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Elchanan G. Stern
Cleveland-Marshall College of Law

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PARENS PATRIAE AND PARENTAL RIGHTS: WHEN SHOULD THE STATE OVERRIDE PARENTAL MEDICAL DECISIONS?

ELCHANAN G. STERN, CLEVELAND MARSHALL COLLEGE OF LAW, J.D. 2020

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I. INTRODUCTION

“The death of a baby is like a stone cast into the stillness of a quiet pool; the concentric ripples of despair sweep out in all directions, affecting many, many people.” - John DeFrain

“Grief fills the room up of my absent child; Lies in his bed, walks up and down with me; Puts on his pretty look, repeats his words; Remembers me of his gracious parts; Stuffs out his vacant garments with his form.” - William Shakespeare, *The Life and Death of King John*

Alfie Evans was a terminally ill British child whose parents, clinging to hope, were desperately trying to save his life.¹ Hospital authorities disagreed and petitioned the court to enjoin the parents from removing him and taking him elsewhere for treatment.² The court stepped in and compelled the hospital to discontinue life support and claimed that further treatment was not in the child’s best interest.³

Alfie’s story is a complicated one. It weaves passionate emotions together with cold and detached legal analysis. It pits parents and authorities against each other in a battle of who is most properly suited to determine the “best interest” of a child.⁴ Should the historical right of the parents prevail or the court’s obligation to protect the child’s welfare? Are the parents violating their child’s autonomy in his medical decision-making or is the court usurping the parents’ responsibility of care? It is a profoundly moving human-interest story of pain and suffering that tugs at one’s heartstrings.

What ought to happen when the wishes of parents and the concerns of the state collide? This note discusses the heartbreaking stories of Alfie and two other children, whose parents’ medical decisions on their behalf were overridden by the court. It argues that courts should never decide that death is in a child’s best interest and compel parents to withdraw life support from their

¹ *Timeline: How parents fought to save Alfie*, SKY NEWS (Apr. 28, 2018), <https://news.sky.com/story/timeline-the-fight-to-keep-alfie-evans-alive-11344694>

² *Id.*

³ *Id.*

⁴ The expression “best interest of the child” is commonly used by courts as the dominant consideration in all actions concerning children. It is primarily used in the context of child welfare laws regarding abused and neglected children as well as in family law. *See* Child Welfare Information Gateway, *Determining the Best Interests of the Child*, www.childwelfare.gov. *See also* *Reno v. Flores*, 507 U.S. 292, 303 (1993) (“‘The best interests of the child,’ a venerable phrase familiar from divorce proceedings, is a proper and feasible criterion for making the decision as to which of two parents will be accorded custody. But it is not traditionally the sole criterion—much less the sole constitutional criterion—for other, less narrowly channeled judgments involving children, where their interests’ conflict in varying degrees with the interests of others. ‘The best interests of the child’ is not the legal standard that governs parents’ or guardians’ exercise of their custody: so long as certain minimum requirements of child care are met, the interests of the child may be subordinated to the interests of other children, or indeed even to the interests of the parents or guardians themselves.”). The “best interest of the child” principle is derived from Article 3 of the UN Convention on the Rights of the Child, which says that “in all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.” G.A. Res. 45/25, *Convention on the Rights of the Child* (Nov. 20, 1989). *See also* Committee on the Rights of the Child, *General Comment No. 14* (2013), par. 47. (requiring the relevant authorities to evaluate and balance “all the elements necessary to make a decision in a specific situation for a specific individual child or group of children.”).

children.⁵ Such a decision is outside the scope of the judiciary. Furthermore, it argues that even in those instances when the court may or must intervene, a new framework is necessary because the current framework used by the court to determine the best interest of the child ignores fundamental realities of child psychology. Too often, as a result of the court's mistaken framework, the court illegitimately trespasses into the parental domain. By adopting a new framework, the court will intervene only when actual abuse or neglect is suspected. In all other cases, judicial restraint will be practiced, and the court will show greater deference to the parents' wishes.

Part II of this note lays out the basic legal landscape regarding parents' rights over their children. In addition, it addresses the notion of autonomy, specifically in the arena of medical care, that underlies the analysis surrounding the courts' determination of the child's best interest. Furthermore, it shows how these concepts were used in deciding the Evans, Gard, and Ali cases.

Part III of this note delves into the parental rights/obligation debate from a historical and philosophical perspective. It discusses how much deference the courts must give to parental decisions regarding alternative medicine treatments for their children. It analyzes the court's framework in deciding when the child's care is not in his best interest. It shows that the court improperly inserted itself to override the wishes of the parents in Evans and Gard.

Part IV of this note provides a new and better framework for judicial intervention based on accepted psychological research and judicial prudence. It argues that children so strongly identify with their parents from birth that the parents' decision must be construed as the wish of the child as well. The courts should only intervene when parents are abusing or neglecting their child. It also provides boundaries for defining abuse and neglect. Finally, it applies the new framework to three specific cases. It shows how the court overstepped its authority in Evans and Gard, while in the case of Ali, the court rightfully determined that the parents' inaction had crossed the line into neglect.

II. BACKGROUND

The range of philosophical approaches concerning the relationship between children and those who raise them are astounding in their disparity. Aristotle believed that children are the property of their parents.⁶ Plato, in the Republic, considered children to be the property of the state.⁷ In modern times this debate is much more nuanced. Do parents have a constitutionally protected right, derived from natural law, to direct the upbringing of their children, or do parents have a duty, derived from the state, to care for their children?

The question of a parental right vs. a parental duty is a hotly contested topic among contemporary philosophers and legal scholars.⁸ If there is a constitutional right, how far does it

⁵ The decision whether to begin, continue, or discontinue necessary medical therapy is commonly based on a number of different approaches. *See generally* J. GLOVER, CAUSING DEATH AND SAVING LIVES, 92-116, (Penguin Books 1977). *See also* WHO SPEAKS FOR THE CHILD? (W. Galvin et al. eds., Penguin Books, 1982). *See also* J.M. Freeman & K. McDonnell, *Termination of Care of Newborn Infants*, 4 SEMINARS IN NEUROLOGY (Mar. 1984), <https://www.ncbi.nlm.nih.gov/pubmed/11649665>

⁶ Aristotle, NICOMACHEAN ETHICS, 1134b.

⁷ Plato, REPUBLIC, 423e6-424a2. (“[T]he wives of our guardians are to be common, and their children are to be common, and no parent is to know his own child, nor any child his parent.”).

⁸ *See* LEWIS HOCHHEIMER, THE LAW RELATING TO THE CUSTODY OF INFANTS, 22, 3^d ed. (Baltimore, H.B. Scrimger, 1899) (“[T]he general result of the American cases may be characterized as an utter repudiation of the notion, that there can be such a thing as a proprietary right or interest in or to the custody of an infant. The terms ‘right’ and ‘claim’ when used in this

extend? If there is no constitutional right, rather a state-mandated parental obligation to care for one's child, how much deference should the state give parents regarding the upbringing of their children? One thing for certain is that, practically, the primacy of parents over everyone and everything else to determine what is best for their child is an idea firmly rooted in our social fabric and conscience.⁹ As a corollary, the state will not interfere unless the parents are not fulfilling their legal obligation to act in the best interest of their child.¹⁰

In the United Kingdom, both parental obligations to their children and the power of the state to intervene is statutory.¹¹ The Children Act of 1989, passed by the British Parliament, assigns the welfare of children to state authorities, courts, and parents. Its purpose is to ensure that children are safeguarded, and their welfare is promoted. It centers on the idea that children are best cared for within their own families;¹² however, it also makes provisions regarding the removal of a child from his/her family in instances when parents and families do not cooperate with statutory bodies.¹³

Underpinning the state's common law and statutory authority to intervene and override parental decisions is the notion that children have individual autonomy and a right to self-determination.¹⁴ Personal autonomy, in the context of medical decision-making, is a basic and

connection, according to their proper meaning, virtually import the right or claim of the *child* to be in that custody or charge which will subserve *its* real interests." [emphasis in the original]. See also CHRISTOPHER G. TIEDEMAN, A TREATISE ON STATE AND FEDERAL CONTROL OF PERSONS AND PROPERTY IN THE UNITED STATES, vol. 2 § 195 (F. H. Thomas Law, 1886) ("[T]he authority to control the child is not the natural right of the parents; it emanates from the State, and is an exercise of police power."). Cf. *Kraft v. Jacka*, 872 F.2d 862, 871 (9th Cir. 1989) (basing protection of intimate associational rights on the fourteenth amendment); *IDK, Inc. v. Clark County*, 836 F.2d 1185, 1192 (9th Cir. 1988) (same).

⁹ See *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944) ("It is cardinal with us that the custody, care and nurture of the child reside first in the parents, whose primary function and freedom include preparation for obligations the state can neither supply nor hinder. It is in recognition of this that these decisions have respected the private realm of family life which the state cannot enter.")

¹⁰ See *Custody of a Minor*, 393 N.E.2d 836 (Mass 1979) (determining that use of laetrile in the case of a three-year-old boy who suffered from acute lymphocytic leukemia was "not consistent with good medical practice," and ordered that the child undergo chemotherapy.). *But cf.* In the *Matter of Joseph Hofbauer*, 393 N.E.2d 1009 (NY 1979) (determining that parents were justified in their concern over conventional treatments, that there was medical proof of the effectiveness of laetrile, and that metabolic therapy had fewer risks than radiation or chemotherapy.).

¹¹ Claire Fenton-Glynn, a legal scholar at the University of Cambridge, described the accepted understanding of the parental role in the United Kingdom as follows: "The concept is called parental responsibility: That is, the parent has a responsibility to make decisions, to look after the child. Parenthood doesn't give them rights; parenthood gives them responsibilities." Susan Scutti, *Could Charlie Gard's case happen in the United States?* CNN (July 6, 2017), <https://www.cnn.com/2017/07/06/health/charlie-gard-us-laws/index.html>.

¹² Children Act 1989, c. 1, § 3 (Eng.).

¹³ Children Act 1989, c. 1, § 1 (Eng.).

¹⁴ According to some bioethicists one's "right to life" and one's "autonomy" flow from one's "personhood." One is deemed to have "personhood" if one recognizes and appreciates one's existence and has hopes and dreams for one's future. See J. Harris, *Consent and end of life*

accepted patient right.¹⁵ It is also the ethical theory which supports the legal concept of informed consent,¹⁶ requiring doctors to disclose information to the patient as well as to obtain authorization before conducting medical intervention.¹⁷ Typically, if patients cannot decide for themselves, a legal guardian will decide for them.¹⁸ With young children, as in the cases at hand, the primary authority to decide for the child is given to the parents.¹⁹

A. *The Tragic Story of Alfie Evans*

Alfie Evans was born in May of 2016 as an apparently healthy child, but he began experiencing seizures in December of that year.²⁰ His parents brought him to Alder Hey Children's Hospital in Liverpool, where he remained in a semi-vegetative state until his death in April of 2018.²¹ Doctors were unable to diagnose Alfie's mysterious degenerative neurological condition, but were insistent that his condition was worsening and that the damage done was irreparable.²² Subsequently, against the express wishes of the parents, Alder Hey Hospital decided to remove life support, asserting that further treatments were futile and that keeping Alfie alive, in his state of suffering, was "unkind and inhumane."²³

decisions, J. MED. ETHICS, Feb. 29, 2003 at 10; M. Tooley, *Decision to Terminate Life and the Concept of Person*, in ETHICAL ISSUES RELATING TO LIFE & DEATH (T. Beauchamp et al. eds.) (Oxford University Press 1979); R. Gillon, *Ethics needs principles—four can encompass the rest—and respect for autonomy should be "first among equals,"* J. MED. ETHICS, Sept. 30, 2003 at 307; *See also* B.P. Himmelstein et al., *Pediatric palliative care*, N. ENG. J. MED., Apr. 22, 2004 at 1752; P. Allmark, *Death with dignity*, J. MED. ETHICS, Aug. 1, 2002 at 255.

¹⁵ Regarding a child's competence and his/her ability to engage in informed consent *see* T. Sensky, *Withdrawal of life sustaining treatment*, BMJ, July 27, 2002 at 175; K. Street et al., *The decision-making process regarding the withdrawal or withholding of potential lifesaving treatments in a children's hospital*, J. MED. ETHICS, Oct. 2000 at 346.

¹⁶ *See* Schloendorff v. Soc'y of N.Y. Hosp., 105 N.E. 92, 93 (N.Y. 1914) (Cardozo, J.) ("Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent, commits an assault, for which he is liable in damages.").

¹⁷ RUTH R. FADEN, TOM L. BEAUCHAMP, A HISTORY AND THEORY OF INFORMED CONSENT, Oxford Univ. Press (1986); *See also* JESSICA W. BERG ET AL., INFORMED CONSENT: LEGAL THEORY AND CLINICAL PRACTICE, 6th ed., Oxford University Press (2001)

¹⁸ Aviva L. Katz et al., *Informed Consent in Decision-Making in Pediatric Practice*, 138, AM. ACAD. OF PEDS. TECH. REP. (2016).

¹⁹ *Id.*

²⁰ Tara Isabella Burton, *The controversy surrounding the death of British toddler Alfie Evans, explained*, VOX (Apr. 28, 2018), <https://www.vox.com/policy-and-politics/2018/4/27/17286168/alfie-evans-toddler-uk-explained>

²¹ *Id.*

²² *Id.*

²³ Alder Hey NHS Trust v. Evans [2018] EWHC 308 (Fam) (Eng.).

Alfie's parents disagreed with the doctors' conclusions. His father claimed that Alfie "looks him in the eye" and "wants help."²⁴ The parents considered Alder Hey Hospital's decision to remove life support from Alfie to be a violation of their parental rights to decide what is in the best interest of their child.²⁵ They even lobbied for additional care for Alfie at the Bambino Gesù Hospital in Vatican City.²⁶ Alder Hey Hospital officials refused, insisting that transporting Alfie would create risks to his life as well as cause him undue pain.²⁷

The battle went to the courts. In the United Kingdom, as in the United States, when parents and doctors disagree over the proper care for a child, the courts make the final decision.²⁸ Alfie's case began on December 19, 2017 in the Family Division of the High Court in London.²⁹ Lawyers arguing on Alder Hey Hospital's behalf claimed that there was "no hope" for Alfie.³⁰ The hospital further asked the Court for a declaratory judgment that it would be unlawful to continue Alfie's treatment and that life support should be discontinued.³¹ Alfie's parents countered that it was their right to determine the appropriate medical care for their son and that their consent was necessary before Alder Hey Hospital could make any medical decisions on behalf of their child.³²

On February 20, 2018, the High Court ruled in favor of Alder Hey Hospital.³³ Justice Anthony Hayden wrote in his decision that "[I]t was entirely right that every reasonable option should be explored for Alfie. I am now confident that this has occurred. The continued provision of ventilation, in circumstances which I am persuaded is futile, now compromises Alfie's future dignity and fails to respect his autonomy. I am satisfied that continued ventilatory support is no longer in Alfie's best interest."³⁴

²⁴ *Id.*

²⁵ *Alfie Evans: Parents and doctors to discuss sending toddler home*, BBC NEWS (Apr. 26, 2018), <https://www.bbc.com/news/uk-england-merseyside-43904809>

²⁶ Josh Halliday, *Alfie Evans: continuing life support 'inhumane'*, *Liverpool court hears*, THE GUARDIAN (Feb. 1, 2018), <https://www.theguardian.com/uk-news/2018/feb/01/alfie-evans-continuing-life-support-inhumane-liverpool-court-hears>.

²⁷ *Alder Hey NHS Trust v. Evans* [2018] EWHC 308 (Fam) (Eng.) (Hayden J).

²⁸ Tara Isabella Burton, *The controversy surrounding the death of British toddler Alfie Evans, explained*, VOX (Apr. 28, 2018), <https://www.vox.com/policy-and-politics/2018/4/27/17286168/alfie-evans-toddler-uk-explained>

²⁹ *Timeline: The fight to keep Alfie Evans alive*, SKY NEWS (Apr. 28, 2018), <https://news.sky.com/story/timeline-the-fight-to-keep-alfie-evans-alive-11344694>.

³⁰ *Alder Hey NHS Trust v. Evans* [2018] EWHC 308 (Fam) (Eng.) (Hayden J).

³¹ *Id.*

³² *Alfie Evans: When are parents denied the final say?* BBC NEWS (Apr. 28, 2018), <https://www.bbc.com/news/uk-43893709>.

³³ *Alder Hey NHS Trust v. Evans* [2018] EWHC 308 (Fam) (Eng.) (Hayden J).

³⁴ *Id.*

On March 1, 2018, Alfie's parents appealed the High Court's decision to the Court of Appeal.³⁵ The appellate court upheld the lower court's decision, and claimed that the court had been "meticulous and thorough" in its investigations, had "heard high-quality expert evidence, and accorded weight to all the arguments raised."³⁶ On March 20, Alfie's parents appealed again to the Supreme Court of the United Kingdom, but the court rejected their claim for another appeal.³⁷ Alfie's parents continued to argue that Alder Hey Hospital's refusal to allow Alfie to receive treatment elsewhere deprived him of his liberty and violated Article 5 of the European Convention on Human Rights.³⁸ They then brought his case before the European Court of Human Rights, which found no human rights violation and dismissed the case.³⁹

There was significant public reaction and attention given to the case.⁴⁰ Pope Francis, after a 20-minute meeting with Alfie's father on April 18,⁴¹ tweeted that: "Sincere hope that everything necessary may be done in order to continue compassionately accompanying [sic] little Alfie Evans, and that the deep suffering of his parents may be heard...moved by the prayers and immense solidarity shown little Alfie Evans, I renew my appeal that the suffering of his parents may be heard and that their desire to seek new forms of treatment may be granted."⁴²

On April 23, it was reported that life support had been removed from Alfie.⁴³ Alfie continued to breathe unassisted, and Alfie's father requested the next morning that life support be reinstated.⁴⁴ Alfie's parents appealed again to Justice Hayden, of the High Court, to allow Alfie to be flown to a hospital in Italy for treatment. Justice Hayden again denied their request, stating that it was impossible for Alfie to recover from the corrosion to his brain, and that all the hospital in Rome

³⁵ *Timeline: The fight to keep Alfie Evans alive*, Sky News (Apr. 28, 2018), <https://news.sky.com/story/timeline-the-fight-to-keep-alfie-evans-alive-11344694>.

³⁶ E (A Child), Re [2018] EWCA (Civ) 550 (Eng.).

³⁷ In the matter of Alfie Evans [2018] UKSC (Eng.).

³⁸ *Evans v. the United Kingdom*, 118 Eur. Ct. H.R. (2018).

³⁹ *Id.*

⁴⁰ Steve Graves et al., *Alfie Evans timeline: How one young boy captured the hearts of millions*, THE LIVERPOOL ECHO (Apr. 28, 2018), <https://www.liverpoolecho.co.uk/news/liverpool-news/alfie-evans-timeline-legal-battle-14312017>; @AndrzejDuda, TWITTER (Apr. 24, 2018) ("Alfie Evans must be saved! His brave little body has proved again that the miracle of life can be stronger than death. Perhaps all that's needed is some good will on the part of decision makers. Alfie, we pray for you and your recovery!"); *Alfie Evans granted Italian citizenship*, BBC NEWS (Apr. 23, 2018), <https://www.bbc.com/news/uk-england-merseyside-43872678>.

⁴¹ Sergio Centofanti, *The Pope's meeting with the father of Alfie Evans*, VATICAN NEWS (Apr. 18, 2018), <https://www.vaticannews.va/en/pope/news/2018-04/pope-francis-meeting-with-father-alfie-evans.html>.

⁴² *Pope Francis renews appeal for Alfie Evans*, VATICAN NEWS (Apr. 24, 2018), <https://www.vaticannews.va/en/pope/news/2018-04/pope-alfie-evans-twitter-appeal.html>.

⁴³ *Life support has been withdrawn from Alfie Evans, says father*, THE GUARDIAN (Apr. 23, 2018), <https://www.theguardian.com/uk-news/2018/apr/23/alfie-evans-european-court-human-rights-life-support>.

⁴⁴ *Alfie Evans' father reveals son has been breathing unassisted after life support stops*, THE TELEGRAPH (Apr. 24, 2018), <https://www.telegraph.co.uk/news/2018/04/24/alfie-evans-father-reveals-son-has-breathing-unassisted-life/>.

could do was provide an alternative palliative care plan.⁴⁵ On April 28, 2018, at 2:30 AM, Alfie passed away.⁴⁶ Tom Evans, Alfie's father, wrote in a Facebook posting later that day, "My gladiator lay down his shield and gained his wings... absolutely heartbroken."⁴⁷

The Alfie Evans saga followed the similarly high-profile and contentious case of Charlie Gard, also involving an incapacitated child and the legal battle over his "best interest." Much of the legal/ethical discussions found in Evans are relevant to the Charlie Gard case. A brief synopsis of Gard is therefore in order.

B. *The Tragic Story of Charlie Gard*

Charlie Gard was a British infant born in London, England on August 4, 2016, with a rare fatal genetic disease known as mitochondrial DNA depletion syndrome.⁴⁸ This disease causes progressive brain damage and muscle failure for which there is no treatment.⁴⁹ In October of 2016, Charlie's parents brought him to Great Ormond Street Hospital (GOSH) because he had difficulty breathing.⁵⁰ He was put on a ventilator.⁵¹

In November of 2016, Charlie was formally diagnosed, and his parents and doctors agreed to try experimental treatment.⁵² In January 2016, before any treatment had commenced, Charlie suffered seizures that caused more brain damage, and the doctors withdrew their support for continued treatment.⁵³ They claimed that subjecting Charlie to more treatment was futile and would only prolong his suffering, and they therefore advocated the removal of life support.⁵⁴ Charlie's parents disagreed, and the case went to court.⁵⁵ The courts consistently agreed with GOSH's position and Charlie's parents eventually dropped their challenge.⁵⁶ On July 27, Charlie

⁴⁵ Alder Hey Children's NHS Foundation Trust v. Evans & Anor [2018] EWHC 953 (Fam) (Eng.).

⁴⁶ Chris Graham, *Alfie Evans dies after long-running legal battle*, THE DAILY TELEGRAPH (Apr. 28, 2018), <https://www.telegraph.co.uk/news/2018/04/28/alfie-evans-dies-long-running-legal-battle/>.

⁴⁷ *Legal battle toddler Alfie Evans dies*, BBC NEWS (Apr. 28, 2018), <https://www.bbc.com/news/uk-43933056>.

⁴⁸ Robert Mendick, *Charlie Gard: The tragic case of a too short life*, THE TELEGRAPH (July 28, 2017), <https://www.telegraph.co.uk/news/2017/07/28/charlie-gard-tragic-case-short-life/>.

⁴⁹ *Id.*

⁵⁰ Mr Justice Francis Great Ormond Street Hospital v Yates & Ors [2017] EWHC 972 (Fam).

⁵¹ *Id.*

⁵² *Id.*

⁵³ *Id.*

⁵⁴ *Id.*

⁵⁵ *Charlie Gard's parents say their 'beautiful boy' has died*, THE TELEGRAPH (July 28, 2017), <https://www.theguardian.com/uk-news/2017/jul/28/charlie-gard-dies>.

⁵⁶ *Id.*

was transferred to hospice and was removed from life support the next day.⁵⁷ He was given morphine to eliminate any possible residual pain and died within minutes.⁵⁸

Public reaction to the dispute between Charlie's parents and GOSH was quick and furious. Charlie's parents set up a GoFundMe campaign in January 2017.⁵⁹ By April, more than £1.3 million had been raised.⁶⁰ Support for Charlie's parents was expressed by President Donald Trump, Vice President Mike Pence,⁶¹ and Pope Francis.⁶² Serious questions of medical ethics surrounded the case.⁶³ Was it in Charlie's best interest to receive experimental treatment whose efficacy was still unproven? Did the potential benefits of this experimental treatment outweigh its potential risks?⁶⁴ Medical ethicists debated whether the courts were right to override the parents' wishes.⁶⁵ Some argued that the court should decide a child's fate if there is a disagreement between

⁵⁷ Robert Mendick, *Charlie Gard: The tragic case of a too short life*, THE TELEGRAPH (July 28, 2017), <https://www.telegraph.co.uk/news/2017/07/28/charlie-gard-tragic-case-short-life/>.

⁵⁸ *Id.*

⁵⁹ Richard Hartley-Parkinson, *Fund for sick baby reaches £400,000 – but another £800,000 is needed*, METRO (Mar. 21, 2017), <https://metro.co.uk/2017/03/21/fund-for-sick-baby-reaches-400000-but-another-800000-is-needed-6523035/>.

⁶⁰ *£27,000 donation to fund to send sick Charlie Gard to US for treatment*, YORKSHIRE EVENING POST, April 27, 2017.

⁶¹ Robert Mendick, *Hospitals refuse to take Charlie Gard as relations between his parents and Great Ormond Street plummet*, THE TELEGRAPH (July 11, 2017), <https://www.telegraph.co.uk/news/2017/07/11/hospitals-refuse-take-charlie-gard-relations-parents-great-ormond/>.

⁶² Vincenzo Paglia (Archbishop), *Vatican's Academy for Life issues statement on baby Charlie Gard*, VATICAN RADIO (June 29, 2017), http://www.archivioradiovaticana.va/storico/2017/06/29/vaticans_academy_for_life_issues_statement_on_baby_charlie_gard/en-1322138; Divya Kishore, *Pope Francis says wishes of brain-damaged baby Charlie Gard's parents should be respected*, INT'L BUS. TIMES U.K. (July 3, 2017), <https://www.ibtimes.co.uk/pope-francis-says-wishes-brain-damaged-baby-charlie-grads-parents-should-be-respected-1628658>.

⁶³ See Clare Dyer, *Law, ethics, and emotion: the Charlie Gard case*, BMJ, July 4, 2017, <https://www.bmj.com/content/358/bmj.j3152.full>; Dominic Wilkinson et al., *The Charlie Gard Case: British and American approaches to court resolution of disputes over medical decisions*, JOURNAL OF PERINATOLOGY, Dec. 2017, at 1268; Dominic Wilkinson, *Debate Response: Charlie Gard, Interests and Justice – an alternative view*, PRACTICAL ETHICS, University of Oxford (Apr. 26, 2017), <http://blog.practicaethics.ox.ac.uk/2017/04/debate-reponse-charlie-gard-interests-and-justice-an-alternative-view/>.

⁶⁴ *Reality Check: Why don't Charlie Gard's parents have the final say?* BBC NEWS (July 14, 2017), <https://www.bbc.com/news/uk-40600932>; Susan Scutti, *Could Charlie Gard's case happen in the US?* CNN (July 6, 2017), <https://www.cnn.com/2017/07/06/health/charlie-gard-us-laws/index.html>.

⁶⁵ Dominic Wilkinson, *Agreement and disagreement about experimental treatment. The Charlie Gard Appeal* PRACTICAL ETHICS, University of Oxford (May 22, 2017), <http://blog.practicaethics.ox.ac.uk/2017/05/agreement-and-disagreement-about-experimental-treatment-the-charlie-gard-appeal/>; Richard Doerflinger, *A More Human Society – Who speaks for Charlie Gard?* ST. LOUIS REV., Roman Catholic Archdiocese of St. Louis (July 20,

the parents and the hospital, provided that the parents' position is deemed "unreasonable." They disputed, however, whether the disagreement in the case at hand met that criterion.⁶⁶

In the cases of both Alfie Evans and Charlie Gard, the issue before the court was the parents' right to choose affirmative treatment for their child. The courts evoked the principle of autonomy and the human dignity of the child in determining that the parents' choice of treatment was improper. The court ordered life support to be removed. It would be better for Alfie and Charlie to die, the court reasoned, than to continue living in such a compromised state.

In the case below, the opposite prevailed. A child was at risk of dying if treatment was not given. Her parents wanted to take an alternative/holistic approach in lieu of accepted, empirically based medical treatment. The court evoked the above principles of autonomy and best interest of the child and compelled the parents to provide the court-ordered treatment in order to save the child's life.

C. *Zara Ali and Her Untreated Brain Tumor*

Zara Ali was a fourteen-year-old girl who came to the Cleveland Clinic Emergency Room in September of 2017 with headaches and vomiting.⁶⁷ Doctors diagnosed her with a rare, slow-growing, noncancerous brain tumor.⁶⁸ The tumor was inoperable and had already left her legally blind in one eye.⁶⁹ In October, Dr. Stacey Zahler, a pediatric cancer specialist at the Cleveland Clinic, recommended two chemotherapy drugs which would potentially shrink the tumor or at least keep it from growing.⁷⁰ Zara's parents, who are of Moorish background, wanted to treat her holistically with frankincense, turmeric, and tea.⁷¹ Doctors agreed to hold off for some time while they monitored the tumor and to wait and see if the parents' approach would help.⁷² By the end of December, doctors told the Alis that Zara needed chemotherapy.⁷³ The Alis refused and the

2017), <https://www.archstl.org/a-more-human-society-who-speaks-for-charlie-gard-1543>; *The Moral Maze*, BBC RADIO 4 (July 12, 2017), <https://www.bbc.co.uk/sounds/play/b08xbjj6>.

⁶⁶ Dominic Wilkinson, *The sad case of Charlie Gard and the rights and wrongs of experimental treatment*, PRACTICAL ETHICS BLOG (July 6, 2018), <http://blog.practicaethics.ox.ac.uk/2017/07/the-sad-case-of-charlie-gard-and-the-rights-and-wrongs-of-experimental-treatment/>; Julian Savulescu, *The Moral of the Case of Charlie Gard: Give Dying Patients Experimental Treatment...Early*, PRACTICAL ETHICS BLOG (July 5, 2017), <http://blog.practicaethics.ox.ac.uk/2017/07/the-moral-of-the-case-of-charlie-gard-give-dying-patients-experimental-treatment-early/>.

⁶⁷ Andrea Simakis, *Cleveland Clinic, parents clash over girl's brain tumor treatment; court to decide*, THE PLAIN DEALER (May 13, 2018), https://www.cleveland.com/metro/2018/05/cleveland_clinic_parents_clash.html.

⁶⁸ *Id.*

⁶⁹ *Id.*

⁷⁰ *Id.*

⁷¹ *Id.*

⁷² *Id.*

⁷³ *Id.*

doctors reported them to Cuyahoga County's division of Children and Family Services for suspected child abuse and neglect.⁷⁴

A dramatic and heated court battle ensued. The Ali's were adamant that they had a right to decide the proper course of treatment for Zara "without outside interference."⁷⁵ The prosecutor, Amy Carson, countered that "there is settled case law that the religious faith of the parents . . . does not permit [them] . . . to expose the child to progressive ill health and death, which I think is the case here."⁷⁶ She asked Cuyahoga County Juvenile Court Magistrate Ginny Millas to compel medical treatment but allow Zara to stay with her family.⁷⁷ Millas ordered that Zara would have to begin chemotherapy in April of 2018.⁷⁸ The Alis asked the court for more time to seek a second medical opinion.⁷⁹ By July, Zara still had not received chemotherapy treatment.⁸⁰ On July 29th, Zara fell unconscious at home and was rushed to the hospital. She remained in a coma until she died on August 8th, after being removed from a ventilator with her mother at her side.⁸¹ On August 10th, a judge, who was unaware of her death, ordered chemotherapy to begin immediately.⁸²

III. ANALYSIS

For centuries, society has balanced two fundamental imperatives: (1) the parents' right to raise and provide for their children as they see fit, and (2) the state's responsibility to care for the child's best interest. At times, these two imperatives have come into conflict. Courts have stepped in to override parental decisions in cases where the court held the child's best interest was served otherwise. I contend that, in some cases, the court enters a millennia old quagmire of philosophical, theological, and teleological questions by rendering decisions regarding which lives are worth living. In doing so, the court engages in judicial overreach, which ought to be restrained. The courts should never condemn an innocent person to die and should never compel parents or hospitals to remove life support.

Courts may intervene, however, in cases where the life of the patient is at stake and the dispute between the parents and the hospital is over which life-saving treatment is best for the child. At the same time, courts must not intervene at whim or intrude into the parental sphere unnecessarily. Deference must still be given to parental decisions. Here I contend that the courts use a mistaken

⁷⁴ *Id.*

⁷⁵ *Id.* Zara herself came across to the doctors as having the maturity of an 8-9-year-old rather than a 14-year-old. They therefore considered her opinion to carry less weight in determining the proper course of treatment for her tumor. *Id.*

⁷⁶ *Id.*

⁷⁷ *Id.*

⁷⁸ *Id.*

⁷⁹ *Id.*

⁸⁰ Natalie Rahhal, *Girl, 14, dies of untreated brain tumor after a year-long legal battle over the chemotherapy her homeopathic parents didn't want her to have*, DAILY MAIL (August 13, 2018), <https://www.dailymail.co.uk/health/article-6056419/Girl-14-dies-brain-tumor-year-long-court-battle-chemo-despite-parents-wishes.html>.

⁸¹ *Id.*

⁸² *Id.*

formula by viewing the (young and incapacitated) child as a wholly separate entity from his/her parents. Based on this view, the courts give the child an independent role in deciding his/her medical care (through a state-appointed trustee). This approach ignores the fundamental principle of primary identification, which posits that emotionally, the parents and child are one.

A. *Constitutional and British Common Law Basis of Parental Rights*

Before elaborating on what I believe is the proper standard to determine the best interest of the child, a brief discussion of the foundational principles of parental rights is appropriate. It is commonly assumed that parents have a constitutionally protected right to care for their children as they see fit. This notion may be one of the oldest liberty interests recognized by the Supreme Court.⁸³ It has been upheld in many contexts including education,⁸⁴ custody,⁸⁵ and medical care.⁸⁶ This constitutional right is protected by the Fourteenth Amendment;⁸⁷ its roots are found in British common law, predicated in natural law, and predate the founding of this country. John Locke, in his *Second Treatise of Civil Government*, first published in 1690, states: “From him (Adam) the world is peopled with his descendants, who were all born infants, weak and helpless, without knowledge or understanding; but to supply the defects of this imperfect state, till the improvement of growth and age hath removed them, Adam and Eve, and after them all parents were, by the law of nature, [emphasis added] under an obligation to preserve, nourish, and educate the children they had begotten. . . . This is that which puts the authority into the parents’ hands to govern the minority of their children [emphasis added]. G-d hath made it their business to employ this care on their offspring and hath placed in them suitable inclinations of tenderness and concern to temper this power, to apply it, as his wisdom designed it, to the children’s good, as long as they should need to be under it.”⁸⁸

Others disagree with the notion that parents have a constitutional right, per se, to raise their children as they see fit. This view classifies the parental interest in child-rearing as a trust. The state entrusts parents with the custody and care of their child. Parents have duties and obligations to care for their children – not rights over the care and custody of their children. As Supreme Court Justice

⁸³ *Troxel v. Granville*, 530 U.S. 57, 65 (2000) (“The liberty interest...of parents in the care, custody, and control of their children is perhaps the oldest of the fundamental liberty interests recognized by [the] Court.”). *See also* *Wisconsin v. Yoder*, 406 U.S. 205, 232 (1972) (“The history and culture of Western civilization reflect a strong tradition of parental concern for the nurture and upbringing of their children. This primary role of the parents in the upbringing of their children is now established beyond debate as an enduring American tradition.”).

⁸⁴ *Pierce v. Soc’y of Sisters*, 268 U.S. 510 (1925) (act which required parents to send their child to public school violated parents’ constitutional right to direct their child’s education).

⁸⁵ *Troxel*, 530 U.S. at 66.

⁸⁶ *Parham v. J. R.*, 442 U.S. 584, 603 (“Most children, even in adolescence, simply are not able to make sound judgements concerning many decisions, including their need for medical care or treatment. Parents can and must make those judgements.”).

⁸⁷ U.S. CONST. amend. XIV; *See Oglala Sioux Tribe v. Van Hunnik*, 993 F. Supp. 2d 1017, 1036 (D.S.D. 2014) (“The Due Process Clause of the Fourteenth Amendment protects the fundamental right of parents to make decisions concerning the care, custody, and control of their children.”).

⁸⁸ JOHN LOCKE, *TWO TREATISES OF GOVERNMENT* 305-09 (Peter Laslett ed., Cambridge Univ. Press 1988) (1690).

Joseph Story wrote in 1816, “[T]he right of parents, in relation to the custody and services of their children, are rights depending upon the mere municipal rules of the state, and may be enlarged, restrained, and limited as the wisdom or policy of the times may dictate.”⁸⁹

Those who follow the view, based on Locke, that child-raising is indeed a constitutional right, it is presumably considered an unenumerated right which is protected by the Due Process Clauses of the Fifth⁹⁰ and Fourteenth⁹¹ Amendments, as noted above.⁹² Supreme Court precedent has construed the “liberty” interest found in the Due Process Clause to shield and protect citizens from government infringement of those rights, deemed by the Court to be “fundamental.”⁹³ The Court has defined a right to be “fundamental” if it is “so rooted in the traditions and conscience as to be ranked as fundamental.”⁹⁴ Such rights receive enormous judicial protection. Courts will apply a standard of “strict scrutiny” and will presume that the law is unconstitutional unless it can be justified by a compelling governmental interest⁹⁵ and the law or policy is narrowly tailored⁹⁶ to achieve that goal or interest.⁹⁷

⁸⁹ United States v. Bainbridge, 24 F. Cas. 946, 949 (C.C.D. Mass. 1816) (emphasis added). See CHRISTOPHER G. TIEDEMAN, A TREATISE ON THE LIMITATIONS OF POLICE POWER IN THE UNITED STATES, 554 (F. H. Thomas Law 1886); see also TIEDEMAN at 552 (“By the abolition of the family relation as a political institution, the child, whatever may be his age, acquires the same claim to liberty of action as the adult, viz.: the right to the largest liberty that is consistent with the enjoyment of a like liberty on the part of others; and he is only subject to restraint, so far as such restraint is necessary for the promotion of the general welfare or beneficial as a means of protection to himself. The parent has no natural vested right to the control of his child.”).

⁹⁰ U.S. CONST. amend. V.

⁹¹ U.S. CONST. amend. XIV, § 1.

⁹² See *Oglala*, 993 F. Supp. 2d, *supra* note 44

⁹³ See e.g. *Skinner v. Oklahoma*, 316 U.S. 535, 541 (1942) (Douglas, J.) (“We are dealing here with legislation which involves one of the basic civil rights of man. Marriage and procreation are fundamental to the very existence and survival of the race. The power to sterilize, if exercised, may have subtle, far-reaching and devastating effects. Any experiment which the State conducts is to his irreparable injury. He is forever deprived of a basic liberty.”). See also *Griswold v. Connecticut*, 381 U.S. 479, 502 (1965) (White, J. concurring) (“In my view this Connecticut law as applied to married couples deprives them of “liberty” without due process of law, as that concept is used in the Fourteenth Amendment.”).

⁹⁴ *Michael H. v. Gerald D.*, 491 U.S. 110, 122 (1989) (citing *Snyder v. Massachusetts*, 291 U.S. 97 (1934) (Cardozo, J.))

⁹⁵ Courts have never clearly defined the parameters of a “compelling state interest.” However, it usually refers to an interest which is deemed necessary or crucial as opposed to something merely arbitrary. See *Kramer v. Union Free School District*, 395 U.S. 621, 627 (1969).

⁹⁶ The law is *not* narrowly tailored if its regulatory reach is overbroad by encompassing too much or if it fails to address essential aspects of the protected right. See *Eisenstadt v. Baird*, 405 U.S. 438, 463-464 (1972) (White, J., concurring in result).

⁹⁷ *Skinner*, 316 U.S. at 541 (“We advert to them merely in emphasis of our view that strict scrutiny of the classification which a State makes in a sterilization law is essential, lest unwittingly, or otherwise, invidious discriminations are made against groups or types of individuals in violation of the constitutional guaranty of just and equal laws.”); See also *Roe v. Wade*, 410 U.S. 113, 155 (1973) (Blackmun, J.).

Modern courts have echoed the common assumption that parents have a long-standing and time-honored right to direct the upbringing of their children.⁹⁸ However, the Supreme Court has yet to regard the right of parents as fundamental and apply a standard of strict scrutiny. Case law has shown a varied standard of judicial review regarding the regulation of parental authority.⁹⁹

In any event, whether parents have a court perceived constitutional right to raise their children, as recent cases show, or hold their children in trust, as expressed by Story, it is understood that parents are in the most-fitting position to decide what is best for their child, and the optimal place for the child to be raised and nurtured is in the family nucleus.¹⁰⁰

B. Limitations on Parental Rights – Compelling State Interest

This putative constitutional right is not without limitations. *Parens patriae*, Latin for “parent of the nation,” is the common law legal doctrine which gives the state the power to intervene when children, or those who can’t take care of themselves, are being neglected. This rule, dating back to at least the 17th century,¹⁰¹ was first applied to adults who were mentally incompetent. Gradually, it evolved to cover state interests involving the welfare of children.¹⁰² This doctrine makes the child’s welfare the court’s paramount concern. It requires the court to step in and enforce parental responsibilities for the welfare and wellbeing of their child. In some cases, even when the parents agree to follow the ruling of an independent arbitrator, if the court holds that the arbitrator’s ruling conflicts with the child’s best interest, the court is obligated to intervene.¹⁰³ However, the state must show a compelling state interest before it deprives parents of this essential right.¹⁰⁴

⁹⁸ *Troxel v. Granville*, 530 U.S. 57, 65 (2000)

⁹⁹ *See Pierce v. Soc’y of Sisters*, 268 U.S. 510 (1925); *see also Meyer v. Nebraska*, 262 U.S. 390, 402-403 (1923) (struck down a state law that prohibited the study of a foreign language as a subject and a means of instruction before the eighth grade). Both *Meyer* and *Pierce* stand for the proposition that the state *can reasonably regulate* all schools. In addition, both *Meyer* and *Pierce* accept the undisputed principle that parents have a duty to educate their children and the state *can define and enforce* this parental obligation.

¹⁰⁰ *Parham v. J. R.*, 442 U.S. 584, 602 (1979) (“The law’s concept of the family rests on a presumption that parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life’s difficult decisions. More important, historically it has recognized that natural bonds of affection lead parents to act in the best interests of their children.”).

¹⁰¹ The Reports of Sir Edward Coke, Knt. [1572-1617]: In Thirteen Parts (John Henry Thomas, ed., John Farquhar Fraser ed., J. Butterworth and Son 1826).

¹⁰² Daniel E. Witte, *People v. Bennett: Analytic Approaches to Recognizing a Fundamental Parental Right Under the Ninth Amendment*, 1996 BYU L. REV. 183, 227-34 (1996).

¹⁰³ An example of the court’s intervention may occur when spouses have executed a Jewish religious divorce (*get*) before a Jewish rabbinical court (*beth din*). Although terms of custody may have been arbitrated between the parents, the secular court must review the decision and override it if it deems it to conflict with the child’s best interest. *See Stanley G. v. Eileen G.* N.Y. L. J., Oct. 13, 1994, at 22.

¹⁰⁴ *In re Marriage of Howard*, 661 N.W.2d 183, 190-192 (Iowa 2003); *Craig v. Craig*, 253 P.3d 57, 62 (Okla. 2011) (custody and visitation). *See also Hoff v. Berg*, 595 N.W.2d 285, 288-291 (N.D. 1999).

Unwarranted state interference is a violation of the parents' Fourteenth Amendment due process rights.¹⁰⁵

C. Parental Rights and Limitations as Applied to Evans and Gard

In both the Alfie Evans and Charlie Gard cases, a suit was filed by hospital authorities to the High Court based on The Children Act of 1989.¹⁰⁶ The hospitals maintained that further treatment of the children was detrimental and petitioned the courts to intervene.¹⁰⁷ It was therefore the courts' responsibility to determine if Alfie's and Charlie's parents were acting in their children's best interest.¹⁰⁸ If they were not acting in their child's best interest, the courts were obligated to override the parents' decision, which is exactly what the courts did.¹⁰⁹ In both cases, the court ruled that it was not in the best interest of the child to continue treatment.¹¹⁰ The courts reasoned that the child would not recover from his illness and further treatment would simply prolong his suffering.¹¹¹

D. Patient Autonomy and Parental Medical Decision-Making

The courts in Evans and Gard spoke of autonomy and the independence of the patient.¹¹² The courts acknowledged, very movingly, that the parents were doing their best to care for their children and faithfully carry out their duties as the children's guardian. As Judge Francis stated in Gard: "I must, again, pay tribute to Chris Gard and Connie Yates for the love and care which they have at all times given to their wonderful boy Charlie. I said in my judgment on 11 April that there are few, if any, stronger bonds known to humankind than the love that a parent has for his or her child. . . ."¹¹³

Judge Hayden in Evans echoed those thoughts: "It says much about his [Alfie's father] commitment to his son and the time and energy he has directed to this case that he has absorbed

¹⁰⁵ *Cleveland Bd. of Educ. v. LaFleur*, 414 U.S. 632, 639 (1974) ("This Court has long recognized that freedom of personal choice in matters of marriage and family life is one of the liberties protected by the Due Process Clause of the Fourteenth Amendment."). *See also Troxel* at 66. ("In light of this extensive precedent, it cannot now be doubted that the Due Process Clause of the Fourteenth Amendment protects the fundamental right of parents to make decisions concerning the care, custody, and control of their children. The Due Process Clause does not permit a State to infringe on the fundamental right of parents to make childrearing decisions simply because a state judge believes a 'better' decision could be made.").

¹⁰⁶ *See* Discussion, *supra* II (A) and (B)

¹⁰⁷ *Id.*

¹⁰⁸ *Id.*

¹⁰⁹ *Id.*

¹¹⁰ *Id.*

¹¹¹ *Id.*

¹¹² In the matter of Charlie Gard [2017] UKSC (Eng.) (Lady Hale), <https://www.supremecourt.uk/news/permission-to-appeal-hearing-in-the-matter-of-charlie-gard.html> ("Furthermore, where there is a significant dispute about a child's best interests the child himself must have an independent voice in that dispute.").

¹¹³ *Great Ormond Street Hospital v. Yates and Gard* [2017] EWHC 1909 [1] (Fam) (Eng.) (Francis J).

the issues so completely and intelligently. He believes passionately that his view of Alfie's future is the correct one."¹¹⁴ At the same time, the courts said, we must keep in mind what the child would say if he could decide for himself. Based on the data presented to the court, the court moved to determine that it was in the child's best interest to die.¹¹⁵

E. What is Alternative Medicine?

1. Introduction and Definitions

The Zara Ali case brought to light the ever-evolving relationship between alternative medicine and the law, specifically in the context of parental rights. What is alternative medicine and its relationship to conventional medicine? What deference should courts give to parents who, in good faith, want to treat their ailing children with non-conventional medical care? What standard should courts apply in determining that, by withholding standard medical care, the "best interest of the child" is being compromised? These basic questions must be addressed as we analyze whether or not the court was right to intervene and compel chemotherapy for Zara.

Alternative medicine¹¹⁶ is broadly defined as any medical treatment, practice, or theory which is perceived by its user as having the same healing effect as medicine without any empirically based scientific proof.¹¹⁷ In addition, a medical practice will be deemed alternative medicine if it is not part of biomedicine or if its theories are directly contradicted by the scientific evidence and principles established by biomedicine.¹¹⁸ Biomedicine is a part of medical science that uses scientific methods to test the efficacy of treatments and is based on scientific principles such as biology, physiology, and other natural sciences.¹¹⁹ Alternative medicine, on the other hand, is not based on scientific methods and may be based on superstition, hearsay, fraud, propaganda, or pseudoscience.¹²⁰ It is generally accepted by the scientific community

¹¹⁴ Alder Hey NHS Trust v. Evans [2018] EWHC 308 [36] (Fam) (Eng.) (Hayden J).

¹¹⁵ *Id.* at ¶¶ 62, 66.

¹¹⁶ For a comprehensive analysis of the history of alternative medicine see JAMES C. WHORTON, NATURE CURES – THE HISTORY OF ALTERNATIVE MEDICINE IN AMERICA, (Oxford University Press 2002); Ian D Coulter & Evan M Willis, *The Rise and Rise of Complementary and Alternative Medicine: a Sociological Perspective*, MED. J. AUSTL., June 2004, at 587.

¹¹⁷ See W. Sampson, *Antiscience Trends in the Rise of the "Alternative Medicine" Movement*, 775 ANNALS OF THE NEW YORK ACADEMY OF SCIENCES, 188–97 (1995); See also M.H. Goldrosen & S.E. Straus, *Complementary and alternative medicine: assessing the evidence for immunological benefits*, 4 NATURE REVIEWS IMMUNOLOGY 912–21 (2004).

¹¹⁸ TERENCE HINES, PSEUDOSCIENCE AND THE PARANORMAL (2nd ed. Prometheus Books 2003); Walter Sampson, *The Need for Educational Reform in Teaching about Alternative Therapies*, 76 ACADEMIC MEDICINE 248–50 (2001); Coulter, *supra* note 116.

¹¹⁹ NATIONAL SCIENCE BOARD, CHAPTER 7: SCIENCE AND TECHNOLOGY: PUBLIC ATTITUDES AND PUBLIC UNDERSTANDING, SECTION: BELIEF IN ALTERNATIVE MEDICINE (2002), <https://web.archive.org/web/20090302095432/http://www.nsf.gov/statistics/seind02/c7/c7s5.htm#c7s512a>

¹²⁰ *Id.* See also M. Angell et al., *Alternative medicine--The risks of untested and unregulated remedies*, 339 NEW ENG. J. OF MED. 839–41 (1998) ("It is time for the scientific community to

that the efficacy of alternative medicine is at best unproven and in many cases is demonstrably invalid.¹²¹

2. Lack of Clear Statutory and Adjudicatory Standards Regarding Alternative Medicine

Most laws regulating parental care and custody are found on the state level.¹²² However, there are no clear or comprehensive state statutory frameworks governing parental choice of alternative medicine for their children.¹²³ Some states require parents to provide care which is in “the best interest of the child.”¹²⁴ Others require parents to provide necessary medical care,¹²⁵ explicitly

stop giving alternative medicine a free ride. There cannot be two kinds of medicine – conventional and alternative. There is only medicine that has been adequately tested and medicine that has not, medicine that works and medicine that may or may not work... speculation, and testimonials do not substitute for evidence.”). Edzard Ernst, an academic physician and researcher specializing in the study of complementary and alternative medicine, is an outspoken critic of alternative medicine. Ernst has described the evidence for many alternative techniques as weak, nonexistent, or negative. E. Ernst, *The HealthWatch Award 2005: Prof. Edzard Ernst: Complementary medicine: The good the bad and the ugly*, UK: HEALTHWATCH (Mar. 9, 2015), <https://www.healthwatch-uk.org/news/20-awards/award-lectures/54-2005-prof-edzard-ernst.html>. Ernst has also concluded that 95% of the alternative treatments he and his team studied, including acupuncture, herbal medicine, homeopathy, and reflexology, are “statistically indistinguishable from placebo treatments.” *Placebo and other Non-specific Effects, in HEALING, HYPE, OR HARM? A CRITICAL ANALYSIS OF COMPLEMENTARY OR ALTERNATIVE MEDICINE*, (E. Ernst ed. 2008).

¹²¹ See H. Kent, *Ignore growing patient interest in alternative medicine at your peril - MDs warned*, 157 CAN. MED. ASS'N J. 1427–28 (1997); M.H. Goldrosen, et al., *Complementary and alternative medicine: assessing the evidence for immunological benefits*, 4 PERSPECTIVE, NATURE REVIEWS IMMUNOLOGY 912–21 (2004). See also D. Brown, *Scientists speak out against federal funds for research on alternative medicine*, THE WASHINGTON POST (Mar. 17, 2009), http://www.washingtonpost.com/wpdyn/content/article/2009/03/16/AR2009031602139.html?utm_source=reddit.com (citing Steven Novella, a neurologist at Yale School of Medicine, who criticized government funded studies of mainstreaming alternative medicine techniques who stated that such funding was “used to lend an appearance of legitimacy to treatments that are not legitimate.”). For the appeal and social factors which contribute to the relative prevalence of alternative medicine see B.L. Beyerstein, *Psychology and 'alternative medicine' social and judgmental biases that make inert treatments seem to work*, 3 SCIENTIFIC REVIEW OF ALTERNATIVE MEDICINE (1999); D.O. Weber, *Complementary and alternative medicine considering the alternatives*, 24 PHYSICIAN EXECUTIVE 6–14 (1998).

¹²² When a state law or regulation allegedly infringes on a constitutional right, a suit may be brought challenging that law or regulation. The suit is federal in nature as it implicates the constitution but the law being challenged is a state law.

¹²³ See generally, Child Welfare Enacted Legislation Database, NAT'L CONF. OF ST. LEGISLATURES, <http://www.ncsl.org/research/human-services/2012-child-welfare-enacted-legislation-database.aspx>. See also Child Welfare Information Gateway, *Grounds for Involuntary Termination of Parental Rights*, U.S. DEP'T OF HEALTH AND HUM. SERVICES, CHILD'S BUREAU (Jan. 2013), <https://www.childwelfare.gov/pubPDFs/groundtermin.pdf>.

¹²⁴ TENN. CODE ANN. § 36-1-113(i) (West 2013).

¹²⁵ MINN. STAT. ANN. § 260C.007(6) (West 2014).

prohibit neglect,¹²⁶ and specifically include medical neglect.¹²⁷ However, virtually all states, with the exception of Minnesota,¹²⁸ do not draw distinctions between accepted conventional medical treatment and alternative medicine.

The lack of state statutory schemes which take alternative medicine into account regarding parental decision-making has led to conflicting judicial opinions. In *McGrath v. Mountain*, 784 So. 2d 607 (Fla. Dist. Ct. App. 2001), the Florida Court of Appeals allowed the child's mother, over the objections of the child's father, to make decisions regarding the child's immunization. This conclusion was made, in spite of the fact that the mother was a "chiropractor who used holistic medicine and homeopathy in treating her son," and who "opposed immunization."¹²⁹ By contrast, in *Winters v. Brown*, 51 So. 3d 656 (Fla. Dist. Ct. App. 2011), the Florida Court of Appeals decided in favor of the child's father, who desired that "the minor child receive traditional medical care, including well-baby exams, blood draws, urinalysis, and vaccinations," over the child's mother, who was a "chiropractor and a proponent of holistic medicine."¹³⁰

The case most analogous to Ali is that of Daniel Hauser, a thirteen-year-old Minnesotan who suffered from Hodgkins disease.¹³¹ Doctors ordered Daniel to undergo six rounds of chemotherapy, but after he completed one round, his parents refused further treatment.¹³² Instead, Daniel and his parents began treating his cancer with homeopathic remedies which his mother had learned about on the internet, such as herbal supplements, vitamins, broccoli, beans, eggs, and other natural alternatives.¹³³ The court, taking into account the testimony of five doctors who agreed that Daniel needed chemotherapy, charged Daniel's parents with "medical neglect."¹³⁴ The

¹²⁶ MISS. CODE ANN. § 43-21-105(l) (West 2013).

¹²⁷ FLA. STAT. ANN. § 39.01(47) (West 2014)

¹²⁸ MINN. STAT. ANN. § 146A.025 (2014) ("Nothing in this chapter shall restrict the ability of a local welfare agency, local law enforcement agency, the commissioner of human services, or the state to take action regarding the maltreatment of minors under section 609.378 or 626.556. A parent who obtains complementary and alternative health care for the parent's minor child is not relieved of the duty to seek necessary medical care consistent with the requirements of section 609.378 and 626.556. A complementary or alternative health care practitioner who is providing services to a child who is not receiving necessary medical care must make a report under section 626.556, subdivision 3.").

¹²⁹ *McGrath*, 784 So. 2d at 608. *See also* *Hill v. Hill*, No. 94CA22, 1995 WL 432616, at *1-2 (Ohio Ct. App. July 20, 1995). In a divorce proceeding, the court determined that a mother was legitimately caring for her child, although she was relying on homeopathic medicine. *Id.* The court believed that the homeopathic remedies were harmless, based on the doctor's testimony that the child's condition predated the homeopathic treatment. *Id.*

¹³⁰ *Winters v. Brown*, 51 So. 3d 656, 657 (Fla. Dist. Ct. App. 2011).

¹³¹ *Parents of 13-year-old sought to treat his cancer with alternative medicine*, NBCNEWS.COM (May 19, 2009), http://www.nbcnews.com/id/30763438/ns/health-childrens_health/t/judge-rules-family-cant-refuse-chemo-boy/.

¹³² *Id.*

¹³³ *Id.*

¹³⁴ *Id.*

judge stated that Minnesota statute requires parents to provide necessary medical care for a child and that alternative health care methods are not enough.¹³⁵ The judge wrote further that the state's interest in protecting the child overrides the constitutional right of a parent to direct a child's upbringing.¹³⁶

The resemblances between Ali and Hauser are striking. In both cases a child was diagnosed with cancer and ordered to undergo chemotherapy. In both cases the child's parents refused the doctors' orders and provided their child with alternative medical treatments instead. In both cases the court required the child to be given the necessary medical treatment as directed by doctors.¹³⁷ The cases of Ali and Hauser are instances where the court intervened and compelled treatment to prolong the children's lives. We will first discuss the cases of Evans and Gard where judicial intervention was used to withhold treatment and end a child's life.

F. A Call for Judicial Prudence

What is most profoundly troubling about the courts' decisions in Evans and Gard is the fact that courts are deciding, literally, who lives and who dies. This decision offends primary instinct. In both Evans and Gard, the court did not simply rule on which life-saving medical treatment was in the best interest of the child; it determined that life itself was not in the best interest of Alfie and Charlie and ordered life support to be removed. This determination is shocking. Granting such decision-making power to human authority allows mere mortals to assume that prerogative which has always been allocated to the Creator and opens the floodgates of irresponsibility. Deciding between life and death is different in kind from other medical decisions, not simply in degree. Arguably, life itself is a dignity of a magnitude and order greater than any other dignity.¹³⁸

¹³⁵ *Id.*

¹³⁶ *Id.*

¹³⁷ In *Hauser* the court went so far as to charge the parents with medical neglect. In *Ali*, there is no indication from the record that such a charge was leveled against Zara's parents. Furthermore, it is important to note that there is no indication from the record, in either *Hauser* or *Ali*, that the children's parents relied on expert medical advice to treat their children homeopathically. In both cases the parents' choice was based on their own subjective beliefs.

¹³⁸ The principle that the human life is of infinite worth is a basic tenet of Jewish law. Maimonides in *Hilkhot Rotse'ah*, 2:6 rules, based on Talmudic sources, that one who kills a moribund individual is guilty of the same crime of murder as one who kills a young healthy person. This notion is found in the Anglo-American legal tradition as well. The Supreme Court of South Carolina stated: "But though a human body must be alive in order that it may be the subject of homicide, yet the quantity of vitality which it retains at the moment the fatal blow is given, and the length of time life would otherwise have continued, are immaterial considerations. If any life at all is left in the human body, even the least spark, the extinguishment of it is as much homicide as the killing of the most vital being." *State v. Francis*, 149 S.E. 348 (S.C. 1929) (quoting 21 A. & E. *Encycl of Law*, 92 (2nd ed)); *see also* CA 506/88 Shefer v. State of Israel 48(i) PD 87 (1993) (Isr.) ("[T]hese remarks: 'the phrase dying with dignity is a contradiction in terms' . . . go to the root of one of the main issues in this field. There is a conflict between the death of a person and the dignity of a person. By contrast, the life of a human being is itself the dignity of man, and there is no conflict between the life and dignity of man, nor could there be a conflict. The same is true with regard to expressions such as 'the right to die' and 'mercy killing', etc. These statements should be examined with great caution in order to discover their nature and the circumstances in which they are coined"). *See* Yoel Jakobovits, *Neonatal Euthanasia, Jewish Views of a Contemporary Dilemma*, 22 TRADITION 13 (Fall 1986). For further discussion on the Jewish view of euthanasia and end-of-life issues *see* J. David Bleich, *Treatment of the Terminally Ill*, 30 TRADITION 51 (1996); IMMANUEL JAKOBOVITS,

Thus, the issue the courts are grappling with is when do painful medical treatments to prolong a patient's life become unkind and inhumane, especially when the alternative is death.^{139,140} This issue is an existential question that courts should not meddle in, one that ought to be left to individuals to decide for themselves.¹⁴¹ In short, it is not a question of whether the court made the

JEWISH MEDICAL ETHICS 121-25, 275-76 (Bloch Publishing Company 1975); AKIVA TATZ, DANGEROUS DISEASE AND DANGEROUS THERAPY (Targum Press 2010). For general views on euthanasia and end of life issues see NEIL GORSUCH, THE FUTURE OF ASSISTED SUICIDE AND EUTHANASIA (Princeton University Press 2006); SHELDON EKLAND-OLSON, WHO LIVES, WHO DIES, WHO DECIDES (Routledge 2015).

¹³⁹ Raanan Gillon, Emeritus Professor of Medical Ethics at Imperial College London and President of the Institute of Medical Ethics argued on the BBC radio program "The Moral Maze" that many children are being kept alive by artificial ventilation with the accompanying pain and discomfort. This, he says, does not suffice to override the parent's wishes. *The Moral Maze*, BBC RADIO 4 (July 12, 2017), <https://www.bbc.co.uk/sounds/play/b08xbj6>.

¹⁴⁰ Dr. Michio Hirano, chief of the Division of Neuromuscular Disorders at Columbia University Medical Center was quoted by the judge in the Gard case, "I appreciate how unwell he is. His EEG is very severe. I think he is in the terminal stage of his illness. I can appreciate your position. I would just like to offer what we can. It is unlikely to work, *but the alternative is that he will pass away*" [emphasis added]. *Great Ormond Street Hospital v Yates & Ors* [2017] EWHC 972 [127] (Fam) (Eng.) (Francis J).

¹⁴¹ It is germane to our discussion to briefly explore Judaism's approach to life and its termination. As one of the co-founders of the Judeo-Christian tradition, a moral order upon which Western civilization is founded, Judaism is uniquely qualified to shed light on some of these perplexing and profoundly compelling questions of life and death. One of the most significant differences between modern secular medical ethics and Judaism is the notion of "quality of life." In the world of secular medical ethics "quality of life" is often given primary consideration over life itself. Practically, this means that if the quality of life is poor then the life may not be considered worth sustaining. By contrast, Judaism, although very sensitive to the reality of pain and suffering, considers life itself to be a primary value of infinite worth. There are times when in practice, *halakha* (Jewish law) will accord with the secular view. However, the respective default position of each approach is diametrically opposed to the other. *Halakha* does not require that all lives be sustained under all circumstances, but the burden of proof always rests on the side arguing of the primacy of "quality of life" over life itself. This raises several fundamental issues: Does anyone have a moral right to reject life under any circumstance? In the absence of a person's own free will, as with neonatal or incapacitated patients, is there anyone who can make such a decision on another's behalf? Are there any circumstances, sanctioned by *halakha*, in which a human life would be allowed to expire without attempting any life-saving intervention? A full-blown analysis of these questions are beyond the scope of this note. This author would like to address the third question posed above from the perspective of *halakha*. The rules outlined below are simplifications of very complex issues and are for general reference only. (1) Deliberately depriving anyone of a moment of life is completely forbidden. *Halakha* makes no distinction between age or quality of life in this regard. Active physical euthanasia is regarded as murder. *Shulhan Arukh, Yoreh De'ah* 339:1. Furthermore, in Jewish law, motivation is not an element of homicide. Euthanasia, or mercy-killing, done out of compassion with the noblest of intentions, is not exculpatory. Rabbi Jacob of Mecklenberg, *Ha'Ketav ve-ha-Kabbalah*, Genesis 9:5. (2) Passive Euthanasia – withholding treatment in terminal circumstances – is permissible in certain situations. Although nothing may be done to hasten death, if something is inhibiting the soul's departure, i.e. near-by noise, then it is permissible to remove the hindrance. This is not considered an act rather, the removal of an impediment. *Shulhan Arukh, Yoreh De'ah* 339:1. According to Rabbi Shneur Zalman of Ladi

right decision in choosing between life and death, but whether the court had the right to decide in the first place. The answer is a resounding no.

When parents and hospitals disagree over whether it is in the best interest of the child to remain alive, the resolution should be left to the respective parties to decide. Hospitals have their own code by which they must abide. If the hospital determines that, ethically, it cannot continue treating the patient, then it can follow its own internal procedures and deny treatment.¹⁴² In such a case, courts should not compel the hospitals to provide treatment.¹⁴³ At the same time, parents should be free

in such a situation it would be *obligatory* to remove the impediment in order to spare the patient the prolongation of the death agony. *Shulhan Arukh ha-Rav, Yoreh De'ah* 339:4. Rabbi Moses Feinstein, one of the premier halachic decisors of the last generation encouraged passive euthanasia in situations where (a) the patient is irrevocably terminally ill because of the advanced stages of the disease, (b) the patient is suffering greatly, (c) the patient has not expressly wished to prolong his life. *Iggerot Moshe, Yoreh De'ah* III no. 132. Therefore, one may discontinue resuscitation efforts for a terminally ill patient on a respirator. Additionally, if such a patient is taken off a respirator periodically to suction out the accumulation of pulmonary secretions, as most are, the patient may be left unattached to the respirator. This is sanctioned as passively allowing death. (3) *Halakha* makes a distinction between artificial needs, i.e. mechanical respirators or renal dialysis, and natural needs, such as food, water, oxygen, and blood. Although at times it is permissible to withhold artificial needs from a dying patient, it is strictly forbidden to withhold essential natural needs from the patient. See Rabbi S.Z. Auerbach, *Treatment of the Dying*, in HALAKHA AND MEDICINE, vol. II, 131 (M. Hershler ed. 1981) (“It is logical to suppose that nutrition and oxygen would have to be provided in spite of (prolonging) severe agony, even against the patient’s wishes. However, if the patient demands it, it would be permitted to withhold treatments which cause the patient more suffering. Nevertheless, one is always obliged to try to convince the patient that ‘one moment of repentance in this world is worth more than all the life of the world-to-come.’”). See also AMA Statement on Euthanasia (Dec. 4, 1973) reviewed by D.J. Horan, in *Euthanasia, Medical Treatment and the Mongoloid Child: Death as a Treatment Choice*, 27 BAYLOR L. REV., 76, 78 (1976); see also *In re Storar*, 52, N.Y. 2d 363, 438 N.Y.S. 2d 266 (1981) where the court overrode a mother’s decision to halt treatment and authorized blood transfusions for a 52-year old profoundly retarded man suffering from terminal, metastasized bladder cancer. In this case, although the cancer threat to the patient’s life was deemed untreatable, the bleeding was deemed treatable. The court analogized the treatment - blood transfusion - to food rather than to major surgery or respirators. In Judaism as well, denial of such necessities is unacceptable and amounts to homicide. This basic distinction between artificial needs and natural needs has been recognized by courts in the civil context as well as by Church authorities. See *MDs Charged with Murder*, 25 AM. MED. NEWS 22 (Sept. 3, 1982); Pius XII, *The Prolongation of Life*, 4 THE POPE SPEAKS 393-398 (Spring 1958). See generally Jakobovits, *Neonatal Euthanasia, Jewish Views of a Contemporary Dilemma*, *supra* note 138; Tatz, *supra* note 138.

¹⁴² See, e.g., The American Medical Association Code of Medical Ethics, Opinion 5.5, <https://www.ama-assn.org/delivering-care/medically-ineffective-interventions>.

¹⁴³ Although a patient’s wishes must be accorded deference and legal protection, at the same time, a physician must not be compelled to act in a manner which she finds morally objectionable. Forcing a physician to violate her conscience compromises her ethical integrity and will most certainly affect the level of diligent care that she provides to her patients. This conflict between a patient’s rights and a medical practitioner’s conscience creates a moral and legal dilemma. In *Grace Plaza v. Elbaum*, 588 N.Y.S.2d 853 (App. Div. 1992) Dr. Lester Corn, the medical director of Grace Plaza, testified that he would not remove a feeding tube from a patient even if ordered to by a court. *Id.* at 859. Dr. Corn “further testified that he would not disconnect a patient from a feeding tube because to do so would be condemning the patient ‘to death, which is in essence contrary to the dedication of medicine [to] the preservation of life

to take their child elsewhere for treatment. Courts should never deny parents an opportunity to provide life-saving treatment for their child.

G. The Parent; State; and Child Dynamic

Although in cases of life and death, like Evans and Gard, the court should stay out of the dispute entirely, it may intervene when the issue is between life and life, i.e. when the dispute is between which life-saving measure is best for the child. I contend, however, that the current framework used by the courts to determine the best interest of the child is mistaken. From the vast literature surrounding Evans and Gard, much of which has been cited above, it is clear that the courts viewed the conflict as involving three distinct parties - the parents; authorities/state/court; and the child.

Justice Francis wrote in his decision in Gard, "In circumstances where there is a dispute between parents and the hospital, it was essential that Charlie was himself independently represented [emphasis added] and a guardian was therefore appointed to represent Charlie so that there was someone who could independently [emphasis added] report to the court as to what was in his best interests."¹⁴⁴ The parents, in their capacity as guardians, were acting as their conscience dictated was in the best interest of their child. The authorities, in their capacity as *parens patriae*, felt obligated to intervene to prevent what they deemed conflicted with the child's best interest. Finally, the incapacitated child was too young and ill to express what he believed was the best course of action for himself.

and not the discontinuance of life." *Id.* at 863. Noncompliance by a medical practitioner, to a court order, as expressed by Dr. Corn, creates the danger of anarchy, an inherent risk of civil disobedience. In *Brophy v. New England Sinai Hosp., Inc.*, 497 N.E.2d 626, 633 (Mass. 1986), the court ordered the medical facility to discontinue the artificial feeding and hydration of a comatose patient. The court further stated that the medical facility must honor the wishes of a patient in a persistent vegetative state. *Id.* However, the court held that a medical facility is not required to violate its own moral convictions which precludes it from honoring the patient's wishes. *Id.* at 639. The court proposed that in such a situation the patient's guardian should remove him and place him in another facility which would accommodate the patient's wishes. *Id.* at 640. The court cited precedent which recognized the "maintenance of the ethical integrity of the medical profession" over a countervailing state interest and concluded that so long as the objecting hospital is not itself compelled to remove the feeding tube there is no violation of the integrity of the medical profession. *Id.* at 638. Regarding the parameters of the consideration of maintaining the ethical integrity of the medical profession vis-à-vis other compelling state interests, see *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977). Both *Brophy* and *Saikewicz* were concerned with the preservation of the integrity of the medical practice as determined by the existing mores established by the medical practice itself. *Brophy*, 497 N.E.2d at 638; *Saikewicz*, 370 N.E.2d at 426. The court in *Saikewicz* stated that the state's interest in protecting the judgment of the practitioner is only when said judgment is "in accord with the generally accepted views of the medical profession." *Id.* What is most disturbing to this author about the establishment of medical ethical standards is the deference the courts give to the medical profession *itself* to determine standards of ethical practice. Medical professionals, by virtue of their training, are clinical experts, qualified to diagnose medical illnesses and to determine the most effective course of treatment. They are by no means ethicists and should not be the arbiters of medical ethical norms any more than regular citizens should be. See J. DAVID BLEICH, *THE PHILOSOPHICAL QUEST, OF PHILOSOPHY, ETHICS, LAW AND HALACHA* 375-398 (Daniel Z. Feldman ed., Maggid Books 2013).

¹⁴⁴ *Great Ormond Street Hospital v. Yates and Gard* [2017] EWHC 1909 (Fam) (Eng.) (Francis J); *E (A Child)* [2018] EWCA (Civ) 550 (Eng.) (King LJ) (quoting Baroness Hale).

Consequently, this framework, which sees the child as an autonomous third party, gives the court too much latitude to contradict the parents and ascribe its views to the child. It allows for a formulation which is too open-ended and speculative,¹⁴⁵ and creates the danger that the court will insinuate itself into an unwarranted decision-making position.¹⁴⁶ Certainly, the court has no right to impute its judgment regarding the best interest of the child, to the child, simply because it opines its decision would be “better.”¹⁴⁷ It must first conclusively determine that the parents’ course of action is harmful to the child. In cases such as *Evans and Gard*, the courts are not properly defining harm and are using the wrong formulation to determine the dynamic at play between the parties while a more accurate and disciplined alternative exists.

IV. SOLUTION

A. *The Identification of a Child with His Parents*

There is another way to view the underlying relationships here, an approach rooted in Talmudic jurisprudence as well as modern developmental psychology. According to this view, emotionally, the child and parents are one. A child self-identifies with his parents and intrinsically wants what his parents want for him. No longer are the parents and courts fighting over the child, a passive third party; rather, the wishes of the parents and the child are on one side while the court is on the other. Questioning “What would the child want?” is answered by simply asking the parents.

The exception would be parental actions which are abusive or neglectful - treatment which a child can never consent to. Parents are still bound by a duty of care and cannot always do whatever they want with their children. The court, in adopting this approach, will stay clear of the complicated notion of “best interest of the child” while still asserting its overriding authority in more clear-cut cases of parental abuse and neglect.

This principle can be seen in Jewish law regarding conversion. Under Jewish law, conversion to Judaism requires intent. In the case of a minor, who legally lacks mature intelligence, a Jewish court will not involve itself in his/her unsolicited attempt to convert.¹⁴⁸ However, if a parent brings the child for conversion (or converts with him/her), the conversion is valid.¹⁴⁹ The Talmud justifies this with the principle that “we can assume that they are satisfied to go along with what their parent

¹⁴⁵ See *Aintree University Hospital NHS Trust v. James* [2013] UKSC 67 (Baroness Hale) (“The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude towards the treatment is or would be likely to be; and they must consult others who are looking after him or are interested in his welfare, in particular for their view of what his attitude would be.”).

¹⁴⁶ See generally ANTONIN SCALIA, *A MATTER OF INTERPRETATION, FEDERAL COURTS AND THE LAW*, (Amy Gutmann ed., Princeton University Press 1997); STEPHEN BREYER, *ACTIVE LIBERTY* (Vintage Books 2005).

¹⁴⁷ *Troxel v. Granville*, 530 U.S. 57, 72-73 (2000) (“The Due Process Clause does not permit a State to infringe on the fundamental right of parents to make childrearing decisions simply because a state judge believes a ‘better’ decision could be made.”).

¹⁴⁸ *Shakh, Yoreh De’ah* 268:16, from *Mordekhai, Yevamoth* ch. 4 §40; see also *Bakh* *ibid*.

¹⁴⁹ Babylonian Talmud, Tractate *Ketuboth* 11a.

is doing.”¹⁵⁰ The Talmud is conveying a profound and fundamental insight into human psychology. A child, from birth, identifies entirely with his/her parents. Whatever “good” a parent conceives for his/her child, the child is satisfied with.¹⁵¹

This notion of “identification” is well established in psychological literature as well.¹⁵² The roots of the notion of identification can be found in the writings of Sigmund Freud.¹⁵³ Broadly speaking, identification is when an individual absorbs a quality or attribute of another and thereby becomes transformed by the model of the other.¹⁵⁴ The first main kind of identification, according to Freud, is called primary identification.¹⁵⁵ This is the original and base form of emotional attachment that one has to one’s parents before one develops a relationship with anybody or anything else.¹⁵⁶ This means that the baby is incapable of seeing himself outside of his parents. The emotional attachment that he has to his parents causes him to identify so closely with them that he experiences them as part of himself.¹⁵⁷

If the courts apply the doctrine of identification, it would mean that the parents’ decision regarding the best interest of their (young) child ought to be considered the “decision” of the child himself. The child is no longer a third party in the debate over his best interest. He has expressed himself through his parents. If the court intervenes and overrides the parent’s wishes, it is in effect overriding the wishes of the child. This violates the concept of patient autonomy.

This principle can be applied whether one believes parents have a constitutionally protected right, per se, over the upbringing of their child or parents hold their children in trust and have obligations to their children. The very notion of a child as a wholly independent decision-making entity from his parents is contradicted by the doctrine of identification. Therefore, the autonomy of the child is not threatened by his parents’ decisions and should not trigger state intervention.

¹⁵⁰ *Id.*

¹⁵¹ In addition, a young child has no preconceived notion of “good” that the parent is overriding. See generally PAUL BOU-HABBIB ET AL., *AUTONOMY AND CHILDREN’S WELL-BEING* (A. Bagattini et al. eds., 2015).

¹⁵² See MALCOLM MACMILLAN, *FREUD EVALUATED* 497 (Elsevier Science 1997) (“By and large, psychoanalysts grant the importance and centrality of primary identification, even though...the concept varies ‘according to each author and his ideas, its meaning in consequence being far from precise’”).

¹⁵³ *Id.*

¹⁵⁴ J. LAPLANCHE ET AL., *THE LANGUAGE OF PSYCHOANALYSIS*, (The Hogarth Press 1976).

¹⁵⁵ *Id.*

¹⁵⁶ W.W. Meissner, *Notes on Identification I. Origins in Freud*, 39 *PSYCHOANALYTIC QUARTERLY*, 563-89 (1970); See also SIGMUND FREUD, *METAPSYCHOLOGY: THE THEORY OF PSYCHOANALYSIS, THE EGO AND THE ID* 370 (James Strachey ed., Joan Riviere trans., Hogarth Press 1927) (1923) (“An individual’s first and most important identification, his identification with the father in his own personal prehistory...with the parents”).

¹⁵⁷ Freud distinguishes identification from imitation, which is a conscious act. Through the process of emotional attachment, a child develops a superego that is similar to the moral values and behavior of his parents. This allows a child to flourish in the atmosphere and culture in which he is raised. The concept of identification has been referred to as “The most perplexing clinical/theoretical area in psychoanalysis.” See Macmillan, *supra* note 152 at 496 (quoting Rangell). Further elaboration is beyond the scope of this note.

Furthermore, as the fallout from both Evans and Gard shows, government intervention in life and death matters regarding children are fraught with tension, uncertainty, and volatility.¹⁵⁸ It thrusts the authorities into a confrontational position by contradicting parents and inevitably leads to protracted and contentious legal battles.¹⁵⁹ For these reasons, the court would do well to exert restraint and prudence by spreading the broadest net of deference to parents' choices and to weigh in only in cases of suspected abuse or neglect.¹⁶⁰

B. Applying the Principle of Identification to Evans and Gard

As argued above, in cases of "life and death" such as Evans and Gard, the court should refrain from injecting its opinion altogether. Only in matters of "life and life" is state intervention warranted. However, in Evans and Gard, had the courts applied the principle of identification, I believe they may have come to a different conclusion. As the record indicates, in both cases, the parents were acting in what they believe was their child's best interest.¹⁶¹ They disagreed with the courts' assertion that their child would be better off dead than assuredly living with a diminished standard of life.¹⁶²

This debate over quality of life versus sanctity of life is a loaded and charged question about which reasonable people may differ. What should be clear is that if the patient chooses to continue treatment it is within his right to do so. In the case of a parent deciding for a child, the patient is in fact the one deciding. The record in both Evans and Gard indicates that the courts recognized the love and care of the children's parents.¹⁶³ There was no case made that continued treatment would constitute abuse.¹⁶⁴

In the context of parental medical decision-making, I believe, as long as parents choose a path of treatment that is condoned by an expert medical opinion, even if not promoted, abuse cannot be charged. Just as an adult can choose to follow a minority expert medical opinion, so too, parents can make the same determination for their child. In both Evans and Gard, a respected hospital in Rome was willing to treat the terminally ill children.¹⁶⁵ This fact alone should have been enough for the courts to allow the children to receive the treatment. Courts should be very wary before deciding that a parent's lifesaving attempt is not in a child's best interest. If the parents' decision is based on an expert medical opinion, they are legitimately caring for their child and should be left

¹⁵⁸ See Discussion *supra* § II (A) and (B).

¹⁵⁹ *Id.*

¹⁶⁰ See Discussion *infra* § IV (B) for the parameters of abuse and neglect in the parental medical decision-making context.

¹⁶¹ See Discussion *supra* § II (A) and (B).

¹⁶² Alder Hey NHS Trust v. Evans [2018] EWHC 308 [51] (Fam) (Eng.) (Hayden J) ("Life itself has intrinsic value, however tenuous or vestigial it's hold. I am very much aware that both parents are Roman Catholics, brought up in that tradition.... In his closing remarks F said that Alfie is 'our child and a child of God.'").

¹⁶³ Great Ormond Street Hospital v. Yates and Gard [2017] EWHC 972 (Fam) (Eng.) (Francis J); Alder Hey NHS Trust v. Evans [2018] EWHC 308 (Fam) (Eng.) (Hayden J).

¹⁶⁴ Great Ormond Street Hospital v. Yates and Gard [2017] EWHC 972 (Fam) (Eng.) (Francis J); Alder Hey NHS Trust v. Evans [2018] EWHC 308 (Fam) (Eng.) (Hayden J).

¹⁶⁵ In *Gard*, Dr. Michio Hirano an eminent neurologist also agreed to try experimental treatment. See Discussion *supra* note 140.

alone.¹⁶⁶ The courts, therefore, should not have intervened in Evans and Gard and should have allowed the parents to continue to direct their children's care.¹⁶⁷

C. *The Neglect of Zara Ali*

In the Zara Ali case however, a strong argument of neglect can be made. Even under the more restrictive formula for state intervention that we have laid out, the court rightly decided to compel medical treatment. Parents have no right to neglect their child, and we will not apply the doctrine of identification in such a case. No child wants to be abused or neglected and can never consent to such treatment by his/her parents. Zara's parents refused chemotherapy treatment for her and instead chose to treat her tumor homeopathically.

¹⁶⁶ A clear example of abuse would be a phenomenon known as Munchausen Syndrome by Proxy (MSBP). MSBP is a psychological syndrome where a parent manufactures his/her child's medical symptoms in order to obtain unnecessary medical treatment for the child. At times, this has resulted in the death of the child. Incidentally, based on MSBP, a new diagnosis called Medical Child Abuse (MCA), has appeared. It asserts that parents are abusing their child by subjecting them to needless medical treatment. However, MCA itself has been misused and applied to parents who disagree with a hospital's opinion and wish to seek treatment elsewhere based on a different medical opinion. See Maxine Eichner, *Bad Medicine: Parents, the State, and the Charge of 'Medical Child Abuse'*, 50 U.C. DAVIS L. REV. 205 (2016).

¹⁶⁷ This is not to say that parents are infallible. Parents are human, *as are judges*. Parents can make mistakes regarding their child's best interest *as can the courts*. Based on the facts presented, one can legitimately question the wisdom of Alfie's and Charlie's parents. Certainly, the question regarding the cessation of life support in general is not an easy one to be objective about, for it is packed with dynamic emotional overtones. The loss of a child, G-d forbid, is a parent's worst nightmare. Far be it from this author to judge parents who must make excruciatingly painful life and death decisions regarding their child. It is perfectly understandable why parents would want to prolong their sick child's life as long as possible. It is also easy to sympathize with a court who, in its overwhelming desire to ease the pain of a suffering child, hastens the eternal peace that death offers the hopelessly afflicted. It is simply this author's belief that, in this world of unknowns, the *right* to decide the literally existential question of whether a sick child should live or die resides in the child's loving parents, not the courts. Courts, who have a duty to protect children from parental abuse and neglect, should only intervene in cases that trigger that duty. Otherwise, they are overstepping their authority and illegitimately imposing their personal beliefs and values on others. Connie Yates, in her statement announcing her acquiescence to the removal of her son's life support, poignantly expressed the conflict and complexity inherent in these charged parental decisions, as follows: "Now we will never know what would have happened if he got treatment, but it's not about us. It's never been about us. It's about what's best for Charlie now. At the point in time when it has become too late for Charlie, we have made the agonizing decision to let him go. This has also never been about "parents know best". We have continuously listened to experts in this field and it has raised fundamental issues, ethically, legally and medically – this is why the story of one little boy from two normal everyday people has raised such conflicting opinions and ferocious arguments worldwide. We will always know in our hearts that we did the very best for Charlie and I hope that he is proud of us for fighting his corner. We will have to live with the "what ifs", which will haunt us for the rest of our lives. But we're thinking about what's best for our son. We have always believed that Charlie deserved a chance at life, and we knew that his brain was not as bad it was made out to be, and that's why we continued." *Connie Yates: we will always know we did the very best for our son Charlie Gard*, THE GUARDIAN (July 24, 2017), <https://www.theguardian.com/uk-news/2017/jul/24/connie-yates-we-will-always-know-we-did-the-very-best-for-charlie-gard>.

Settled case law indicates that parents have an obligation to provide reasonable medical treatment for their child. If parents withhold such treatment, the court may take custody of the child to provide the needed medical treatment.¹⁶⁸ For Zara, chemotherapy was the necessary and reasonable treatment for her tumor. It is the standard treatment given to cancer patients nowadays.¹⁶⁹ Its efficacy is empirically and scientifically proven and was the overwhelming medical consensus of the doctors who were treating Zara. By contrast, the effectiveness of homeopathic/alternative medicine is scientifically unproven. Depriving Zara of chemotherapy and instead subjecting her to unscientifically based methods would potentially expose Zara to “ill-health and death.”¹⁷⁰ Thus, the court rightly intervened to compel scientifically proven medical treatment.

¹⁶⁸ *In re Willmann*, 493 N.E.2d 1380 (Ohio Ct. App. 1986) (“The ‘religious faith’ of the parents of a sick child, as firm and clear as that faith may be, does not permit the parents, under the law of this state and the nation, to expose the child to progressive ill health and death. Under such circumstances, in a dependency proceeding, the juvenile court has no alternative but to exercise the authority of the state under the doctrine of *parens patriae* to protect the child’s welfare and, indeed, to act to save his life.”).

¹⁶⁹ When the parents’ choice to provide their child with alternative medicine treatment is based on religious objections, historically courts have shown the parents greater deference. This is because in such instances the state has a greater burden of proof to show a compelling state interest before it infringes on the parents’ first amendment right of the free exercise of religion. One factor courts use in determining whether or not to intervene, is the prognosis of the disease. If the treatment has a high likelihood of success and the alternative is the death of the child, courts are more likely to intercede. In the event that the treatment does not have a good chance of success or the predicted outcome is not death, courts will be less likely to intercede. In *Newmark v Williams*, 588 A.2d 1108 (Del. 1990), the Supreme Court of Delaware ruled in favor of parents who wanted to forgo chemotherapy for their son with Burkitt’s lymphoma because it only had a 40% chance of working. Instead of putting their son through uncertain and painful medical treatment the parents decided to treat him through the church. The court reasoned: “[T]he spiritual treatment exemptions reflect, in part, ‘the policy of this State with respect to the quality of life’ a desperately ill child might have in the caring and loving atmosphere of his or her family, versus the sterile hospital environment demanded by physicians seeking to prescribe excruciating, and life-threatening, treatments of doubtful efficacy.” *Id.* at 1112. The determining factor for the court was the fact that the proposed treatment had a greater chance of not being effective. In *In the Matter of D.R.*, 20 P.3d 166 (Okla. Civ. App. 2001) the court ruled in favor of the state who charged parents with medical neglect after they discontinued therapy for their child who suffered from seizures. As the child’s condition was potentially life threatening, the treatment had a high chance of success, and the potential harm of the treatment was limited, the court sided with the state. The court stated that it was “well-settled that the state may order medical treatment for a nonlife threatening condition, notwithstanding the objection of the parents on religious grounds, if the treatment will, in all likelihood, temporarily or permanently solve a substantial medical problem.” *D.R.*, 20 P.3d at 169. The court also noted that the state could not order treatment over the religious objection of the parents if the treatment was “risky, extremely invasive, toxic with many side effects, and/or offers a low chance of success.” *D.R.*, 20 P.3d at 70.

¹⁷⁰ See generally C. Jenny et al., *Recognizing and responding to medical neglect*, 120 COMMITTEE ON CHILD ABUSE AND NEGLECT, AMERICAN ACADEMY OF PEDIATRICS, Dec. 2007, at 1385-1389; W. F. Malecha, *Faith healing exemptions to child protection laws: keeping the faith versus medical care for children*, 12 J LEGIS 243-263 (1985); J. Trahan, *Constitutional law: parental denial of a child’s medical treatment for religious reasons*, 1989 ANN. SURV. AM. L. 307-341 (1989).

Ali is the reverse of Evans and Gard. In Evans and Gard, the state mandated that lifesaving treatment not be performed and that life support be removed. Here, the state's interest was to save Zara's life. The court was tasked with deciding which life-saving treatment was best for Zara. When parents choose a medically and scientifically unproven method to treat their child's illness, which otherwise will be fatal, they are endangering their child.¹⁷¹ The best interest of the child is to be cured of her illness and live life to the fullest.

Ignoring established and effective chemotherapy for an unproven and non-empirically based alternative, is putting a child's life at undue risk.¹⁷² As the court in Willman put it: "Although parents may be free to become martyrs themselves, they are not free, under identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves."¹⁷³ The court appropriately ordered her parents to allow chemotherapy treatment to be administered to Zara.¹⁷⁴

V. CONCLUSION

There are times when parental decisions regarding their child's best interest conflict with the state's notion of the same. Typically, the state will show deference to parents' wishes, but not always. The need for state oversight is necessary to ensure every child receives the care and concern he/she is due. In the past, by claiming that the child's independent voice must be heard, the state has asserted its right to decide what is best for the child. However, by insinuating that the child is an autonomous entity, separate from the parents, the state ignores the psychological reality of identification. Furthermore, this conflict becomes especially charged when matters of life and death are at stake. The court should never decide that a terminally ill child should be removed from life support and be doomed to die. In doing so, the court engages in existential speculation that is beyond its purview.

Courts may intervene in matters of "life and life"; however, they should adopt a new framework based on the notion of identification. This notion posits that, emotionally, the child and parent are one. What the parent decides is in fact what the child wants. In all matters pertaining to the medical care of the child, the broadest deference should be given to parents, provided they are

¹⁷¹ Jenny, *supra* note 170.

¹⁷² *Id.*

¹⁷³ *In re Willmann* 493 N.E. 2d at 1381.

¹⁷⁴ As noted above, there is no clear statutory framework in most states regulating parents' decisions regarding the use of alternative medicine treatments for their children. See Discussion *supra* III (E)(2). Some parents, in good faith, strongly value the principles and methods of alternative medicine. They want the best for their children and in no way want to cause their children any harm. Unfortunately, at times, alternative medicine does not meet the needs of their children, and the state must intervene to protect the child. One author has suggested a statutory scheme which would show deference to parents' choices yet require them to fulfill their parental duty to provide their children with necessary medical care. It calls for a statutory provision which allows parents to choose alternative medicine as the primary method of treatment for their children. However, when a homeopathic physician or any other individual who is subject to a reporting requirement recommends traditional medical intervention, the parents would then have an affirmative duty to provide that level of care. If parents fail to fulfill that duty they would be in direct violation of the statute and can be charged with "medical neglect per se." See John Pevy, *Homeopathy, Holistic Medicine, and Parental Rights: What Role Should the Government Play in Regulating Parents' Rights to Choose Appropriate Care for Their Children?*, 21 UC DAVIS J. JUV. L. & POL'Y 145.

not engaged in abuse or neglect. Practically, this means that as long as the parents' decision to prolong the child's life is medically condoned, they should be left alone. The state should only step in when the medical care is not warranted, medically condoned, or if sound, effective, and empirically based treatment is substituted for an unproven and unscientific alternative.