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Reasonable Parental and Medical Obligations in Pediatric Extraordinary Therapy

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Abstract

The English cases of Charlie Gard and Alfie Evans involved a conflict between the desires of their parents to preserve their children's lives and judgments of their medical teams in pursuit of clinically appropriate therapy. The treatment the children required was clearly extraordinary, including a wide array of advanced life-sustaining technological support. The cases exemplify a clash of worldviews rooted in different philosophies of life and medical care. The article highlights the differing perspectives on parental authority in medical care in England, Canada, and the United States. Furthermore, it proposes a solution that accommodates for both reasonable parental desires and professional medical opinion. This is achieved by looking at concepts of extraordinary therapy, best interest, reasonable parenthood and medical objections.

Summary: In cases where a child's treatment involves extraordinary therapy, there is often a conflict of opinion between the medical team and the parents with regard to the best course of action. The assumption should be that responsible, caring parents make reasonable and acceptable decisions for the good of their children. Rather than focusing on making a hypothetical best interest judgment, courts should in the first instance side with the parents. Only when parents act unreasonably or malevolently should their wishes be overridden. This should not affect the medics' right to conscientiously object towards carrying out procedures that they deem to be medically unnecessary or harmful.

Keywords

Care of dying minors, End-of-life care, Family, Minors/parental consent, Rights of conscience, Right to healthcare

In recent years, two pediatric medical situations in England[1] gathered considerable attention from the media: the stories of Charlie Gard and Alfie Evans. In each case, conflict arose between the parents' and physicians' views of the children's "best interests." It is clear that both sides of the argument thought that what they did was for the good of each respective child. The parents wanted aggressive disease-directed treatments and life support; the medical teams wanted to focus on patient comfort and not aggressive interventions. In light of this conflict, the cases were referred to court.

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In such circumstances in England, the court's role—like all medical surrogate's in England—is to determine what is in the patient's best interest. The law states that there is only one possible "best interest decision," of which the courts are the final arbiters; providing treatment which was not considered to be in the patient's best interest would be equivalent to acting without the patient's consent, violating his/her autonomy, and, as such, be liable to prosecution (In Re S. (Adult Patient: Sterilisation) [2000] 3 WLR 1288; *NHS Trust A* v. *M*; *NHS Trust B* v. *H* [2001] 1 All ER 801; see also *An NHS Trust* v. *A and Another* [2005] EWCA Civ. 1145). Thus, if a court deems that doctors are free to withdraw treatment to serve a child's best interest, this would simultaneously preclude the parents from transferring their children to a different institution that would provide such treatment. This practice to many, especially North American readers, might seem controversial, and we discuss it in more depth in a later section.

The cases of Gard and Evans are briefly outlined below. Gard was born with infant-onset mitochondrial DNA depletion syndrome, resulting in progressive brain and muscle damage (Birchley 2018). He suffered from seizures, paralysis, and required ventilator support, which—some contended—left Gard with a low quality of life (The Anscombe Bioethics Centre 2017). There was no effective treatment for his condition, but it was proposed that nucleoside therapy might have been helpful in some way. Owing to Gard's extensive brain damage, caused by refractory seizures, the medical team judged that there was no realistic hope for an improvement in his condition and decided against nucleoside therapy, which his parents still favored (Birchley 2018). The key question under dispute between the parents and the medical team was not the worthiness of Gard's life or the level of its quality, but the efficacy of the proposed experimental treatment (Cave and Nottingham 2018).

Evan's case involved primarily a neurodegenerative disorder (*Alder Hey Children's NHS Foundation Trust* v. *R* [2018] EWHC 308 (Fam)). It was unclear whether Evans could experience pain or simple pleasures (The Anscombe Bioethics Centre 2018). It was the opinion of the hospital staff that there were no effective therapeutic options available and that his survival prognosis was poor. His parents were seeking to obtain long-term treatment for Alfie, as they preferred for him to die on his "own time" with extensive medical support including ventilation via tracheostomy and percutaneous endoscopic gastrostomy (*Alder Hey Children's NHS Foundation Trust* v. *R* [2018] EWHC 308 (Fam)).

In both cases, the courts decided that further treatment was not in the children's best interest and as such should not continue; in Gard's case, the English court's decision was also endorsed by the European Court of Human Rights (The Anscombe Bioethics Centre 2017). This meant that Gard's and Evans' care could not be transferred to a different institution as requested by the parents and that no further treatment of the underlying pathology would be provided for them.

This article will consider whether it is possible to have a legal framework that could accommodate both the preference of the parents and that of the medical teams. Key to this will be considerations of what is known as extraordinary therapy, as well as best interest medical decisions, and the role of parents in the provision of care for their children.

Extraordinary Therapy

The concept of extraordinary therapy has its origins in Catholic moral theology (see Eijk, Hendriks, and Raymakers 2014, 313–15, 568–71), but its principles have also been described and defended in broader philosophical terms (Spielthenner 2007; Sulmasy 2005). Considerations of extraordinary therapy have an important bearing on medical law and ethics but have additional relevance to both cases at hand. Evans and Gard came from Catholic families, and their situations attracted prominent advocacy from the Pope and a Catholic hospital in Rome (Brockhaus 2018; Catholic News Agency 2017; Hitchens 2018; Thompson 2018; Fitzpatrick 2017).

The attitude underlying the concept of extraordinary therapy is one of respect for life, but it is not vitalist—it does not seek to preserve life at all cost (Keown 2002). In this framework, patients and their families are not obliged to continue extraordinary treatment that does "not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community" (United States Conference of Catholic Bishops 2009, para. 57). As such, such assessments are made on the basis of the worthiness of the treatment, not on the worthiness of the patient's life.[2] Medical professionals may withdraw such extraordinary therapy when appropriate, though ordinary care (enteral or parenteral nutrition, hygiene and comfort measures) should normally continue (see e.g., Catechism of the Catholic Church, n.d., para. 2278, 2279; John Paul II 2004). Notwithstanding, this understanding of treatment does not prevent one from receiving or choosing (for oneself or by proxy) extraordinary therapy.

Best Interest

From the English legal perspective, as stated above, the courts are obliged to seek the child's best interest (Griffiths and Danbury 2015), even if this means—in the case of minors—overriding the decisions of competent parents at times. A nuanced comparison of applicable English and American laws has been written elsewhere (Dauber 2018). However, in short, in the United States and Canada, parents tend to be given greater latitude to determine a child's best interest. US courts have ruled that the state may only interfere in the decisions of competent parents if they neglect their "high duty" to recognize symptoms of illness and to seek and follow medical advice (*Parham* v. *J.R.*, 442 U.S. 584 (1979)). That is to say, parents are allowed discretion as long as they "choose from professionally accepted treatment options" (*Bowen* v. *American Hospital Association*, 476 U.S. 610 (1986); *Miller Ex Rel. Miller* v. *HCA, Inc.*, 118 S.W.3d 758 (Tex. 2003)) when significant medical events occur.

In Canada, courts have found that the state may only interfere in the medical decision of parents if those decisions "override the child's right to life and security of the person" (*B. (R.)* v. *Children's Aid Society of Metropolitan Toronto* [1995] 1 SCR 315, 1995 CanLII 115 (S.C.C.)) by refusing to consent to a recommended treatment approach ((ON) Child and Family Services Act, R.S.O. 1990, c. C.11, s. 37(2)(e), among similar legislation from other provinces). This holds even if the parents refuse to consent because of a sincerely held religious belief (*B. (R.)* v. *Children's Aid Society of Metropolitan Toronto* [1994] S.C.J. No. 24 [1995] 1 S.C.R. 315 (S.C.C.)). The risk of harm to the child, though, must be substantial for the state to intervene and violate parental rights. For instance, courts have ruled that lifesaving blood transfusions meet such a standard but more minor interventions do not, such as routine vaccinations (*Newfoundland (Director of Child Welfare)* v. *B. (C.R.)*, [1995] N.J. No. 389, 137 Nfld. & P.E.I.R. 1 (Nfld. T.D.); *B. (R.)* v. *Children's Aid Society of Metropolitan Toronto* [1994] S.C.J. No. 24, [1995] 1 S.C.R. 315 (S.C.C.)). Notwithstanding this, an Aboriginal mother was controversially permitted by an Ontario court in 2014 to decline apparently lifesaving chemotherapy for her daughter's leukemia and instead avail of traditional native remedies (Shehata 2016).

Briefly, English precedent has allowed for the state to veto the "best interest" determination of responsible, competent parents. US and Canadian jurisdictions tend to defer to the best interest determinations of responsible, competent parents who avail of the possible treatment options. Noteworthy, while Canadian law errs on the side of preserving life, the English rulings prefer to err on the side of preventing future suffering. The Gard and Evans judgments are currently unlikely to exert any change on Canadian court rulings, especially since Canadian law grants parents a greater dominion over their children's health care than does English law. Nevertheless, English case law exerts a substantial influence on Canadian rulings, more so than do cases from the United States (Clarke 2010). As the recently enacted Medical Assistance in Dying (commonly known as MAID) legislation was proposed to be extended to competent minors (DeMichelis, Shaul, and Rapoport 2018), it remains to be seen if voices within Canada will begin to suggest a competing right of children to "freedom from suffering" and so called "death with dignity," in cases where extraordinary therapy is being administered (see Kirkey 2018; for why Canadian developments in peadiatric MAID should be of particular interest to those based in the United States, see Smith 2018).

It seems only reasonable for the courts to protect vulnerable members of society from abuse. Yet, in the cases of Gard and Evans, it would be hard to argue that parents were being malevolent. Furthermore, these cases contrast strongly with other instances in which courts intervened to help to preserve the child's life, such as when Jehovah's Witnesses refused blood transfusion for their child (Griffiths and Danbury 2015). In the cases of Evans and Gard, the parents were clearly trying to preserve their children's lives (what they deemed to be the child's best interest). The state, however, adopted and vigorously pursued a different view of the children's best interest: preventing the respective treatments/care and barring the parents from seeking treatment for their children elsewhere (for another example of a similar decisions made by British authorities, see BBC 2015). The state went so far as to enforce this decision by installing a police presence to ensure that Evans' parents would not take him away from the hospital (Cooke 2018), though undeniably, the police were also there to keep peace due to the large number of protesters present. Such enforcement of "best interest" of the child seems disproportionate when contrasted with the leniency given to those who, out of a sense of compassion, assist others in ending their lives (The Director of Public Prosecutions 2014).

The medical facts and prognosis of such situations are not always certain (e.g., Evans fared much better after he was taken off the ventilator than originally predicted). Defining suffering and determining whether it is caused by the condition or the treatment is not always easy (The Anscombe Bioethics Centre 2018). Further, opinions about the best course of action might vary from one professional's opinion to another's (Caldwell 2018; *Alder Hey Children's NHS Foundation Trust* v. *R* [2018] EWHC 308 (Fam)). When medical practitioners are judged for malpractice, they are judged as to whether reasonable treatment was exercised with ordinary skill (*Bolitho* v. *City and Hackney HA* [1996] 4 All ER 771). In the two cases discussed here, it would be hard to label the medical teams on either side of the arguments as incompetent. As such, it is difficult to judge what is the best medical interest for the child based on differing, but competent, medical opinions. While it might be sensible for courts to protect children from abuse and questionable medical science, it is not for them to judge in favor of one competent worldview and medical ethos over another.

Parental Authority

Mothers and fathers, by the nature of their relationship with and responsibility to their children, have a freedom and autonomy to choose between sensible treatment options for their offspring (Treloar 2018), and jurisdictions must acknowledge this. The family is a natural society. It is an institution not only existing before the state but on whose foundation the state exists (Irish Government 2018, sec. 41; Holy See 1983; United Nations General Assembly 2014). Even a recent British prime minister highlighted the role of the family as "the building block of a strong, cohesive society" (BBC 2010), and it is hard to imagine how a modern notion of autonomy could be defended while simultaneously denying, what Catholics understand as, subsidiarity—one of the principles forming the foundation of parental rights.

Briefly, the doctrine of subsidiarity states that higher levels of authority should only intervene when tasks cannot be performed at a lower one (Oxford Dictionary n.d.). It is one of the principles of Catholic social teaching (Jones, Beck, and Gately 2011, 36–39), but also a principle of the European Union (Panizza 2018), of which the UK (at the time of writing) is a member. Additionally, it is somewhat reflected in the adage that "an Englishman's home is his castle" (see William Pitt, Earl of Chatham (1763) 2016), which, while not implying that one could break the law within the grounds of one's home, does imply a certain autonomy of the family unit. Subsidiarity, in the context of parenthood, implies that parental powers belong to the parents, and the state should only intervene when the parents are unable to properly exercise them (what such a proper execution would imply is discussed in the next section).

In the UK, the somewhat similar concept of devolution is also applied.[3] Devolution is the delegation of, for example, a power usually reserved to the central governmental to a lower level, such as a constitutive nation (e.g., Scotland; Oxford Dictionary n.d.). Yet, in the case of devolution, the power properly belongs to the central government. Parental authority (and thus children under parental authority), in this case, would truly belong to the state and could be withdrawn from the parents at any time.

Parental authority, importantly, should not be understood as a right, but, perhaps more crucially, also as a duty—it is stewardship. Its origins are best understood through Natural Law, and Locke (2008, para. 56 and 58) has expressed this quite well:

> Adam was created as a complete man [. . .] The world has been populated with his descendants, who are all born infants, weak and helpless, without knowledge or understanding. To make up for the defects of this imperfect state [. . .] Adam and Eve and all parents after them were obliged by the law of nature to preserve, nourish, and bring up the children they had begotten—not as their own workmanship, but as the workmanship of their own maker, the almighty God, to whom they were to be accountable for them.
>
> So the power that parents have over their children arises from their duty to take care of their offspring during the imperfect state of childhood. What the children need, and what the parents are obliged to provide, is the forming of their minds and the governing of their actions; that is while the children are still young and ignorant; when reason comes into play the parents are released from that trouble.

This echoes what Aquinas (n.d.) notes when discussing whether the children of unbelievers should be baptized against their parents' will (Summa Theologica II-II q. 10, a. 12): "Hence it would be contrary to natural justice, if a child, before coming to the use of reason, were to be taken away from its parents' custody, or anything done to it against its parents' wish" (see Brown 2017). This understanding that parents are by the law of nature the guardians of their children, acting out of affection for their interest where their children themselves do not yet have capacity for such judgments, has been reflected in both English and US law (Parental Rights Foundation n.d.; Feikert 2015).

Parental proxy consent is hence a reflection of the responsibility before God that parents have in preserving the well-being of their children, but also a reflection of the autonomy that the children will be able to exercise in future. Yet, with such an understanding of parental stewardship, it is clear that parents making malevolent decisions are committing an injustice. Subsidiarity, in these circumstances, would allow for an intervention. If a lower level is unable to perform the task, the higher can intervene. Such an intervention would be geared to the protection of the child's well-being and their future autonomy, when their parents endanger these goods. Yet, this intervention can only happen when the parents do not exercise their duty conscientiously. The intervention must not happen because the authorities simply prefer a different course of action. As such, it is not our objection that in the UK the Crown is the *parens patriae* (Feikert 2015). Justice demands that the vulnerable be taken care of, and Aquinas—in the aforementioned passage—acknowledges the civil authority of monarch. Following Aquinas's argument, our objection is that the way the courts in these cases have acted was contrary to the natural order, for the parents who were acting reasonably in their children's interest—indeed in Evan's case, the judge said that (*Alder Hey Children's NHS Foundation Trust* v. *R* [2018] EWHC 308 (Fam), para. 36):

> [A]nybody sitting in Court would immediately recognise, F's [Evan's father's] presentation of his case was extraordinarily impressive. His knowledge of the paperwork and the medical records was prodigious. His understanding of the functioning of the brain and his exploration of competing hypothesis was remarkable. At one point in the evidence when he had asked a question of particular complexity I asked him if somebody had been providing the questions for him. He told me, entirely convincingly, that he had written it out a moment or two before. His uncle, sitting next to him, confirmed it. F left school at 16. He served an apprenticeship as a plasterer. It says much about his commitment to his son and the time and energy he has directed to this case that he has absorbed the issues so completely and intelligently. He believes passionately that his view of Alfie's future is the correct one. As I said during the course of the evidence it can only be in Alfie's interest for all the available theories to be evaluated. On this premise therefore Alfie could have had no more articulate voice on his behalf than his father's in this Court room.

If only one management option will be accepted by medical teams and courts, one should begin to wonder why parents are asked to consent to begin with. Seeking parental consent begins to appear as a masquerade, the outcome already being predetermined—parenthood is reduced to a devolved power—a retractable license.

Standard Case of Parenthood

When considering what is reasonable for a parent to do regarding the treatment of their child, one should briefly consider the concept of the standard case (Finnis 2011, 9–11—"central case"; Braine 1993, 81–82—"normal case") of a parent—that is, an ordinary (decent) parent, as opposed to the ideal parent or bad parent. As the maxim goes, "hard cases make bad laws." Thus, the law should be based on what ordinary parents should be expected to do.

It is virtually impossible to define exactly what "ideal parents" should do when faced with a challenging medical situation. But is clear that we would ordinarily expect parents to be making decisions directed toward the flourishing of their child's life, health, and well-being. The law should only demand that parents make decisions guided in this manner, rather than demanding an impossible best interest decision, an intimate, nuanced adjudication that the state is ill-equipped to make. Best interest decisions must encompass any relevant "broader ethical, social, moral and welfare consideration" (In Re S. (Adult Patient: Sterilisation) [2000] 3 WLR 1288). It seems hard to comprehend how a liberal state could judge between competing ethical and moral frameworks, since liberalism cannot judge among competing goods (MacIntyre 2013, 337).

While extraordinary medical interventions do not always enhance well-being, they can in certain circumstances be effective in tempering a pathology, though often at the cost of significant suffering. As such, it is not unreasonable for parents either to seek such extraordinary measures for their children (ideally with input from the palliative team) or to choose comfort care alone for them. Balancing between suffering and medical gains is formidable, and we do not expect parents to make perfect choices for their children, we only expect them to make informed and reasonable choices (Griffiths and Danbury 2015; The Anscombe Bioethics Centre 2017). Parents must be acting against their child's best interest in a very unambiguous manner for the state to veto the best judgments of parents and impose its will on the governance of a family.

One might wonder why physicians even approach parents for consent in their children's end-of-life decisions, if those parents' choice to act on a reputable second opinion prompts calls for the brusque intervention of the state. It is further questionable how the state can presume to have superior moral reasoning than competent parents. England, it appears, will grant only "hobby" autonomy to parents while circumstances are of minor significance.[4] Should the situation be of import, the parents must either ensure that their choices are congruent with zeitgeist or the state will make that "proper" choice on their behalf. The existence of such a dynamic is baffling in an era where medical paternalism is a virtual byword for tyranny.

Medical Objections

Healthcare professionals are trained to provide good care for their patients and to judge which treatments are appropriate. They are not obliged to provide treatments that are not geared toward their patients' health (Selinger 2009; NHS Choices 2015). As such, they should be free to object to performing treatments that they do not deem to be beneficial to their patients (Saad 2018). However, it is not the physician's role to consent to treatment. In the case of a minor,[5] this is the role of the competent and informed parent or guardian. The physician's role is merely to ensure that the parents are informed, competent, and reasonably responsible, not perfect (and parents should not be labeled irresponsible merely on the grounds that they disagree with the physician).

Rather than having a system where courts must side with one opinion or another, it could be possible to have a process where the courts simply agree that it is appropriate to withdraw extraordinary means of treatment, while not banning the parents from transferring their children's care to other competent healthcare professionals who are willing to provide the sought treatment.[6] Under such circumstances, similar to the provisions proposed by O'Loan (2017) regarding conscientious objection, the medical team would not be obliged to treat the patient or facilitate their transfer, they would merely be required not to actively prevent it; a similar approach has been previously advocated elsewhere (Jonsen, Siegler, and Winslade 2015, 31). This approach respects both the parental instinct to care for their children, as well as the professional expertise and medical outlook of those carrying for the patient.

Conclusion

Jurisdictions where parental preference is easily overridden by the courts, such as England, would do well to reassess their vision of parenthood, and the rights and obligations that come with it. It is critical that the family remains the key building block of society and that we only expect parents to make reasonable, not perfect, decisions. Indeed, parents, in general, make their decisions in such situations with the love of their children in mind. Where there is doubt as to what is in the child's best interest, it would be wise to heed to the parents' determination. Similarly, the medical staff's expert opinion should be respected, and they should not be forced to act against their conscience, but they should not obstruct their patients' transfers of treatment. In jurisdictions where parental preference is respected, especially those systems kin to the English legal system, careful reflection should be given before the cases of Gard and Evan are allowed to sway law or judicial opinion.

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Notes

1. The article will refer to English law, as there are some differences in the laws between the various constitutive

nations of the United Kingdom, though most points highlighted in this article are applicable to the whole of the United Kingdom.

2. By contrast, an adjudication of the worthiness of Evans's life did play a part in the courts judgment (Wee 2019).
3. The reader should be aware that there is some discussion regarding concepts such as subsidiarity, devolution, and federalism (Ditchley 2000).
4. In the United States, some signs of such judicial incursion into parental rights have been seen in cases regarding gender transitioning (see, e.g., Richardson 2018). Contrastingly, in the UK, once a child is deemed capable of giving informed consent, either by satisfying the Gillick criteria (*Gillick* v. *West Norfolk and Wisbech Area Health Authority and Another*—[1985] 3 All ER 402) or once they have reached their sixteenth year of life (and do not have any relevant impairments), parents cannot override their child's consent for a medical procedure; parents could only override such a child's refusal to undergo treatment (Care Quality Commision 2017).
5. Barring cases of abuse and neglect.
6. The converse should be allowed as well. If parents want extraordinary therapeutic means withdrawn, but the medical team refuses to do it (e.g., because they hold a vitalist worldview), the team should not prevent the child's transfer to a facility where those extraordinary means would be removed. The exception would be if the medical team suspected that at the new location ordinary care would also be refused.

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