authority decided: “the substantial expenditure on treatment with such small prospect of success would not be an effective use of resources”.⁵¹

When the case was heard in the High Court, the judge (Laws) said that Child B’s fundamental right to life required that the Health Authority show compelling objective reasons for giving other patients priority over her. He said that it was not sufficient to state merely that resources were limited. He said, “the responsible authority ... must do more than toll the bell of tight resources.”⁵²

However, this viewpoint was not upheld in the Court of Appeal.

Sir Thomas Bingham, Master of the Rolls, said, “Difficult and agonizing judgments have to be made as to how a limited budget is best allocated to the maximum advantage of the maximum number of patients. That is not a judgment the court can make.”⁵³

Jaymee Bowen was denied a second transplant by the court. However, she did end up receiving one after support from a private donor. The transplant was not prevented in her best interests.

4. QALYs

Health economists have attempted to combine all these factors into the QALY (quality adjusted life year) approach to allocating health resources. A QALY is a year of life adjusted by its quality.

“The essence of a QALY is that it takes a year of healthy life expectancy to be worth 1, but regards a year of unhealthy life expectancy as worth less than 1. Its precise value is lower the worse the quality of life of the unhealthy person (which is what the quality adjusted bit is all about)”⁵⁴

Cost-effectiveness requires assigning a Cost/QALY for each drug or medical procedure. There is currently a threshold of about £20 000/QALY for new drugs, though more expensive drugs can be approved in special circumstances.

Cost-effectiveness is a form of consequentialism, aiming to maximise the health outcomes of medical interventions. One of the challenges of consequentialism is to apply this approach consistently across medicine. While it is uniformly used in the approval of pharmaceuticals, it is not uniformly used when evaluating procedures, including surgery, or complex interventions, such as the provision of intensive care. We have attempted elsewhere to show how it could be more widely applied.⁵⁵

Strengths of Consequentialism

1. Well-Being

The sole focus of welfare consequentialism is promoting well-being. If anything matters in ethics, how well people’s lives go matters. Well-being is a common currency of all ethical theories.

Wellbeing is also clearly a centrally important consideration for the law. One of the prime functions of the law is to safeguard the wellbeing of citizens.

51 Ibid

52 Ibid

53 Ibid

54 A Williams, ‘The value of QALYs’, (1985) HSSJ, 94: 3

55 D Wilkinson, SPetrou and JSavulescu, ‘Expensive care? Resource-based thresholds for potentially inappropriate treatment in intensive care’ [2018] MBR <10.1007/s40592-017-0075-5>

Consequentialism is a good place to start in ethical deliberation. If the consequentialist course of action is not adopted, that implies that somebody is suffering or their life is not going as well as it could go for the sake of some rule, principle or moral. It is important to ask: is it worth this person's life going worse for the sake of this rule or moral? In many cases, it is hard to justify. In some cases, for example, a commitment to some non-consequentialist theory of distributive justice (for example priority to the worst off), it might be worth it.

2. Impartiality and Equality

According to consequentialism, everyone's health gains or well-being matter equally. Utilitarianism was a revolutionary philosophy in the 1700s because the pauper's happiness mattered as much as the prince's.

This egalitarian ethos is shared with the law. The law is committed to strict impartiality.

3. Clear link to moral responsibility

For consequentialists, moral responsibility is a function of the foreseeability and avoidability of outcomes. If one has knowledge and control, one is responsible, whether or not one acted or omitted to act. Consequentialists are not primarily concerned with intentions, or virtue, but with consequences and the goodness or badness of those. If one chooses a course of action foreseeing it is likely to have worse consequences, one is morally responsible or blameworthy.

4. Consistency

Consequentialism is a highly consistent theory. It treats acts and omissions, treatment withholding and withdrawal, active and passive euthanasia, intentions and foresight the same, where these would have the same consequences.

Again, the fundamental desire for consistency is shared with the law.

5. Demanding

Consequentialism, at least utilitarianism, is a highly demanding theory. Provided that the benefit to one is greater than the harm to another, consequentialism demands action.

Challenges

We have already discussed the challenge of defining well-being, gathering evidence relevant to the probabilities of different outcomes and comparing the expected utility of different options. There are other challenges.

Distribution and Separateness of persons

John Rawls famously objected that utilitarianism fails to recognise the separateness of persons [theory of justice]. By this he means that consequentialism generally doesn't take account of where or how well-being is distributed, just that it is maximised. One instantiation of this problem in health care is that consequentialism (and health economics and QALYs) potentially favours providing a very small good to a very large number of people rather than one very large good to a single person. Thus, consequentialism favours public health (and very small reductions in risk across a whole population) rather than life saving interventions for smaller, discrete populations.

Discrimination

Another problem with consequentialism is that it is said to discriminate against the old, the disabled and those with a poorer prognosis.⁵⁶ It does give lower priority to potentially life saving treatment, such as transplants, to

those who will derive less benefit, either because it will prolong their life less, or their life will be a lower quality or the chances of success are smaller. For this reason, heart transplants have sometimes not been offered to children with significant disabilities, such as Down syndrome or Trisomy 18.⁵⁷

A Consequentialist Manifesto for the Evolution of Medical Law

If the medical law were to fully embrace consequentialism, at least 14 potential changes would be warranted.

1. Legalise active euthanasia

Consequentialists have been the most ardent proponents of active euthanasia⁵⁸ arguing for a quality of life ethic. However, if there were evidence of worse outcome overall in countries that have legalized assisted dying, that would potentially lead the welfare consequentialist to support restricting access to this option. For example, “slippery slope” type objections are often rejected by consequentialists because of lack of evidence that the feared negative outcomes of legal change would necessarily (or probably) eventuate. Yet, if such evidence emerged, consequentialists would potentially change their minds about policy. Consequentialists would support scientific evaluations of the impact of different legislative options.

2. Limit costly and ineffective treatment on the basis of distributive justice

Within public healthcare systems, providing highly expensive treatment for little benefit may harm other patients (by consuming limited resources). A consistent consequentialist application of the law would find it justified to withhold (or withdraw) such treatment, even if that treatment is desired by the patient (or family) and would be in their best interests.⁵⁹

3. Reject the right to conscientious objection

Many consequentialists are against a right to conscientiously object (usually on religious grounds) to medical interventions which are legal, in the patient’s interests, desired by the patient and consistent with distributive justice.⁶⁰ Examples include assisted dying, contraception, sterilisation, assisted reproduction and abortion.⁶¹

4. Human Enhancement

Consequentialists are generally in favour of biological interventions to enable people to have better lives, not merely healthier lives.⁶² So consequentialists are in favour of genetic selection to select children who will have

56 J. Harris, ‘What Is the Good of Health Care?’ (1996);, *Bioethics*.10: 262–91..

57 J Savulescu, ‘Resources, Down Syndrome and Cardiac Surgery’, (2001) *BMJ*, 322:875–6 PubMed PMID: 11302884.

58 J Rachels, ‘Active and Passive Euthanasia’, (1975) *NEJM*, 292, 78–80 PubMed PMID: 1109443.;

58 Peter Singer, *Rethinking Life and Death* (Oxford University Press1995);

58 H Kuhse and PSinger, *Should the Baby Live?: Problem of Handicapped Infants* (Oxford University Press1985)

59 D Wilkinson and JSavulescu, ‘Knowing when to stop: futility in the ICU’ (2011) *COA*24;2, 160–165;

59 D Wilkinson, SPetrou and JSavulescu, ‘Rationing potentially inappropriate treatment in newborn intensive care in developed countries’ (2017) *SFNM*, 23;1, 52–58.

60 J Savulescu, ‘Conscientious Objection in Medicine.’ (2006); *BMJ*.332: 294–297. PubMed PMID: 16455733.

61 J Savulescu and USchuklenk, ‘Doctors Have no Right to Refuse Medical Assistance in Dying, Abortion or Contraception’ (2017) *Bioethics*, 31: 162–170 PubMed PMID: 27716989..

62 J Savulescu, ‘Genetic Interventions and the Ethics of Enhancement of Human Beings’, in BSteinbock (ed), *The Oxford Handbook of Bioethics* (Oxford University Press2007) 516 – 535

greater abilities and dispositions associated with higher well-being⁶³ and the use of gene editing and other biological interventions to increase well-being.

5. Autonomy

Liberal welfarist consequentialists like Mill place great weight on autonomy and favour interventions which promote autonomy.⁶⁴ Thus, interventions like gender reassignment or body modification (such as amputation of a health limb in Body Identity Integrity Disorder) could be provided on grounds of respect for autonomy, even if there were minimal effects on well-being.

6. Sale of Body Parts

Consequentialists often favour allowing people sell organs, such as kidneys, and tissues.⁶⁵ They might support different legal approaches in different countries (for example, prohibition of organ sales might be justified in countries where abuse or exploitation is more likely).

7. Organ Procurement

Consequentialists generally favour opt-out systems for organ donation⁶⁶ to increase supply or organ conscription, or even organ donation euthanasia.⁶⁷

8. Risk

Research ethics places significant limits on the risk human participants can be exposed to in research. Consequentialism places no absolute limits on risk either in research or innovation. Thus, consequentialists may support challenge studies and the use of experimental treatments.

9. Animals

Consequentialists draw no moral distinctions between humans and other animals. The belief that suffering matters equally, whether it is in human nor a non-human animal. They are thus against the use of animals in research unless it is clear that consequences justify it.

10. Harm Reduction

Consequentialists favour harm reduction strategies over preservation of moral fabric, principles or rules. Thus, they are in favour of legalisation of drugs and prostitution, together with harm reduction strategies. While it may be preferable for people not to consume nicotine, nicotine replacement therapy might produce less harm overall than efforts to avoid tobacco and nicotine completely.

63 J Savulescu, 'Procreative Beneficence: Why We Should Select the Best Children', (2001) B15;5, 413–426

64 J Savulescu, 'Autonomy, the Good Life, and Controversial Choices', in RRhodes, LPFrancis and ASilvers (eds), *The Blackwell Guide to Medical Ethics* (Blackwell Publishing, 2007) 17 – 37

65 Janet Radcliffe Richards, *The Ethics of Transplants*, (Oxford University Press 2012)

66 W Isdale and JSavulescu, 'Three proposals to increase Australia's organ supply' (2015) MBR33(2–3):91–101

67 D Wilkinson and JSavulescu, 'Should We Allow Organ Donation Euthanasia? Alternatives for Maximizing the Number and Quality of Organs for Transplantation' (2012) B26:1: 32–48

11. Artificial Reproduction

Consequentialists may permit cloning,⁶⁸ same sex reproduction (for example by using pluripotent stem cell derived gametes,⁶⁹ creation of saviour siblings,⁷⁰ surrogacy and any alternative form of reproduction provided it has good consequences.

They usually do not believe that early human life has moral status and that destruction of early human embryos for research or reproduction is wrong.

12. Disability

Some consequentialists have advanced a welfarist account of disability that holds that any state of biology or psychology which tends to reduce well-being in a given social or environmental circumstance is a disability.⁷¹ This view encompasses many human characteristics and is consistent with a widespread programme of human enhancement.

13. Natural vs Non-Natural

Consequentialists do not see any moral relevance in the natural vs non-natural distinction. What matters is well-being and nature should be modified to improve well-being.

14. Playing God

Consequentialists typically deny that there is any divine order to the world and subscribe to a Darwinian view of humans as the product of evolution. Thus, they believe there is great imperfection and natural inequality that science and medicine can improve or correct.

Consequentialism is a fundamental element of common sense morality, while attention to the consequences of decisions appears to be an element of any plausible moral theory. Consequentialism is already incorporated into the law in many places, however, in others current medical law appears to retain deontological prohibitions or norms that appear overall to lead to worse outcomes. There is a strong case for carefully and rigorously evaluating the outcomes of any legislative change. That can help to identify the consequences of policy. This evidence would be compelling for the consequentialist. However, it can also be important in helping to establish what price our societies are willing to pay for retaining or endorsing the non-consequentialist features of the law.

68 M Tooley, 'The Moral Status of the Cloning of Humans', in JM Humber and RF Almeder, (eds) *Human Cloning; Biomedical Ethics Reviews*, (Humana Press 1998) 65–101

69 T Douglas, CHarding, HBourne and JSavulescu, J, 'Stem Cell Research and Same Sex Reproduction', in MQuigley, SChan and JHarris (eds), *Stem Cells: New Frontiers in Science and Ethics*, (World Scientific Press 2011)

70 RJ Boyle and JSavulescu, 'Ethics of Using Preimplantation Genetic Diagnosis to Select a Stem Cell Donor for an Existing Person', (2001) *BMJ*, 323: 1240–3 PubMed PMID: 11719418.

71 G Kahane and JSavulescu, 'The Welfarist Account of Disability', in ACureton and KBrownlee (eds.), *Disability and Disadvantage*, (Oxford University Press 2009) 14 – 53