THE PATIENT-PHYSICIAN-PARENT RELATIONSHIP AND MEDICAL DECISION-MAKING FOR CHILDREN

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ABSTRACT

ELIZABETH R. BRASSFIELD: The Patient-Physician-Parent Relationship and Medical Decision-Making for Children
(Under the direction of Doug MacLean)

I consider how the deliberative model defended by Emanuel and Emanuel might be modified to accommodate cases in which the patient is a very young child whose parent is the presumed medical decision maker. Drawing on a *parent-centered* account of parents' rights to explain why, in most cases, parents can justifiably make medical decisions for their children, I argue that on the modified version of *the deliberative model*, physicians should pressure or try to override a parent's medical decision when this is necessary to preserve significant welfare or agency interests on behalf of the child. Importantly, this account is consistent with parents being justified in making medical decisions for a child that do not promote the child's *best* interests.

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TABLE OF CONTENTS

Introduction

In this paper, I will discuss an influential model of the patient-physician relationship called *the deliberative model*, as described by Ezekiel Emanuel and Linda Emanuel. I will consider how this model might be modified to accommodate cases in which the patient is a very young child whose parent is the presumed medical decision maker. I will draw on Brighouse and Swift's *parent-centered* account of parents' rights to explain why, in most cases, parents can justifiably make medical decisions for their children. I will then explore the limitations of this parental right, and suggest that, on the modified version of *the deliberative model*, physicians should pressure or try to override a parent's medical decision when this is necessary to preserve significant welfare or agency interests on behalf of the child. Importantly, this account is consistent with parents being justified in making medical decisions for a child that do not promote the child's *best* interests. I use a parent-centered account of parent rights because I take it to provide the strongest case for leaving medical decision-making power with a child's parents. Thus, my argument that this account admits of cases in which parental decision-making ought to be overridden will translate to accounts on which parent's rights are derived from the interests of children or the interests of society.

In this paper, I aim to argue that there are limits on the *morally justifiable* medical decisions that parents can make on behalf of their children. There are, of course, *legal* limitations already in place on such decisions, which give physicians a formal mechanism through which to override a parent's decision without fear of (legal) repercussions. My account does not aim to justify the laws that are already in place, and thus to a large extent I will not take the law into account at all in delineating my position. I take it that the limitations I argue for are in some cases more restrictive and in other cases more permissive than the law. The implication is that in some cases, there is a moral reason for physicians to override parents' medical decisions even when the law does not support doing so. Whether or not physicians *ought* to break the law in these cases, all things considered, will depend on many other factors, the details of which I will not investigate here. And, conversely, in some cases in which the law *would* support physician override of parental decisions my account holds that doing so is not morally justified. This is because the law generally requires that parents act in the *best interests* of their children, whereas I follow Brighouse and Swift in maintaining that parents are sometimes morally justified in acting against their child's best interests.

The Deliberative Model of the Physician-Patient Relationship

Various models of the ideal physician-patient relationship have been proposed. Over the past century, advances in technology, shifting societal perceptions of physicians and other medical personnel, and patient advocacy movements have resulted in an increasing focus on patient autonomy within this relationship. However, it has become clear that patients are not completely independent 'consumers' of medical care, and thus more is required of the physician than merely offering a buffet of treatment options and delivering whichever one the patient chooses. Emanuel and Emanuel argue that although different models of the physician-patient relationship are appropriate under different circumstances, what they label 'the deliberative model' both is and ought to be the sought-after ideal.[1]

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[1] Emanuel and Emanuel p. 2225

Before describing their preferred model I will give a brief overview of the other three models they discuss, pointing out where these models fall short. For each model, Emanuel and Emanuel describe the different conceptions of patient autonomy that are in play. Although they do not explicitly acknowledge it, their discussion of the four models suggests that they are assuming a background requirement for physicians to respect patient autonomy. The question then becomes *what* this respect for autonomy involves, rather than *whether* each model involves such respect. I take it that similar results could be achieved by holding constant our conception of what patient autonomy involves, and instead arguing that the different models require that physicians respect patient autonomy to varying extents.

On the *paternalistic model*, the physician determines what will best promote the overall health and well-being of the patient and then implements the necessary medical interventions accordingly. What is 'best' here tracks some objective medical standard, as opposed to the preferences or values of the individual patient. On this model the concept of patient autonomy is that of assent,[2] where it is assumed that the patient will acquiesce to the physician's decisions, either presently or at some later time. Emanuel and Emanuel note that while this model is still appropriate in the limited set of circumstances in which obtaining patient consent would preclude pursuing the intervention that is in the patient's best interest,[3] it is now widely recognized that it is a mistake to aspire to some more general, objective standard of what's best for all patients.

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[2] "Assent" is the term used by Emanuel and Emanuel, although it should be noted that this term is sometimes reserved for describing agreement given by someone who lacks the capacity for autonomous decision making. However, Emanuel and Emanuel do not mean to imply that patients are not *capable* of autonomous decision-making. Rather, they mean that on the paternalistic model physicians are concerned with patient autonomy only insofar as they are concerned with patient assent.

[3] E.g., a gunshot wound victim brought into the emergency department who is unconscious due to blood loss and needs emergency surgery and blood transfusion to survive

Rather, the values and preferences of the individual patient determine, at least in part, what constitutes her overall well-being.[4]

The second model Emanuel and Emanuel consider is the *informative model*. On this view, the physician is a provider of expert knowledge and technical skill, whose obligation is to provide the patient with whatever medical information is necessary for her to decide on a treatment plan and then to execute the decisions the patient makes. The physician has privileged knowledge of medical *facts*, whereas the patient has privileged knowledge of her *values*. Patient autonomy, on this conception, involves the patient taking control of the medical decision-making process.[5] This model, however, fails to account for the importance patients place on their physicians being caring and understanding rather than mere technical experts. Patients expect their physicians to make *recommendations* about what they should do, and doing so requires that they understand each individual patient's values and how those values are impacted by her disease.[6]

Essentially, Emanuel and Emanuel seem to take issue with the concept of an expert that the informative model relies on. On this model, the medical expertise possessed by physicians privileges them as distributors of a particular type of information and as executors of a particular skill-set, but nothing more. In contrast, another way of viewing experts (and the way that Emanuel and Emanuel ultimately seem to endorse with the *deliberative model*) holds that their expertise licenses them not only to distribute information and perform technical procedures but also puts them in a uniquely qualified position to make recommendations to non-experts. That

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[4] Ibid., p. 2224

[5] Ibid., p. 2221

[6] Ibid., p. 2224

is, the role of experts is to integrate knowledge of their field with information about the goals of those they interact with in order to come to a conclusion about what *should* be done, not just what *could* be done.[7]

Further, Emanuel and Emanuel point out that the *informative model* assumes that patients have fixed values that they can draw upon to make medical decisions. In reality, disease can impact not just a patient's health but also her values, and part of what is central to the patient-physician encounter is the elucidation of these values.[8]

The third model they consider is the *interpretive model*, which addresses the shortcomings of the *informative model* by including such elucidation of patient values and discussion of how those values are impacted by the various treatment options among the physician's obligations. The physician helps the patient to understand and resolve conflicts between his values, but she does not judge or evaluate the values that come out. The conception of patient autonomy on this model is self-understanding.[9] Emanuel and Emanuel argue that precluding evaluation of the patient's values unacceptably constrains the recommendations that a physician may make. Patients want physicians to give them advice about what they should do that not only takes into consideration the values they actually hold, but that also indicates which

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[7] There is evidence that patients do in fact want their physicians to provide recommendations and advice rather than merely information. One qualitative study found that patients want their physicians to "evaluate and explain" medical interventions and that they want their physicians to "demonstrate that they have patients' best interests at heart." The same study found that only 4% of people surveyed thought it was important for their physician to "provide choice." (Wen and Tucker)

[8] Emanuel and Emanuel., p. 2224

[9] Ibid., p. 2221-2222

health-related values the physicians takes to be primary.[10] Physicians have expertise not only when it comes to medical *information*, but also when it comes to health-related *values*. The physician's expertise licenses her not only to tell patients that, for instance, UpToDate (a database of physician-authored, evidence-based articles) is a better source of medical information than Wikipedia, but also that certain health-related values are better than others.[11]

On the *deliberative model*, the patient-physician interaction aims to help the patient pick the best health-related values that she can pursue in the clinical context, where health-related values are, roughly, those that "affect or are affected by the patient's disease and treatments."[12] The physician's role includes providing clinical information, such as an explanation of the patient's medical condition(s) and details about the available treatment options. She also helps to illuminate the health-related values embedded in each treatment option, and further takes a stance on which health-related values are best and should be aspired to. This discussion of health-related values takes the form of moral deliberation, with contributions both from the physician and from the patient. Importantly, Emanuel and Emanuel emphasize that while the physician can engage in persuasion, coercion must be avoided in the discussion of which health-related values the patient should adopt. Thus, the patient autonomy that this model supports is moral self-development.[13]

This conception of autonomy, Emanuel and Emanuel hold, is true to our idea that real autonomy requires critical assessment of one's own values and subsequent affirmation that these

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[10] Ibid., p. 2224-2225

[11] A more detailed explanation of health-related values comes in the next section.

[12] Ibid., p. 2222

[13] Ibid., p. 2222

are the values on the basis of which one is justified in acting. Mere freedom to act as one wishes is not sufficient, although this conception of autonomy ultimately obligates the physician to accept the decisions made by the patient.[14] A physician's values, they argue, do in fact matter to patients; their inclusion in the physician-patient relationship is warranted to the extent that they are directed at improving the overall well-being of the patient. Moreover, society expects physicians to promote health-related values. And patients, for their part, demonstrate a willingness to adopt the best health-related values when they seek a treatment recommendation from their physicians. The caring physician of the deliberative model who seeks to improve all health-related aspects of her patient's life, both physiologic and moral, captures our idea of the ideal physician as akin to a friend or a teacher who happens to have extensive medical knowledge and skill.[15]

Emanuel and Emanuel do not say much to indicate exactly what they have in mind when they say that discussion of health-related values should take the form of 'moral deliberation'. I take it that the idea is to capture the discussion and assessment of health-related values that takes place between the patient and physician, part of which involves both parties indicating which values they take to be primary or best in the particular context and further giving reasons for this primacy.

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[14] At least, when those decisions involve genuine treatment options. A physician would not, for example, be required to acquiesce to a patient's request for treatments that require illegal or immoral behavior.

[15] Ibid., p. 2225

Health-Related Values

Apart from the rough description mentioned above, Emanuel and Emanuel do not elaborate on what they take health-related values to be. But it is important to have a clear understanding of what they mean to pick out with this term, as the scope of health-related values will partly determine the scope of the discussion that the physician ought to engage in with the patient. One possibility, suggested by the claim that health-related values are "values that affect or are affected by the patient's disease and treatments,"[16] is that the *only* requirement for a value to count as a health-related value is for it to affect or be affected by the patient's disease and treatment. On this conception any value, or nearly any value, could at least in theory count as a health-related value. Different values will qualify as 'health-related' for different people under different circumstances.

This conception, however, is likely too broad to be useful. To take an example, most people of the Christian faith highly value eternal salvation. What is thought to be required to achieve this salvation varies for each specific denomination. Notably, Jehovah's Witnesses believe that accepting blood products disqualifies one from receiving eternal salvation.[17] For such a patient, the religious value of eternal salvation will affect any medical treatment decision in which receiving blood products is an option. In these contexts, then, this patient's religious value would count as a health-related value. It would thus be the role of the physician to

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[16] Ibid., p. 2222

[17] Exactly what is prohibited varies depending on who you ask. Some people will accept autotransfusions, that is, they believe that donating their own blood before a surgery and then receiving it back does not violate the prohibition. Some believe that accepting blood products before being baptized as a Jehovah's Witness will not disqualify you from salvation. Others believe that being given blood products against one's will (e.g., due to a court order) does not count against you.

consider this religious value along with other relevant health-related values, and assess its relative worth or importance. The physician is further supposed to *persuade* the patient to adopt whichever health-related value she deems most worthy and to make treatment decisions in accord with that value. But directly evaluating a patient's religious values, whatever the outcome of that evaluation, and recommending either that he act in accord with or against those values both seem firmly outside the scope of the physician's role.[18]

In addition to religious values, it is plausible that cultural values too are categorically outside the scope of appropriate physician evaluation and recommendation. But further, it seems implausible to hold that there is anything about being a physician that makes one especially qualified to evaluate *any* and *all* values that could interact with medical decisions in the minimal way suggested above.

Alternatively, we might understand health-related values as those values whose *content* refers to health, where health is understood roughly as mental and physical well-being.[19] So, for example, some health-related values that I take to be commonly held by many physicians include the alleviation of pain and suffering, the eradication of disease, the protection of life and the promotion of healthy lifestyles.[20] In many cases, the treatment options available represent a trade-off between two or more of these values. For instance, sometimes the amount of morphine necessary to alleviate a terminally ill patient's pain also hastens the moment of her death. The question, then, is whether to prioritize alleviation of pain or prolongation of life in circumstances like these. In many cases, the treatment necessary to cure a patient's disease or to protect his life

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[18] At least, in most modern healthcare settings.

[19] But not, importantly, spiritual well-being.

[20] I take it that the modern Hippocratic Oath demonstrates at least these last three values.

will cause pain, either for the duration of the treatment or for the remainder of the patient's life.[21] Thus, I take it, part of the moral deliberation described by Emanuel and Emanuel as constitutive of the deliberative model of the physician-patient relationship involves elucidating which of two conflicting health-related values ought to take precedence in the particular circumstances, for the individual patient.

Other times, patients might hold health-related values that physicians do not themselves hold. For example, Christian Scientists, although they do not have a strict *prohibition* against modern medical treatment, value the healing power of prayer over scientifically-based medical interventions.[22] Similarly, some patients value "natural" healing and are thus prone to choose homeopathic or naturopathic methods over things like antibiotics or surgery.[23] While it was suggested above that physicians value the alleviation of pain, some patients may hold that *enduring* pain is more valuable, perhaps because they value toughness more than comfort.

There may, further, be a lot built into what physicians versus patients consider to be "diseased" states of the body. While the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) defines autism as a mental disorder, some people argue that it is better thought of as just an alternative (but not pathological) neural organization.[24] Similarly, sensorineural deafness

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[21] For example, resecting a breast tumor sometimes causes disruption of the lymphatic system on that side of the chest, leading to a chronic condition called lymphedema, a painful swelling of the chest and arm.

[22] That is, they hold that their physical well-being and not merely their spiritual well-being can be ensured by engaging in prayer, and that this type of physical healing is superior to the healing offered by modern medical modalities.

[23] Of course, this sort of thing relies on where the distinction is drawn between natural and artificial treatments – a distinction that is admittedly difficult to rigorously draw for most people.

[24] See Glannon (2007) and Fenton & Krahn (2007). It is important to note that I am not suggesting here that the DSM is *authoritative* or *infallible*, only that it likely influences the

results from several different genetic mutations. Physicians talk about these as being genetic disorders, and consider the resulting deafness a pathological condition that should be treated (e.g., with cochlear implants or other forms of hearing aids). However, some members of the deaf community would not consider deafness to be a disorder or a disease, and accordingly refuse cochlear implants for their deaf children. These are the types of health-related values about which physicians can engage patients in moral deliberation. Although I'm not suggesting that physicians are the *authority* on all health-related values as they are understood on this account, I do think that the extensive training they undergo learning about health, disease, and medical interventions along with their commitment to promoting the health and well-being of their patients does make it plausible to hold that they are at least in a better position than *many* people to evaluate these types of values. That is, as suggested above, the domain of medical expertise includes not just medical facts but also health-related values.

Patient-Parent-Physician Relationships

Emanuel and Emanuel articulate the deliberative model of the physician-patient relationship as it applies to direct relationships between physicians and competent adult patients. But not all physician-patient interactions are of this form. When patients are temporarily or permanently incapable of making their own decisions, the discussion of the patient's medical condition and treatment options is with a proxy rather than with the patient herself. More needs to be said about how the deliberative model ought to apply in these cases. One important type of patient unequipped to make their own medical decisions is children, whose proxies are usually their parents.

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conception that physicians have of disease far more than it influences the conception lay people have of mental disorders.

The first question that arises is *whose* values are the relevant ones under consideration: the child's or the parent's? This will likely depend at least to some extent on the age of the child. For sufficiently young children or those with significant intellectual disability, the only values available will be those of the parent. While in the case of competent adult patients it is never appropriate for the physician to coerce the patient or otherwise impose her own values onto his decisions, it is not clear that this restriction also holds in cases of parents as proxy decision-makers for their children. That is, when a parent's health-related values conflict with the health-related values of the physician, the physician may in some cases be justified or even required to impose her values in the form of overriding the parent's treatment decision for the child. As long as parents do not have an unlimited right to impose all and any of their values on their children, there is space for the assertion that sometimes physician values should be overriding. I will now turn to justifying this claim.

The Foundation of Parents' Rights

The first step in investigating how the *deliberative model* needs to be modified to deal with the patient-child-physician relationship is to determine the form and boundaries of the parent-child relationship. Current practice is to defer medical decision-making for minors to parents (or other legal guardians), unless the parent has been determined to be unfit, in which case a court-appointed guardian is put in place. Although children cannot *consent* to medical interventions and so this responsibility falls to their parents, the *assent* of older children is often sought prior to implementing the decisions of her parents.

The notions of consent and assent are far from straightforward, and I don't have space here to thoroughly discuss each of these concepts. It will suffice for my purposes to think of consent as an act that requires that the agent who engages in it is rational, un-coerced, and relevantly informed. Assent, in contrast, merely involves indicating that one is okay with what is being proposed. Thus children, at least very young children, are unable to consent because they lack the requisite level of rationality and understanding, whereas they can assent because they can, from a very young age, indicate that they are okay (or not) with various things. While the absence of assent or expression of dissent from a child may sometimes require that the physician and parent pause and reconsider what is being done, the presence of assent does not have the same power as the presence of consent in justifying going forward with some treatment.

Let's grant, for now, that minor children cannot be responsible for making their own medical decisions. That is, let's grant that they lack the capacity to *consent*, even if they are capable of assenting or dissenting. What, then, justifies our current practice of leaving medical decisions regarding minor children to their parents rather than to some other rational adult?

Brighouse and Swift argue that parents have fundamental but limited and conditional rights to exercise authority over their children. They define as fundamental those rights which are owed to someone simply in virtue of her being a person, whose justifications stem from the benefit they bring to the rights-holder.[25] This is in contrast to *instrumental* rights, which are justified either because their recognition helps promote some or other fundamental right or because of the benefits they confer on someone other than the rights holder. Thus, their account is *parent-centered*, in that it argues that certain rights are owed to parents by virtue of their own interests, rather than by virtue of the interests of the child or the interests of society at large. Brighouse and Swift acknowledge that there are also child-centered and society-centered

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[25] Brighouse and Swift p. 87

justifications for ascribing rights to parents; however, they do not think that these reasons can justify all of the rights we are interested in granting and explaining.[26]

The interests that ground fundamental parental rights, on Brighouse and Swift's account, are the interests that adults have in receiving the unique benefits that can come only from the particular type of intimate relationship between them and the children that they parent. Intimate relationships in general are a crucial part of a flourishing life. But, Brighouse and Swift claim, the moral character of parent-child relationships is not replicable in any other type of relationship, and these relationships contribute in a unique way to a flourishing life on behalf of the parent. Thus, at least for many people, a fully flourishing life cannot be brought about by substituting other types of intimate relationships in place of the parent-child relationship. If, therefore, we understand rights as being justified just in case they protect substantial interests of the parties that hold them, then the substantial interest parents have in engaging in the parent-child relationship can ground a set of rights necessary in order to ensure their ability to develop this type of relationship.

The unique character of parent-child relationships stems from four important differences between these types of relationships and other intimate relationships. I take it that most or all of these features hold while the children in question are truly children, or are very young, and perhaps not once they've grown into adolescents or adults. For simplicity, and as a starting place, I will primarily consider very young children in what follows. That is, I am interested initially in delineating the extent of the rights parents have with regard to children who are too young to be thought of as having values or as capable of giving even meaningful assent to medical treatments. This is not to suggest that the relationship between parents and their adult

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[26] Ibid., p. 87

children is not also unique, but it is much more similar in character to other intimate relationships between adults. And, of course, we typically don't take parents to have the same rights of authority over their adult children that we take them to have over their minor children.

First, parents and children do not have equal standing in the parent-child relationship. Parents, Brighouse and Swift note, at least initially have the power of life and death over their children, and further they have the power to make their children's lives miserable or enjoyable for many years. Children never have the power of life and death over their parents,[27] and their power to affect the quality of their parents' lives is significantly more limited.[28] Second, children are unable to exit or escape the relationship with their parents. While how much power each party has to exit an intimate relationship between adults will depend on the particular circumstances, adults generally have at least *some* power to exit a relationship whereas very young children have no power *whatsoever* in this respect.[29] Third, the qualitative character of the love that children have for and give to their parents is drastically different than the love that develops in intimate relationships between adults. Brighouse and Swift describe it as follows:[30]

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[27] At least, not the very young children I am considering, or at least not in the same significant way that parents can be thought to have the power of life and death over these children. While a toddler could, e.g., get ahold of a poorly secured gun and shoot his father, this ability depends on there being an unsecured loaded gun that the child can reach, and on the child having the poor luck to figure out how to pull the trigger while the barrel of the gun is pointed in the direction of his father. In contrast, the ability parents have to refuse to feed or clothe their children is widespread and does not depend on things being just-so, as in the former case.

[28] Ibid., p. 92

[29] Ibid., p. 93. Again, at least no *reliable* power to exit the relationship. Even a very young child may figure out how to call 911, and if circumstances are just right this may result in his being placed in protective custody. But this will rely on the intervention of other adults in a way that the power of an adult to exit a relationship generally does not.

[30] Ibid. p. 93

> *The love one receives from one's children, again especially in the early years, is spontaneous and unconditional and, in particular, outside the rational control of the child. She shares herself unself-consciously with the parent, revealing her enthusiasms and aversions, fears and anxieties, in an uncontrolled manner. She trusts the parent until the parent betrays the trust, and her trust must be betrayed consistently and frequently before it will be completely undermined.*

In contrast, Brighouse and Swift note that intimacy with others adults is not automatic – active use of one's will is required to become intimate with another adult – nor is it as complete. Fourth, they argue that the moral quality of the relationships between parents and their children differs from the moral quality of relationships between adults. The parent-child relationship is a fiduciary one, but it is further distinguished from other fiduciary relationships in that the parent is not only obligated to guarantee the child's *immediate* well-being, but also obligated to "oversee and ensure her cognitive, emotional, physical, and moral development."[31]

Taken together, these four features distinguish the parent-child relationship from other types of intimate relationships. Brighouse and Swift further argue that engaging in this type of relationship serves the interests of parents (as well as children) because it allows them to exercise and develop capacities which are necessary for many, though not all, people to live fully flourishing lives. Exercising and developing these capacities in the unique context of the intimate parent-child relationship allows the parent to discover things about herself she otherwise wouldn't, to develop further as a person, and to gain satisfaction unavailable from other relationships. Successful parenting of her child contributes to the success of a parent's life as a whole.[32]

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[31] Ibid., p. 94

[32] Ibid., p. 95

Importantly, none of these benefits are meant to be the fulfillment of mere *desires*. The contribution to the flourishing and well-being of the parent that this relationship makes is far weightier than the mere satisfaction of some set of desires.[33] Further, for these important interests to ground a fundamental right it is neither necessary that *all* adults have these interests *nor* for it to be the case that anyone who does have these interests would *fail* to flourish without participating in a successful parent-child relationship. Rather, the mere fact that for many people parenting contributes to *fully* flourishing in a way that nothing else could is enough to ground fundamental parental rights.[34]

Limitations and Conditions on Parents' Rights

What exactly do these parental rights amount to? Brighouse and Swift hold that parents have a right to: "enjoying a particular kind of relationship with "their" children and that that relationship involves not only the enjoyment of intimacy with but also the exercise of certain kinds of authority over those children."[35] However, this right is limited by the interest that justifies it. That is, only those parental rights necessary to maintain the parent-child relationship as conceived above are justified by this parent-centered approach. In particular, Brighouse and Swift hold that parents do not have the right to infanticide nor to give their children "a drug that would produce firm and unshakable belief in the divine right of kings" were it to be available.[36] This is because parents are required to protect the interest children have in developing autonomy;

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[33] Ibid., p. 98

[34] Ibid., p. 98-99

[35] Ibid., p. 101

[36] Ibid., p. 102

they are required to protect and help develop the child's capacity to form her own values and life-plan.[37] That is, the future interest in autonomy held by a child takes precedence over the present interests her parents may have. Brighouse and Swift suggest that the fundamental right parents have to engage in a parent-child relationship unpacks into a set of associated rights that are necessary to maintain this kind of relationship. These include the right to:[38]

1) Determine whether and which religious services the child attends
2) Live with the child and spend a substantial part of the day with her
3) Share one's enthusiasms with the child, including cultural heritage

In unpacking these rights, Brighouse and Swift distinguish between associational rights and control rights. They appear to hold that the associational rights parents have to engage in the parent-child relationship are fundamental, and that these associational rights in turn license some instrumental control rights over the children they parent. They admit that the distinction between associational and control rights isn't particularly sharp, especially with very young children, as associational rights in these cases will also involve control rights. But they urge that any control rights parents have are immediate and do not extend arbitrarily far into the future. Of course, there is no way to ensure that parents exercising immediate control rights don't do so in a way that will extend their influence unduly into the future: Brighouse and Swift note that "it is impossible to allow people to take their children to church without allowing them to use that right to try to indoctrinate their children in their faith."[39] Although there is no way *in practice* to divorce the fundamental associational rights parents do have from this type of control, in theory parents *do not* have a fundamental right to indoctrinate their children in such a way.

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[37] Ibid., p. 103

[38] Ibid., p. 102

[39] Ibid., p. 104

But the unique character of the parent-child relationship as described above does appear to license *some* control rights. After all, it is not just *any* relationship between an adult and a child that will contribute to flourishing in the special way Brighouse and Swift take the parent-child relationship to contribute; they explicitly deny the claim that adults might get the same benefits from serving as teachers at state-sponsored boarding schools. Rather, the *raising* of children seems to centrally contribute to the benefits conferred onto the parent by the relationship in question. This is brought out in their discussion of the unique moral quality of the parent-child relationship. Insofar as *raising* children requires a right to exercise control over them, then some parental control rights can be justified.

One way to demarcate the extent of the control rights that parents legitimately have is by appeal to the future agency rights of children. Brighouse and Swift argue that children themselves have a fundamental interest in prospective autonomy. Parents are legitimately justified in exerting control over their children insofar as doing so does not infringe on the prospective agency rights of those children. Thus, while it might in practice be impossible to grant parents the kinds of rights necessary to protect the parent-child relationship and at the same time prohibit them from influencing their children in ways that preclude some exercise of future agency, we can in theory make this kind of distinction. Further, I take it that while of course we recognize that different people have different values and that being able to transmit one's values to one's child is important, we also think that the best kind of parent, the kind of parent that we aspire to be, is one who equips her child to think for herself and who encourages just the kind of autonomy that Brighouse and Swift think is important.

Brighouse and Swift note that the interests of children will justify some control rights for parents, and additionally the fundamental association rights held by parents will require that we grant parents some other control rights. But parents are only justified in controlling their children to the extent that such control is necessary to guarantee their fundamental associational right and to satisfy the best interests of the children. Thus, it is consistent with this account that, in order to best satisfy the interests of children, some control rights will fall to other adults instead of parents.

These control rights are *conditional* in the sense that one must be an adequately good parent in order to enjoy them. That is, the right of a parent to engage in a parent-child relationship and the associated rights described above are only granted to those parents who meet some threshold of ensuring that their child's interests are "well-enough served."[40] It is not entirely clear what they think this threshold amounts to; however, some of their remarks suggest that they would consider protection of the future agency of the child a requirement of being an adequately good parent. It further seems that certain interests held by the child are non-negotiable, in that parents must promote them in order to satisfy the threshold of adequately good parenting. For example, I take it that it is relatively uncontroversial that children have an interest in continuing to live; a parent who failed to promote this interest would thus forfeit her right to engage in the parent-child relationship. Further, a child has a strong interest not just in life but in a minimally acceptable quality of life – what exactly this amounts to will likely be context dependent, in the sense that what a parent in the United States could reasonably be expected to provide for her child will be drastically different from what a parent in Malawi could be expected to provide.

Federal legislation defines child abuse and neglect as, at a minimum, "any recent act or failure to act on the part of the parent or caretaker which results in death, serious physical or

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[40] Ibid., p. 102

emotional harm, sexual abuse or exploitation; or an act or failure to act, which presents an imminent risk of serious harm."[41] In practice, Child Protective Services (CPS) in the US, run by each individual state, determines the minimal threshold that parents must meet in order to retain custody of their children. Nationally, five categories of child abuse and neglect are reported. They are:[42]

1) Physical abuse – e.g., disciplining of a child that leaves a mark for more than 24 hours
2) Psychological maltreatment
3) Sexual abuse – this can be distinct from physical abuse in that it includes merely showing a child pornography
4) Neglect – e.g., not feeding or adequately clothing a child
5) Medical neglect – a specific form of neglect in which the medical needs of a child are not met

A sixth category labeled 'Other' is included as a catch-all for types of abuse reported by individual states which don't fit into one of the above five categories. These represent, at the national level, the minimum legal requirement that parents have to promote the interests of their children. This is a good starting point for thinking about what is required to meet the kind of threshold that Brighouse and Swift have in mind, although of course much more needs to be done in order to thoroughly describe and defend the kind of threshold we are interested in. However, above this threshold, wherever it turns out to precisely lie, Brighouse and Swift argue that parents are under no *general* obligation to consider or act in the child's *best* interests as they exercise their parental rights.

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[41] The Child Abuse Prevention and Treatment Act (CAPTA), (42 U.S.C. §5101)

[42] *Child Maltreatment 2015*.

Parental Rights' and Medical Decision-Making

In the context of medical decision-making, it is not strictly true that parents do not have legitimate power of life and death other their children. Sometimes the decision to either pursue or forego life-extending or life-saving medical treatments for a child must be made, and unless a parent has previously been deemed an unfit guardian (that is, unless she has failed to meet the threshold identified above), then she is the one to whom this decision falls.

While, on this account, parents are under no *general* obligation to act in their child's best interest, it might turn out that they have a specific obligation to act in their child's best medical interests, or, that they have an obligation to act in their child's best interests in the medical context. This condition, however, will likely end up being too restrictive. That is, it seems plausible that there are times in which what is overall in the child's best interests is contrary to what is in their medical best interest. This could be because acting in the medical best interest of the child would limit her future agency, if we hold that agency is more valuable on the whole than health. For example, the medical best interests of a child may require a tracheostomy and home ventilator support to treat chronic lung disease. A tracheostomy involves creating an opening from the front of the neck to the trachea (the windpipe) through which a tube is advanced down into the lungs. A mechanical ventilator is connected to this tube and ensures that the proper amount of oxygen is ultimately delivered to the child's circulation. The ventilator is an electric machine, and as such it requires a reliable power source and thus limits the mobility of the child who depends on it. Thus, while being on a home ventilator may minimize the effects of a patient's *disease* on her well-being, it may limit her mobility to such an extent that other areas of her life (besides her health) are more negatively impacted than they would be by increased disease progression.

Before addressing the question of when parents are obligated to act in the best interests of their children, I will turn to a discussion of what rights children can be thought to have.

Children's Rights

Brighouse argues that children have welfare rights, but not agency rights. In contrast, adults have both welfare and agency rights. Welfare rights he defines as "rights to certain sources of well-being, which sources are taken not to be distinctive at all but to be, broadly, the same for all."[43] These rights, he argues, both justify themselves and are justified by the important contribution they make to other things, such as agency rights.[44] Agency rights in turn protect the fundamental interest people have in being able to develop and exercise their capacity for choice.[45] We have this fundamental interest in choosing because "choice is a powerful mechanism for inducing the identification normally required for the execution of a decision to serve our interests."[46] Merely having good things in life, even those good things that fit with our individual conception of the good, is insufficient to guarantee that we fully flourish: it is further necessary that we feel we have had some say in how our lives have turned out.

Of course, not all philosophers agree with Brighouse that children lack agency rights. Some instead hold that even young children are agents and thus have agency rights, but that these rights differ from the agency rights held by adults. I am not going to take a stance either way in this paper. Brighouse's account, in asserting more limited children's rights, effectively

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[43] Brighouse, p. 38

[44] Ibid., p. 39

[45] Ibid., p. 38

[46] Ibid., p. 37-8

provides the most robust account of parental control rights. Thus, any conclusions I draw using this strong account of parental rights as background for when parents lack the right to make certain medical decisions will carry over to accounts on which children have more robust rights.

Brighouse further distinguishes between *immediate* and *future* interests: one's interests in what happens to one in the present and one's (vaguer) interests in what happens to one in the future, respectively. Although they have only welfare and not agency *rights*, Brighouse thinks that children can rightly be ascribed both immediate and future welfare and agency *interests*. Adults and children differ with respect to these interests in that for a child, her immediate welfare and agency interests are very different in kind from her future such interests.[47] The immediate agency interests of the child are "determined by service to future agency interests, especially personal autonomy."[48] Future agency interests include personal autonomy and the child's ability to act on whatever her conception of the good turns out to be. Immediate welfare interests include shelter, food, and love, and are valuable both in themselves and for their contribution to future welfare interests. Notably, immediate welfare interests increasingly include the opportunity for the child to exercise her agency as she gets older. Finally, future welfare interests include both particular interests, which depend on the conception of the good the child ends up developing, and universal interests, which everyone has in virtue of being a person and do not rely on any individual's particular conception of the good.[49]

Agency rights, as understood by Brighouse, require a minimum threshold of competence and rationality. Although he acknowledges that both competence and rationality are matters of

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[47] Ibid., p. 41

[48] Ibid., p. 44, figure 2

[49] Ibid., p. 44, figure 2

degree rather than binary states, he argues that we can still hold that those people above the minimum threshold can justifiably be treated differently than those below it: in this case, by granting agency rights to the former group only. The claim is that children are below this minimal threshold, whatever it turns out to be, and so we are therefore justified in not ascribing agency rights to them.[50] However, in Brighouse's view, children nevertheless have fundamental welfare *rights* in the same way that adults do, since the welfare *interests* of children are not significantly structurally different from those of adults. The difference between a child's welfare rights and an adult's welfare rights is rather that, in the case of adults, the rights-bearer is the one charged with exercising the rights, whereas in the case of children some other agent is charged with exercising the welfare right.[51] That is, it falls to adults (usually the child's parents) to promote the welfare interests and protect the welfare rights of a child. This is because children do not understand or endorse their needs in the same way that adults do. This also explains why agency rights are not properly granted to children: an adult's welfare interests are in large part determined by the exercise of her agency, whereas a child's welfare interests do not connect to agency in this way. Thus, Brighouse holds, while parents are obligated to promote the development of their child's capacity for agency, this obligation does not derive from *agency rights* of the child; rather, it derives from a specific welfare right: the right to the kind of upbringing that prepares her for competent agency.[52]

What is the upshot of all of this? We can get a better understanding, above and beyond the law, of what constitutes being an "adequately good" parent by holding as a minimum

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[50] Ibid., p. 45

[51] Ibid., p. 45-46

[52] Ibid., p. 46

requirement that an adequately good parent must respect her child's rights, which turn out to all fall under the category of welfare rights. Importantly, a central component of the interests protected by these welfare rights is the development and protection of the child's autonomy such that she will turn out to be the kind of person who can rightly be said to hold agency rights. The discussion offered by Brighouse suggests that he would be in favor of holding that a child's agency interests, or at least her future agency interests, must be privileged over many welfare interests, especially future particular welfare interests. Since future particular welfare interests are dependent on the specific conception of the good developed by the child in question, and since the development of one's own conception of the good in a way that is capable of giving meaning to and conferring flourishing on one's life requires the exercise of one's agency, it is reasonable to hold future agency interests as primary.

So, while there is no *general* obligation for parents to promote their child's best interests *per se*, I would argue that there is a general obligation for them to promote and give priority to their child's future agency interests. Thus, the latitude that parents have in raising their children how they see fit is constrained in an important way by the future agency interests of the child. Brighouse argues that the promotion of these interests and the development of a child's capacity for autonomy and rationality requires the involvement of adults. This is because children are both physically and emotionally dependent on "very particular people, whom they have not chosen,"[53] and, further, they are not well-informed about their future interests because they

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[53] Ibid., p. 43

cannot conceive either what those future interests will be or the details of how adult society functions in a sufficiently robust way to inform decision-making.[54]

Modifying the Deliberative Model for Parent-Child-Physician Relationships

Let's get back to the question we started with: how does the deliberative model of the physician-patient relationship need to be modified for those cases in which parents act as proxy decision-makers for minor children? In many cases, it seems that it will be appropriate for physicians to engage a very similar type of moral deliberation with parents as they would when the parents were their own patient. That is, it will still be important for the physician to help elicit and elucidate the parent's health-related values, and to thoroughly discuss how those values are expressed or affected by the available treatment options for the child. It will still be important for the physician to indicate which health-related values she holds to be worthy of aspiring to in the given circumstances, and to persuade the parent to adopt those health-related values and make medical decisions accordingly. However, when the parent holds health-related values that recommend a course of action that conflicts with some *central* interests of the child, the physician, whose primary duty is to her patient, will be obligated to resort to otherwise unacceptable methods of persuasion, or other efforts to override the parent's decision in order to ensure a suitable outcome for the child if persuasion and moral deliberation do not change the parent's mind.

Understanding the parent-centered account of parental rights is important because it gives us a moral reason rather than merely a practical reason to continue to allow parents to make

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[54] E.g., Brighouse notes that adult interests often include participation in sexual relationships, but even a child who were to recognize that her future interests would include such a relationship is not in a position to understand the full implications of this interest.

medical decisions for their children in most situations. This is a welcome result, because I take it that even if we could systematically improve medical outcomes for children by automatically handing over control of medical decision-making to some state-appointed agent in every case, unless the results of doing so were *significantly* better than allowing decision-making power to remain with parents we would be loath to take this step. On a child-centered account of parental rights, even a modest increase in the welfare of children would justify this kind of exclusion of parents from the medical decision-making process. Similarly, a society-centered approach to parental rights would justify this exclusion when some combination of more efficient resource-allocation and better medical outcomes were achieved. The parent-centered approach thus licenses the highest threshold for taking decision-making power away from parents in the medical setting. So, the claims I will make about when parental decision-making ought to be overridden will hold on all three accounts of how parental rights are justified.

Medical Decisions That Aren't Justified by Parental Control Rights

Parents are not always obligated to act in the absolute best interests of their children. This includes medical care: there is no general obligation for parents to make the medical decisions that are strictly in their child's best interests. Parents should be permitted to make medical decisions based on their own health-related values that do not maximize their child's interests when:

1) What the child stands to lose is sufficiently small; or,
2) The effects of the decision are not permanent; or,
3) The effects of the decision do not significantly constrain the future agency interests of the child

On the deliberative model, the physician should still try to *persuade* parents to adopt what she takes to be the best health-related values and to choose the recommended medical interventions in these cases. However, the physician is not justified in resorting to coercion if the parent remains unpersuaded, and, like in the case of competent adult patients deciding for themselves, must respect whatever decision is ultimately made.

In contrast, parental control rights, including the right to share their values with their children, do not justify medical decisions that are either substantially against the child's best interests, or that significantly constrain the child's future agency interests. Of course, most medical decisions are not 'reversible' in any significant way; but some that might otherwise be unjustifiable may be justified on the grounds that the child can later choose to pursue a different option.

My position is not that it is *never* acceptable for parents to make medical decisions that negatively impact the future agency rights of their children. But rather, that the impingement of future agency rights by parents must be justified by something further than the interests *of the parent*, where the interests of the parent include conferring their own health-related values onto their children. So, in cases of children with complex chronic diseases or cancers for which treatment is burdensome and not guaranteed to be life-saving, the welfare interests of the *child* might justify foregoing treatment even though doing so will result in their death, which clearly precludes the satisfaction of any future agency interests.

The determination of whether to merely persuade a parent to make a particular medical decision or to pressure or override the parent's decision will largely require case-by-case evaluation. In particular, the notion of a "sufficiently small" impact on the child's well-being is inherently vague. By suggesting that the physician "pressure" a parent's decision, rather than merely engaging in persuasion, I mean to pick out a set of persuasive tactics that are generally wrong for the physician to employ but which can be justified under the circumstances I'm considering: for example, using graphic language to describe a procedure that the physician thinks the parents should decline: "If we do CPR, the chest compressions will violently crack your son's ribs and we will have to shove a tube down his throat, all without pain medication." Alternatively, the physician may heavily emphasize the risks of one intervention while downplaying the risks of the preferred treatment: "Failing to vaccinate your daughter against Human Papilloma Virus (HPV) is to risk viral infection that can lead to infertility, cancer, and ultimately death. Studies show that the vaccine is generally safe." Another persuasive tactic that is generally unacceptable involves leaving out important information. For example, a physician who thinks a parent ought to make the decision to take her child off of a ventilator may say to her "Your son may be able to breathe on his own when we extubate him, or he may not," when the physician actually thinks that, while this statement is true, the overwhelming likelihood is that the child will not be able to breathe on his own.

Practical considerations will often make "pressuring" a parent's decision like this a better option than trying in more explicit ways to override it. In many cases these tactics may better preserve the relationship between the physician and the parents, which is especially important when the decision is being made within the context of ongoing medical care.

To clarify the position I've described, I'll now present some cases, starting with those in which parents are justified in acting against their child's medical best interests.

I. Home Ventilators

As previously described above, some chronic respiratory diseases are best treated by the use of a home ventilator. When the child who requires this treatment is sufficiently young, we can plausibly stipulate that this treatment is in her best interest just in case it is the best treatment for her respiratory disease. That is, the problem of mobility outside the home for very young children is not a significant factor.

However, having a child on a home ventilator is still a significant burden for her parent. It requires that someone come to the residence and determine if there is a stable electric supply; if there isn't then the parent must move to a new residence. And reduced mobility of the child also inconveniences the parent, not just the child.

Therefore, if the negative impact on the child's overall health is sufficiently small (e.g., perhaps without the home ventilator the child will require four hospitalizations per year rather than three), it is permissible for a parent to prioritize her own interests in this kind of case over the best interests of her child. Given that the medical impact is sufficiently small, it is unlikely that this decision will significantly impact the future autonomy interests of the child. The parent (or the child, once an adult) can later decide to pursue the home ventilator option; in this sense the decision to forgo it is reversible. Thus, a physician should not resort to pressuring or overriding the decision of a parent to forego a home ventilator for her child.

II. Cold Medicine

As mentioned above, some people value "natural" or "alternative" medicine over traditional treatments. In many cases, when a child has a cold (or some other minor illness) her discomfort could be relieved or her disease course shortened by the administration of traditional medicine. Foregoing the cold medicine has only a small and temporary impact on the health and well-being of the child, and does not impact her future agency rights at all. Therefore, physicians ought not to pressure or override parents' decisions in these situations.

III. Jehovah's Witnesses and Bloodless Surgeries

Recall the health-related value held by people of the Jehovah's Witness faith that precludes the administration of blood products. Many major surgeries usually involve the administration of blood and blood products. However, due to pressure from this community to avoid use of blood products, some hospitals can now perform "bloodless" surgeries: those which traditionally required administration of blood products but can be modified in order to mitigate the need for blood. Doing these surgeries in this modified way poses a higher risk to the patient, and thus from a purely medical perspective is unadvisable.

If the increased risks to the child are sufficiently small, then parents ought to be able to choose to have their children undergo bloodless surgeries when doing so best accords with their health-related values. The child will get the surgery either way, and so the effects of this decision are not objectionably "irreversible". And the type of procedure used to deliver the necessary surgery is unlikely to have a significant impact on the future agency interests of the child.

This is, of course, not an exhaustive list of cases in which parents can make medical decisions that do not accord with the best interests of their children. But I hope that it starts to demarcate the space in which these decisions are morally permissible and should be supported by the physician. To further elucidate, let's now turn to several cases which demonstrate when physicians should not allow parents to make decisions that are detrimental to their children.

I. Cochlear Implants & Deafness

Children with particular types of sensorineural deafness, which is often but not always an inherited condition, can be treated with cochlear implants. These are prosthetic devices implanted under the scalp and into the cochlea (a part of the inner ear) attached to an external, battery-powered processor which electrically stimulates the cochlea in response to sound waves. For children, who are in the process of developing audition and language, the earlier the cochlear implant surgery is done the better the outcome in terms of audition and speech gains.

Some deaf parents value deafness for the opportunities it provides children to participate in the deaf community; they thus refuse cochlear implants in favor of allowing their children to remain deaf. Since cochlear implants must be implanted before a child reaches a sufficient age to decide for herself whether she values hearing or deafness more, a parent's decision to refuse this therapy significantly limits the future agency interests of her child. Further, at least as society is currently structured, there are good reasons to think that being deaf constitutes a disadvantage in many circumstances.

Choosing to have one's child undergo this surgery and thus develop normal audition and language, on the other hand, is compatible with the child still learning sign language and participating in the deaf community in significant ways. When she reaches adulthood, she could then, in theory, choose to disconnect the external processor portion of the cochlear implant and thus become functionally deaf. Thus, in a way, the decision to get a cochlear implant for one's child is reversible, whereas the decision to forego a cochlear implant has permanent effects. On the model I've proposed, physicians should pressure parents who refuse cochlear implants for their children.

II. Insulin & Diabetic Retinopathy

Children with diabetes mellitus require insulin therapy in order to control their blood glucose (sugar) levels. Poor insulin control results in chronic hyperglycemia, which damages the cells in the retina of the eye.[55] This leads to progressive visual loss and eventually irreversible blindness.

The same health-related values at play in the cold medicine case may also be at play here: that is, some parents will reject insulin on the basis of their health-related value of naturopathy. But what the child stands to lose here (i.e., eyesight) is significantly worse than what they stand to lose if a parent refuses the administration of cold medicine. Plausibly, this visual impairment limits the future agency rights of children in a significant way. And, once diabetic retinopathy has progressed to blindness, the administration of insulin will not reverse this pathology. Thus, physicians ought to pressure or override the decisions of parents who refuse to give their diabetic children insulin therapy.

III. Measles, Mumps, and Rubella (MMR) Vaccine & Sterility

Measles is the 5th most common cause of death for children under five years of age, although it primarily occurs in areas with low vaccination rates. Children who survive infection are at risk for neurologic complications, which can themselves be fatal or result in permanent intellectual disability, among other complications. While less deadly than measles infection, mumps infection predisposes children who contract it to a risk of decreased fertility or sterility in the future.

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[55] In addition to having other negative systemic effects.

Being able to decide if or when one has children seems like a central agency right. The fact that failing to vaccinate one's child against measles, mumps, and rubella puts the child at risk of death or future infertility, therefore, appears to be a very weighty reason to compel parents to provide this vaccination for their children.

IV. Open Wounds & Pain Management

Some parents refuse pain medications for their children when, from a medical perspective, they clearly need them. Or, to put it more mildly, often parents refuse to consent to the administration of pain medicine to their children when that pain medicine would almost certainly reduce or relieve the child's pain.

Some parents may espouse the health-related value that enduring pain engenders strength, or is in some way more valuable than taking medicine to alleviate pain. However, severe pain constitutes a significant impact to both the immediate and future[56] welfare interests of children. Thus, physicians should not accept the decision of parents to forego pain management for their children, at least when the pain is more than minor.

V. Antibiotics

Some parents value "natural" healing or "alternative" medicine over modern medical interventions, which will sometimes lead them to refuse antibiotics when children need them. One case in which antibiotics are clearly indicated is that of sepsis, or bacterial infection of the blood. While in the case of localized infections it might be less clear whether antibiotics are strictly necessary, sepsis is a life-threatening condition which can

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[56] There is evidence that poorly-managed pain predisposes children to pain syndromes later in life.

> rapidly lead to death if appropriate antibiotic therapy isn't initiated. Other bacterial infections require antibiotic treatment to prevent spread to the central nervous system, damage of which could have significant long-term negative cognitive effects on the child. The most common bacterial cause of strep throat requires treatment with antibiotics in order to prevent a complication called rheumatic fever, an autoimmune disease in which the patient's immune system attacks her heart tissue.
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> When there is a more than negligible risk of death, or when there is a more than negligible risk of permanent agency-limiting effects, physicians should pressure, if necessary, parents to change or re-order their health-related values when the values they hold preclude antibiotic therapy for children.

Conclusion

The presumption that parents have a right to make medical decisions for their children can be justified by appeal to a parent-centered account of parents' rights. However, the control rights that this account justifies are importantly limited by both the interests of the parents and the interests of the child. This account is consistent with the delegation of medical decisions to other competent adults, specifically, physicians, when doing so is necessary to preserve significant welfare or agency interests on behalf of the child.

In this discussion, I have been assuming that the children involved are sufficiently young so as not to be able to express their own opinions or preferences regarding the medical treatment options. More will need to be said about the evolving role the child plays in the patient-parent-physician relationship as she grows up and is increasingly able to exercise her agency.

Additionally, a more thorough discussion of which persuasive or decision-influencing tactics are justified under what conditions needs to be developed.

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