

***The Trauma of Disregard: Doing Justice to Parental Healthcare Values
in Conflicts
in Pediatric Medical Care***

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Abstract

Studies and policy advancement have long excluded a keystone niche within the development of the healthcare decision-making process: the parental perspective. Incorporating accounts of parents who have encountered traumatic occurrences in the healthcare system can help develop a respect for their healthcare values and allow doctors understand the parent's positions and emotions and adjust accordingly. This paper argues that healthcare practitioners have failed to appreciate the weight and negative effects of actions violating parental healthcare values.

INTRODUCTION

Re-theorizing the experience of the parent in the hospital setting could better inform hospital policy, physician behavior, and ethics committees about the impact of their behaviors and decisions. Public policy and debate as well as hospital policy around the role of parents in

healthcare decision making fail to incorporate the lived experience of parents, a failure that leads to one-sided actions and policies. Much of the research about parents in the medical care setting does not grasp the breadth of parental experiences and the strength of parental healthcare values. Specifically, the negative impact of the doctor or organization's decision not to respect parental healthcare values on parents' respect for healthcare practitioners, hospitals, and even pharmaceutical companies and public health professionals is not deeply explored in the literature but it may have long-lasting impact on the parents, the family unit, and the child. This paper argues that bioethics research studies have by and large failed to grasp the parent experience often by design, language, and conceptual framework. A movement toward constructivism and phenomenology or narrative-based accounts might align with treatment of parents as equals in social status and present an ethical framework that does justice to the trauma in the lived experience of parents.

I. A Preference or a Healthcare Value

The crux of the failure of the current theory regarding parental decision-making stems from a misunderstanding that parental "preferences" are often a placeholder for healthcare values. A disregard of parental opinions, decisions, or feelings results in the sense of invisibility, disregard, and even abandonment as a decision maker. Losing control over a young child's healthcare decisions is traumatic for parents.¹ I argue the trauma stems from the depth of the parents' healthcare values, not from a disagreement over preferences. Studies use the word preference,² but parental healthcare values are much deeper, more important, personal, and even reflective of constitutional rights. For example, preference may be appropriate when discussing acetaminophen versus ibuprofen, but I would use healthcare values when discussing palliative care versus chemotherapy.³ Most parental medical decisions fall into murkier territory: for example, whether to choose antianxiety medicines, opioids for pain relief, or first- or second-generation anticonvulsants for epilepsy, when there are safe, efficacious alternatives, a contentious subject that seems uncontentious when framed as a mere preference. Furthermore, parents may prefer proven alternatives which are incorrectly associated with doing nothing. There may be room for rethinking the role and application of the standard of care to be more inclusive under safe circumstances.

There are also liberties that some parents value more deeply than others, leading to questions of which authorities are in a position to decide, and why they hold that power.⁴ Parental liberty must not outweigh child safety, but it is a well-established cornerstone of free society.

Healthcare values should be defined not just as "preferences, concerns, and expectations"⁵ but as deeply held beliefs, the violation of which affects people personally. Healthcare values dictate personal behaviors and can be limited when those behaviors violate a law, as possible in cases of medical neglect. Healthcare values in a liberal democracy are moral values that may be legally protected parenting rights as elucidated and limited by courts.⁶ Healthcare values in the broad sense encompass a policy view on how people should access care and who should pay (one person's healthcare values may prioritize freedom of choice while another person's might

prioritize access to care for everyone; such values may dictate voting behavior). On a personal level, healthcare values may address whether natural or herbal remedies should be exhausted before medicines are tried or whether medicines should be tried first even if they have severe side effect profiles. Or they may dictate whether there is a moral responsibility to keep as healthy as possible using lifestyle, exercise, and diet, and if so, whether that moral responsibility should or should not be considered in policy. Healthcare values also connect to other values. For example, certain diets are environmentally friendly and correlated with prevention. Those adhering to such diets may have varying healthcare values, favoring either reason to varying degrees, health-wise something that may benefit them depending on environmental, genetic, and other health influences. Moving away from “preference” to “healthcare values” better highlights the importance of parental choice as a tenet of sociopolitical, family, individual, or community life in a liberal democracy.

II. The Role and Nature of Bioethics Research

The misunderstanding of healthcare values as preferences has resulted in a research methodology that too often calculates parental healthcare values through a numerical lens of efficiency and patient satisfaction. While I acknowledge the need for empirical research, empirical research methods that try to identify issues or incorporate ways to improve care are not the best approach to ensuring that highly personalized healthcare values are respected.

Health care as a consumer endeavor has moved toward patient engagement and partnership through various new models, yet the models and the literature continue to be healthcare practitioner-driven⁷ rather than reflective of the individual experience of parents. The “Partnership in Care” approach looks to patients as active partners or experts, values the patient experience, and aims to harness the expertise developed by patients as they know about living with medical conditions and accessing services.⁸ This model is especially helpful from a customer service perspective and leads to a smoother process and an appreciation of the many skills parents develop. It also provides a mechanism for the healthcare organization to promote sharing information, enabling parents to learn from each other. But this model is insufficient to address the role of parents as decision makers, conflicts between practitioners and parents, and the deeper moral issues involved in care, which go well beyond customer service in that they impact families in daily life and arguably shape their attitudes toward medicine, the pharmaceutical industry, and public health.

There are studies that look at how the family would be affected by a care decision, and how to evaluate parental and surrogate decisions, especially refusals of care.⁹ The “family surrogate decision-making models”¹⁰ tended to exhibit paternalism in study structure, as the studies focused on the attitudes and preferences of physicians, reflected the use of physician-centric language (whether they are “accepting of”), and assumed that it was up to the physician to decide how much the family mattered. That is, the family voice was nowhere in the research method. While there has since been progress and significant attention to patient experiences and healthcare quality, parental healthcare values are not addressed in a fully informative, holistic,

experiential way in the research or literature, which tends to be written by, or subject to peer review by, physicians. Some studies remain logistical. For example, in a study of the NICU in which the design did include parental perceptions, the family meetings were considered from a customer service perspective concluding that parents would like to be better prepared for meetings.¹¹ The study, while informative about meeting preparation and logistics, did not offer a mechanism for including parental healthcare values or inform methods to solve moral disagreements over treatment decisions in the NICU. An article evaluating the “four quadrants approach” in decision making in burn scenarios said, “In our experience, patients and family members are unlikely to make appropriately informed decisions during this acute period.”¹² That language is a red flag in several ways: It negatively stereotypes families and patients; it is dismissive of patients; and it implies doctors adequately decide for patients. A 2016 article asserts, “The various perspectives of nurses, chaplains, physicians, social workers, lawyers, and others bring variety to the debate and serves the patient in the best way possible.”¹³ The direct voice of the person receiving care is absent in the “variety.”

Despite a recognition of the importance of care decisions to the parents, there is no pervasive, acceptable framework for assessing the impact on the parents of a violation of healthcare values. The literature on refusals is generally one-sided and revolves around efficacy. In doing so it may inflate the costs to the child of a parental decision the healthcare practitioners dislike while ignoring many of the undocumented costs to the child, family unit, and parents of a decision forced on parents.

Alexander Kon recognizes the unreasonable expectations healthcare providers may have and their view of “death as failure.” He recommends that “healthcare providers enter any such conversations with an open mind and a willingness to listen first and talk later.”¹⁴ His examples of cases of practitioners coming around to the parent point of view are so vastly different from the many experiences in which practitioners have been unbudging, righteous, or willing to engage in duress that there may be a need to collect more stories, especially from the point of view of those parents whose decisions were not respected in non-dangerous situations where there was no potential harm or no imminent harm. Kon specifically addresses the life-at-all-costs attitude that practitioners may have, which reflects healthcare values. The Kon method appears to exist more in theory than in practice, representing an aspiration, not a reality.

In the arena of refusals, parents’ views may be disregarded in favor of the doctor’s recommendation even if there are multiple solutions with similar efficacy.¹⁵ I suggest that one of the reasons could be the insufficiency of the body of research to account for the lived experience. That insufficiency may distort the physician’s view of the importance, leaving them unaware of the detriment to the parents or family unit. Physicians do not know how parents feel and how the parents’ future engagement with the healthcare system may be negatively impacted. One hypothesis seemingly untested is that the physician believes the parents will be indifferent to or thankful for the unwanted intervention, or for a failure to provide something the parents wanted, or for any conflict’s resolution in the physician’s favor. The doctor and hospital may think all is well

that ends well. I argue physicians underestimate the role of the helplessness, hopelessness, loss, and grief of an ignored parent in the lived experiences of that parent. The result may include an irreconcilable distrust for the doctor, hospital, medical profession, public health profession, and even the government. The trauma experienced by parents seems overlooked by the literature.

III. “Doing Justice”: A New Approach to Critiquing Research Methods

Thomas Teo argues that the quality of research methodology is based on “the degree to which a method is *doing justice to the object...*,” something central to the ethics of the research.¹⁶ When a research design fails to incorporate viewpoints, the ethics of the research become compromised. In the narrow sense, doing justice to parental healthcare values likely requires subjective information, parental lived experiences as described by them. Yet studies that recommend overriding parental refusals, even if the refusals were based on healthcare values, generally reflect research methods that rely on efficacy alone, completely numbers-based endeavors.¹⁷ For example, studies based only on medical statistics are used to address refusals of chemotherapy and depression and anxiety medicines.¹⁸ Parents can be declared wrong even when they understand the efficacy data, have valid reasons, offer an equally efficacious alternative, or when the care refused is not guaranteed to help or cure the condition, or it has severe side effects. For now, in the bulk of the research, efficacy numbers often serve as the sole justification for overriding the parents’ wishes. But does such research do justice to the issue?

In the broad sense, certain bioethics studies do not do justice because they do not contextualize a family’s political, socioeconomic circumstances. Sometimes an injustice may be done when there is an acceptance of a refusal by a wealthy parent, and not only a failure to accept a poor parent’s refusal, but neglect charges against the poor parent refusing. Is the poor parent less entitled to healthcare values that conflict with those of the physician? Similarly, many cite racial bias in the context of pediatric medical care.¹⁹ If parental healthcare values involve quality of life concerns, limited medicalization in favor of natural remedies, or broader values like socioeconomic circumstances that influence the decision, it is difficult to see some of the questionnaires and studies in the bioethics literature as deep enough to take on the topic. The parental role in health care is the subject of a great deal of literature, but the literature fails to do justice to the trauma of the lived experience of the parents, leading to policies and practices that fall short for families. As is, the current research methods employed by bioethicists, predominantly published in journals with doctors as peer reviewers or holding positions on the journals’ boards, aiming to define or limit the role of parents in healthcare decision making do not do justice to breaches of parental healthcare values.

Bioethicists sometimes suggest majority views should dictate; for example, one author suggests the rightness of overriding based on evidence that doctors usually override refusals of chemotherapy at 33 percent or better efficacy.²⁰ Moral rightness based on current practices can disenfranchise minority viewpoints, and even lead to unconstitutional results. For example, many parents prefer anxiety medication or ADD medication for their child. Yet that prevalent preference alone should not invalidate those whose healthcare values indicate otherwise. Disease creep and

treating conditions of regular life (moods or physical conditions that used to be widely accepted, not seen as needing treatment) are contrary to many people's values, something seen in aging with a push to use medical advances to keep people "young."²¹ It may be that within a certain zone, physicians will "allow" parents to make minor decisions, but the more serious the problem and the greater the efficacy, the less physicians will succumb to parental influence,²² a distinct insult to the role of parents. In exploring the role of patients as research subjects from the views of both hospital staff and the patient-subjects, Salla Saxén and Heikki Saxén argue that a "care-research nexus" must combine the "bird's eye view of the doctors and researchers with the personal views, life story, and social network of the patient."²³ The same concepts could extend to parents in their involvement in the delivery of care to their children. The Saxén triangle²⁴ puts medical professionals and the patient's personal criteria on a more even playing field.

In referencing the healthcare conflicts resolved in favor of physicians rather than parents, the existing research also fails to do justice by not reflecting the weight of individual constitutional rights including the right to refuse care, violations of which feed the resulting trauma parents endure. Autonomy in bioethics literature speaks to decisions that direct care but does not acknowledge the weight of constitutional rights, or the feelings that accompany a violation of rights. "Autonomy rights" might be a better phrase than just autonomy to situate autonomy even more forcefully at the top among the four principles.

Some articles tee up a weighing process in which potential benefits to the child appear in conflict with the parents' choice when often they are not. In the dominant discussions, the parents appear to be uneducated, misinformed, or ill-motivated.²⁵ Yet broadscale research also confirms the overprescribing, overuse, and heavy use of pharmaceuticals that many professionals within medicine and the natural and social sciences question.²⁶ For example, overprescribing is implicated in the opioid epidemic. The on-the-ground parental experience is not often contextualized properly with the largescale data.

The unwillingness to go along with a sea change in emotional health care when understood in the context of overprescribing²⁷ requires a deep look at values, where values arise, who has authority to determine norms for other people and why, and how a violation of deeply held values affects people and society. Yet some argue that a parental refusal to approve medicine for anxiety and depression is medical neglect even if there is not an imminent danger --- the American Association of Pediatrics includes the failure to provide for "emotional-behavioral" needs in its definition of neglect.²⁸ Historically, emotional needs were met with nonmedical emotional support by families, friends, and community, rather than within a healthcare system. Continuing such longstanding traditions is values-based and reflects a historic norm. Medicine need not be used to resolve societal issues.

When more is presumed better at the individual level, parents wishing to refuse medicines are forced to defend their healthcare values. Yet the parents are often supported by the epidemiology and largescale public health data.²⁹ Parents going along with recommendations are not asked to defend their choice, despite known risks to children and the context of significantly

more pharmaceutical use among children and adolescents. Informed consent reflects going along with the physician, while informed refusal's inherent conflict is treated differently.³⁰ Research on overuse of prescription drugs should dominate individual treatment discussions, leading to a balanced perspective where all parents are alerted to the concerns, and those choosing medicines weigh the pros and cons fully informed.

Research is generally supported by a presumption of verifiable, observable patterns. Positivism limits what is included in the sphere of "genuine knowledge," based on its philosophical presumptions about the nature of knowledge, and limitations on what can logically be concluded.³¹ Arguably, when parental healthcare values are ignored, positivism could yield a picture of the observable results. Using proxies to represent hurt, anger, and trauma could be informative and objective. An approach steeped in logical analysis of the data could shed light on the ill effects that some bioethicists acknowledge.³² Constructivism and theories rooted in the lived experience include diverse points of view and a fuller picture of the social world in contrast to positivism and other reality-oriented correspondence theory.³³ By accounting for emotions, social circumstances, and worldview, constructivism looks for human perception. Separating the person designing the research from the research can prove difficult. Possibly parents themselves are the best researchers, but they do not have the means to put together research studies. Phenomenology, whose iterations allow for the chronicling of subjective experiences, could elucidate parental experiences more accurately, and be a logical platform for those researchers interested in how parents feel and what parents do in response to those feelings when their healthcare values are violated or ignored. Yet it is important to see the logic: when their healthcare values are ignored, parents logically and predictably experience trauma and develop distrust.

IV. Beyond Research: Exploring the Lived Experience

Due to the richness, individuality, and diversity of parental healthcare values, they may not be best served by traditional bioethics empirical research. One problem with bioethics research and with professional applied ethics in the fast-paced hospital environment is that something that is a problem for one family might be especially valued by another. From the customer service approach, a hospital or physician might want to please a majority. From a healthcare values standpoint, an approach that accommodates the most views (even if only one person holds the view) without risking the child's safety is warranted. Healthcare values, whether seen on a continuum or otherwise charted, are personal and may look most accurate on a scatterplot. For example, someone may firmly avoid opioids and antidepressants, but use generous amounts of NSAIDs or acetaminophen. They are not anti-medicine, yet they are discriminatory in its use. Another discriminating parent might approve of opioids but not acetaminophen based on side effect concerns or its possible failure to address the pain as well. Most parents fit somewhere in the middle ground but vary greatly as to how they engage with medicine in their lives. There are vastly different views on quality of life, on what makes life worth living, and on how to harness medicine in a way that aligns with their healthcare values. People vary significantly on the appropriate amount of distrust of pharmaceutical companies, government in its regulatory roles,

and for-profit hospitals, if any. Healthcare values are broad and deep. Data on parental conflicts does not reveal how much the conflict means to the parent. Whether lacking data or engaging in vestiges of paternalism, physicians in my experience underestimate the trauma caused when parents are forced to deviate from values dear to them. Beyond that disconnect, it is unpredictable whether physicians would behave differently if they knew the trauma they trigger likely leads to significant dislike for the profession of medicine, public health, and the pharmaceutical industry.

CONCLUSION

While more empirical research and a phenomenological approach could yield supporting data, I assert that the trauma resulting when physicians disregard healthcare values is more significant than currently understood, has emotional and psychological effects, and contributes to long-term distrust. Efficacy data, medical traditions, and research on ways to incorporate patient or parent preferences do not cover the moral rightness or wrongness because they fail to adequately measure or account for the type and degree of the actions' harm. The research or a collection of narratives that I would recommend gathering would do justice to the topic by aiming to understand to what degree trauma, distrust, and dislike result from infractions (the parent data), and how the healthcare system as a whole and even public health is harmed by the lack of trust (the public data).

Narratives by parents might elucidate the stories of the many parents who feel disenfranchised, whose voices were not heard, who were unable to protect their children from medicines,³⁴ who could not get a diagnosis because the facts they relayed to doctors did not correspond well to scans,³⁵ who experienced a lack of empathy in a system they needed, and who could not instill healthcare values in their children due to competing information presented without enough context like broad data on overprescribing and addiction. A personal narrative of the lived experience of an inability to operate according to one's healthcare values would be a valuable addition for physicians so that they may fully digest the extent of the emotional trauma that parents experience when their healthcare values are ignored.³⁶

¹ This paper addresses those younger than would be expected to “assent”, those situations where the conflict is between parents and the doctor, or where the person receiving care agrees with the parents. As per many laws and provisions, the ability to seek care when parents are neglectful, abusive, or absent is well documented. And New York offers clarity on the ability to seek certain types of care without parental input. See NYCLU, Teenagers, Health Care, and the Law: A Guide To Minors’ Rights in New York State, 3rd Ed, 2018.

<https://www.nyclu.org/sites/default/files/thl.pdf>

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³ Tomlinson, et al.

⁴ Shapiro, M. Pediatric Depression: When Does Parental Refusal for Treatment Constitute Medical Neglect? *Journal of the American Academy of Child & Adolescent Psychiatry*. 2018;57(6):363-365. doi:10.1016/j.jaac.2018.02.014

⁵ Marzorati C, Pravettoni G. Value as the key concept in the health care system: how it has influenced medical practice and clinical decision-making processes. *J Multidiscip Healthc*. 2017;10:101-106, p. 102. Published 2017 Mar 21. doi:10.2147/JMDH.S122383

⁶ Meyer v. State of Nebraska, 262 U.S. 390 (1923); Pierce v. Society of Sisters, 268 U.S. 510 (1925); Prince v. Commonwealth of Massachusetts, 321 U.S. 158 (1944).

⁷ Gustavsson S, Gremyr I, Kenne Sarenmalm E. Designing quality of care - contributions from parents. *Journal of Clinical Nursing*. 2015;25(5-6):742-751. doi:10.1111/jocn.13050 (Researchers conclude that healthcare professionals overvalue their importance for value creation and underestimate the ability of parents to influence quality.)

⁸ Bouabida, p.5.

⁹ For example, see Rhodes R, Holzman I. The Not Unreasonable Standard for Assessment of Surrogates and Surrogate Decisions. *Theoretical Medicine and Bioethics*. 2004;25(4):367-386. doi:10.1007/s11017-004-3138-6; See Winters JP. When Parents Refuse: Resolving Entrenched Disagreements Between Parents and Clinicians in Situations of Uncertainty and Complexity. *The American Journal of Bioethics*. 2018;18(8):20-31. doi:10.1080/15265161.2018.1485758 citing Gillam L. The zone of parental discretion: An ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child. *Clinical Ethics*. 2015;11(1):1-8. doi:10.1177/1477750915622033 (recognizing overriding parents can cause harm.); about refusal of opioids, see 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. *Pediatric Anesthesia*. 2020;30(8):852-858. doi:10.1111/pan.13941 (The authors evaluate the best interests, harm principle, zone of parental discretion, and Lainie Friedman Ross’s constrained parental autonomy.); Ross, LF. Against the Tide: Arguments against Respecting a Minor’s Refusal of Efficacious Life-Saving Treatment. *Cambridge Quarterly of Healthcare Ethics*. 2009;18(3):302-315. doi:10.1017/s0963180109090471 (arguing in favor of treatment against a minor’s or the parents’ will when survival rate is 75 percent or more regardless of intrusiveness of the treatment.)

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- ¹⁷ Ross, 2009.
- ¹⁸ See Zimmerman, 2021.
- ¹⁹ Lang, K., Dupree, C., Kon, A., Dudzinski, D. Calling Out Implicit Racial Bias as a Harm in Pediatric Care. *Cambridge Quarterly of Healthcare Ethics*. July 1, 2016. <https://doi.org/10.1017/S0963180116000190>
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For data on doctors treating despite parental refusals, see Talati ED, Lang CW, Ross LF. Reactions of Pediatricians to Refusals of Medical Treatment for Minors. *Journal of Adolescent Health*. 2010;47(2):126-132. doi:10.1016/j.jadohealth.2010.03.004 (With 80 percent 5-yr survival, doctors treated 325 of 404 over family refusals.)
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³⁵ Caron RM. Co-producing healthcare in a volume vs. value-based healthcare system: perspective of a parent of a patient and a health professions' educator. *Patient Experience Journal*. 2019;6(2):16-19. doi:10.35680/2372-0247.1373

³⁶ For an example of a narrative woven into a report on the importance and societal value of refusals, see Zimmerman, A., 2021; and, for a narrative about the experience trying to get appropriate care, see Caron, RM. (a health educator chronicles tribulations in achieving a diagnosis for her daughter and notes lacking empathy and difficulty getting doctors to pay attention to the person rather than the scans.)