

Opting Out: The Importance of Parental Informed Refusals

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Abstract

Parental refusals concern both the doctor-patient relationship and the role of science in society. Parents make medical decisions for their children exercising both a responsibility to provide for them and a duty to protect them. While informed consent is looked upon favorably – doctors accept consent as it often evidences parents following recommendations – informed refusal can cause rifts in the doctor-patient relationship, sometimes resulting in a loss of parental decision-making power. Many refusals by attentive, caring parents are safe and result in benefits to children, for example by avoiding exposure to drugs with dangerous side effects. Other refusals could endanger children. The most difficult cases for doctors and parents touch on personal questions about quality of life or how much pain or which side effects a parent is willing to allow their child to endure from a medical treatment. The complexity grows when the care being refused would not guarantee an agreed upon success or even continued life. The Supreme Court has long recognized parental rights in the arenas where choice is personal and reflects flourishing and freedom. Philosophy and law support the ability to make personal decisions for children yet both moral philosophy and law limit the extent to which parents have full reign. Navigating the refusal landscape in the hospital or doctor’s office poses special challenges and requires balance with an eye to protecting vulnerable children while respecting parental autonomy. Refusals collectively comprise a necessary check on the role of scientific advancement in society. This paper also explores the role of refusals in pluralistic liberal democracies, how refusals may spark scientific innovation, and how overriding refusals disparately impacts marginalized communities, sparking discriminatory treatment and contradicting social justice. The ability of members of society to opt out of certain scientific advances is crucial to freedom and provides a much-needed check on the ever-changing status quo. Science should not make moral pioneers of skeptics who have worthy alternative solutions for their children. There should not be a presumption that accepting the recommended medical care is ethically preferable or that all medical care is a moral good. Democracy provides the ability of the electorate to configure valuable checks on science, industry, and medicine.

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Introduction

Refusal of recommended medical care is difficult, even for adults. Navigating the landscape of pediatric refusals exposed weaknesses, disparities, and inconsistencies. Many parents are surprised when their efforts to refuse non-life-saving care result in condemnation of them as decision makers, physician duress, or legal action. More certainty is needed to remedy the disparate ways that the medical community currently navigates parental refusals. Refusals are often beneficial and reflective of the parents' worldview, an informed assessment of pros and cons of the recommended care, and values specific to the family. Overriding refusals can pose risks to children, families, and parents by creating distrust, fostering paternalism, and even subjecting children to harm when the side effects associated with the treatment occur. The parental duty to protect can conflict with a doctor's duties to care, to protect vulnerable children, and, in some cases, to preserve life, when there are fundamental disagreements about what is best for the child, the family, the parents, and even for society. This paper explores parental refusals of medical care, detailing the depth of the moral conflicts, and the personal and societal value of refusals.

Background and Value of Refusals

Informed Consent and Informed Refusal

While informed refusal appears to go hand in hand with informed consent, doctors and courts treat refusals differently. Generally, informed consent operates on an important premise: doctors are delivering information (disclosure) and requesting permission to treat, making the delivery of the information more of a "guidance."¹ In refusals, the inherent difference is that the delivery of information about the treatment sparks disagreement. Refusal speaks to the power in the doctor patient relationship while consent merely validates the power structure. Disclosure in the effort to seek

¹ Benjamin, Ruha Informed Refusal: Toward a Justice-based Bioethics. *Science, Technology, & Human Values*. 2016;41(6):967-990. doi:[10.1177/0162243916656059](https://doi.org/10.1177/0162243916656059)

informed consent takes on a box-checking, institutionalized feel. Disclosure followed by refusal represents upheaval in a longstanding power structure.

The approach doctors and courts apply to determine when overriding refusals by non-neglectful parents is acceptable, or even compelled, should not penalize parents who refuse care when the child would have benefited or had similar results from the refusal as they would from the care being court-compelled or accepted under duress. I argue that non-neglectful, attentive parents refusing the standard of care, in non-life-saving situations, and where there is not a risk of imminent harm, should be respected absent special circumstances. When attentive parents refuse to treat curable severe pneumonia for religious reasons, an override would be morally compelled. An inquiry into why, or *what the ethical difference is*, touches on rationality, reasonableness, and the scope of parental autonomy. It is surprisingly difficult to refuse opioids, something known for addiction risk. Certain treatments may impinge on quality of life to a degree the parents find unacceptable, especially drugs with severe side effects or treatments or surgeries that may cause long-term changes in abilities. Many difficult cases concern whether a child is owed a small chance at continued life, and at what cost to the child and the parents. While the refusal landscape varies, all things considered, the moral backdrop must recognize the vulnerability of children, and the moral rights afforded children, yet also acknowledge the validity or the value of parental refusals.

Informed refusal is an autonomy-based concept, but it also speaks to relationships in society. The topic encompasses rights, social standing, bodily integrity, and the ability of those without power to stand up to structures that inherently hold power. The relationship of individuals to doctors, government, institutionalized medicine, pharmaceutical companies, social leaders, and their communities converge in medical refusals. The autonomy analysis is not merely one of bodily integrity, parental rights, flourishing, and the US Constitution. In the life-saving care arena, it speaks to parents' ability to have input over quality of life and the extent to how much physical pain or which debilitating conditions are acceptable when extraordinary care would be necessary to continue life. With children facing high dose chemotherapy protocols, life-altering surgeries, and other treatments that entail severe short- and long-term side effects, the decision, whether by doctors or parents, to resort to extraordinary measures that would continue a painful life reflects values, norms, and personal choices. Allowing doctors to have veto power over parents threatens more than personal autonomy. It threatens the ability of an electorate to check corporate power and devalues less medicalized views even when they are a legitimate viewpoint among many. The sphere of protecting the child's interest, protecting life, and protecting the vulnerable should not negate parental decisions that also serve the child's legitimate interests in avoiding pain or avoiding extremely risky care.

Why is it so difficult for non-neglectful, competent, informed parents to refuse even non-life-saving care, but so easy to choose invasive treatments with poor efficacy? What about superfluous care that became the standard of care but does not represent what is best for the child because there are alternatives with fewer side effects? Something is amiss in parental refusals: to parents, it seems as though almost all refusals are suspect. "Parents will have to contend with the consequences of the

choices they make on behalf of their children.”² There is a corollary truth: Parents will also have to contend with decisions doctors force on them.

The Value of Doctors & the Power Asymmetry: Reconciling Protection of the Vulnerable Child and Potential Conflicts of Interest

The power asymmetry comes from the knowledge that doctors have (appropriate information asymmetry) and the standing in society they have traditionally enjoyed. Medical professionals are essential for their expertise, experience, and information. They are shaped by their medical education and the depth of their scientific knowledge. Many (probably the vast majority of) parents rely on doctors as their primary source of information and advice.

Doctors’ recommendations also reflect values. Doctors who want what they deem best for the child are influenced by their own traditions, culture, and values, and they may fail to consider competing norms. Their ability to analyze parental choices depends on their background, preconceived notions about certain treatments or medicines, and sometimes a distrust of natural remedies, or bias or stereotyping certain parents. They may have little experience with non-Western medicine, natural alternatives, or the many medical and biological alternatives to the one they are recommending. In some cases, their views may be corrupted by financial relationships with pharmaceutical companies. In others, a subtle disease creep may have made them more amenable to treatments that are not necessary. Even well-intentioned doctors may experience a pro-pharmaceutical tendency. Parental refusals act as a necessary check. Some doctors already rightly project their expertise, are evidence-based in their clinical practice, avoid projecting their values or biases, and are more open to parental refusals. In choosing a pediatrician, parents should find an expert who also respects them even when they disagree about health issues that have multiple solutions. Parents also must acknowledge that sometimes there is only one workable solution, and, in serious cases, the child may be owed the solution. As parents, we rely on doctors for the medical expertise we do not have yet we use caution in following some of the advice without exploring less intrusive options. In general, a desire to “help” or to “do good” does not give latitude to doctors to force care.

According to professional guidelines on ethics and professional responsibility, doctors must allow people to seek second opinions and they must provide accurate information enabling parents to give informed consent.³ The procedural and substantive issues surrounding parental refusals should be evaluated in the context of the power that big science, technology, and medicine wield. Public trust in both the doctor and the pharmaceutical company is imperative and would be improved by even more transparency and disclosure of relationships, and initiatives to close the revolving door between government and pharmaceutical companies.

Doctors may have an incentive to use a treatment that is not the best for the patient due to bias, a standard of care that is applied too broadly, financial conflicts of interest, or to see a therapy they

² Yoram Ungaru, Chapter One, “Pediatric decision-making: informed consent, parental permission, and child assent,” *Clinical Ethics in Pediatrics: A Case-Based Textbook*, ed. Douglas Diekema, Mark Mercurio, and Mary B. Adam, Cambridge University Press (2011).

³ Children’s Oncology Group, <https://childrensoncologygroup.org/index.php/second-opinions> (provides an exception to allowing for second opinions when time is of the essence.)

developed or prefer in use.⁴ In the research setting, clinical research and learning while doing can be devoid of therapeutic value. Proper research ethics practices should manage people's expectations of therapeutic value.

According to Donald Berry, patients often give too much "credence to people with whom they are talking." There are biases built into data collection and analysis. Berry even indicates (half-jokingly) that sometimes asking a doctor is the "worst thing you can do."⁵ Data can be found beneficial to a subset of the population and may or may not be generalizable. Yet, the reliance on the standard of care often results in everyone trying the same first line treatment. The precision medicine approach could help people who do not respond well to some treatments, and with more data, specific approaches might help more people more quickly. Trying and failing the standard of care should not be a required step prior to trying something that either has a beneficial side effect profile, is all natural, or uses a different metabolic or biological process. When the standard of care is the only proven cure, the analysis is different, as in the refusal of pediatric cancer care. It is difficult to justify trying something unknown when there is a known cure. When there is not, the analysis considers views of harm, or how much harm can rightly be required against the wishes of the parents on the path to an uncertain outcome.

Educating the patient is a goal often cited by those addressing parental refusals. A push for education assumes the doctor is correct and that an educated parent would follow the recommendation. To parents, sometimes doctors are asking the wrong question: how do we get parents to comply? Yet doctors do not always convey uncertainty with clarity. Parents have the same problem. If both sides could recognize the breadth of the zone of uncertainty, many parent doctor conflicts might disappear. Doctors should inform parents, deliver information in an accessible way, help parents access medical journals, encourage second opinions, and help people access groups in which parents share information about conditions and treatments.

The distinction between refusals that would cost children their lives, like refusing to treat meningitis or severe pneumonia, and refusals of care that either would not be likely to save them or addresses a non-life-threatening or non-debilitating condition is crucial in the evaluation of refusals. Parents cannot expose their children to dangers like treating meningitis with unproven herbs, but they have broad discretion when treating things like pain or poison ivy, or when an herbal or natural treatment is proven, like lysine for cold sores from a herpes virus. There is an issue surrounding where and how to draw the line. Some pneumonia and meningitis deaths occur due to religious refusals, something unacceptable as known cures are accessible and once the situation is dire, the likelihood of success from doing nothing or engaging in alternative therapies diminishes.

The special vulnerability of children also makes children potentially vulnerable to the scientific community, and parents have a duty to protect them. Non-neglectful, caring parents want to protect their children and act in accordance with their best interests. With many choices, there is often no basis for the medical community trumping the parents when results are unpredictable, treatments carry risks,

⁴ New York Academy of Science, Conflicts of Interest in Healthcare Symposium.

<https://www.nyas.org/events/2021/conflicts-of-interest-in-healthcare-opportunities-for-self-reflection-and-action/>

⁵ Donald Berry, Panelist, Conflicts of Interest in Healthcare Symposium; the New York Academy of Sciences, March 10 & 11, 2021. <https://www.nyas.org/events/2021/conflicts-of-interest-in-healthcare-opportunities-for-self-reflection-and-action/>

or less invasive alternatives are available. Detailed ethical priorities agreed upon in society would be a better approach when sorting out who is protecting children from whom. Then, applying a case-by-case approach would allow ethical rules to apply fairly to each distinctive fact pattern.

Doctors may see refusals as an action thrust on a child, presenting different moral and legal issues from refusals by adults of their own care. Yet, when put in terms of the moral rights of a child, or a moral right to health care, often parents respect those rights equally to or more than the medical community does.

Children have both moral and legal rights. In the US, legal rights include constitutional rights like equal protection, statutory and liberty interests that give protection from neglect and abuse, and codified rights to health care that impose obligations on parents. The US did not ratify the UN Convention on the Rights of the Child,⁶ yet many states independently did, and arguably the state interests relevant to basic needs and medical care in the US are commensurate with the UN requirements despite different language. One of the biggest disconnects between the convention and the US laws is the imposition of best interests under the convention compared to the meeting basic needs requirement under many US state and federal laws.

Refusals on a Societal Level

The primary societal benefit of refusals is innovation. A secondary effect is that when the proposed alternative has fewer side effects and works for the patients, healthcare savings may be generated. Each treatment or solution really needs to work only for the child in question. With moderate efficacy, the least risky alternatives are worth a try. For example, epilepsy drug side effects can require hospitalization, a need for additional (add-on) medications to control seizures, or a need for other medications for side effects, but the keto diet is not associated with those costs.

In the pediatric cancer care arena, where refusals are rare, many parents raise money and change cancer treatment. Parents support scientists' and doctors' efforts to find treatments that are less invasive because their child has had chemotherapy and they are intimately aware of its pros and cons. While we chose chemotherapy many times, parental refusal highlights the importance of continuing to look for alternatives that work and would have a better side effect profile. In the types of cancer with high odds of success with chemotherapy, research becomes stagnant. Refusals (while fraught with ethical dilemmas) could stimulate funding toward orphan diseases like leukemia and lymphoma research where the success is high, but the treatment is so intrusive.

Some refusals push back against disease creep.⁷ The number of new pharmaceuticals for common conditions should cause concern. For example, many people happily live with children with ADD, while others treat it with herbs or pharmaceuticals. Overdiagnosis and expanding the parameters of diseases have the same effect, pulling more people into pharmaceutical use.⁸ Refusals are especially important considering pharmaceutical advertising directly to consumers. Consumers taking in ads define themselves as sick and ask for pharmaceuticals. Other people refuse the medicines when offered, and taken together, can become a powerful voice against disease creep.

⁶ United Nations Convention on the Rights of the Child, <https://www.unicef.org/child-rights-convention>

⁷ Moynihan, Ray. "Caution! Diagnosis creep." *Australian prescriber* vol. 39,2 (2016): 30-1.
doi:10.18773/austprescr.2016.021

⁸ Moynihan.

Refusal of routine dental x-rays and other scans has led many doctors to make do without excessive radiology which can be costly and accounts for significant medical spending. While insurance coverage often dictates what method is chosen, those deemed irrational in their desire to avoid radiation may have benefited the healthcare system. Evidence also indicates there would be a defined health savings from reducing diagnostic testing that delivers radiation.⁹

Parents do not have conflicts of interest inherent in pharmaceutical relationships and may be wary of medicalized dogma behind certain doctors' recommendations. Doctors often have research relationships and can have financial ties to industry. While generally such ties must be disclosed especially in published research, parental refusals are an additional check on the conflicts of interest that can arise when doctors have relationships with both patients and drug manufacturers. Those relationships lead to the production of new, sometimes better and less dangerous, pharmaceutical solutions, so a check on industry relationships need not shut down the doctor-manufacturer agreements that create innovation.

Parents are often best suited to protect their children, although parents can lose the presumption and even lose custody of their children if they shirk their responsibilities or behave with malintent. Authoritarianism and criminal law intersect with pediatric refusals, adding structural, societal, and legal dimensions to doctors' behavior. In setting up a society with justice as a fundamental principle of liberalism, the people who do not want doctors to wield power to inflict legal remedies on attentive, non-neglectful parents with whom they disagree should have input in defining the structures and legal system.

The role of autonomy is interspersed with the role of justice. Bioethics delineates four principles that set autonomy and justice apart, yet they overlap. Those at the most risk of being denied the opportunity to exercise their parental autonomy are suffering an injustice. In the scientific arena, the marginalized, the less educated, the weaker voice, and the non-doctor can be disenfranchised. Because doctors use courts and argue neglect, families risk losing custody and medical decision-making status when they challenge recommended medical treatment. The scientific status quo carries undue weight and can eliminate the case-by-case analysis that many parental refusals should warrant.

Religious organizations sometimes have a voice in governmental scientific policy. The old Presidential Commission for the Study of Bioethics and the President's Council on Bioethics¹⁰ for example brought together participants whose collective input led to rules regarding stem cell research, etc. Various states have commissions on the value of life that shape rules concerning abortion, genetic enhancement, or other societal interests.¹¹ The stigma of refusals of medical care is expanding, as refusals are more likely to be incorrectly evaluated as against life because they sometimes go against the concept of life at all costs, or against the standard of care. Some religious organizations are brought into the fold, while

⁹ Linet, Martha S et al. "Cancer risks associated with external radiation from diagnostic imaging procedures." *CA: a cancer journal for clinicians* vol. 62,2 (2012): 75-100. doi:10.3322/caac.21132

¹⁰ List and history of the Presidential Bioethics councils.
<https://bioethicsarchive.georgetown.edu/pcsbi/history.html>

¹¹ For example, New York's Task Force on Life and the Law was established in 1985 by Governor Mario Cuomo and addressed many bioethical issues including organ transplant, assisted reproductive technology, refusals of life-saving care, and genetic testing. The task force's reports can be found at https://www.health.ny.gov/regulations/task_force/reports_publications/

others, especially those whose participants have refused care, are not included, e.g., Amish, Jehovah's Witness, Hasidic Jewish, etc. Refusals for religious reasons generate a cultish reputation for the sect which is often further projected on those engaging in non-religious refusals as well. Religious support for policies like limitations on assistance in dying or late-term abortion is well accepted, while religious support of refusals is controversial, even when the refusal would otherwise be acceptable or seen as rational based on the medical conditions or the alternatives.

Collectively people should hold power to investigate and create checks on the scientific community. All people are entitled to participate in defining the moral role of biological and technological innovation. Nikolas Rose and Carlos Novas use the term biocitizenship to explain the rights and responsibilities that accompany technological development as they apply to enhancement and highly medicalized global consumer goods.¹² They assert people are exploitable. Ruja Benjamin asserts "biodeflection", the failure to go along, is wrongly stigmatized, that opting out of a discovery is valuable but costly. Parents denying enhancements, superfluous new pharmaceuticals, and even rejecting a highly medicalized standard of care are collectively challenging the larger scientific community's power. Society can destigmatize refusal, promote acceptance of the benefits of parental refusals, and recognize that biodeflection can be a collective action for the common good. Refusals can better society by limiting the ability of the scientific establishment to define the rights and wrongs of individuals in their own relationships to science.¹³ The philosophy behind the use of science is open for discussion by society – scientists should not have the power to make people into "moral pioneers" and many people rightly object to the science itself dictating moral boundaries.¹⁴ Discovery alone should not be an impetus to require participation in the discovery. There are many factors that elucidate the value of the discovery, and the potential for moral good in its use.

The media plays a further role—refusals of vaccination, for example, are stigmatized in a way that demonstrates the social risks of biodeflection. The refusal of chemotherapy insights anger and disbelief without two equally empowered sides. The stigmatizing of Steve Jobs exemplifies the reputational costs of biodeflection.¹⁵ The scientific community creates the assumption that refusals signify an inability to digest scientific information rather than a legitimate set of goals and priorities. In doing so, doctors create a moral status quo and a system of blaming those choosing an alternative to cutting edge medical treatment for their child. The appropriate limits on non-neglectful competent parents are at the point when state interests prevail over parental interests, or when the refusal might violate the child's moral rights to a treatment.

¹² Nikolas Rose and Carlos Novas, Chapter 23 Biological citizenship, *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*, editors Aihwa Ong and Stephen J. Collier Malden, MA : Blackwell Publishing, (2005).

¹³ Benjamin R. Informed Refusal: Toward a Justice-based Bioethics. *Science, Technology, & Human Values*. 2016;41(6):967-990. doi:[10.1177/0162243916656059](https://doi.org/10.1177/0162243916656059) Benjamin uses the term biodeflection a corollary to the term biocitizenship. Biocitizenship speaks to the "rights and responsibilities" that accompany technological advances. Biodeflection recognizes the "stigma or penalties" for "opting out" of the scientific discoveries. P. 968.

¹⁴ Rapp, R. (1999). *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America* (1st ed.). Routledge. <https://doi-org.ezproxy.cul.columbia.edu/10.4324/9780203011348>

¹⁵ Wapner, Jessica, "Did Alternative Medicine Extend or Abbreviate Steve Job's Life" *Scientific American*, Oct 27, 2011. <https://www.scientificamerican.com/article/alternative-medicine-extend-abbreviate-steve-jobs-life/> (arguing the evidence for the alternatives Jobs chose to use was "thin" but likely not outcome-determinative.)

Many medical decisions do not indicate a rejection of science. Often, parents choose reasonable alternatives within Western medicine, indicating a desire to treat the condition, just not in the way that the doctor recommends. The chosen treatment method may be a less intrusive medicine or procedure. The medical community's stigmatizing of parents choosing Tylenol or Advil over opioids, seemingly reasonable alternatives, is problematic and costly to society. The option to treat something naturally (outside of new Western technology or invention) is often judged more harshly than choosing a medicine that was not recommended. Natural treatments that work biologically and have been researched and proven (like the keto diet for epilepsy) should not fall within biodeflection and should not be stigmatized.

Pharmaceutical products, advanced technology, genetic tools, and medical devices are consumer goods and services, yet when science operates in the moral pioneer landscape, it receives a presumption that its products are moral goods. Products for pain relief for a headache, and even chemotherapy have a consumer purpose: they solve a problem. The company has the goal of selling more. In chemotherapy, it may be arguable that the drugs are a moral good used to save a life. (Those drugs have saved my child's life.) In many areas of medicine, drugs solve an inconvenience or provide an option for those wishing to use them. Courts and doctors often step in, validating the degree to which some interventions have moral implications, and therefore, more power, or less power as some morals reflect personal decisions. But to analyze consumer goods as moral goods, certain conditions must be met. Moral supremacy is not owed to all inventions, something recognized in the study of genetic enhancement and cloning where limitations restrain activist doctors. For its use to be compulsory, balancing the value of the refusal against the value of the treatment requires moral and practical considerations.

Public and Private Moral Philosophy for Evaluating Parental Refusals

Philosophy Applied to Refusals at Societal Level: Morals, Rights, and Liberty

Many norms are not cross-cultural—metanormative principles exist outside of cultural norms. Arguably, some rights are so strong and agreed upon that they could be considered “socially embedded moral fact.”¹⁶ Some argue metanormative principles cannot be infringed by legislation¹⁷ – and that “cultural moral rights” are ripe for legislation because so many agree on them. Yet, majorities should not decide things central to flourishing and pluralism for minorities. Majorities and minorities have equal decision-making power over many personal things (especially those to which there is a negative right, a right to be free of government intrusion). Those items ripe for popular vote, some of which may be cultural moral rights, must be won with rational argument, and then the majority rule becomes legislation or sets legal precedent applied to everyone uniformly.

Medical care is metanormative. Society does not universally agree that everyone should treat every symptom in the same way. There is not cultural moral consensus on many aspects of child raising. There is near consensus on certain issues like meeting children's basic needs, striving to do what is in their best interests, and providing education. There are also laws to reflect the social compact that defines civilized society, holding people to fair standards. If doctors make claims based on ethics, their cultural norms, or

¹⁶ Paul Menzel, The Cultural Right to a Basic Minimum of Accessible Health Care. *Kennedy Institute of Ethics Journal*. 2011; 21(1):79-119.

¹⁷ Robert Sade, Foundational Ethics of the Health Care System: The Moral and Practical Superiority of Free Market Reforms. *The Journal of Medicine and Philosophy*. 2008; 33:468.

personal opinions (beyond legal claims) and then assert the law should support those claims, they are outstepping the principle that allows parents decision-making capacity. Most quality-of-life decisions are personal.

While the metanormative speaks to the setup, the oughts and normative justice exist in the operation of successful free society. Metanormative justice respects natural rights. Metanormative justice favors autonomy and operates at the level of the setting up of a system within which people can operate according to normative justice in their relationships, opinions, and actions.¹⁸ While we have agreed upon laws to avoid societal mayhem, there are also agreed upon protections for deviations from the status quo. For example, the constitution and the ethical frameworks applied in bioethics protect religious views, minorities, and speech, and ensure minority viewpoints are permitted.

Negative rights protect people from government interference while positive rights can compel an action or support one's ability to participate in an action. In refusals, the negative right to be free to make personal decisions without government intrusion operates as a pillar of society. Medical refusals for adults are respected because the refusal is a negative right: government generally cannot interfere with it. Legislation compelling care for adults would be unconstitutional, although there are some limitations on adult refusals, primarily due to competency issues absent directives. (Adults must be competent and informed to refuse care for themselves.) Parental refusals do not have the status of adult refusals, partly due to a government interest in protecting vulnerable children. When viewed as moral or legal negative rights, the onus is on the government to demonstrate a need to intrude on parental rights.

Society cannot punish everyone for the mistakes of the few. When doctors and public health officials compel care, they should justify the decision in the circumstance. If one set of parents refuses care and has a bad outcome, that is singularly a poor justification for a blanket policy. As an opposite corollary, it is unlikely that a parental refusal of the same care resulting in a positive outcome would be enough to say doctors and courts may never compel that care for that condition. Many say that extreme cases make bad law. In medical duress or compelled care, the medical community should avoid using scare tactics to foster compliance even when efficacy is not high and side effects are significant.

Sometimes, for example with a tetanus vaccine or any vaccine for something nontransmissible, the standard of care, prophylactic vaccination, is not really related to prevention of imminent harm. In such cases, the moral impetus to override refusals is weak. Often the public health rationale cites a big-picture advantage. A COVID-19 vaccine is easily justified by imminence; and arguably a measles vaccine may be justified by prevention of a largescale public health crisis. (Even without imminence, the largesse of the potential problem might justify the ask when people are not voluntarily achieving herd immunity.) Public health operates on a different level where some are asked to sacrifice for the good of all. The ask is often valid and there may be a strong moral compulsion to participate, although coercion ethically requires stronger justification. The tetanus vaccine may protect the child, and some parents may feel morally compelled to participate prophylactically; a measles vaccine may serve both a protective purpose and a societal purpose making the moral compulsion stronger depending on the herd immunity and presence of local cases; but a COVID-19 vaccine may protect society as part of a larger social compact and imminent public safety measure, justifying both public and private moral requirements.

¹⁸ http://solohq.org/Articles/Younkings/Principles_of_Metanormative_Justice.shtml

Public health policy can make refusal difficult. For example, seat belt requirements and decisions to fluoridate community water at the supply source (so individuals cannot refuse) all may be morally compelled based on the sacrifice or small risk for the common good. Absent special circumstances, the moral compulsion to participate at the society level is based on altruism but the law or the action is in place. In some cases, community activism can shape the public policy when there are legitimate concerns that increase the risk or decrease the common good. Public health operates at a level with its own goals and reasons, kept in check by legal constraints. Health departments and state and local governments have latitude to exercise discretion and have leeway in emergencies. The ethics of public health actions can be kept in check by activism, refusals by groups, innovations that solve problems in a less risky or intrusive way, and class actions as well as individual lawsuits. Activism has resulted in group refusals including refusal by asylum-seekers to accept a UK DNA testing requirement, and refusal by neighborhood residents of a dangerous biosafety lab. Ruha Benjamin suggests group refusals are “collective forms of conscientious objection.”¹⁹

At the society level, there are many benefits to parental refusals. The disbelief that all currently available medical care is worth the risk fuels innovation. At any given time, if everyone bought into the medical status quo, there would be no improvements.

Philosophy at a Personal Level: Frameworks to Address Parental Refusal

Bioethicists often apply frameworks to ethical conflicts enabling an organized analysis. The frameworks, when applied improperly, can operate as checklists for easy ethical decision making, supplanting deeper ethical analyses. Complex thought is needed to address each ethical issue. Context, worldview, and priorities make the issues personal. There is a movement in bioethics to have ethics committees work at an arms-length. There is also pushback that recognizes that medical decisions are personal and bodily and thus not conducive to an arms-length analysis which might either impose one set of values on everyone or create a rule that applies to everyone eliminating contextual analysis. Competing definitions of fairness and justice can lead to a disparate application of analytical tools. The following frameworks have limitations.

Application of the Four Principles of Bioethics

The four principles of bioethics, autonomy, beneficence, nonmaleficence, and justice²⁰ provide meaningful ways to evaluate some parental refusals, but are not equally helpful, and have limited application as they can be clunky and problematic. While many bioethicists apply them exclusively, deeper analyses and case-by-case considerations expose their weaknesses. Fundamental philosophical frameworks and alternative sources for their authority inform each principle (autonomy is steeped in libertarianism and political tradition; beneficence has humanitarian and communitarian ideals; non-maleficence can be linked to laws and early moral teachings; and justice adapts deontological philosophy as well as legal and moral theory). Principlism faces criticism as narrow. One critic argues, “A diet of general principles alone” has drawbacks -- “a morality based entirely on general rules and principles is tyrannical and disproportionate.”²¹ The four principles come without instructions, often

¹⁹ Benjamin (refers to neighborhood rejection of a Biosafety level 4 lab in Roxbury, Massachusetts, and a UK Border Agency Human Provenance Pilot Project.)

²⁰ Beauchamp TL, Childress JF. *Principles of biomedical ethics*. 5th. New York: Oxford University Press; 2001.

²¹ Toulmin S. The tyranny of principles. *Hastings Cent Rep*. 1981;1(6):31, 38.

leading to a box-checking analysis that does not deeply respect exceptions and circumstances. In refusals, there is an ever-present conflict between autonomy and beneficence.

Autonomy is protected by law: while it is a principle, its role in liberal society is fundamental. Despite its role as a pillar of liberal democracy, when it conflicts with other principles or when one person's autonomy conflicts with another's, autonomy is subject to compromise.

The phrase parental autonomy was developed in the bioethics literature to explain the special status of familial relationships. While autonomy means self-direction, authority can make it appear as though the parent rules the child and may miss the fundamental reason that some other ruler is inappropriate. Arguably, families operate as a unit—the parental autonomy is the parent acting in a self-governing way, governing the unit of which the parent and child are each a part. Parental autonomy is essentially a self-rule that reflects the parents' role in the family, the inability of minors to consent to medical care, and the child's role with deference based on the extent to which the child is an extension of the parents.²² Many do not see children as an extension of their parents or take that phrase to mean parents are egotistical and overruling their children's thoughts or wishes. I use extension of self to reflect the specialness that parenthood is to non-neglectful parents, the creation of an independent thinking being, and the impetus to protect that being from harm as if it were an extension of oneself. In the neonatal arena, at childbirth the mother and child are physically attached. The parental autonomy doctrine in law holds that parents may make fundamental decisions for their children free from government intervention.²³ Parents are not the same as other surrogate decision makers. The reason parental autonomy is used in this paper (rather than parental authority) is the recognition that absent conflicts in the care desired, parents acting on behalf of the child are acting autonomously as to the family unit, and autonomously to the degree to which they accept the child as an extension of themselves. Parents often protect children more than themselves.

The hospital, doctor, or state should generally not have decision-making authority unless circumstances arise negating parental rights. When discussed in the right terminology, there should be a strong burden of proof to have authority over someone else's children, while parental autonomy, absent specific conditions, is the standard. *Parens patriae* or even the physician lawsuits to compel care should be narrow exceptions—they are not an act of autonomy, but of power over a unit of which they are not a part. The state acting as a substitute parent does so with specifically granted authority, not with autonomy. In the area of policy and laws surrounding neglect and abuse, there is a willingness (and a need) of government to intrude on space traditionally reserved to parents.²⁴ Parents maintain parental autonomy unless their action or inaction jeopardizes the child's health and safety. Parenting has both rights and responsibilities. Arguably, in most families, children are precious, parents are protective, and the value of the family is both intrinsic and instrumental.

²² With age, children engage in assent for their care, and may eventually be recognized as mature minors with the ability to choose or deny care without the support of their parents.

²³ *Meyer v. State of Nebraska*, 262 U.S. 390 (1923).

²⁴ Scott, Elizabeth S., "Parental Autonomy and Children's Welfare," *William and Mary Bill of Rights Journal*, Vol. 11, Issue 2, (2003).

<https://scholarship.law.wm.edu/cgi/viewcontent.cgi?referer=https://www.google.com/&httpsredir=1&article=1291&context=wmborj>

Beneficence and nonmaleficence are applied disparately, leading to confusion. Beneficence is the general rationale for use of the best interest analysis. Beneficence is a problematic principle as the word simply means the quality of doing good. Doctors often do good by providing a service or product that their customers want. Similarly, people in other professions do good. Beneficence is fraught with arbitrary applications and room for physician abuse. Controversy arises when medical professionals wish to do good in one way despite a parent wanting to do good in another way. Refusals are arguably beneficent, and often in the best interest of the child. Beneficence empowers industries, the government, and medical professionals to do “good” without really fleshing out good for whom, good at the expense of what other goods, and how much harm is appropriate to achieve the good. The pharmaceutical industry may claim it is good to have more people take more prescription drugs. Many doctors genuinely and sincerely favor pharmaceutical solutions. Some fail to educate themselves about Eastern medicine, herbs, alternatives, diet, exercise, meditation, and a host of lifestyle changes that have significant effects on health. While they do not need to educate themselves about non-Western-medical goods, they do need to understand the limitations and application of their expertise.

Non-maleficence, the principle of doing no harm, is also subject to disparate treatment when applied to parental refusals. Harm to the family unit should be considered but is often overlooked. Harm to parental autonomy is palpable to families and goes unnoticed by physicians. Harm to the child, something parents and doctors aim to avoid, has subjective elements. To many parents, medications with harmful side effects should be avoided. Doctors tend to be more comfortable with severe side effects, yet the parents will experience harm to the child differently, daily, and in depth while to the doctor, one patient among many may have varying impacts on the doctor personally and professionally. While many doctors are personally invested in the patients, they are not invested to the degree that parents are.

Justice ties into legal principles. Children must be treated justly. Among parents with a non-neglectful mindset, societal reasons or state interests may compel overriding refusals for the sake of respecting the child’s moral rights or protecting the vulnerable. Even parents with a non-neglectful mindset may not refuse all care, fail to meet the child’s basic needs, or ignore pressing medical concerns. Especially in life-saving care, the right to refuse is limited.

Many of the decisions to override consider parents’ education, socioeconomic factors, or simply reflect prejudices. Both socioeconomic factors and race can make parenting practices more visible to those in a position of authority to question it. Things some people do in private tend to be more public in lower income brackets. (For example, drug use is observable if done in public, a practice more common among those living in tighter spaces.) Living in close quarters or sending children to schools where discipline is often referred to police carries a special burden.

Justice may be interpreted to mean treating everyone the same or treating people with like conditions the same; it can refer to distributive justice or to fairness. Bioethical refusals can refute some notions of justice. Doctors struggle to determine whether parents are well informed and will provide appropriate care. If a parent of a child with a certain condition refuses a hospital stay, a blanket justice approach would either reject all refusals, making parents who are capable of caring for the child at home stay in the hospital, a costly problem, or allow all refusals possibly jeopardizing a vulnerable child’s health. Justice in the refusal arena concerns giving each person a reason to explain the refusal, to provide data on the benefit of the chosen alternative, and to provide assurance they will follow up appropriately. For

example, justice does not necessarily say every parent can use the keto diet instead of epilepsy medicine. But justice should not ban all families from the diet as a first-line treatment. A just outcome would ensure that parents with knowledge and wherewithal to follow through may choose it. Evidence that parents do not plan to provide the necessary food should create a case for overriding a refusal to medicate. Assuming most parents would behave like the least informed, the wrongfully intentioned, or those incapable of providing care is unjust to parents who are attentive, who understand the science, and will carry out the care. Making all parents treat all conditions in the same way could protect some vulnerable children at too big a societal sacrifice by attentive, caring parents. Like treatment for all also would mean an increase in the number of cases of side effects or risks associated with the medicalized recommendation.

Justice also should address the role of large corporate structures in the development of drugs and technology used for care. Pharmaceutical companies use massive marketing budgets to promote drugs while certain alternatives cannot compete. Doctors and researchers often combine forces to create pharmaceutical options, a system that fuels and finances innovation to the benefit of many. The power structure behind the innovation sparks labeling new discoveries moral goods and makes refusals more difficult. Refusal of an herb that grows in one's garden would be not only accepted but the refusal would be praised, even if the herb proved curative. To reject a drug is more difficult partly because of the corporate structure combined with the power of the professionals offering it.

Teleology in Bioethics: Consequentialism, Utility, and Virtue

Teleology explains actions in terms of the purpose for the action. Teleology is results-oriented rather than focused on the morals of the actions that are the means of achieving the results. For example, teleology might justify or condemn stealing based on the reason for the stealing. Doctors often use teleology to justify overriding refusals incorrectly: they accept harm on the way to an unpredictable ending rather than justifying harm only when there is a predictable ending. The teleology philosophical umbrella includes consequentialism and virtue ethics. Teleology is to some degree about doing good, based on performing actions that result in good, and can open the issue of whether the ends justify the means. Deontology evaluates goodness differently, proposing a duty to do good, and holding that the rightness or wrongness of an action is intrinsic and not to be determined by purpose or by the outcome. Applied to parental refusals, teleology should evaluate and possibly justify the refusal based on its purpose. To that degree, teleology would not justify refusals merely for the sake of exercising autonomy but may justify refusals based on the reasons for them.

Consequentialism and Utilitarianism

Consequentialism generally asserts that the consequence is the best way to determine the rightness or wrongness of an action. Utilitarianism is a consequential ethical theory. Utilitarianism seeks to maximize good, often resulting in applying weighing processes, based on maximizing utility or happiness.²⁵ Rather than just determining whether the good outweighs the bad, utilitarianism also compares goods or allows comparison of harms—doing the least harm is a corollary to maximizing happiness or utility. Utilitarianism aims to achieve a desired end. Within consequentialism, some may argue that a desirable

²⁵ Bentham, Jeremy. *An Introduction to the Principles of Morals and Legislation*. Printed in the Year 1780, and Now First Published. By Jeremy Bentham. London: printed for T. Payne, and Son, 1789.

end may justify the means in hindsight, but the theory's moral validity rests on uniformly predictable outcomes.

An important limitation to consequentialism as it applies to parental refusals is that medical interventions do not always have predictable ends. It is difficult to give weight to unknown outcomes. Maximizing utility or happiness would not always justify medical interventions at the time of the intervention and should not lead to blanket neglect without proof the intervention works. Consequentialist theory may justify overriding refusals of blood transfusions or antibiotics as success is predictable. The application of utilitarian philosophy to some cancers and heart disease poses more problems because doctors cannot bank on event-free success. Teleological philosophy justifies harm on the road to success more easily, although when success cannot be predicted, its application should be avoided.

John Stuart Mill evaluates government interference from the perspective that, even if it is out of caring or compassion, limits to personal freedom are suspect.²⁶ Erring on the side of restraint in restricting liberty, Mill supports free society. The benefits of intervention (even if there are great benefits) should rightly be sacrificed to "deter 'intrusively pious members of society.'"²⁷ John Kultgen asserts "choosing and acting ... provide the higher pleasures and contribute to real happiness."²⁸ Kultgen applies consequentialist reasoning yet values both the intrinsic and instrumental value of autonomy.²⁹ Kultgen suggests that society should use influence and institutions to promote rationality for the sake of motivating people to use their freedom in a way that promotes general happiness. The suggestion speaks to education: parents that are knowledgeable about their child's illness would tend to make rational decisions based on a combination of scientific data, facts personal to them, and personal priorities. "Mankind are the greater gainers by suffering each other to live as seems good to themselves, than by compelling each to live as seems good to the rest."³⁰ Parental refusals maximize happiness or utility from the perspective of the parents, encompassing characteristics deeply personal to the family. Applying utilitarian principles appropriately should lead to a broader understanding of harms caused to families by doctors who override refusals, counterbalancing the possibility that consequentialist applications would allow many interventions to justify life-at-all-costs.

A consequentialist argument made by many in bioethics is simply the right ending justifies immense physical harm as well as harm to autonomy. When success is defined as life-at-all-costs, terrible harms along the way become justifiable. The prevailing reasoning overvalues *a chance at* a good ending. Using duress or court orders to compel unusual care like heart surgery, chemotherapy, or other risky interventions demonstrates the willingness to stray from consequentialism's legitimate applications. Even when there is a high chance of survival or success, the uncertainty works against using consequentialism as the sole philosophical justification.

²⁶ Mill, John Stuart, 1806-1873. *The Basic Writings of John Stuart Mill: on Liberty, the Subjection of Women, and Utilitarianism*. New York: Modern Library, 2002.

²⁷ John Kultgen, *Autonomy & Intervention: Paternalism in the Caring Life*, New York: Oxford University Press, 1995, p. 134, quoting Mill, *On Liberty*.

²⁸ Kultgen, p. 135.

²⁹ Kultgen, p. 134.

³⁰ Kultgen, 134 citing Mill, on liberty, p 227

Virtue Ethics

In virtue ethics, actions exhibit virtue, and virtue provides a reason for taking or refraining from an action. Virtue ethics fit within teleology because the virtue is the purpose for a given action. In medical care, parents, doctors, and organizations should be held to virtuous actions. Establishing virtue as a purpose for each action would drive doctors to carefully consider parental refusals. Relevant virtues like honesty, benevolence, courage, compassion, justice, and professionalism should inform behaviors. Virtue ethics competes with rights talk in that what is good for society is emphasized over individual's moral rights. Behaving with virtue is different from following moral rules.

Virtue ethics can also complement deontological and other teleological theories. Operating according to virtues has significant overlap with the language of principlism and the rules associated with societal fundamentals. The benefit of virtue ethics over universal principles is that virtue calls for deeper thinking, evaluating each situation according to virtues, and relies on the moral conscience.³¹ Other ethical theories seem less pliable in their application. Yet, one of the challenges of virtue ethics is competing virtues and a lack of universal definition of a virtuous person.³² Virtue ethics applies to parents and doctors. In my experience, the very same virtue is subject to competing actions demonstrating a downside of the use of virtue ethics to answer the practical question of whether an override of a parental refusal is appropriate. However, there is an upside to recognizing that often doctors are acting virtuously, there is common ground, and they fundamentally want what they honestly and, in their wisdom, believe is best for the child. When the doctors and parents see each other as acting morally, the disconnect may be deescalated and the focus can move to the practical solution or compromise.

Deontological Philosophy: Can Anyone Agree on a Moral Good?

Deontology forces people to confront difficult decisions about quality of life, societal freedom, and painful end-of-life decisions in the name of moral duties. Actions may be required or forbidden even if doing so sacrifices the opportunity to achieve good. But can we view acts according to uniform moral rules of right and wrong where human flourishing includes views on medical care? Competing goods interfere with rules; and moral good may not be justified by an immoral action. For example, strict deontology would not permit stealing to avoid starvation because the ends would not justify suspending the duty not to steal. In parental refusals, ignoring the parents' wishes would be a moral wrong not necessarily justifiable by a good result. There would need to be some other competing moral rule that favors the override.

Rationality is a moral good that is universally applied. There is difficulty assessing rationality, yet it provides a solid foundation of inquiry that would allow both sides to explain their reasoning. In religious or non-logic-based refusals, rationality may not drive parental decision making. While that is acceptable due to the generosity and fundamental pluralism in liberal democracies, there are necessary limits to non-rational medical decisions for children.

The risk of deontology is that the duty that is morally right could lead to a bad result. I see this as the crux of what it is to care for a child with life-threatening conditions and with treatments that alter

³¹ Mark H. Waymack, "Rights and Character," Chapter 2, *Ethical Issues in Aviation*, Ed. Elizabeth A. Hoppe, 2nd Edition (2019) Routledge: New York.

³² Waymack, p. 24.

quality of life. The difficult decisions may involve forgoing something that prolongs life when the life prolonged is extremely painful. Duty-based ethics would be simple if the duty were always to keep the child alive. Parents struggle over the self-inflicted ideal of what it is to be a good parent. Many parents operate in a rules-based way. When doctors try to impose something that violates the rule the parents set for themselves, their personal notion of doing the best thing for the child, parents might refuse. Doctors then must decide whether a motion to compel is justified and they should not act with duress.

Ethics of Care, a Normative Approach

In ethics of care, relationships are the basis of human identity.³³ The ethics of care approach looks to formulate ethical responses to individuals rather than to use justice's one size fits all approach, something that often creates unjust actions.³⁴ Ethics of care assume many people and complex relationships, a clear goal of protecting the vulnerable, and an understanding of interdependence. Parents need doctors and doctors should have a moral duty to parents as well as to vulnerable children. Ethics of care complement the other philosophies. Yet caring can be seen as a personality trait that some people do not exhibit. Caring itself can mean different things and applied as a singular method of analysis, could result in stalemates where the doctor and the parents are caring differently.

Ethics of care as a normative theory can be criticized for the lack of generalizability. In parental refusals, that lack of generalizability would prevent the ethics box checking and require a depth of analysis. Ethics consults would never be "arms-length"; they would be performed with an understanding that the response is personal and should be based on empathy and caring.

Why Is it Acceptable for Parents to Decide to Treat? What We Learn from Non-conflicts

Parents as Advocates for Children's Bodily Integrity

"Every human being of adult years and sound mind has a right to determine what shall be done with his own body..."³⁵ Adults do have power to behave autonomously in their own medical care. Parental power to decide stems from the self-governing that allows parents to decide their own care as well. All agree children, especially young children, can be vulnerable and deserve special attention and protection. Proactive treatment enjoys special protection. Refusals do not. This section explores why parents are the appropriate decision makers when they are choosing the recommended treatment.

Parents have the power to authorize dangerous treatments without guaranteed success. For example, parents may approve chemotherapy, the very painful 3F8 antibody, radiation, and heart surgery. Parents choose treatments that will require long-term lifestyle changes, radiation that may cause a

³³ Gilligan, Carol. "Moral Orientation and Moral Development." In Alison Bailey and Chris J. Cuomo (eds.). *The Feminist Philosophy Reader*. Boston: McGraw-Hill, 2008. Page 471 Print. See Gilligan, Carol. *In A Different Voice*, Cambridge: Harvard University Press (1982)

³⁴ Noddings, Nel: *Caring: A Feminine Approach to Ethics and Moral Education*, page 3-4. University of California Press, Berkeley, 1984. Kultgen aptly notes "the tendency of men to lose sight of care when viewing moral matters in terms of justice and women to lose sight of justice when viewing them in terms of care." Kultgen, p. 29 (That men also nurture and care is much more accepted now and arguably a commonplace assumption.) (Caring requires attention to rules and rights sometimes. Care must inform guidelines which should determine when to look at immediate needs and nurture relationships and when to focus on rights.)

³⁵ *Schloendorff v. Society of New York Hospital*, 105 N.E. 92 (N.Y. 1914).

change in IQ, chemotherapy with devastating effects on hearing, organs, and other debilitating side effects, opioids with high risk of addiction, or obesity surgery generating a need for a special diet and long-term care. Chemotherapy tends to be in the short term against the child's interest but, in the long term, it works toward an interest in continued life and playing odds. Parents may choose surgery that is not medically necessary like circumcision or cosmetic surgeries. Life at all costs may be a theme underlying the broad discretion parents have to choose risky procedures.

Parents have personal views on prolonging life, on acceptance of those with physical and mental differences, on acceptance of risk, and on medicine, the role of pain and the appropriate tolerable amount. Parents also have information, data, the risk profile of treatments, and efficacy information enabling them to make educated, personal decisions on behalf of children. Parents who choose to take extreme measures to save children against the odds (choosing treatments that have a small chance of working), often do so because of their attitude of acceptance of differences. We chose surgery and high-dose chemotherapy for something that had no previous survivors at all.³⁶ People who are open-minded about mixed abilities, learning differences, and physical differences may be more likely to embrace risky procedures. An environmental model of disability also contributes to seeking longshot care, while a strict medical model propels fears of differences. An important prerogative in raising children, and even in deciding to continue pregnancies, is the ability to choose to accept differences according to one's own personal views. Attacking the option to refuse care can also threaten the ability to choose unproven, risky, or any care when the prognosis is poor, threatening a right to try, as well as a right to continue pregnancies when it is known that the child will have a known disability. Refusals and assertive requests for care are a check on powerful medical structures at both ends of the spectrum.

For many common problems, there is a wide array of treatments that work and are proven to a degree acceptable to parents. (I fully support the many parents who choose medication, even if merely because they want what they see as a quick fix.) Some doctors did not believe CBD oil could work for epilepsy until it was proven to their particular standard and marketed by a pharmaceutical company under the name Epidiolex. Many parents believed it and used it for their children all along, something I did (along with managing sleep patterns) with success for my child. Our choice to use CBD was not an abandonment of science, it reflected our acceptance of smaller studies, anecdotes, longstanding traditional medicine documentation of the role of marijuana in epilepsy throughout history, and our preference for avoiding certain well-documented side effects of epilepsy drugs. Our daughter also at times used the keto diet for epilepsy, a well-proven solution that is not amenable to double-blind, placebo-controlled studies. The refusal of epilepsy pharmaceuticals cost me significantly, a price paid in anxiety and anger associated with the loss of control and the power struggle, twice (years apart) succumbing to duress, and watching her experience unacceptable side effects,³⁷ the situation dissolving much of my strong respect for medicine. What we wanted was to try the solutions with less harmful side

³⁶ Trilateral retinoblastoma with a pineoblastoma greater than one and a half centimeters had no known survivors at that time. Our daughter's tumor was almost four centimeters.

³⁷ Terrible depression with unexplained crying for several days on one medicine and about six and a half years later an allergic reaction to another. The interim six and a half years were completely seizure free without medicine against doctors' recommendations. The keto diet was perfect for her and she remained on it with a few breaks until college.

effects first, a logical priority.³⁸ Prior to what I call the “epilepsy wars”, I had differences of opinions with doctors on simpler things like dietary recommendations where my approach was evidence-based, primarily epidemiological and biological. Having a child who has survived five cancers, it surprises many that the conflicts arose over something so ancillary in the scheme of her overall physical snapshot. Refusals of opioids and epilepsy medicine have caused us more consternation than any discussions about cancer treatments, despite the heavy costs in short- and long-term side effects. A chemotherapy was implicated as causing the epilepsy, yet we would never second-guess using that drug or its value to her survival. We do not fit the profile of parents that are anti-Western medicine, refusing on religious grounds, or unreasonably highly suspicious of pharmaceuticals, all profiles that face bias.

We experienced the fundamental logical problem in decision making: parents are the decision makers only when they are following doctor’s orders. Parents who are considered competent and informed when they agree with doctors find their competence or their understanding of the information challenged when they refuse. Doctors and hospital ethics committees may be relying on a logical fallacy when they take a second look at the parents’ ability or power to make the medical decision on behalf of the child. All agree when competence is established and information is delivered to and understood by the parents, the parents can provide informed consent. An issue arises when the same parents who have been consenting all along, whether that is taking kids for annual check-ups, or in the case of many chronically ill children, attending numerous appointments, procedures, surgeries, and other medical interventions, refuse something the doctor has recommended. The logical fallacy in parental refusals occurs when doctors use the refusal itself to question the parents’ capacity or ability to digest the information. Using the decision to refuse as an impetus to label competent parents irrational undermines trust in the system and exposes doctors who may be trying to impose their will on competent informed parents, when there are proven options, without serving a legitimate protective interest.

The difficulty I have faced in refusal leads me to conclude, I never really was the decision maker. Doctors know they have power over parents, courts, and children. Agreeing with the people who are in a position of power is not necessarily a reflection of true decision making.

Supreme Court Cases on Parental Autonomy in Raising Children

There are established limitations on parental rights. Laws and law enforcement are generally the arena to enforce those limitations. Otherwise, parents have wide discretion in parenting decisions.

In *Meyer v. Nebraska*, the Supreme Court held that, like a right to marry, establish a home, and raise children, the parents have the right to have their children taught German.³⁹ The state was not permitted to interfere with liberty, even if the liberty was not explicit in the US Constitution. The state interference was impermissible because it was arbitrary, served no legitimate purpose, and interfered with parents’

³⁸ In 2011, elongating an ifosfamide dose to a 24-hour drip from one hour was the agreed upon solution which worked; in 2018, managing sleep patterns and using short-term medication in times of sleep deprivation (lorazepam), CBD, and the keto diet all worked very well; in 2020, our daughter chose an epilepsy medicine (Onfi) due to a desire to return to “normal” eating habits and to stay up later in the beginning of college. Under duress in 2011, we accepted Keppra and in 2018, lamotrigine to the detriment to her health and our autonomy. She had about three days on each.

³⁹ *Meyer v. State of Nebraska*, 262 U.S. 390 (1923) While the case also included a teacher’s right to teach German, its holding addressed family rights. In the case, German was part of the family’s heritage.

rights and the teacher's right. The Court noted that education is generally associated with the pursuit of happiness and common law negative rights. "Corresponding to the right of control, it is the natural duty of the parent to give his children education suitable to their station in life..." The *Meyer* Court noted that knowledge of German cannot be regarded as harmful, an indication that outside the realm of parental rights concerning medicine, a harm principle applies. The Court also leaned heavily on common law notions of freedom and noted that, in parenting, rights to control tend to correspond with duties to provide.

In *Pierce v. Society of Sisters*, a right to attend schools other than public school was established.⁴⁰ Yet, there are limitations on parental rights. For example, *Prince v. Massachusetts* forbids parents from failing to educate their children, making it illegal for children to preach all day rather than attend school.⁴¹

As privacy cases later established, many aspects of family planning and raising a family are constitutionally protected. Cases govern the ability to choose contraception, abortion, and protect procreation.⁴² Medical care that is nearly futile for infants and children can also reflect a personal family hope to keep the child alive. In the US, the leeway parents have in choosing to treat is broad, and often advanced diseases are treated here that would not be treated in other countries. This is partially due to our system that includes private insurance and the ability to privately pay for care. Absent rationing, parents may have access to treatments that are less likely to succeed but that are the only hope. Parents seeking out drastic measures at the end of life are often honored here. Furthermore, some parents have gone beyond the legitimate medical ask. In Payton Summons case, in Texas, hospitals and organizations scrambled to transfer the girl who had been declared dead,⁴³ a sign that those people who support any glimmer of hope, regardless of science, seem to have weight in medical decisions, while parents making reasonable refusals are disparaged.

The US Constitution and Substantive Due Process

"Where an issue is so deeply important that citizens must be able to reach their own conclusions without the 'compulsion of the State,' the same Fourteenth Amendment that protects the decision to exercise the right simultaneously protects the decision not to participate in or support the exercise of the right."⁴⁴ Protecting participants and dissenters alike, the Supreme Court's substantive due process cases concerning liberty were designed to preserve personal decision making, not to inflict one moral code on everyone in the sphere of personal liberties or beliefs.

Children should have protections, as they are vulnerable and young children especially cannot voice their concerns. The parents are responsible for protecting children. The role of doctors who often act with the power of the court or the state in parenting decisions must be limited. Absent special circumstances, courts should not override parents under the guise of protection. As scientific

⁴⁰ *Pierce v. Society of Sisters*, 268 U.S. 510 (1925)

⁴¹ *Prince v. Commonwealth of Massachusetts*, 321 U.S. 158 (1944)

⁴² *Griswold v. Connecticut* 381 U.S. 479 (1965), *Roe v Wade* 410 U.S. 113 (1973). *Casey v. Planned Parenthood of Eastern Pennsylvania* 505 U.S. 833 (1992).

⁴³ "Payton Summons: Girl at centre of life support battle in Texas dies," BBC News, BBC.com, October 20, 2018. <https://www.bbc.com/news/world-us-canada-45929396>

⁴⁴ Mark L. Rienzi "Substantive Due Process as a Two-Way Street: How the Court Can Reconcile Same-Sex Marriage and Religious Liberty" *Stanford Law Review*, Vol 68, May 2015

advancements are made, parents may have neither a responsibility nor desire to participate in the discoveries depending on the ability of the discovery to save a life or prevent a substantial imminent harm. The structural piece of free society rests on liberty and autonomy, the moral foundation, and the laws that proscribe behavior that refutes a social compact, often appropriately limiting freedom. The operational aspect of free society rests on diverse cultural norms and preferences. Government rightly limits liberty when it has compelling reasons like national security, and even protection of an endangered child, but when it merely micromanages parents, government wrongly limits liberty. In substantive due process cases, when a fundamental liberty is infringed, the government generally needs to have a compelling reason. In the US, there is not truly a legal right to health care, but competent adults have a well-established right to refuse.⁴⁵

The right to refuse is integral to the right to make medical decisions. But courts recognize some state interests that could limit the right to refuse, for example, preserving life, preventing suicide, safeguarding the integrity of the medical profession, and protecting the innocent.⁴⁶ The limitations exist to protect the vulnerable.

Why the Procedure to Determine the Decision Maker Relies on the Refusal Itself

Procedure and Substance Together

Refusals have both a procedural and a substantive component: they reflect the role of parents as decision makers and the underlying decision. Looking to the substance of the actual decision is required to formulate a procedure for determining the decision maker. A fair procedure which is also safe must adhere to ethical parameters and flesh out whether the solution proposed by the parents is a safe alternative. Once the parents' decision is questioned, rather than limit an inquiry to competency or whether parents are informed, the inquiry automatically broadens to the substantive question. Rather than saying competent informed parents decide, the first-line inquiry addresses the refusal substantively: how would this refusal effect this child? Then, doctors or even courts work backwards. Varying standards lead to inquiries into whether the decision is likely to be harmful, is in the child's interest, meets the basic needs, is within a zone of parental discretion, or meets a reasonableness relevant to surrogate decision making. Doctors and hospitals use these substantive evaluations at the time of the refusal to decide whether parents are permitted to refuse. The seemingly illogical analysis exists to protect vulnerable children but can disempower well informed competent parents. Identifying the decision maker is not procedural.

Doctors call in ethics committees, impose their will and strong views, and sometimes even inform law enforcement when parents refuse recommended care. The only logical way to correct the current illogical process would be to follow a logical, fair, and transparent process. A rule that applies logic to refusals would match the logic applied to accepting care: *If parents are informed and competent, they may decide*. I strongly profess that this should be the primary rule and that exceptions should be explicitly justified. However, there is a caveat: *their decision must meet the child's basic needs and*

⁴⁵ In the matter of Karen Quinlan, 355 A.2d 647 (1976); Cruzan v. Director, Missouri Department of Health, 497 US 261 (1990); Bush v. Schiavo, 885 So. 2d 321 (Fla. 2004)

⁴⁶ In re Conroy, 188 N.J. Super. 523, 457 A.2d 1232 (N.J. Super. Ch. Div. 1983).

should be in their best interest. Essentially, application of a harm principle would meet my criteria for overriding refusals and would allow parents to then choose from those treatment options that meet the child's needs. (It is likely that choices would be treatments in the child's best interests, a better outcome.)⁴⁷

One problem that I seek to address is whether the *inquiry should be limited to whether the basic needs would be met by the parents' proposed solution.* The usual analysis tends to go well beyond the cursory and applies higher standards like best interests in disparate and arbitrary ways. The nature of the standards is subjective although some would argue reasonableness standards can be applied objectively. If a parent decides to forgo medication, and the doctors plan to override or evaluate the decision, doctors, hospital, or ethics committees determine whether forgoing the medicine is potentially harmful usually applying a best interest standard or other analysis of the substantive decision at that point. Legally, the question would center around basic needs unless a prevailing government interest requires more. Basic needs are a low bar. The real issue is that parents may be in a better position to understand the child's best interest.

Hospital ethics committees need to operate with clear parameters; they may not insert themselves in the decision-making process as if they equal the parents in status. They should not supplant courts as the arbiter of parental rights.⁴⁸ Doctors or ethics committees may evaluate whether parents have digested the scientific information, but, absent criminal behavior, they should at first stay out of evaluating norms, cultural beliefs, or views on natural care and medicalization. The family, itself or through representation, should be permitted to present its rationales for the refusal whether based on cultural norms, philosophical objections, or biological alternatives. The medical community should be limited to protecting the child who may be vulnerable to choices that conflict with the child's needs. There is not an open door to overruling parents. There are opportunities to override parental decisions to save lives and prevent imminent harm. Difficult cases like actions that may or may not save a life, and actions that avoid death with certainty but offer only the possibility or probability of long-term life, or that may alter quality of life are a murky area where case-by-case analysis allows room to figure out whether to try to compel care, an area where restraint should be a guiding principle. The doctor's point of view, a professional recommendation of care, is not enough ethical justification to compel refused care. The analysis is warranted not merely to indulge the doctor's point of view, but rather because the point of view may be substantially linked to furthering a legitimate state interest in protecting the vulnerable.

The best interest standard⁴⁹ is wishy washy at best and poses many procedural questions. Doctors must institute a procedure for revoking the parents' ability to decide. A more distinct process for determining when to invoke a best interest standard is needed. Other issues include defining who knows what is in a child's best interest, and how to incorporate consideration of a family's best interest, a community's best interest, and society's best interest into an application of beneficence in bioethics. The best interest

⁴⁷ There are not always lots of choices. Scenarios where chemo A would meet basic needs, but chemo B would be in best interests are less common. Or surgery A v surgery B. Often the choices are do no nothing or do everything. Sometimes there are lots of options...

⁴⁸ Truog RD. Tackling medical futility in Texas. *N Engl J Med.* 2007 Jul 5;357(1):1-3. doi: 10.1056/NEJMp078109. PMID: 17611201.

⁴⁹ Kopelman best interest std 1997 ad Kop and Kop 2007

standard can be used as a trigger for overriding parental refusals, but also to define reasonable treatment.⁵⁰ “Best interest” is not really taken literally in medical care as that could be brought *ad absurdum* easily and lead to parents catering to children or even a one-child policy to avoid splitting attention and financial support.

Among those doctors who have children of their own, many do not have children who have had significant health problems. Professional experience alone is arguably not the full body of expertise necessary to make parenting decisions. The full realm of treatments within the standard of care does not indicate good parenting. Parents, who will live with the medical decisions, should maintain decision-making status whenever possible.

The Standards

The harm principle, the zone of parental discretion, and the not unreasonable standard speak more to the procedure offering parameters within which parents may make choices. The best interest standard is often used the same way; it is also used when parental decision making is revoked to hold surrogates to a standard that is above basic needs. To many, the harm principle triggers a best interest analysis. Others apply the best interest standard to the parental refusal before revoking the decision-making power.

The Harm Principle

The harm principle in pediatric ethics is a take on John Stuart Mill’s harm principle applied to government interventions. It is one way to figure out when to override a parental refusal. It would trigger intervention when the refusal causes imminent danger of substantial harm. Doug Diekema argues that eight conditions must be met to warrant state intervention and a failure to meet a best interest standard is not satisfactory to trigger state involvement.⁵¹ The strict harm principle would eliminate many superfluous applications of the best interests test by allowing parents more leeway before legal action would be justified. The harm principle comports with many state’s neglect laws, as meeting basic needs tends to be the relevant legal standard. Diekema’s harm principle is interpreted disparately—some argue it sets forth a rule for when the best interest standard applies, while others argue it replaces the best interest standard.

Many bioethicists oppose the harm principle, arguing that it allows parents too much leeway at the expense of doing what is best for children. Johan Bester criticizes Diekema’s harm principle analysis in several ways. He criticizes the application of the harm principle as first elicited by John Stuart Mill.

⁵⁰ Kopelman 1997

⁵¹ Diekema, Douglas, “Parental Refusals of Medical Treatment: The harm principle as a threshold for state intervention,” *Theoretical Medicine* 25:243-264, p. 252. <https://doi-org.ezproxy.cul.columbia.edu/10.1007/s11017-004-3146-6> (Table 1, page 252: “By refusing to consent are the parents placing their child at significant risk of serious harm? Is the harm imminent, requiring immediate action to prevent it? Is the intervention that has been refused necessary to prevent the serious harm? Is the intervention that has been refused of proven efficacy, and therefore, likely to prevent the harm? Does the intervention that has been refused by the parents not also place the child at significant risk of serious harm, and do its projected benefits outweigh its projected burdens significantly more favorably than the option chosen by the parents? Would any other option prevent serious harm to the child in a way that is less intrusive to parental autonomy and more acceptable to the parents? Can the state intervention be generalized to all other similar situations? Would most parents agree that the state intervention was reasonable?”)

Bester argues the principle was intended for society and grounded in utility, not applicable to special relationships. Bester also argues the harm principle is “superfluous” as best interest analysis already incorporates the utilitarian measure of maximizing benefit and avoiding harm.⁵² Bester also criticizes the principle from the opposite angle: there is a concern for “harm creep” whereby in the absence of a best interest analysis, the definition of harm might expand.⁵³ Bester criticizes the low bar of harm avoidance, but he favors broad discretion to override parental decisions that either are not supported by reasonable argument that the action is in the child’s best interest or where there is “obvious risk of harm.” While his analysis has broad leeway to evaluate the parents’ viewpoints, he seems to imply all medical care is held to a best interest standard, rather than the lower bar of meeting basic needs. He does not necessarily value the role of parents who may be in the position to know what is in the child’s best interest.

Physical or medical harm is an objective criterion and definable. Normally, medical care has uncertainty. Weighing multiple harms is challenging. Avoiding a substantial likelihood of imminent harm by taking a non-harmful action is an easier case. Doing so by taking a purportedly less harmful action is much more complex. The harm principle requires imminent physical harm and likelihood of success to trigger state action, providing more protection for well-meaning, non-neglectful, informed parents to refuse treatments.

Harm to the child is a better starting point than a system where all refusals of the standard of care are questioned. The standard of care should not be a legally enforceable concept—it is something arrived at by doctors and organizations of doctors trying to streamline care and educate those within their field. When the AAP or ASCO describe a standard, they do not do so with authority over parents. If their rightness were assumed, society would sacrifice the role of parents as a check on power run amok. Especially in the realm of chemotherapy, if the standard treatment were always accepted, there would be little reason to financially support the development of new less harsh treatments.

Zone of Parental Discretion

A zone of parental discretion arguably goes further to protect parental autonomy by acknowledging the array of choices of treatments and options available to parents. Lynn Gillam suggests a wide latitude of parental discretion should replace the concept of one right and one wrong action. The other noteworthy feature of the zone of parental discretion is the explicit acknowledgement “that overriding parents may create harms,”⁵⁴ something I personally find doctors are quick to dismiss. Janine Winters cites some problems in overriding refusals including bias, errors of omission (failure to analyze the harms of overriding), and the simplification of the analysis to one metric, like survival rate. Gillam cites a gap between what is best and what would cause harm. Applying the zone, the result could mimic the harm

⁵² Johan Christiaan Bester, “The Harm Principle Cannot Replace the Best Interest Standard: Problems with Using the Harm Principle for Medical Decision Making for Children,” *American Journal of Bioethics*, 18(8):9-19 (2018). <https://doi-org.ezproxy.cul.columbia.edu/10.1080/15265161.2018.1485757>

⁵³ Bester, p. 15.

⁵⁴ Janine Penfield Winters (2018) When Parents Refuse: Resolving Entrenched Disagreements Between Parents and Clinicians in Situations of Uncertainty and Complexity, *The American Journal of Bioethics*, 18:8, 20-31, DOI: [10.1080/15265161.2018.1485758](https://doi.org/10.1080/15265161.2018.1485758) citing Lynn Gillam (2016), The Zone of Parental Discretion: An ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child,” *Clinical Ethics* 11 (1): 1-8.

principle by creating a floor that effectively prevents imminent harm, but it also would provide an ethical tool that alleviates the pressure to choose the doctor's solution if the parents' solution is within the accepted zone.

The zone of parental discretion and the harm principle both provide important ethical foundations for overriding refusals, although neither is accepted by mainstream pediatrics organizations, which favor the best interest analysis. The timing issue creates an opening for abuse. The best interest analysis, if applied when harm is not imminent, leads to an intrusion into the privacy and decision-making rights of parents.

The Not Unreasonable Standard

The "not unreasonable" standard espoused by Rosamond Rhodes and Ian Holzman seeks to separate two questions: whether the surrogate is qualified to make the decision and whether the "decision should be accepted or refused."⁵⁵ Meant as an alternative the best interest standard, substituted judgement, and a reasonable person standard, the not unreasonable standard is valuable in that the approach does not necessarily force unwanted care as much as it prevents errors in parental judgment based on misunderstanding the information. The other aspect of the approach is that it speaks to the sincerity of the surrogate's relationship. In one example of unreasonableness, an incarcerated mother tries to inflict nearly futile care so that she can have access to a better physical space within the prison.⁵⁶ In another example, the not unreasonable approach would allow parents to refuse a risky separation of conjoined twins.⁵⁷

However, there are several limitations to the approach that Rhodes and Holzman recommend. First, it treats all surrogates (nonparents and parents) alike, eliminating a special recognition of family autonomy and the intrinsic or instrumental value of parents and families. They define autonomy differently as "the ability to be a good ruler over oneself."⁵⁸ Most in bioethics define autonomy as the ability to make decisions for oneself. To be consistent with the law and the broader bioethics use, autonomy should include the ability to make decisions that others may find terrible. Second, the not unreasonable standard exhibits the same logical flaw that is almost inescapable: it recommends questioning refusals by caring, well-informed parents based on unreasonableness of the refusal itself. Essentially, Rhodes and Holzman are espousing something like my approach that recognizes an inability to separate procedure and substance. Their view that "apparent unreasonableness" calls for evaluation is much better than broader views that allow the evaluation of competency for merely refusing the standard of care. Rhodes and Holzman limit the not unreasonable standard to situations "of imminent and serious harm."⁵⁹ Their approach is significantly more useful than the best interest standard and would dictate a more appropriate scope within which doctors can ethically challenge parental decisions.

⁵⁵ Rhodes, R., Holzman, I. The *Not Unreasonable* Standard for Assessment of Surrogates and Surrogate Decisions. *Theor Med Bioeth* **25**, 367–386 (2004). <https://doi-org.ezproxy.cul.columbia.edu/10.1007/s11017-004-3138-6>

⁵⁶ Rhodes and Holzman, at 380-381.

⁵⁷ Rhodes and Holzman, at 378.

⁵⁸ Rhodes and Holzman, at 370.

⁵⁹ Rhodes and Holzman, at 371.

Approaches to Parental Refusals

A limited definition of an informed parent is one who has digested the science. Informed does not speak to personal preferences or societal norms. When determining that the parents are deemed uninformed, the next step should be to inform, not to coerce. A motion to compel care should be used as a limited last resort when a child is in imminent danger and a treatment has a substantial likelihood of curing the patient or ending the imminent danger in a constructive way within reasonable quality of life parameters. The procedural piece must follow a principled practice.

Considerations

The analysis requires examination of the broad factual assertions (the medical data, the risks, survival rates) and sometimes of the subjective and objective reasons for the refusals. The substantive analysis would determine the likelihood that the proposed and refused treatment would avoid the imminent harm, offer a substantial likelihood of survival, and at what costs in terms of bodily invasion, short- and long-term side effects. An inquiry into worthy alternatives and what treatment or approach the parents would pursue comprises the medical, factual inquiry.

The substantive analysis must address the efficacy of the recommended care. Difficult ethical questions arise when a treatment fraught with side effects is nominally effective but is the sole treatment for a disease that is otherwise terminal. Many treatments that are unlikely to succeed are the standard of care. The refusal of those will depend on parental views on life and quality of life as well as courts' determinations on whether there is a state interest in compelling care.

The parents' rationale is still not necessarily a relevant or appropriate inquiry for doctors, hospitals, ethics committees, or courts. Bringing in rationales when refusal is safe can overvalue or dismiss religious refusals, ignore strong parental convictions, eliminate the option of natural remedies, and substitute the judgment of Big Medicine for the parents' judgment unnecessarily. When parents make a decision that is not the standard of care and the doctor finds the decision dangerous, the parents must have the opportunity to demonstrate an alternative's efficacy or the likely result of doing nothing. If the parents have a way to avert the danger, there is no need for further inquiry. If parents choose not to treat something which doctors suggest requires treatment to avoid an imminent danger, the rationale could give the care team or the court insight, and even result in proof that the refusal does not actually endanger the child. Sometimes, courts do side with the parents. For example, it is arguable that to treat an infection in a terminally ill child who suffers from chronic pain would prolong a life that parents have an interest in not prolonging as they wish to limit the duration of the child's pain. While a court may or may not agree, a doctor feeling strongly could try to compel the care and then the parents should be certain their voice is heard in the proceedings. If parents are informed and competent but are behaving so irrationally that the child is endangered, or if they turn out to be misinformed, the court might intervene. However, simply increasing avenues for information would be preferred to court orders. Duress is more common as doctors have the benefit of the power structure that works in their favor and does not always require the use of courts.

Religious Refusals and Secular Convictions

Sometimes, a religious or other social group may have a norm that violates US law—the court would protect the vulnerable child from illegal practices. Religious refusals and philosophical secular refusals should be treated similarly. Only 16 states have no religious exemptions from child abuse or neglect

laws.⁶⁰ In New York, there is no religious exemption, meaning not only that courts may compel care, but that parents could face criminal charges for refusals that endanger children, even if they are compelled by sincere religious belief. The law protects children who could be victimized due to religious beliefs. The exemption states vary, with 17 having a statutory carve-out that allows courts to compel treatment in specified circumstances, generally to save the life. Regardless of manslaughter, neglect, or abuse exemptions, life-saving care usually can be compelled over religious refusal. The legal exemptions tend to govern criminal or family court civil charges of abuse and neglect,⁶¹ rather than prohibit court-compelled care.

Legal exemptions when parents seek “spiritual treatment through prayer” or other “faith-based healing” are misplaced and are said to be responsible for several deaths in states with exemptions. Some states’ statutes specifically deem those seeking care from Christian Scientist practitioners not neglectful. Holding the religious parents to the standards applied to all would be fair: it could save lives and would recognize how important avoiding superfluous or optional medical care is to the nonreligious. The free exercise clause allows for exemptions to many laws, and, in the context of parental refusals, it rightly should dictate when there is not imminent harm. When the likelihood of harm increases, free exercise protection decreases. When laws apply to everyone equally, states do not necessarily owe the religious an exemption.⁶²

Religion enjoys special protections compared to other groups which arguably have similarly strong and sincere convictions. Convictions about what makes life special are personal and their importance should not depend on whether the person holding the point of view is part of a group of people holding the same convictions. Many people have social, moral, and political convictions that are fundamental to their moral compass and support refusing highly chemicalized treatments, treatments that risk making a person unable to enjoy those things they deem to make a life worth living, and unnecessary or superfluous treatments. Convictions about natural remedies do not hold the power of religious convictions, although religion also sometimes espouses natural remedies.

The sincerity of the religious belief is a defining aspect of the free exercise of religion in the United States. Yet for those sincerely believing in god, there is an arbitrary element to deciding precisely what a god would want. Societal rules or doctor and hospital guidelines should neither question nor dictate religious minutia as it is inherently subjective and does not rest on rational explanations. The poking into religious beliefs is unnecessary and can alienate the religious or encourage them to hide their beliefs and fail to disclose actions that could pose an imminent harm.

Control by religious authorities over those within the community may indicate a lack of autonomy governing the refusal.⁶³ In evaluating the Jehovah’s Witness blood transfusions, the degree of the

⁶⁰ <https://www.pewresearch.org/fact-tank/2016/08/12/most-states-allow-religious-exemptions-from-child-abuse-and-neglect-laws/>

⁶¹ <http://idahochildren.org/> (map with explanations of different exemptions).

<https://www.pewresearch.org/fact-tank/2016/08/12/most-states-allow-religious-exemptions-from-child-abuse-and-neglect-laws/> (map with explanations.)

⁶² Employment Division, Department of Human Resources of Oregon v. Smith, 494 U.S. 872, (1990).

⁶³ Zimmerman, Anne, “Philosophy of Bioethics, Four Principles,” Unpublished Paper, Fall, 2018, footnote xviii.

“Beauchamp, 270. Discussing the 18-year-old Jehovah’s Witness scenario and referencing in footnotes journal articles exploring views on whether religious followers are autonomous. There must be some behavioral practices

parental autonomy is questionable. Parents alone outside the earshot of religious mentors might be more accepting of transfusions, and even choose the blood transfusion, an indication that their belief in an afterlife from which the child would be barred if the transfusion is accepted is not part of their individual sincere religious beliefs. In Christian Scientist cases, many children wish for mainstream medical care, but are forced to comply with their parents' beliefs, something that could be addressed by mature minor doctrines. Yet, for young children, there are circumstances when courts should step in to compel the care regardless of the parents' exemption from liability or criminal charges. There have been pneumonia deaths,⁶⁴ a clearly preventable outcome, which varies significantly from cases of compelled chemotherapy with uncertainty. Religious leaders can influence, brainwash, and bully people, adding to the difficulty in distinguishing religion from cults.

Religion is too disparate to be a source of legal doctrine, but it often justifies exceptions.⁶⁵ The special status of religion should not be used to elevate respect for religious refusals above secular philosophical refusals, or to undermine all refusals as if they are irrationally non-secular. In Florida, religion's special status is codified in that parents cannot lose custody of a child when a refusal of care is based on religion, although courts may compel the care.⁶⁶ The law disadvantages those refusals for conscientious, philosophical, or medical and information gathering reasons. Treating conscientious objectors like the religious would remedy the disparity. A better baseline in liberal, pluralistic society could be to treat religion and philosophy similarly—that is, to allow everyone refusals that would be allowed if the refusers were religious and refusing on religious grounds. In neglect cases, everyone also deserves the same legal consideration. Elevating philosophical convictions to have the benefits religion enjoys would protect the non-religious from criminal charges and custody loss in some jurisdictions. The religious and the non-religious should have fair terms, be held to standards that do not allow healthy children to risk preventable deaths and be permitted to refuse care when an appropriate alternative (including doing nothing) exists. Narrowing the gap between philosophy and religion would protect atheists from discrimination.

that are so out of line a reasonable adult would not subscribe to them without duress. There is no workable solution to see whether adults came into religion through duress especially if they were raised in the tradition of the religion. (Joining a cult as an adult may call for a second look.) The interest in autonomy (in adults) outweighs allowing beneficence under the guise of not true autonomy. A prioritizing analysis would presume autonomy before evaluating beneficence. Nonetheless, in unusual circumstances where the refusal of treatment seems so odd, it is justified for the doctors to discuss the situation with the patient alone to be certain outsiders are not influencing them or holding them to religious beliefs that they would rather ditch. The medical decision should be the (adult) individual's alone."

⁶⁴ Michael Rubinkam, "2-Year-Old Girl Dies After Faith-Healing Parents Refuse Medical Treatment: Officials," NBC News, 2017. <https://www.nbcphiladelphia.com/news/national-international/ella-foster-faith-healing-death/29977/#:~:text=A%20Pennsylvania%20couple%20who%20told,dying%20child%20to%20a%20doctor>. (The girl's parents were members of the Faith Tabernacle Church). See "Child Abuse in Idaho: Deadly and Legal," Idahochildren.org <http://idahochildren.org/articles/worst-in-nation/>

⁶⁵ Legislating religion would violate the establishment clause.

⁶⁶ Brooke Elvington, Press Release "Court Grants Parents' Motion for Reunification," Brooke Elvington Attorney at Law website elvingtonlaw.com, December 16, 2019. <https://img1.wsimg.com/blobby/go/85a950ad-a090-4d01-9ddb-fcb0c2c03390/downloads/Statement.pdf?ver=1576513526950>

“Life-at-all-costs is a personal religion-like view that must not be inflicted on others despite the established duty of the state to protect children who are victims of abuse or neglect.”⁶⁷ Science, medicine, and even Big Pharma behave like religions. When they try to force moral pioneering through overriding refusals, they provide a formidable deep-pocketed opponent for parents.

Types of Refusals

In refusals, the medical facts fall along a spectrum of three sliding scales: How life-threatening is the medical problem? What is the survival rate? And, how intrusive is the proposed medical intervention? Courts and doctors tend to look to survival rate and ignore the other questions. Refusals range from simple refusals (refusing Tylenol in favor of a relaxation therapy) to refusing chemotherapy, heart surgery, or other serious medical procedures. The medical aspects of the three sliding scales presents questions of fact. While uncertainty surrounds prognoses, a doctor or court overriding a refusal must look to established data in addressing the likelihood of imminent, substantial harm, the survival rate, and the nature and degree of bodily invasion that the treatment entails, including its short- and long-term side effects. These questions of fact will not provide the full picture. Even the imminence of substantial harm can rely on values and definitions that vary among people and cultures. Usually, some type of utilitarian weighing process enters the refusal arena whether in the context of a harm principle or best interest standard. The weighing process is incomplete when those doing the weighing do not understand the harms associated with compelled care. Family circumstances, beliefs, priorities, finances, obligations, health, and many other factors may impact parental decisions. Bright-line rules for refusals fail to address the many factors that go into responsible parental decision making.

Jehovah’s Witness Blood Transfusions: The Fact Pattern and The Reasoning

Courts frequently order blood transfusion for children of Jehovah’s Witnesses even if the parents object. The Jehovah’s Witnesses cases with the array of reasoning presented in the bioethics literature provide a foundation for overriding parental refusals. The general Jehovah’s Witness fact pattern is a life-threatening medical problem, an exceedingly high survival rate, and a relatively non-intrusive intervention. The rule for the Jehovah’s Witnesses should not apply if the fact pattern diverges from any of those three premises. I also argue, the best justification should not include weighing the subjective value to the religious of the beliefs or rituals of a religion. (Some Jehovah’s Witness analyses discuss the value of access to heaven, a concept outside the scope of law and medicine. That someone believes something is factual. Evaluating the belief or the rationality of the belief is outside the relevant inquiry, while evaluating the rationality of the treatment and the refusal might be appropriate.)

Doctors overriding the blood transfusion refusals should be doing so for the right reasons. The appropriate analysis, rationale, and factual limitations lead to a narrow rule. Yet, some philosophers argue that the transfusions are permissible out of beneficence or non-maleficence, empowering doctors without the appropriate limitations.⁶⁸ The best rationale for overriding parents in the blood transfusion

⁶⁷ Anne Zimmerman (2020). “Establishing a parental right to refuse chemotherapy for children with major pediatric cancers,” October 2020, unpublished manuscript.

⁶⁸ Gillon, R., “Four Scenarios”. *J Med Ethics*. 2003; 29(5): 267.

Macklin, R., “Applying the Four Principles”. *J Med Ethics*. 2003 29(5): 277.

Beauchamp, T., “Methods and principles in biomedical ethics.” *J Med Ethics*. 2003; 29(5): 271. Beauchamp cites *Prince v. Massachusetts* to show religion must yield to “sober medical judgment...”

context is saving the child's future autonomy.⁶⁹ The future autonomy rationale makes sense only because the treatment would save a life. There is not room to argue saving future autonomy when the treatment or medication being refused would not unequivocally save a life or when saving a life is irrelevant.

A simple rule should apply. *When the intervention will unequivocally save the life, is the only way to save the life, is not very invasive, and the life saved is expected to have normal life expectancy (no reason to think death is imminent),⁷⁰ then the doctors may save the child for the sake of the child's future autonomy.* For children, a doctor or court may have to step in, not to save them from fanatical parents, but to allow them to grow into adults who can choose to make ill-advised religious decisions for their own medical care or can choose to make sound ones. The rule could not be stretched to apply to refusals of chemotherapy, medications for non-life-threatening or non-dangerous illnesses or conditions, or pain relief. Whenever there is not a substantial likelihood that the life would be saved, or the life saved would be greatly compromised by the side effects (or risks) of the treatment, *some other moral justification would be necessary to override the parents.*

If the transfusions were allowed for the wrong reasons, autonomy might be unnecessarily sacrificed if the reasoning were applied to other situations. Saving autonomy of the future adult is also beneficent, but beneficence is not the rationale. Beneficence is generally the principle applied when a best interests test is invoked. Avoiding or delaying a best interest analysis is valuable to narrow the circumstances where doctors use courts or coercion to override parents.

In evaluating the blood transfusions, a group of bioethics authors apply best interest tests in different ways—one looking to science, another to society, and another to the role of a surrogate. Gillon looks to society but not religion to define the best interests in the family's cultural context.⁷¹ Macklin argues the best interests should be based on "narrow, scientific" grounds only, an argument that would open the floodgates to science dictating medical actions.⁷² The scientific norm to govern, if applied to other scenarios, would lead to forced moral pioneering. Beauchamp set a narrower rule for the application of a best interest test, possibly better reflecting doctor and hospital behavior, arguing that the best interest test should apply when there is a substantial welfare interest. While the Beauchamp rule appears narrower, his language is dismissive of the role of parents, which he analogizes to the role of any surrogate. To him, autonomy is direct to the patient only, and parental autonomy is not elevated to the role it deserves.⁷³ Gillon, Macklin, and Beauchamp overstep the minimalist rule that should apply to the blood transfusions. In doing so, they open potential for the abuse of power and an increased role of the doctor or institution in personal parenting decisions concerning medical care.

⁶⁹ Sheldon, M., "Ethical Issues in the forced transfusion of Jehovah's Witness Children." *J Emerg Med.* March-April 1996; 14 (2): 251-257. His primary claim is that the other authors use problematic reasoning. See Lainie Friedman Ross, "Against the Tide: Arguments Against Respecting a Minor's Refusal of Efficacious Life-Saving Treatment: CQ." *Cambridge Quarterly of Healthcare Ethics*, vol. 18, no. 3, 2009, pp. 302-15; 315-22, arguing a parental duty to prepare children for an autonomous future.

⁷⁰ To some quality of life could be a consideration and with a DNR order in place, perhaps the transfusion could be refused.

⁷¹ Gillon.

⁷² Macklin.

⁷³ Beauchamp.

The Jehovah's Witness transfusion cases have the benefit of appealing to teleological and deontological philosophy. The ends do justify the means because the means are less intrusive. The moral good, saving the life, comes at less cost. Because the ends are predictable, consequentialism, a philosophy built on the ends, can apply appropriately. Utilitarianism's ode to maximizing utility would predictably lead to the life-saving approach. Deontological approaches could have the same result – the duty to do the action that is morally right can be consistent with approving the blood transfusion despite the parents. There is arguably a duty to save a life, when saving the life comes with a slight intervention. The sacrifice (viewed secularly and scientifically) is small, and therefore, deontology would not call for blindly following the parents' wishes. Deontology in other medical scenarios will prove trickier – doing the right thing is not typically easy. The Jehovah's Witness scenario is good starter scenario because it presents a morally achievable good and essentially, an easy case. Overriding the refusal of antibiotics could be a good application of the rules generated by the Jehovah's Witness cases.

An argument discussing the future autonomy of the child accounts for the potential of paternalism to cause harm in other cases. The future autonomy argument eliminates paternalism altogether, rather than providing an excuse for it. The argument declares the action to be preservative, which may incidentally be in the best interests. In discussing state "parentalism," John Kultgen says, "The fact that parentalism is legitimate on a few occasions does not make it less harmful on the many occasions on which it is not."⁷⁴

The definition of life saving makes an extensive application of the Jehovah's Witness logic problematic. Saving lives is a crucial concept in pediatric ethics; improving the odds of living is not the same as saving a life. Saving lives as a goal also fails to acknowledge views on quality of life that can be personal, cultural, and religious.

Refusing Opioids

In my experience, it is incredibly difficult to refuse opioids on behalf of a child. Despite evidence of the addictive nature of opioids, doctors aggressively recommend them for pain. In the post-surgery context, it is assumed patients will need them. but we also have requested acetaminophen and ibuprofen (as well as their IV counterparts) which have worked well after surgery, especially when a nerve block keeps the patient numb for the recovery. After our adolescent's two most recent surgeries, we refused all opioids after surgery. In one case, they required she be sent home with them, and 20 more oxycodone tablets are in my refrigerator, added to the supply that came home with us against our wishes after many hospital discharges. After her most recent surgery, the doctor and hospital staff respected the refusal both in and out of the hospital, but it was a challenge. In 2018, we especially had a difficult time with an aggressive pain management team. Our sense was they peddle opioids at the bedside and do little listening. They also, at that time, repeated their mantra: opioids are unlikely to become addictive when used for only a few days, when the opioids are addressing significant pain, or in the hospital setting. These statements have not been proven true. Data does not support an impossibility of becoming addicted. Some argue five days is the maximum safe limit while more research shows three days may be safe. Other statements say no one is safe from addiction and imply no safe period.⁷⁵

⁷⁴ John Kultgen, *Autonomy & Intervention: Paternalism in the Caring Life*, New York: Oxford University Press, 1995.

⁷⁵ <https://www.mayoclinic.org/diseases-conditions/prescription-drug-abuse/in-depth/how-opioid-addiction-occurs/art-20360372>

Generally, pain is not life threatening and the survival rate of the underlying cause of the pain is not as relevant to the decision to treat pain using opioids. Addiction is a significant long-term side effect of opioid use. Several studies evaluate opioid prescribing practices in pediatrics.⁷⁶ One article examined the use of an algorithm of inpatient opioid use to determine outpatient use, finding that the predictive algorithm cut down on the overall prescribing for pediatric post-operative oncology patients.⁷⁷ While the essay validated the algorithm, inpatient opioid use itself is problematic and should not be absolved of blame in the opioid epidemic.

The harm principle would usually support permitting the refusal of opioids. Opioid refusals are a good example of the subjectivity of the best interest standard, which, if applied, could lead to a stalemate. A zone of parental interest would tend to support the refusal of opioids as opioids are just one option of many pain relief regimens. The benefits of opioids in pain management are sometimes overstated and many people do not like the feel of them or the side effects. Applying teleological ethics, the purpose of the opioid (the marginal increase in pain relief compared to other options) is not necessarily good, especially when the risk of addiction and the side effects are weighed in a utilitarian analysis. Virtue ethics and doctors' professional ethics also work against overriding parental refusals of opioids. In the opioid epidemic, doctors have not been held accountable to the extent one might expect.

Moreno-Galvan, et al. tried to create a decision-making framework for opioids that incorporates some aspects of the harm principle and zone of parental discretion.⁷⁸ They examined the tonsillectomy as a hypothetical. Yet, they essentially speak to doctors and their ability to persuade while barely empowering parents, other than a placating requirement that the doctors consider the well-known analgesic options that parents prefer. The flaws the authors see in the established frameworks are only flaws to the extent that they do not adequately compel or permit overriding the refusal of opioids. To me, doctors should not look for a less compelling reason to override parents under the guise of compromise. The authors' criticism of the harm principle was that it would be too generous to the parents' viewpoint. The best interest standard may be confusing, and the authors did favor the zone of parental discretion, acknowledging its ability to minimize the conflict to the comparison of opioids with the chosen pain relief, something any analysis should do. Generally, when pain was adequately managed for tonsillectomies for generations, it is a tough sell to require parents to approve opioids. Moreno-Galvan, et al. criticized the application of the harm principle here, but its limitation is

⁷⁶ Joshua Dean Horton, Suqrat Munawar, Corinne Corrigan, David White, Robert A. Cina, "Inconsistent and excessive opioid prescribing after common pediatric surgical operations," *Journal of Pediatric Surgery*, Volume 54, Issue 7, 2019, Pages 1427-1431, ISSN 0022-3468, <https://doi.org/10.1016/j.jpedsurg.2018.07.002>. (finding inconsistent prescribing)

⁷⁷ Sara A. Mansfield, Amy Kimble, Lynn Rodriguez, Andrew J. Murphy, Shilpa Gorantla, Eunice Y. Huang, Doralina L. Anghelescu, Andrew M. Davidoff, "Validating an opioid prescribing algorithm in post-operative pediatric surgical oncology patients," *Journal of Pediatric Surgery*, Volume 56, Issue 1, 2021, Pages 110-114, <https://doi.org/10.1016/j.jpedsurg.2020.09.040>.

⁷⁸ Moreno-Galvan, A, Marron, JM, Marsiglio, AM. How should we approach parental refusals of opioids on behalf of children in the perioperative setting? A practical approach based on ethical theory. *Pediatr Anesth*. 2020; 30: 852– 858. <https://doi-org.ezproxy.cul.columbia.edu/10.1111/pan.13941> (The authors evaluate the best interests, harm principle, zone of parental discretion, and Lainie Friedman Ross's constrained parental autonomy.)

appropriate—there likely is no harm that should compel post-tonsillectomy opioids. The authors analysis is essentially a harm principle anyway, so it does limit blanket overrides.

The authors provide a guide that addresses the family’s reasons for refusal. The questions about family history of opioid addiction imply that absent a special risk factor, the fear of addiction is misplaced. I think more careful wording would improve the credibility of the Moreno-Galvan paper. Parents should not need to prove or discuss their risk factors for opioid addiction because it is commonly known that many people without risk known factors become addicted. It is relevant in the medical history to the extent that it may bar or limit offering opioids to certain children. The authors describe both medical and other reasons to avoid opioids. The authors also suggest “providing education regarding any misconceptions, misinformation, or other gaps easily identified in the information gathering phase. If the parents are generally worried about opioids without any risk factors, for example, gentle education about the role of opioids, titrating doses to the lowest necessary, and providing a limited discharge prescription might be helpful.”⁷⁹ I would argue the parents should educate themselves using unbiased data. Hospitals cannot guarantee any patient is not going to become addicted. If they seem to be guaranteeing that, they have misinformed the parent. I would advise doctors to stay away from “gentle education” and to be sure not to sugarcoat the facts. Even among hospitalized patients and controlled use of low doses, addiction is possible. To the authors’ credit, the article rightly advocates for the use of other analgesic options and for respecting parents when those options may result in similar or even an acceptable reduction in pain management giving a quite acceptable conclusion despite an argument focused more on reasons to override parental refusals.

I argue that “subtherapeutic doses” of pain medicines are not necessarily an ethical issue at all. Moreno-Galva, et al. refer to undertreatment but measuring undertreatment based on questions like a pain scale predetermines that a certain amount of pain is not just bad, but is a moral bad, or is so bad that parents must treat it a certain way. Meeting basic needs should not equate to keeping children pain free. While no one likes to experience a child in pain, our child, through five cancers, many surgeries, painful tests, and treatments has managed well with limited opioid use. She has certainly had post-surgical opioids which have interfered with recovery and with physical therapy. In the days where a pain pump was set up and doctors, nurses, and physical therapists were permitted to “push the button,” she lost valuable recovery time. Whenever we were able to have the apparatus dismantled, she did better with pain management, and primarily alternated ibuprofen and acetaminophen. By 2018 a policy had changed so that only the patient may push the button on the pain pump—hospital staff, doctors, and nurses could no longer do it. Now, she advocates for herself and tells doctors and nurses she does not want opioids.

In times of surgeries without anesthesia, and when anesthesia was first introduced, the issues were different, and saving a life might depend on a very painful surgery.⁸⁰ To see the discovery of opioids, something that caused almost 70,000 deaths in the US last year alone but does help with pain management as a moral good is difficult. *Pain went from something we all experience at some point to taboo*. Surgeons do have a special relationship that may require them to address pain with patients,⁸¹

⁷⁹ Moreno-Galvan, at 5.

⁸⁰ Martin S. Pernick, “The Calculus of Suffering in Nineteenth Century Surgery,” *The Hastings Center Report*, Vol. 13, No. 2 (April 1983), p. 26-36.

⁸¹ Furthermore, in the same article, Moreno-Galvan, et al. wonder whether the surgeon creating the pain has entered a “special contract with these children.” Moreno-Galvan.

but opioids do not serve so crucial a purpose compared to other pain relief methods. Pain care can be discussed up front and doctors have the autonomy and power to refuse to offer the surgery. In some cases, another doctor might offer it with appropriate safeguards that do not include opioids. In the tonsillectomy example, a doctor could refuse to do the surgery—it is normally an elective surgery.

There are extreme events (like the 3F8 antibody) where if the parents refuse the recommended pain care in advance, the doctors would be justified in withholding the treatment. 3F8 is a special circumstance unlike most surgery.

In my observations, plenty of parents favor opioids and are rather free with their use. To me, overriding refusals undermines the real danger, the 760,000 people who have died of overdoses in the US since 1999, by focusing on fleshing out the limited times when pain causes “adverse health consequences.”

Shalini Shah of UCI found that a decrease in opioid prescriptions did not result in an increase in pain scores among post-surgery patients. “Alternatives include anti-inflammatory drugs, nerve medications, muscle relaxants, nerve blocks and catheters. Complementary options such as acupuncture and mindful meditation are also useful.”⁸² Especially in minor surgeries, when the pain is expected to be short term or not severe, refusals should be acceptable.

Refusing Treatment for Depression and Anxiety

Parents often try to make an informed refusal of drugs for depression or anxiety after acknowledging both the potential benefits, the efficacy rates (including the chances that the drug will not cure the child), and the various warnings including the black box suicide warnings. Overriding parental refusals of drugs with black box warnings about increased suicidal thoughts and actions undermines informed consent. Yet, some argue refusal of pharmaceutical options is neglect. While doctors seem quite comfortable with the black box warning, parents rightfully are not.⁸³

Some literature supporting antidepressants for adolescents suggests that there is consensus that potential benefits outweigh the risks. The AAP notes that neglect is “refusing to provide for serious emotional-behavioral, physical health, or educational needs.”⁸⁴ The AAP’s medical neglect criteria do not apply well to mental health as there is not true consensus. One author argues that the pharmaceuticals are effective and “although no single modality guarantees remission, a comprehensive, integrated plan...should offer significant benefit.”

⁸² UCI Live Well website, “Treating post-surgical pain without opioids,” University of California, Children’s Hospital of Orange County <https://www.ucihealth.org/blog/2019/07/opioids-postsurgery>

⁸³ Neil Osterweil, “Kids and Antidepressants: A Growing Problem: No. 3 of the Top 10 Stories of 2004: The FDA warned of a drug-suicide link this year. Are we rushing to medicate our kids or rushing to judgment about drugs that may truly help some of them?” WebMD <https://www.webmd.com/depression/features/kids-antidepressants-growing-problem> (article describes risks and a personal example of a suicide by a 13 year old taking Zoloft.) See Craig J Whittington, Tim Kendall, Peter Fonagy, David Cottrell, Andrew Cotgrove, Ellen Boddington, “Selective serotonin reuptake inhibitors in childhood depression: systematic review of published versus unpublished data,” *The Lancet*, Volume 363, Issue 9418, 2004, Pages 1341-1345 <https://www.sciencedirect.com/science/article/abs/pii/S0140673604160431> (researchers showed that unpublished data confirmed that the risks outweighed the benefits. After this report, the FDA added the black box suicide warnings.)

⁸⁴ Michael Shapiro, “Pediatric Depression: When Does Parental Refusal for Treatment Constitute Medical Neglect?” *Journal of the American Academy of Child and Adolescent Psychiatry*, Vol. 57, Number 6, June 2018.

Medication as a first line treatment can deprive people of the opportunity to make diet, lifestyle, and life situation changes that would improve or eradicate the condition. There is strong evidence that an exercise plan, a support system of friends, and a healthy diet have some effect on mood, depression, and anxiety. According to the Anxiety and Depression Association of America (ADAA), some studies show that “regular exercise works as well as medication for some people to reduce symptoms of anxiety and depression, and the effects can be long lasting. One vigorous exercise session can help alleviate symptoms for hours, and a regular schedule may significantly reduce them over time.”⁸⁵ While the organization recognizes that is not true for everyone, there are circumstances in which it is reasonable and rational to exhaust the use of exercise and diet before engaging in pharmaceutical options. The ADAA offers regimens to try. Sixty-six percent of all adults are on prescription drugs and antidepressants as a class are the second most commonly prescribed.⁸⁶ A thirty-five-fold increase from 1987 to 2007 in mental illness diagnosis as a qualifying disability in children may signify overdiagnosis and overprescribing.⁸⁷ The pharmaceutical profits⁸⁸ from antidepressants create a conflict of interest and rightly cause parents to question drugs as a first-line treatment.

Refusing Chemotherapy

The Factors and Philosophy

I am not in the business of suggesting that parents choose not to treat pediatric cancer. I recommend that parents be fully informed and that they personally evaluate how the worst-case scenarios and even the average scenarios might play out for their family. I am supportive and often help families navigate the circumstances. My strong sense that courts and doctors should not be in the business of compelling care is based on knowing how invested a parent must be in the care. I support care entered willingly with hope and trust in a medical system, but when a system handcuffs patient to beds⁸⁹ or removes children from the custody of their caring, loving parents,⁹⁰ my faith in the system is shaken. I support parental education and self-reflection. I would not judge non-religious refusals because I understand both that there are people without the emotional, financial, and physical wherewithal to support the child, and that there are legitimate risks of quality-of-life compromises that a reasonable, rational parent might wish to avoid. The incredible costs of surviving cancer and high dose chemotherapy are borne by

⁸⁵ “Exercise for Stress and Anxiety” <https://adaa.org/living-with-anxiety/managing-anxiety/exercise-stress-and-anxiety#:~:text=According%20to%20some%20studies%2C%20regular,significantly%20reduce%20them%20over%20time.>

⁸⁶ Health Policy Institute, Georgetown University. <https://hpi.georgetown.edu/rxdrugs/>

⁸⁷ Marcia Angell, “The Epidemic of Mental Illness: Why” *The New York Review*, July 2011.

<https://www.nybooks.com/articles/2011/06/23/epidemic-mental-illness-why/> (Angell suggests there has been expansion of the criteria for mental illness and a trend toward using drugs before other modalities.)

⁸⁸ Allied Market Research, “Antidepressant Drugs Market to Reach \$15.98 Bn by 2023, Globally at 2.1% CAGR, Says Allied Market Research,” PRNewswire, November 21, 2018. <https://www.prnewswire.com/news-releases/antidepressant-drugs-market-to-reach-15-98-bn-by-2023-globally-at-2-1-cagr-says-allied-market-research-873540700.html>

⁸⁹ W.W., “Cassandra’s Catch-22: A Connecticut teen forced to undergo chemotherapy is a victim of circular logic,” *The Economist*, January 14, 2015. <https://www.economist.com/democracy-in-america/2015/01/14/cassandras-catch-22>

⁹⁰ Matt Keeley, “Parents Seek to Regain Custody of 4-Year-Old Cancer Patient After Taking Him Off Chemotherapy,” *Newsweek*, August 19, 2019. <https://www.newsweek.com/parents-seek-regain-custody-4-year-old-cancer-patient-after-taking-him-off-chemotherapy-1455130>

the family, not the doctor. The parents suffer the consequence of choosing chemo and some live with terrible regret over having allowed the child to suffer.⁹¹

Cancer is life threatening, has varying survival rates, and many treatments for cancer entail a huge bodily intrusion. The factual inquiry covers those factors. For many childhood cancers that enjoy high survival rates, the treatment presents an extreme bodily invasion, making blanket neglect inappropriate. All refusals at one given survival rate should not be deemed categorically neglectful in nature. This section focuses on cancers including brain tumors, neuroblastoma, osteosarcoma, other sarcomas, Wilms tumor, rhabdomyosarcoma, lymphoma, and leukemia, which are the predominant cancers requiring systemic high-dose chemotherapy. (Retinoblastoma can require it but the introduction of intraarterial chemotherapy has changed the retinoblastoma landscape somewhat.)⁹² This section is not meant to address cancers with simple solutions like laser treatments, surgery, or removal of a skin lesion.

In adult cancers, refusal would usually be accepted. In pediatrics, the vulnerability of children and the potential life years ahead of them are the justification for imposing cancer care. Yet protecting the vulnerable alone does not account for imposing such intrusive care, and it places a wedge between parents who want to protect the vulnerable child and doctors who are trying to remedy the vulnerability differently. Parents and doctors often agree that vulnerability and a lack of capacity to consent make the parents the default decision makers. Vulnerability “to what” is the real issue.

Disclosure of side effects, informed consent, and signatures indicating consent serve no purpose if parents are not permitted to refuse. Compelling care violates the basic bioethics standards. The reason to cast aside those fundamentals when embarking on serious, dangerous, risky medical care must be compelling. In chemotherapy, and especially in stem cell transplants, there are serious risks including the risk of death.⁹³ One study concluded that compelling care is not related to increased likelihood of survival.⁹⁴ Poverty is linked to graft-versus-host disease as well as lower survival rates after stem cell

⁹¹ Lori Resnick-Fleishman, “My daughter is struggling with chemo effects. I am struggling with guilt.” *Washington Post – Blogs*, September 15, 2016 <http://ezproxy.cul.columbia.edu/login?url=https://www-proquest-com.ezproxy.cul.columbia.edu/docview/1819605728?accountid=10226> (accessed October 6, 2020). <https://search-proquest-com.ezproxy.cul.columbia.edu/docview/1819605728?accountid=10226&pq-origsite=summon>

⁹² Zimmerman, Anne, (2020). “Establishing a parental right to refuse chemotherapy for children with major pediatric cancers,” October 2020, unpublished manuscript.

⁹³ In the realm of gene therapy, the Jesse Gelsinger case at University of Pennsylvania provided a costly lesson, one in which a refusal would have saved a life. The scientists offered a risky treatment, and the family willingly embarked on a medical experiment that led to Jesse’s death. While refusal was not relevant, it later appeared some red flags had been ignored, and more complete disclosure may have led the family to avoid enrollment in the study.

⁹⁴ Amy E. Caruso Brown, Amy R. Slutzky, “Refusal of Treatment of Childhood Cancer: A Systematic Review,” *Pediatrics*, December 2017, 140 (6) e20171951; DOI: 10.1542/peds.2017-1951 <https://pediatrics.aappublications.org/content/pediatrics/140/6/e20171951.full.pdf>

transplants.⁹⁵ Compelling the care has far-reaching personal consequences and may result in food insecurity for impoverished families.⁹⁶

Philosophically, there is a distinction between ordinary care and extraordinary care in the context of refusals. Generally, it is easier to refuse extraordinary care than ordinary care, a concept played out in many adult refusals of life-sustaining treatment. A parental legal duty to provide care may not match the ethical duty to provide care. And a best interests test might compel more care than a more relaxed standard under which parents provide for children's basic needs, a legal minimum absent special circumstances or imminent harm. Some authors have asserted that cancer care is a basic medical need.⁹⁷ While to those wanting it, I see how that language furthers their ability to access cancer care, for those not wanting it, defining it as a basic need makes its absence more likely to fall within neglect. Trying to categorize chemotherapy as ordinary because it is considered the standard of care leads to conclusions based merely on prognosis. When something as intrusive and with such a strong assault on the body becomes the standard of care, a standard of care argument to compel the care should be less effective. Chemotherapy feels extraordinary to those consenting to it.

"...[t]he largest study of its kind found that most oncologists reject parental refusals when treatment has a 33% or greater chance of success."⁹⁸ If there is a 33 percent survival rate and a treatment is forced on 100 additional people whose parents have refused, then 33 additional people would survive (at a great cost) while 67 additional people experience a different path to death than what the family wants, and parents experience a loss of parental autonomy for nothing. Even at a 15 percent survival rate, some doctors polled said they would override refusals.⁹⁹ The harm of not treating a child with cancer is clear: the child will almost certainly die. But the harms associated with coerced or court-ordered care are plentiful as well.

Doctors often try to override refusals of chemotherapy based on prognosis alone. Lainie Freidman Ross attempts to justify a simple line to determine whether overriding parents is appropriate. She argues that

⁹⁵ Kira Bona, Leslie E. Lehmann, Wendy B. London, Joanne Wolfe, Prevalence and Impact of Poverty in Pediatric Allogeneic Hematopoietic Stem Cell Transplant, *Biology of Blood and Marrow Transplantation*, Volume 20, Issue 2, Supplement, 2014, Pages S166-S167, ISSN 1083-8791, <https://doi.org/10.1016/j.bbmt.2013.12.268>.

⁹⁶ Kira Bona, et al. "Economic impact of advanced pediatric cancer on families." *Journal of Pain and Symptom Management* vol. 47,3 (2014): 594-603. doi:10.1016/j.jpainsymman.2013.04.003; Martin Adam, Corina S. Rueegg, Kurt Schmidlin, and Adrian Spoerri. 06/15/2016. "Socioeconomic Disparities in Childhood Cancer Survival in Switzerland," *International Journal of Cancer* 138 (12): 2856-2866. doi:10.1002/ijc.30029. <https://onlinelibrary.wiley.com/doi/pdf/10.1002/ijc.30029>;

⁹⁷ Lainie Friedman Ross, "Against the Tide: Arguments Against Respecting a Minor's Refusal of Efficacious Life-Saving Treatment," *Cambridge Quarterly of Healthcare Ethics*, 18(3), 302-15; discussion 315-22. doi:<http://dx.doi.org.ezproxy.cul.columbia.edu/10.1017/S0963180109090471>

⁹⁸ Thaddeus Mason Pope, "Parental Treatment Refusals: What Your Responsibilities Are When Mom and Dad Decline Cancer Treatment for a Child," *ASCO Post*, July 25, 2019. <https://srrn.com/abstract=3427271>
For data on doctors treating despite parental refusals, see Erin D. Talati, Colleen Walsh Lang, Lainie Friedman Ross, "Reactions of Pediatricians to Refusals of Medical Treatment for Minors," *Journal of Adolescent Health* 47 (2010) 126-132. With 80 percent 5-yr survival, doctors treated 325 of 404 over family refusals.

⁹⁹ Erin D. Talati, Colleen Walsh Lang, Lainie Friedman Ross, "Reactions of Pediatricians to Refusals of Medical Treatment for Minors," *Journal of Adolescent Health* 47 (2010) 126-132. In the 15 percent survival case, when parents and patients choose to refuse care, the study respondents who would treat over refusals were 11 and 7 percent for 11-year-old and 16-year-old patients, respectively.

if a cancer has a survival rate of 75 percent, doctors must treat.¹⁰⁰ She argues “*the greater the efficacy...the less voice [the parent] should have,*”¹⁰¹ a disturbing position that diminishes the role of parents in serious medical decisions.

Physicians reporting on reasons for treating despite parental refusal cited the child’s autonomy when the child wished to be treated but the parent did not, and parental authority when the child wished to refuse but the parent wished to treat. In both situations, there is strong argument to compel care, all things considered, based on either direct autonomy or parental autonomy. Sacrificing the child’s decision-making power for the parental autonomy reflects the inability of a young minor to consent. Sacrificing the parental autonomy in favor of the child’s shows the strength of assent. Yet, the study demonstrates the power of agreeing with the doctor compared to the stigma of refusal, where the doctor is more likely to ignore the assenting child or the parental autonomy. In the same study, most chose poor prognosis as the reason to allow refusals to stand when both parent and child refused.¹⁰²

The Noah McAdams Case

Noah McAdams parents missed a chemotherapy appointment to seek information about natural alternatives. Skeptical of the terrible and debilitating side effects of chemotherapy, they left the state of Florida to meet with alternative practitioners after Noah had several rounds of chemotherapy. The parents’ distain for chemotherapy was known; their behavior was transparent.

During chemotherapy, there is often a period after a few cycles during which it is “safe” to take a break.¹⁰³ There are well-accepted reasons for breaks: doctors sometimes encourage short vacations and social engagements for the child’s mental and emotional well-being, a longer time for blood counts to recover, time to attend to other health issues and side effects, or respect for those seeking pharmaceutical, mainstream medical alternatives and second opinions. For example, a missed chemotherapy appointment while a family explores switching to proton beam radiation would tend to be acceptable.¹⁰⁴

In Noah McAdams case, when the family left the state, law enforcement chased them and took custody of their child. It undoubtedly felt like kidnapping. The child was forced to continue chemotherapy while living with relatives. If the McAdams missed appointments for a variety of other reasons, including a religious reason or to seek mainstream second opinions, they would have maintained custody of

¹⁰⁰ Ross, Lainie F. "Against the Tide: Arguments Against Respecting a Minor's Refusal of Efficacious Life-Saving Treatment: CQ." *Cambridge Quarterly of Healthcare Ethics*, vol. 18, no. 3, 2009, pp. 302-15; discussion 315-22. doi:<http://dx.doi.org.ezproxy.cul.columbia.edu/10.1017/S0963180109090471>.

¹⁰¹ Lainie Friedman Ross, “Ethical Issues Raised by the Media Portrayal of Adolescent Transplant Refusals,” *Pediatrics*, vol. 146, no. s1, 2020.

¹⁰² Erin D. Talati, Colleen Walsh Lang, Lainie Friedman Ross, “Reactions of Pediatricians to Refusals of Medical Treatment for Minors,” *Journal of Adolescent Health* 47 (2010) 126-132.

¹⁰³ UW Health and Wellness, “Is it Possible to Take a Break from Cancer Treatments?” University of Wisconsin, Interview with Robert Hegeman, MD, November 13, 2018. <https://www.uwhealth.org/health-wellness/is-it-possible-to-take-a-break-from-cancer-treatments/52337>

¹⁰⁴ “Brain tumour boy Ashya King free of cancer, parents say,” BBC News, BBC.com, (March 23, 2015). <https://www.bbc.com/news/uk-england-32013634> (The media did not understand that Aysha King’s family was seeking a better treatment, one which has since become standard of care for those who can afford it.)

Noah.¹⁰⁵ There was a noteworthy absence of imminent harm at the time he was taken from his parents' custody and the mindset of the parents, *mens rea* in criminal law, was not only non-neglectful, but it was also fully supportive of Noah's health and positive outcome.

The scenario that could have played out would look like parents who wish natural therapies would work, gather information, make an educated decision that a natural alternative is not available for the cancer, and return to mainstream medicine. The other scenario, in which parents gather data on natural alternatives and meet other parents who have seen success, could arguably be brought up in a motion to compel care. A court could compel care against the wishes of parents after hearing both sides. And, as some natural remedies do work for some conditions, like CBD or a keto diet for epilepsy, the court may rule in favor of the parents. Questions of fact would be answered based on evidence; experts would provide opinions.

One third scenario is that parents accept the very high risk (or sometimes certainty) of death and prefer that to the quality-of-life compromises associated with chemotherapy. They may use alternative therapies in the way many use mainstream palliative care. Some may even hope the therapies will prolong life or for the discovery of a less intrusive cure in the meantime. The judgments involved in that, to me, seem personal. While I support continuing chemotherapy, I understand that some informed parents would choose to stop it, a decision that happens more in low survival rate cancers. The fundamental issue of the ability to choose death, and the possibility of influencing the circumstances surrounding death, as opposed to being forced to risk death from chemotherapy side effects or death from cancer while end-of-life circumstances are fraught with chemotherapy side effects, is where the push and pull is. Doctors promote life without guaranteeing it or defining which aspects of it are the essence of why families value it. They may not have deeply explored why exactly they value life and what their role is in the legitimate state interest in protecting life. When doctors use courts to compel care, this is where the wiggle room is. Doctors do compel chemotherapy, yet they do not bear the risks associated with it.

Doctors Can Encourage Care Without Duress

"Doctors are not helpless in their effort to convincingly recommend chemotherapy. Doctors must be certain parents understand survival rates, especially when they are high. They also can connect parents with current patients' parents, create warm, welcoming, and energetic hospital environments, and address ways parents can sustain jobs and take good care of the child."¹⁰⁶ Once doctors have conveyed a picture of the experience, under many circumstances, they should accept the parents' decision and, if relevant, offer comfort care keeping the child connected to the hospital environment where the parents may change their mind after observing other patients. Under circumstances where they have sincere reason beyond life-at-all-costs to compel care, they can in good faith use tools like social workers, child protective services, ethics committees, and even motions to compel care. Valid reasons might be evidence-based suspicion that the refusal is based on misunderstanding, a failure to digest the scientific data, ill-motivated parents who lack good will, or parents that truly have a *mens rea* of neglect or a

¹⁰⁵ Brooke Elvington, Press Release "Court Grants Parents' Motion for Reunification," Brooke Elvington Attorney at Law website elvingtonlaw.com, December 16, 2019. <https://img1.wsimg.com/blobby/go/85a950ad-a090-4d01-9ddb-fcb0c2c03390/downloads/Statement.pdf?ver=1576513526950>

¹⁰⁶ Zimmerman, Anne, "Establishing a parental right to refuse chemotherapy for children with major pediatric cancers," October 2020, unpublished manuscript.

selfish desire not to provide the care. Those favoring compelling care cite arguments ranging from a chance at an open future, protection of the vulnerable (children have a special status), and the child's best interest. Society's value of life and the doctor's duty to protect the child arguably trump the parental right to refuse in some cases. To me, those must be evaluated case-by-case and remedied in a way that does not inflict scientific discoveries on everyone.

Public policy could also make refusals even more rare. Financial security, proper education, and other social factors play a role in refusals. "Policies promoting job security, family leave, universal insurance, and universal daycare and pre-K can prevent some of the financial downsides and may help parents afford the ancillary personal costs of treatment."¹⁰⁷

Who Bears the Risks When Care Is Coerced?

Doctors protect themselves from liability through consent documents signed by parents. The doctor can always say that the parents were aware of the risks and signed the consents. To be valid, consent must be informed and entered voluntarily. Parents often feel duress when doctors would describe themselves as persuasive or as making a recommendation, a noteworthy disconnect.

This extreme view is not in the public discourse but there is value in contemplating it: if a motion to compel succeeds or a doctor gets parental consent using duress, hospitals or doctors should assume all the risks. Under duress, parents should not sign the consent. (Legally a contract signed under duress is not valid.) Hypothetically, what if absent parental consent, doctors would be presumed to consent on behalf of the child? Should parents have a cause of action (the ability to sue the doctor) if any harm is caused by the intervention? The hospital and doctor should not be able to later say the parents knew the side effects when they signed off. The hospital and doctor should pay for any unreimbursed care. If this view (one that would not be taken seriously in the current state of bioethics or the doctor patient relationship) were considered as the extreme view, a shift could occur. By examining the theory that doctors be held responsible, the public could recognize that parents who do not want to sign off on certain care carry not only the financial costs of the care, but also the emotional burden of the bad decision if the care proves more harmful than beneficial. Any amount of risk distribution might highlight to doctors how much risk parents bear while doctors and courts do not bear any. There seems to be no financial or emotional responsibility when doctors force people to try epilepsy medications, chemotherapy, heart surgery, and other intrusive interventions and when it is difficult to predict which patients will have success with the treatment.

Justice: Abuse, Neglect, Custody, Incarceration—When Should Refusal Equal Neglect?

Neglect

Beyond duress and simple pressure by doctors, courts become involved in cases of refusal of the standard of care. Some ethicists argue that doctors should override refusals of the standard of care with

¹⁰⁷ Zimmerman, Anne, (2020). "Establishing a parental right to refuse chemotherapy for children with major pediatric cancers," October 2020, unpublished manuscript.

little investigation into imminent harm to the child. Refusal falls into neglect in some cases and varies by jurisdiction.¹⁰⁸

“... there is considerable lack of agreement on an operational definition of neglect within popular culture across the States, within the scholarly literature across disciplines and among professionals working in different areas (e.g., while a health-care provider may consider a child not taking prescribed medicine as neglect, the situation may be interpreted differently by child protective services or even the courts).”¹⁰⁹ Neglect is not simply a failure to follow doctor’s recommendations. A neglected child in New York is one “...whose physical, mental or emotional condition has been impaired or is in imminent danger of becoming impaired as a result of the failure of his parent or other person legally responsible for his care to exercise a minimum degree of care.”¹¹⁰ It is difficult to reconcile the definition of neglect with the references to neglect in the bioethics literature.¹¹¹

Neglect should require a *mens rea*, that is a guilty mind. While the *mens rea* varies, generally to be neglectful one must be aware of a substantial and unjustifiable risk. Generally, negligence is the mindset associated with criminal neglect. While the parents’ behavior may not be acceptable to the doctor, adapting the word neglect to suit the refusal of ordinary or extraordinary care can put caring attentive parents at risk of criminal proceedings or custody loss.

Medicine is not equipped to perform law.¹¹² The American Association of Pediatrics (AAP) created criteria for alleging medical neglect.¹¹³ The AAP encourages doctors to ensure proper care by using

¹⁰⁸ Child abuse pediatricians are a new development in pediatric medicine, and they can increase the number of wrongful convictions and judgments. The system empowers doctors who are not educated in laws of abuse and neglect.

¹⁰⁹ Warehime, M.N., Bass L.E., Chapple C.L. (2018) Child Neglect. In: Levesque R.J.R. (eds) *Encyclopedia of Adolescence*. Springer, Cham. https://doi-org.ezproxy.cul.columbia.edu/10.1007/978-3-319-33228-4_41

¹¹⁰ New York Consolidated Laws, Family Court Act - FCT § 1012

¹¹¹ Thaddeus Mason Pope, “Parental Treatment Refusals: What Your Responsibilities Are When Mom and Dad Decline Cancer Treatment for a Child,” *ASCO Post*, July 25, 2019. <https://ssrn.com/abstract=3427271> (example of bioethics author pushing to define refusal as neglect.)

¹¹² Katie LaGrone, “Florida’s top child abuse pediatrician justifies questionable findings of abuse,” *ABC News I-team Investigations*, February 13, 2020. <https://www.abcactionnews.com/news/local-news/i-team-investigates/floridas-top-child-abuse-pediatrician-justifies-questionable-findings-of-abuse> (Bruce McIntosh is a statewide director of about 25 child abuse physician teams; his training videos tell doctors to look out for common defenses in child abuse cases. He urges doctors to ignore parents’ medical claims and to operate with suspicion, especially considering the rarity of certain medical conditions. They are taught that some parents lie and that some medical diagnoses are so rare that it is appropriate to suspect or even assume parents abused the child. He has been associated with practices that least to unsubstantiated child abuse claims.) See Mike Hixenbaugh, *Do No Harm* podcast, Wondery, (November 2020) <https://wondery.com/shows/do-no-harm/> (several stories of wrongful removal of children from their families and abuse of power by child protective services.)

¹¹³ Jenny Carole, “Recognizing and Responding to Medical Neglect,” *Pediatrics*, Dec 2007, 120 (6) 1385-1389; DOI: 10.1542/peds.2007-2903. Necessary criteria for neglect are “1. a child is harmed or is at risk of harm because of lack of health care;

2. the recommended health care offers significant net benefit to the child;
3. the anticipated benefit of the treatment is significantly greater than its morbidity, so that reasonable caregivers would choose treatment over nontreatment;
4. it can be demonstrated that access to health care is available and not used; and
5. the caregiver understands the medical advice given.”

various tools like engaging the extended family and community, overcoming translational barriers, and understanding the family's concerns. Yet, the guidance also suggests child protective services be engaged, which can result in legal proceedings. A doctor should deliver expert testimony, but the testimony should not be overvalued merely because of status and degree. Physician exceptionalism influence judges.¹¹⁴ Rather than being proven guilty beyond a reasonable doubt, family courts apply a standard of proof relevant to civil cases, usually a preponderance of the evidence. And, in most cases, child protection agencies have the authority to remove the child from the parents' custody before the civil trial.

The substantive due process guaranteed by the Fifth and Fourteenth Amendments covers punitive conditions ordered in civil matters. Family court is a venue of civil proceedings. In a civil venue, actions aim to make one party whole. Proportionality is the "yardstick for measuring the appropriate relationship between the ends and the means of discretionary action."¹¹⁵ Overly zealous courts can outstep the appropriate limitations on their power¹¹⁶ by imposing custody loss unnecessarily, without imminent danger. While the Eighth Amendment covers criminal proceedings, it sets a minimum standard for legal enforcement actions. The Supreme Court in a case regarding those in civil confinement, held that the "*minimum standard allowed by the due process clause is the same as that allowed by the eighth amendment for convicted persons.*"¹¹⁷ Loss of custody, when it is not directly protecting the child, is cruel and a disproportionate response to refusals of medical care. Family court is not tasked with punishing parents. The court should focus only on compelling care; losing custody is problematic and goes beyond the issue of care.¹¹⁸

Criminal proceedings are different. Even in criminal law, the punishment must be proportionate to the crime. When custody loss occurs after criminal conviction, it is accepted in the scope of punishment as custody can be inconsistent with incarceration. (Because of the harshness of custody loss and the value of families, there are even circumstances where an incarcerated mother may keep an infant or young child with her in prison.)

Racial and Socioeconomic Disparity

In impoverished neighborhoods, families have been subjected to welfare checks merely for missed appointments, something common among those juggling children, jobs, and other responsibilities. Racial and socioeconomic stereotyping places certain parents at more risk when refusing medical care for their children. "[R]esearch documents the existence, content, and strength of stereotypes that link

¹¹⁴ Maggie Mang, "The Problematic Virtue of Physician Exceptionalism," Thesis, Emory University. (2017) <https://etd.library.emory.edu/concern/etds/bz60cx10m?locale=en>

¹¹⁵ Elisabeth Zoller, Congruence and Proportionality for Congressional Enforcement Powers: Cosmetic Change or Velvet Revolution? 78 IND. L.J. 567, 568 (2003)

¹¹⁶ Tracy A. Thomas, "Proportionality and the Supreme Court's Jurisprudence of Remedies," 59 Hastings Law Journal 73 (2007-2008).

<https://heinonline.org/HOL/LandingPage?handle=hein.journals/hastlj59&div=11&id=&page=>, Leo Romero, "Punitive Damages, Criminal Punishment, and Proportionality: The Importance of Legislative Limits," 41 Conn. L. Rev. 109 (2008-2009).

¹¹⁷ Hamm v. DeKalb County, 774 F.2d 1567, 1574 (11th Cir. 1985) (emphasis added).

¹¹⁸ Brooke Elvington, Press Release "Court Grants Parents' Motion for Reunification," Brooke Elvington Attorney at Law website elvingtonlaw.com, December 16, 2019. <https://img1.wsimg.com/blobby/go/85a950ad-a090-4d01-9ddb-fcb0c2c03390/downloads/Statement.pdf?ver=1576513526950>

race and social class to child abuse.” The stereotypes have the “...potential to lead to medical misdiagnosis of abuse for Black and poor children.”¹¹⁹ Doctors are more likely to find that an injury is due to abuse in those demographics.¹²⁰ The likelihood of being under the auspices of child protective services or being exposed to mandatory reporters is part of the structural problem.¹²¹ Mandatory reporters often include childcare, foster care, police, and social workers, all of whom tend to have contact with a disproportionate number of poor and Black people. Teachers and doctors, and others in health care are also mandatory reporters. Bias may be implicit in the system that created mandatory reporting by people who work in public services that socioeconomically well-off people do not use in equal proportions to those less privileged.¹²² Like having police in some schools and not others, some will escape scrutiny for behavior that could amount to neglect while many non-neglectful people will be hyper-scrutinized.

In refusals, there is a built-in further prejudice because there is some consideration of education when evaluating how informed patients are. The less educated tend to be less wealthy, demonstrating a further disadvantage to those facing socioeconomic challenges. In a country where health care is not a given, the poor are expected to have the money to meet medical bills and time off to attend appointments. Action is needed to be sure that custody loss for the refusal of medical care that should be optional or has alternatives, or care that a wealthier person could refuse, is not one more way of punishing people for being in poverty.

In the US, six million children a year are part of abuse and neglect cases. In neglect cases, there is “a much larger proportion of total Black children reported for maltreatment compared to White children (11.0% vs. 4.3%).”¹²³ “Black parents are more likely to lose custody of their children to the child welfare system than parents of other races. This racial disparity is highlighted in federal data – 24.3 percent of children in the foster care system are black while they only make up 13.8 percent of the overall child population. One recent study found that 53 percent of all black children will be investigated as potential victims of child abuse by age 18, 16 percentage points higher than the rate for all children combined.”¹²⁴

¹¹⁹ Cynthia J. Najdowski, Kimberly M. Bernstein, Race, social class, and child abuse: Content and strength of medical professionals’ stereotypes, *Child Abuse & Neglect*, Volume 86, 2018, Pages 217-222, ISSN 0145-2134, <https://doi.org/10.1016/j.chiabu.2018.10.006>.

(<https://www.sciencedirect.com/science/article/pii/S0145213418303946>)

¹²⁰ Najdowski citing E.G. Flaherty, R.D. Sege, J. Griffith, L.L. Price, R. Wasserman, E. Slora, *et al.*

From suspicion of physical child abuse to reporting: Primary care clinician decision-making *Official Journal of the American Academy of Pediatrics*, 122 (2008), pp. 610-620 and R.L. Hampton, E.H. Newberger Child abuse incidence and reporting by hospitals: Significance of severity, class, and race *American Journal of Public Health*, 75 (1985), pp. 56-60

¹²¹ Michael Fitzgerald, “New York City Confronts Massive Overrepresentation of Black Children in Foster Care,” *The Imprint*, February 27, 2019. <https://imprintnews.org/featured/new-york-city-de-blasio-black-foster-care/33992>

¹²² Fitzgerald, “New York City Confronts Massive Overrepresentation.”

¹²³ Jonson-Reid M, Drake B, Zhou P. Neglect Subtypes, Race, and Poverty: Individual, Family, and Service Characteristics. *Child Maltreatment*. 2013;18(1):30-41. doi:10.1177/1077559512462452 (“Even after limiting the examination to children with neglect allegations, Black children had much higher rates of both family and community poverty across all subcategories of neglect examined. Further, perpetrators of neglect among Black children were almost universally female (between 98% and 87%), whereas females comprised between 71% and 87% among White children reported.”)

¹²⁴ Michael Fitzgerald, “Top Stories of 2019: Race and Bias in New York,” *The Imprint*, December 17, 2019.

<https://imprintnews.org/featured/race-and-bias-in-new-york/39714>; Michael Fitzgerald, “To Eliminate Racial Bias,

Mandatory reporting often leads to the reporting of parenting choices that the reporter does not like. "Government lawyers then file flimsy "neglect" charges against the parents, rarely making more serious physical abuse claims."¹²⁵

Some argue there is no bias, often asserting that those in poverty do worse for their children and are culpable.¹²⁶ Elizabeth Bartholet argues that because risk factors including poverty, substance abuse, and single parenting exist disproportionately by race, the numbers do not reflect discrimination.¹²⁷ The data possibly reflects bias and the over-exposure of those cohorts to mandatory reporters. Her argument leads to a circular conclusion that some parents at higher risk deserve more scrutiny. In turn, that can put their children at risk of being in a system merely because the system does not like their parenting choices.

One study compares two sets of 81 people divided by race already in the system and analyzes their case data.¹²⁸ Yet the more important issue may lie outside the scope of that study. Even if once both sets are in the system they are treated similarly, a smaller percentage of white children, and an even smaller percentage of wealthy children are in the system at all. Parental refusals of medical care should be evaluated without bias so that unsubstantiated medical neglect charges do not further the racial disparities in foster care, family court, or social welfare programs.

Should We Ensure the Ability to Refuse Genetic Enhancement in the Future?

"...a common response to the disquieting feeling that science is accelerating beyond our capacity to comprehend it -- let alone control it -- is to declare oneself fervently, if confusedly, on its side."¹²⁹

-Margaret Talbot

Enhancement, here defined as choosing the physical (but not explicitly medical) traits like height, strength, intellect, or talent, touches on the essence of what societal values should be protected and who should be part of the decisions to allow or prohibit enhancements. The inability to refuse genetic enhancement techniques would drastically change society. There are competing views on the role of

Child Welfare Breakthrough Tells us to Try Colorblindness," *The Imprint*, April 2019.

<https://imprintnews.org/news-2/color-blind-implicit-bias-foster-care-new-york/34458>

¹²⁵ Michael Fitzgerald, "New York City Confronts Massive Overrepresentation of Black Children in Foster Care," *The Imprint*, February 27, 2019. <https://imprintnews.org/featured/new-york-city-de-blasio-black-foster-care/33992>

¹²⁶ Elizabeth Bartholet, "The Racial Disproportionality Movement in Child Welfare: False Facts and Dangerous Directions," 51 *Ariz. L. Rev.* 871 (2009). <https://heinonline-org.ezproxy.cul.columbia.edu/HOL/Page?collection=journals&handle=hein.journals/arz51&id=888>

¹²⁷ Bartholet.

¹²⁸ Margaret Skrypek, Kyler Woodmass, Maxie Rockymore, Geoff Johnson, Susan J. Wells, Examining the potential for racial disparity in out-of-home placement decisions: A qualitative matched-pair study, *Children and Youth Services Review*, Volume 75, 2017, Pages 127-137, ISSN 0190-7409, <https://doi.org/10.1016/j.childyouth.2017.02.010>.

(<https://www.sciencedirect.com/science/article/pii/S0190740917301378>)

¹²⁹ Talbot, Margaret. *The Cloning Mission: A Desire to Duplicate*. New York Times. Feb. 4, 2001. Referring to the Ralians, a scientific religious cult that is pro-cloning.

enhancement, or the moral obligation to enhance in whatever ways become feasible.¹³⁰ An inability to refuse enhancement would lead to the moral pioneering that I find it crucial to avoid. Big science, medicine, and technology may create valuable options. And many people may want to explore those options, something that should require forethought and regulation. But biodeflection should be expected as a valuable check on scientific advancement that can alter the future human body and the societal landscape. While many find genetic enhancement is outside the ethos of medicine, and it is only at the fringe of the parental refusals explored here, the right to refuse genetic enhancements exemplifies the big picture impact of turning people into scientific moral pioneers by forcing advancements on them. Parental refusals of genetic enhancements would help prevent the adoption of enhancement as a requirement or a future status quo without precautionary measures including regulation. Maintaining parental choice of medical care along the way will help parents be respected in their personal decision making as decisions arise that speak to big picture humanity in the future.

Conclusion

The many types of refusal and the gravity of the underlying medical conditions serve as a backdrop to the fundamental ethical issues that range from personal to societal. The acceptance of parental refusals absent special circumstances is steeped in the traditions of liberal society yet tempered by the responsibility to protect vulnerable children. The refusal of pediatric life-saving care absent special quality of life concerns or terminal illness is often clearly impermissible, follows precedent, and recognizes the role of courts in protecting the vulnerable and protecting life. Refusals in the non-life-saving arena are met with disparate opinions and subjective standards. Parents have no clear expectations of how doctors will react, and they may be caught off guard when they realize they never really were the decision maker after all.

Refusals can benefit children by introducing healthy habits and encouraging nonmedicalized approaches with favorable side effect profiles in safe circumstances. Refusals also can prevent drug addiction. Refusals by non-neglectful parents in dire circumstances where the odds of success are low (neither guaranteed to save the life nor futile) should be analyzed with respect for the parents' notions of quality of life, fairness, and freedom. Rather than creating bioethics rules for "dealing with" parents, doctors should thoughtfully consider choices made by informed, competent parents with more recognition that the deprivation of autonomy is harmful. Some refusals are fraught with ethical quandaries and deeper thinking is necessary to evaluate each case, define what is at stake, and hash out the decision maker and the decision. Compromises will be reached when common ground and the shared goal of caring for the child is emphasized. Well-intentioned doctors should voice their concerns yet deference to them is not always morally required.

Refusals can spark innovation (solutions with fewer side effects), preserve a positive and comfortable status quo, or allow time for the development of regulations (genetic enhancements), and ensure that parents' voices have a place in a society that grapples with the role of scientific advancement in human life. Life-saving treatments and newer less intrusive drugs for serious illnesses play a welcome role in pediatric care. Voluntariness is key to buy-in. Protection of the vulnerable child must be balanced by the

¹³⁰ Elizabeth Fenton, "The perils of failing to enhance: a response to Persson and Savulescu," *Journal of Medical Ethics* 2010;36:148-151; *Mitrović Veselin*, "Arguments pro and con of the 'enhancement' of human beings through genetic intervention," *Sociologija*, 2010 Volume 52, Issue 1, Pages: 75-96 <https://doi.org/10.2298/SOC1001075M>;

recognition that all people view the role of medicine, science, and technology in children's medical care differently.