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Etiology and Manifestations of Iatrogenesis in Pediatrics

Stowe Locke Teti, MA, Kathleen Ennis-Durstine, MDiv, and Tomas Jose Silber, MD, MASS

Abstract

There is general agreement in the literature of what ought to occur following iatrogenic harm. Senior members of the team should disclose what occurred and how the problem will be remedied. Those involved should express heartfelt regrets and apologize sincerely. But in the pediatric setting, parents, as surrogates, can sometimes place clinicians on the horns of a dilemma: respect parental autonomy, which may involve continuing nonadvised therapy, or uphold the patient's best interests, which may indicate another course of care. In other cases, clinicians themselves may initiate or continue care without real benefit. The young patients who may be harmed as a result often cannot understand an explanation, an apology, or, when warranted, receive reparation; what duties are owed them? In this paper, we first discuss iatrogenesis writ large and then propose the formulation of this concept in this latter context, where harm occurs as a result of counterpoise between two or more ethical obligations, which we term *counterpoise iatrogenesis*. We then articulate its etiology and manifestation through two true cases. We conclude with a re-examination of the meaning and function of autonomy in pediatrics and the designation of secondary victims.

Introduction

Iatrogenesis, as we use the term here, refers to any patient harm resulting from treatment by a member of the medical team [1, 2] and is not limited to medical error [1, 3]. Following iatrogenic harm, the clinicians involved, preferably senior members of the team, should inform the patient or family of what happened, how the problem will be remedied, and—particularly when lasting harm has occurred—what can be done for the patient [1, 3]. Physicians should express regret and offer a sincere apology, which patients who have been harmed deserve [4, 5].

Despite these recommendations, a dichotomy continues to exist regarding disclosure of harm [6, 7]. In pediatrics, studies show 99 percent of parent respondents want disclosure, irrespective of the severity of harm [3, 8]. Multiple studies have identified the benefits of disclosure to all parties [6], including decreased chances of litigation [9]. Nonetheless, studies of clinicians demonstrate an obdurate reticence to disclose iatrogenic harm [10].

The history of error disclosure provides insight into why. A 1934 *New England Journal of Medicine* article listed the number one cause of malpractice claims as "inopportune remarks by subsequent attending physicians" [11]. That sentiment aligned with the paternalism of the time, and as the century wore on, innovations in medicine led the public to vest "near total confidence and awed respect" in physicians [12]. Such confidence engendered a sense of obligation to perform flawlessly; errors became an indictment of one's character and competence [13]. The 1999 publication *To Err is Human* [14] shattered those preconceptions [3]. Fear of implicating other clinicians [15], and of legal action [16], focused remediating efforts; discussions of ethical responses to iatrogenesis tended to be reduced to discussions of the obligation to disclose [17].

This focus diverted attention from cases in which all parties have knowledge of the harm that has occurred but do not recognize it as iatrogenesis. Expressions of regret are not—perhaps cannot be—made to the aggrieved; the patient might be a neonate, infant, or young child subjected to nonrecommended, if not nonindicated, medical care at the parents' insistence or to the routine provision of nonbeneficial care [18]. While disclosure is often the barrier to an ethical response to iatrogenesis in adult patients [4, 19], what we call *counterpoise iatrogenesis* exists in pediatrics in plain sight; clinicians are generally aware of the harm these patients experience, but, as one study has documented, the roles of clinicians and parents in decision making can shift in end-of-life care [20]. Counterpoise iatrogenesis can occur due to clinicians' multiple obligations, equivocating between obligations, or as a result of a dilemma in which the priority of obligations may be indeterminate [21].

In this paper, we first examine how parents of severely ill pediatric patients contribute to iatrogenesis by insisting on nonrecommended treatment. We then present two true cases of counterpoise iatrogenesis and analyze the clinician's ethical obligations in each case. We conclude by re-examining the meaning and function of respect for autonomy in pediatrics and note one implication for moral distress as a result of recognizing counterpoise iatrogenesis.

The Role of Parents in Pediatric Iatrogenesis

Parents are generally their children's surrogates, thoroughly invested in their well-being and felicity as part of a familial, generational project. However, that does not mean the wishes of the parents and the best interests of the child are coextensive. While the law recognizes limits to parents' rights to make decisions for their children [22-24], it is commonplace for parents to ask for, and obtain, treatments the medical team knows will cause pain with little chance of benefit but that do not rise to the standard of "martyring" one's children [25]. This is not to suggest parents should not have the decisional authority they do. Prognoses are frequently indeterminate, unknown, or wrong [26], and parents' moral stake in their child's well-being is generally greater than anyone else's [27]; it is they who will care for their children long after those children leave the hospital. Nonetheless, any complete conception of iatrogenesis must account for a full range of its causes, as we explore in more detail in what follows.

Cases of Pediatric Iatrogenesis

Case 1. Baby boy L was diagnosed with trisomy 18, including ventricular septal defect (i.e., a hole in the heart), coarctation (narrowing) of the aorta, and diaphragmatic hernia. After L had been intubated and on a respirator for several weeks, the NICU team met with the parents and explained that L could no longer remain intubated; a decision needed to be made. The parents could choose either a tracheostomy or, given L's poor prognosis, compassionate extubation. The parents asked for more time to make a decision. The team reluctantly agreed.

Due to the intubation, L couldn't be moved significantly; tucking in a blanket caused dramatic desaturation. Numerous efforts were made as the weeks wore on to help the parents reach a decision. L's parents insisted he would be "okay" and that, given time, he would become stronger. A family meeting was arranged to discuss options. The NICU team explained continued intubation was not acceptable: it was necessary to decide on either tracheostomy or compassionate extubation. The parents insisted on more time. The father appeared to be in denial about the need to make a decision and was adamant L remain intubated. At this point, L had been intubated for three-and-a-half months.

The NICU team allowed the parents the weekend to decide. Both parents indicated they could not make a decision. The team social worker indicated that if they refused to decide, the decision could be taken away from them through legal action, to which they responded, "Fine." Child protective services (CPS) took custody of L, who received a tracheostomy.

Commentary. While children can tolerate longer periods of intubation than adults, extended intubation can interfere with normal development and is a primary cause of subglottic stenosis [28]. L's episodes of desaturation contributed to iatrogenic harm, but it was L always remaining in bed and untouched that was most harmful; a tracheostomy would have enabled him to receive stimulation vital for both neurological development and comforting.

As this case illustrates, physicians are sometimes in the position of having to adjudicate between the rights of the child and respect for parental autonomy [29], which can rightly entail assessing the reasonability of the parents' request [30]. In L's case, the parents did not seem to be deliberating but rather subscribing to a false narrative in which their child would simply get better, presumably obviating the need to make the decision. Their belief was arguably not *informed* [6, 24]. The members of the medical team allowed L to remain intubated because they did not want to escalate the conflict with his parents and involve CPS; they believed not that L's parents were being abusive but rather that they were simply unable to make a decision no parent ever wants to face. The clinicians' respect for parental autonomy and their fiduciary duty to care for L counterbalanced one another, resulting in counterpoise iatrogenesis [31].

Case 2. Baby M is a 24-week neonate with short bowel syndrome and in respiratory failure, admitted from an outside hospital for surgical evaluation and bowel rehabilitation. She was on a vent, had significant liver disease, and was postcolostomy and postileostomy. Surgery was performed; the surgeons found profuse liver disease and bleeding. They stopped the bleeding and siloed M's intestines. M never became able to tolerate feeds, even a few milliliters over many hours caused distress—pain, swelling, and gas. When it became necessary to remove the silo several weeks later, M's abdomen could not be closed completely and a fistula formed. The medical consensus was that M would not recover; her liver would not heal unless she could tolerate full feeds, but her intestinal condition prevented all but minimal food intake. M was receiving the maximum dosages of pain medication, but she had breakthrough pain during simple care, such as diaper changes. Her abdomen remained significantly swollen, the sutures were pulling at the outside borders, and the fistula was not healing.

It was explained to M's parents that surgical correction for her short bowel syndrome wasn't possible. However, they insisted on aggressive treatment, believing she would eventually heal. Numerous efforts were made to recommend transition to comfort care, but M's parents remained undeterred. Pressured by the parents, the medical team reluctantly continued attempts to feed her. The staff, seeing M suffering, began experiencing significant moral distress.

M persisted without improvement. Six weeks later, she had a cardiac arrest. The team resuscitated M despite having no ability to treat her underlying condition. As the days wore on, arrests recurred with increasing frequency until M was having multiple arrests per day and subjected to multiple resuscitations. Soon after, her IV failed. The physicians evaluated the situation and considered whether or not to try to reaccess her. A senior physician consulted with the team, and the team informed M's parents the only appropriate option was comfort care. She had been in the NICU for ten months.

Commentary. Acquiescence to parental demands resulted in M being subjected to repeated tube feedings that caused distress with no portent of benefit, while denying her comfort care. M's parents believed that whatever pain she was enduring she wouldn't remember, but that pain was not theirs to bear [25]. Iatrogenesis resulted from both clinicians ceding clinical ground to insistent parents and continuing nonindicated medical care beyond the point it was reasonable to do so as a matter of clinical judgment [18]. The decision to resuscitate M repeatedly was a perpetuation of two faulty judgments. First, the clinicians regarded the obligation to respect parental autonomy as equal to, or more important than, the child's own best interests. Second, they failed to recognize that because the underlying condition could not be treated, resuscitation was not indicated [32]. One must consider multiple factors in assessing best interests, but the first is whether the intervention is *medically therapeutic*. Physicians are under no obligation to provide treatment that is not medically appropriate [33]. It is ethically permissible to decline to escalate treatment in such circumstances, including resuscitation when no means to treat the underlying condition exists [34]. M's case exemplifies how, once started, nonindicated interventions can "cascade," causing more harm [35].

Discussion

The ethical obligations inherent in the patient-physician relationship—including *informed consent* and *respect for autonomy* [36-39]—extend from the right every person has to act intentionally about matters affecting him or her [24]. Intentional acts are predicated on the capacity to make well-informed decisions, but most people are not well informed about medical matters [19, 40]. This asymmetry of knowledge means patients must know they can trust their physician; the physician's adherence to the principle of truth-telling validates such trust is well placed [41]. That trust ceases to be well placed if the physician isn't truthful about matters that affect the patient, underscoring why disclosure of harmful iatrogenic events is *mandatory* [1, 6, 42]. Trust in what their clinician tells them enables patients to make informed decisions, in their best interests, about medical matters for which they do not have specific expertise themselves.

Truth-telling, thus grounded in respect for patient autonomy, is generally the correct focus of the aforementioned ethical considerations following iatrogenesis. However, in cases of counterpoise iatrogenesis involving surrogate decision makers, respect for the patient's autonomy is in some sense transformed into a respect for the surrogate's wishes. Michaelson et al. observes, "Roles are reversed with end-of-life care decisions when parents shift, sometimes acutely, into the role of primary decision maker" [43]. But, as Hester argues, the surrogate's legitimacy is not derived by expressing the young child's *own* values but merely by having authority to decide *for* the child, thus creating a different "moral space" [44]. Following that thinking, respect for autonomy in pediatric ethics can manifest a tension, referring to both the right to make well-informed decisions about matters that affect oneself or one's child and to the child's negative right [45] to be free from being acted upon in harmful ways.

The surrogate's right to be informed and request certain kinds of medical care does not override the patient's right to not be harmed unnecessarily or with little chance of benefit [27, 46]. Stated another way, *autonomy* is not equivalent to *liberty* [22, 24, 47]. As two legal scholars note, "As a legal principle, autonomy's recognition and the potential for its scrutiny allow judgments of whether an apparent expression of will should be followed" [48]. One might envision a reasonable distinction in pediatrics between *reason* autonomy and *act* autonomy, the former being the right of parents to make informed decisions, to be acted upon insofar as their preferences do not abrogate the clinician's fiduciary duties to the child.

A final issue is deserving of mention: even when no claims of wrongdoing are raised, members of the medical team often suffer moral distress. By recognizing L and M suffered iatrogenic harm, we can see the staff members were "secondary victims" deserving of support [3, 42]. However, the patient must always be foremost in mind; expressing respect for parental autonomy does not necessitate ceding professional authority. Clinicians must delimit choices to actions within the bounds of professional practice and clinical judgment [49]. One's fiduciary duty is always to the patient; as Birchley succinctly notes, "the interests of children should never be forgotten within a world of adult concerns" [50].

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Stowe Locke Teti, MA, is the clinical ethics coordinator at Children's National Health System (CNHS) in Washington, DC, and the managing editor of *Pediatric Ethicscope*. Following five years of clinical training in the Children's National Clinical Ethics Consult Service, Mr. Teti now heads the ethics education program of the clinical ethics committee at CNHS. Mr. Teti also serves on the Washington Hospital Center's ethics committee and is currently developing a research electronic data capture-based consult documentation system for pediatric ethics consult cases.

Kathleen Ennis-Durstine, MDiv, is the senior chaplain and manager of pastoral care at Children's National Health System in Washington, DC, where she is also co-chair of the clinical ethics committee. A graduate of Harvard University, Rev. Ennis-Durstine has been appointed as a faculty member and a curriculum developer at the Pediatric Chaplain's Institute, where she has been serving as dean since 2013. Rev. Ennis-Durstine also has presented at the Pediatric Chaplains Network Conference and co-authored a chapter on spiritual care in pediatric oncology in the *Textbook of Interdisciplinary Pediatric Palliative Care* (Elsevier Saunders, 2011).

Tomas Jose Silber, MD, MASS, is a professor of pediatrics at the George Washington University in Washington, DC. He is also the director of the pediatric ethics program at

Children's National Health System, where he is chair of the clinical ethics committee, vice chair of the institutional review board, and ethicist for the Clinical Translational Science Institute. In addition, he served two stints as chair of the Section on Bioethics of the American Academy of Pediatrics. He is editor-in-chief of *Pediatric Ethicscope* and is collaborating with the American Academy of Pediatrics on education relating to iatrogenesis.

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