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FROM THE EDITOR

Preventing and Responding to Iatrogenesis in Pediatrics

Primum non nocere. First do no harm. This phrase embodies the principle of nonmaleficence, a fundamental bioethical standard within health care. However, clinical practice is a human art, and as such it is fraught with imperfection or what has been described as “necessary fallibility” [1]. Harm does in fact occur as a result of health care, but because there are variations in how the term “iatrogenesis” is used in the health professions literature to characterize such harm, the working definition we’ll use in this theme issue is the following: iatrogenesis happens when an adverse outcome is experienced as a result of the health care a person receives. Etymologically, “iatrogenic” comes from the Greek roots *iatros* (“physician”) and *gennan* (“as a product of”) [2]. Iatrogenesis therefore encompasses a wide range of actions and inactions. Examples include risks associated with necessary therapies, such as side effects, imaging-induced radiation exposure, surgical complications, and errors. Finally, iatrogenesis can arise through failure to provide adequate care, for example, when misdiagnoses result in the delay of appropriate therapy or unnecessary interventions [3].

Although the topic of iatrogenesis has become more widely discussed, less has been said about its presence within pediatrics [4]. Yet the pediatric population encompasses some of health care’s most vulnerable patients, demanding that we take special care to protect them and advocate for their best possible care. It is thus an ethical imperative for each pediatrician to educate himself or herself on the topic of iatrogenesis: how to recognize it, how to avoid it when possible, and how to deal with it when it occurs.

Pediatricians go into practice in order to heal illness and foster health in children. For this reason, the topic of iatrogenesis is often a distressing one for pediatricians and all health care professionals who work with children. Episodes of error, complications, health care-induced trauma, and mismanagement might not be adequately addressed due to clinicians’ feelings of guilt and fear of loss of respect or legal retribution [5].

Morbidity and mortality conferences are perhaps the most commonly known avenue within health care for addressing iatrogenesis [6]. These conferences take place across specialties and institutions in which clinicians discuss events that led to an adverse outcome. In the spirit of such an approach, this issue of the *AMA Journal of Ethics* seeks to guide aspiring and practicing pediatricians through the complex process of understanding and responding to iatrogenesis.

Even the best pediatric interventions and therapies come with a set of risks and possible adverse side effects. It is up to the pediatrician to cultivate awareness of these potential outcomes in order to develop an evidence-based risk-benefit analysis for the purpose of informing their recommendations to their patients. But decision making in pediatrics does not take place in a vacuum, and pediatricians must also translate this information for the caretaker and family. Two of the ethics cases this month discuss this role of the pediatrician as communicator in discussions about iatrogenesis. Genevieve Allen and Naomi Laventhal examine factors to consider when assisting families in decision making concerning [resuscitation](#) for infants born at the margin of viability. Thomas D. Steensma, S. Annelijn Wensing-Kruger, and Daniel T. Klink discuss counseling children and adolescents with gender dysphoria on the possible iatrogenic harms of pubertal suppression and [hormone therapy](#) without compromising the care they require. They also discuss the possible iatrogenesis of characterizing gender dysphoria as a disorder, a diagnostic label that pathologizes natural variations in gender but also increases patients' access to care.

Although most clinical interventions can have iatrogenic risks and consequences, some therapies can be thought of as iatrogenic in and of themselves. Bloodletting, for example, was long thought to be a therapeutic intervention by the physicians of ancient Greece [7], and yet today we understand that this practice does not treat disease or alleviate symptoms and is in fact detrimental to the patient. Some health care practices we engage in and endorse today can cause harm. Three articles in this issue address controversial interventions. J. Steven Svoboda, Esq., argues that nontherapeutic infant male [circumcision](#) iatrogenically harms children by removing tissue that has important immunological and erogenous functions and exposes them to the risks of surgery. Samuel Reis-Dennis and Elizabeth Reis argue that physicians might be causing iatrogenic harm through certain [genital surgical procedures](#), such as sex assignment for infants born with ambiguous genitalia, male circumcision, and labiaplasty (or labial remodeling). Silvana Barone and Yoram Unguru explore iatrogenesis at the [end of life](#), arguing that prolonging life has iatrogenic effects and that social and cultural factors can inform countries' conceptions of the moral status of euthanasia.

As stewards of our profession and advocates for our patients, we as physicians have an ethical obligation to respond to iatrogenesis. Four articles examine possible ways we can prevent or mitigate these harms caused by medical care within pediatrics. Alberto Dionigi discusses the iatrogenic stress, fear, pain, and anxiety that children can experience in connection with medical interventions and explains how professional [therapeutic clowning](#) can help minimize these harms, improve healing, and provide opportunities for patient empowerment. Nancy Kassam-Adams and Lucas Butler bring our attention to [trauma-informed care](#) as a way to address the iatrogenic effects of pediatric medical traumatic stress, a concept that utilizes knowledge about trauma to influence policy and practice in order to prevent retraumatization. Lauren E. Hock and Niranjan S. Karnik

explore innovative approaches child psychiatrists can use to treat [aggression](#) in at-risk youth that address not only symptoms but also social determinants in order to promote mental health equality. Finally, in this month's podcast, Gigi McMillan and Robert Nelson discuss iatrogenesis in the context of pediatric brain tumor care and [pediatric intensive care](#) practice.

Even with these thoughtful initiatives and increased awareness of the desired goals of treatment, iatrogenesis is inevitable, and pediatricians must also be prepared to address these instances with compassion and resolve. Stowe Locke Teti, Kathleen Ennis-Durstine, and Tomas Jose Silber examine iatrogenesis in pediatrics through two case studies that focus on an [ethical dilemma](#) clinicians might face, namely, to respect parental autonomy by continuing nonadvised treatment or to uphold the patient's best interests by pursuing another course of care.

To be entrusted with the care of children is a privilege granted to all in the field of pediatrics. Modern health care has provided us with many advances in therapies and interventions that have improved the lives of children across the globe. Yet the reality that health care entails iatrogenic risks, preventable errors, and even misguided treatments, remains. As members of the health professions community, we have ethical obligations to educate ourselves about iatrogenesis and respond to it when it occurs. It is my hope that this issue on iatrogenesis in pediatrics will assist in this pursuit.

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ETHICS CASE

Should Long-Term Consequences of NICU Care Be Discussed in Terms of Prognostic Uncertainty or Possible Harm?

Commentary by Genevieve Allen and Naomi Laventhal, MD, MA

Abstract

We will examine several ethical considerations in the resuscitation of infants born at the margin of gestational viability in analyzing a case of preterm labor. More specifically, we will discuss the obligations of physicians in characterizing expected outcomes, both mortality and long-term morbidity, for extremely premature infants and how potential adverse outcomes should be framed—as complications of prematurity itself or as iatrogenic complications of care. We will also explore how the concept of a “trial of therapy” can support parents and neonatologists in decision making concerning withholding or withdrawing care for periviable infants.

Case

Dr. Mattingly met Miriam and Thomas when Miriam arrived a week ago in preterm labor, which was successfully stopped with tocolytics. Suspecting that Miriam would again have preterm labor, that the baby would be born extremely prematurely, needing NICU care to survive, and that the baby’s prognosis might be poor, he has met with the couple over the last few days to determine which NICU interventions they might want.

Miriam and Thomas wanted to know what sort of life their baby would have if they committed to doing everything NICU staff could to help him live. Dr. Mattingly explained that there had been significant advancements in the care of premature infants, but that the future of their child was still uncertain. He discussed various risks premature infants might face including breathing difficulty related to immature lungs, which might necessitate a breathing tube and could result in long-term problems, and injury to the developing brain and eyes that could result in lifelong sensory, cognitive, and motor impairments. He discussed surgery their child might need for his heart, and the risk of intestinal injury and infections while in the NICU. He told the couple that their child might die early or late in his NICU course. “Of course,” Dr. Mattingly had said, “decisions about when and how much to intervene are up to you.” He also explained the option of comfort care, which would focus on keeping the infant comfortable after birth, without attempts at resuscitation; in this case, the focus would not be on survival, but on making sure the time he had would be as peaceful as possible.

Miriam and Thomas wanted more than anything for their child to live and to give their child the best chance possible, but they also wanted his life, however long or short, to be a happy one. They also wondered how having a child with severe disabilities would affect their four other children. They felt they could not truly grasp what awaited their child in terms of potential complications or disabilities, should they opt for full resuscitation. "Dr. Mattingly," Thomas began, "You see the sorts of futures these children have and the joy and pain the parents go through in either option. What would you counsel us to do?"

Commentary

Miriam and Thomas are in a difficult position. In a matter of hours, they must reconcile their values, their hopes for their child, and Dr. Mattingly's recommendations to decide on a course of action. As busy parents, in addition to considering what is best for their son, they are also evaluating how having a child born at the margin of gestational viability will affect their lives. They might wonder how they will be able to afford the care he could require. They might want to know how this will affect their careers or whether they will even be able to continue working. In addition to finances and their family dynamics, Miriam and Thomas worry about the suffering their son could experience. If they pursue resuscitation, is the chance of survival worth the potential immediate and long-term complications and disability he could suffer? What *is* the chance of survival? If he survives, what might his quality of life be like? Will he be able to go to school, get a job, be happy? In an ideal [shared decision-making](#) scenario, Dr. Mattingly and his team would help Miriam and Thomas assess their values, family circumstances, and medical information to determine whether resuscitation is in the best interest of their child.

Limited Epidemiologic Data Means Limited Prognostic Capacity

Right now, Miriam and Thomas have a lot of questions, but in order to make a decision, they need more information. Dr. Mattingly must present expected outcomes in relation to both mortality and long-term morbidity for an extremely premature infant to honor the autonomy of the parents who must receive enough information to make an informed decision. But which data should he use? Like most parents in this type of situation, Thomas and Miriam want information about the potential outcomes for their child, not the statistical outcomes at a population level [1]. Population-based data are not intended to predict a specific outcome for an individual patient; at best what can be said is something like, "Among a large group of babies more or less like yours, these were their outcomes."

It can be intellectually difficult to understand and apply epidemiologic outcomes to high-stakes decision making for one's own child. Even for those who find value in population-based outcomes, which cohort is used for counseling determines the outcomes used as a basis of comparison, as well as how they are interpreted. In a large study of extremely preterm infants, Rysavy et al. found that among the most premature infants (those born

at 22 and 23 weeks), roughly three-quarters of the variation in survival and in survival without severe impairment were accounted for by differences in rates of resuscitation at birth at different hospitals; the impact of between-hospital variation was diminished by 24 weeks and no longer relevant by 25 weeks of gestation [2]. If Miriam and Thomas's hospital does not routinely offer resuscitation at a given gestational age, an infant born there is dramatically less likely to survive than if he is born at a hospital that more routinely resuscitates infants at that gestational age. That information, in and of itself, however, does not mean that Miriam and Thomas's child will not survive if resuscitated—individual characteristics beyond his gestational age and hospital outcomes will contribute to his likelihood of survival.

To aid in counseling, it is necessary to consider additional factors beyond gestational age, as gestational age alone is an unreliable factor in [predicting long-term outcomes](#) [3–5]. Online, user-friendly, population-based outcome prediction tools exist. For example, the National Institute of Child Health and Human Development (NICHD) Neonatal Research Network “calculator” uses three patient characteristics—gender, administration of maternal steroids, and multiplicity [6]—that are often known before birth to produce the estimated survival outcome for an infant with a given profile. These tools are widely used by neonatologists despite uncertainty about their usefulness and impact [7]. In addition to the NICHD, other research and quality improvement groups have developed algorithms to predict morbidity and mortality that take into account a wide range of variables [8, 9]. These variables include gender, gestation size, gestational age, surfactant administration, mechanical ventilation, and parental education level, among others. While more helpful than gestational age alone, these algorithms also rely on population-level data and variables that might be unknown while the infant is still in utero.

Advantages of Clinical Course Data

At each stage beyond delivery, more child-specific information is available, allowing physicians to move from predictions based on population-level statistics to predictions based on the clinical course of the child [1]. Resuscitating infants in the delivery room and pursuing a trial of therapy in the NICU open up multiple opportunities to reevaluate whether the burdens of invasive and potentially painful treatment outweigh the potential benefits to the child [10]. If the burdens of care appear to be greater than the benefits of aggressive NICU care, redirection of the goals of care towards palliative aims is an option. Because postnatal predictions of death and impaired survival based on factors such as illness severity, diagnostic tests (e.g., cranial ultrasounds), outcome-prediction calculators, and even clinicians' predictions of outcomes are inexact, by pursuing a trial of therapy in the NICU for their child, Thomas and Miriam will be able to make a more informed decision about whether to pursue aggressive care or to transition their child to palliative care based on the clinical course that develops over days or weeks. Although a trial of therapy opens up more decision points and more clinical data,

it is not the right course of action for all parents. A trial of therapy supports parents for whom not pursuing a chance for their child's survival is untenable. A trial of therapy in the NICU, however, might not support parents for whom their child's suffering without guaranteed survival would be an unacceptable option.

Another important implication of a decision to initiate resuscitative efforts after birth is that the resuscitation might not be successful and that the infant will be denied a peaceful death in the arms of his or her parents. Although anticipatory guidance regarding this possibility is crucial to thorough prenatal consultation, those concerned about a "bad death" following aggressive but unsuccessful resuscitation might be assuaged by two considerations. The first is that, although long term survival is by no means guaranteed, in most cases, neonatologists are able to provide at least a short period of stabilization, allowing time for parents to meet the baby and participate in ongoing decision making [11]. Second, if viewed as part of the continuum of NICU care that follows a decision to initiate intensive care after birth, early and compassionate recognition of medical futility can be integrated throughout the infant's NICU course.

Risks Associated with Extremely Preterm Births and Resuscitation

While the initial question for most parents, including Miriam and Thomas, is, "Will my baby survive?," physicians must also counsel parents on the potential complications that can arise from resuscitating extremely premature infants. Dr. Mattingly must convey the benefits as well as the short- and long-term burdens of aggressive treatment in the delivery room and, later, in the NICU. For these extremely premature infants, it is impossible to separate complications arising from the interventions from complications of prematurity. For the most extremely premature infants, without interventions, the chance of survival is negligible [3]. Babies, such as Miriam and Thomas's, born at 23 weeks and 3 days, will need invasive respiratory support to survive, such as mechanical ventilation with provision of surfactant [12]. They will also need IV access to deliver glucose, medications, and parenteral nutrition and to draw labs [12]. These life-supporting interventions, however, are not without risk.

In thinking about potential harms of neonatal resuscitation after extremely preterm birth, it is helpful to distinguish between risks and immediate implications of the resuscitation itself, on the one hand, and the long-term implications of the decision to initiate intensive care after birth, on the other. There are specific and known complications of the procedures that are performed during a resuscitation event. Manual mechanical ventilation can result in pneumothorax, which can be a fatal event, or necessitate additional procedures such as chest tube placement [13, 14]. Endotracheal intubation might result in injury to the vocal cords or trachea [15], which again can be lethal or negatively impact quality of life for survivors. Mechanical complications of cannulation of peripheral or central arteries and veins might also occur [16]. Protracted and aggressive resuscitation can include chest compressions which can cause bruising to

the skin, although chest compressions are rare when contemporary resuscitation algorithms are followed [11]. All of these procedures of course have the potential to be painful to the infant [17]. Exploration of these risks in the larger context of a NICU hospitalization for an extremely preterm infant is a daunting but necessary task in antenatal consultation. Moreover, further complications of interventions and extended NICU stays are possible after initial resuscitation at delivery. Mechanical ventilation can increase the risk for intraventricular hemorrhage and bronchopulmonary dysplasia, which is associated with poor neurodevelopmental outcomes [18, 19]. Hyperoxia from supplemental oxygen has been attributed to inhibition of angiogenesis, leading to retinopathy of prematurity, a common cause of blindness in premature infants [20, 21]. Extended stays in the NICU with central lines and IVs put infants with already vulnerable immune systems at risk for sepsis [22]. Kidney and liver injury can result from nonsteroidal anti-inflammatory drugs (NSAIDs), antibiotics, and total parenteral nutrition (TPN) [23, 24]. Cholestasis, osteopenia of prematurity, and vascular thrombosis from the central line can result from a prolonged requirement for TPN [24, 25]. As these complications can be attributable to interventions that are part of the current standard of care for resuscitated infants born at the margin of viability, they can be considered iatrogenic complications, that is, complications of the interventions themselves.

If parents decide to pursue resuscitation, the interventions are not elective in the sense that they are essential for survival. Although parents might be asked to provide individual informed consent for discreet procedures, consent for admission to and care in the NICU is general and implicitly includes provision of numerous routine interventions. As there are advances in the care of infants born at the margin of viability, currently unavoidable consequences of care will hopefully become preventable. Some recent and proposed advances include less invasive methods for delivering surfactant, better ways to identify infants that need continuous positive airway pressure (CPAP) alone rather than mechanical ventilation, shorter NICU stays, fewer central line days, and newer TPN lipid preparations that reverse cholestasis, among others [19, 25, 26].

Shared Decision Making in the Perinatal Period

Dr. Mattingly and the medical team's position is more difficult than solely presenting research data to Miriam and Thomas. They must also be conscious of how they deliver the information about potential risks and benefits. Physicians can unwittingly influence parental decisions by how they frame information. For example, survey respondents were more likely to elect resuscitation when a hypothetical prognosis was presented positively (i.e., survival without disability) than negatively (i.e., probability of death and disability) [27]. It is important for Dr. Mattingly to present information in terms of both mortality and survival to Miriam and Thomas so his own bias toward either optimism or pessimism does not unduly influence their parental decision making. Many people also struggle with interpreting statistics. Checking for comprehension, using visual aids, and tailoring presentations to parents' learning styles are also vital components of delivering

effective counseling [28], which would enable Miriam and Thomas to make informed decisions.

Coordinated consultation of specialized obstetric and pediatric care clinicians can be supportive to parents facing possible or likely preterm delivery. High-risk obstetricians (maternal-fetal medicine specialists) can provide information and anticipatory guidance and support decision making for families facing premature birth. Joint consultations with obstetricians and neonatologists can help reduce redundancy of and inconsistencies in information that can occur in independent counseling [29]. The authors know of some institutions in which prenatal palliative care consultation is routine or even required at the earliest gestational ages. The training and experience required for neonatologists to provide compassionate, effective, and nonbiased prenatal consultation is an area of current investigation [30-32].

After receiving all this information on risks, possible outcomes, and complications, the question for Miriam and Thomas now is this: Do they want to pursue a trial of therapy in the NICU or palliative care for their child? As described in the vignette, Miriam and Thomas do not know what course is in the best interest of their child and are asking Dr. Mattingly to integrate his knowledge of their [values](#) with his clinical experience to make a recommendation for the care of their child. How should he respond? If he encourages shared decision making, Dr. Mattingly can integrate his medical knowledge with Miriam and Thomas's values to propose a course of treatment. However, Miriam and Thomas have asked his advice, and directed counseling, when solicited, is not paternalistic and provides an opportunity to lessen parents' emotional burden. For example, Miriam and Thomas might be less willing to elect palliative care or to withdraw care once initiated as it might feel like they are "giving up." At the point at which the burden of treatment is felt to outweigh the potential benefit, directive counseling and a clear recommendation of a transition to [comfort care](#) by the neonatologist could relieve both the emotional suffering of parents struggling with the burden of the decision and the physical suffering of the infant by facilitating prioritization of palliative, comfort-directed interventions.

In addition to discussing with Dr. Mattingly survival outcomes and potential complications their son might suffer, Thomas and Miriam might be thinking about and discussing how the decision to pursue aggressive care or palliative care would affect their family, such as who would take care of the children while they were at the hospital and what they would do if one or both of them needed to take extended leaves from work; they might ask Dr. Mattingly to help them work through these considerations. This approach only works, however, if Dr. Mattingly and the health care team have a good understanding of Miriam and Thomas's values, concerns, and circumstances—such as their financial status, their careers, their religious beliefs, and the fact that they have four other children.

Conclusion

Miriam and Thomas must reconcile their values, their family circumstances, and the medical information they receive from Dr. Mattingly to determine if resuscitation is in the best interest of their child. Before birth they have access to population-level risk or outcomes data predominantly based on gestational age. By initiating a trial of therapy in the NICU, Dr. Mattingly can combine child-specific clinical course data with population-level data to improve the diagnostic accuracy and prediction of the child's chances of survival and disability. A trial of therapy, however, is not without risks and potential complications and is not right for every family. Dr. Mattingly's role is to ensure that Miriam and Thomas have the information they need to make an informed decision and to provide guidance, when asked, based on an understanding of the family's values and circumstances and his medical knowledge.

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ETHICS CASE

Should Clinicians Medicate against Structural Violence? Potential Iatrogenic Risks and the Need for Social Interventions

Commentary by Lauren E. Hock, MD, and Niranjan S. Karnik, MD, PhD

Abstract

This paper examines how a child psychiatrist might approach treatment of aggression in foster care youth. We argue that a multimodal approach is best. Physicians should weigh not only the iatrogenic risks of off-label antipsychotic medications but also the possible consequences of failing to treat complicating social factors at hand. Advocates must address structural violence and failures of imagination in their efforts to improve mental health equity among vulnerable youth.

Case

Jordan threw himself down on Dr. Eitel's couch. He stared into the distance with a scowl on his face. Anger and frustration emanated from him—he was in no mood to talk. Jordan had once again gotten into a fight at school resulting in a five-day expulsion. Although the police had been called, thanks to the school's misconduct policy, an official arrest had not been made with the understanding that the school would handle the situation. Nevertheless, this was no victory for Jordan. "He knew exactly how to piss me off!" Jordan yelled at Dr. Eitel, "He did it on purpose. He was *trying* to push me over the edge because he knew this was my last shot!" A string of muttered expletives followed. The principal had warned him that one more misdemeanor would meet criteria for permanent expulsion from the school. Following his five-day expulsion, Jordan would have to attend a committee meeting to determine whether he would be allowed to remain at St. Joseph's Academy. Dr. Eitel felt bad for Jordan—she knew that he had been trying hard to stay out of trouble. He was making an effort, but it just was not good enough. Jordan's demeanor changed to one of resignation and defeat. "Whatever, I heard the alternative school makes you wear jumpsuits. It'd be nice, like wearing pajamas all day," he joked.

Jordan had not been dealt an easy hand in life. At the age of eight he had been placed in the foster care system and was presently in his third foster home. His current foster family seemed to take a greater interest in Jordan than his prior placements, but Dr. Eitel could sense that even their patience was running thin. They had worked hard to get Jordan placed in this school and Jordan knew that his poor behavior had disappointed them.

Jordan was now a junior in high school, and his more recent activity worried Dr. Eitel and his foster parents. His violent actions were escalating, and the possibility of his being incarcerated seemed increasingly likely. He would soon be considered an adult by the state and his behavior would have a permanent impact on his future.

Dr. Eitel shared Jordan's frustration. She was tired of the failing systems that let kids like Jordan down, and she wondered if there was a way to help "level the playing field" for him via an "off-label" prescription for the antipsychotic risperidone. In Dr. Eitel's professional opinion, Jordan did not meet standard criteria for psychosis, yet she wondered if placing him on an antipsychotic such as risperidone could help him control his outbursts and keep him out of the penal system, possibly even affording him opportunities in the future. However, she was also aware of the substantial side-effect profile of risperidone and other atypical antipsychotics. These drugs were known to increase young patients' risk for weight gain and metabolic syndrome, which could predispose them to developing chronic illnesses such as type 2 diabetes and cardiovascular disease. Dr. Eitel wasn't sure which was worse for Jordan: possibly living out the rest of his days behind bars or, assuming risperidone would be helpful for him, living with its iatrogenic consequences. "Maybe there's still something I can do for this kid," she thought as she considered her blank prescription pad.

Commentary

In this case, we have an adolescent boy with behavioral problems who has lived in three different foster homes since the age of eight. Who ends up in foster care? In general, children are removed from the family home due to threats to their safety, including physical or sexual abuse, inadequate housing, parental substance abuse, or neglect [1]. These children are exposed to chronic, heightened stress levels that place them at high risk for mental and behavioral health problems [2]. In Illinois, where these authors reside, over half of school-age foster children were reported to have a mental illness or behavioral problem that made fostering them "very challenging" [3]. Given the high risk of mental health issues among foster youth, the American Academy of Pediatrics (AAP) recommends a formal mental health assessment of all children at entry into foster care and periodically thereafter [4]. The most common mental health diagnoses for children in foster care are attention-deficit/hyperactivity disorder (ADHD), oppositional defiant disorder, and [conduct disorder](#) [2, 5]. Nonexternalizing disorders, including anxiety disorders, eating disorders, and mood disorders, are also common [2].

Not only are children in foster care more likely to be diagnosed with mental illness than their peers without a history of foster care [2], they are also more likely to be treated pharmacologically. Foster care youth covered by Medicaid receive psychotropic medications at more than three times the rate of nonfoster care Medicaid youth [6]. Moreover, atypical antipsychotics like risperidone are disproportionately prescribed to

males, youth in foster care, and those covered by Medicaid [7]. But how is risperidone used? And what reservations, if any, should Dr. Eitel have about prescribing it to Jordan?

Here we discuss common concerns regarding risperidone use in children, especially as it pertains to increasing rates of off-label treatment of aggression. We consider the ethical implications of using medication to mitigate social risks, with a focus on justice and structural violence as they pertain to mental health care within the foster care system. Finally, we propose a multimodal treatment strategy that incorporates psychotherapy, mentorship, and advocacy in possible combination with pharmacotherapy.

Risperidone Use in Children

Approved by the United States Food and Drug Administration (FDA) in 2006 for treatment of irritability in autistic children [8], risperidone has been used off label with increasing frequency to help manage childhood aggression [9], because it is believed to target the impulsivity inherent in reactive aggression [10]. In children with ADHD and oppositional defiant disorder or conduct disorder who exhibit severe physical aggression, risperidone added to stimulant and behavioral therapy has been shown to significantly improve impulsive behaviors [11]. It has also been shown to have significant benefit in reducing aggression among children with disruptive behavior disorders [12]. Although we aren't given psychiatric diagnoses for Jordan, his record of physical violence in response to threats from peers suggests impulsive behavior with real social consequences. In the context of this case, it seems reasonable to consider augmenting Jordan's current treatment with risperidone.

High rates of off-label atypical, or second-generation, antipsychotic (SGA) use nationwide [9] indicate that Dr. Eitel is not alone in augmenting therapy. However, off-label SGA practice patterns have triggered controversy. A 2011 US Health and Human Services Inspector General review [13] of 687 Medicaid payment claims for SGAs cited quality-of-care concerns in 67 percent of claims. A small proportion of all claims (7 percent) cited the iatrogenic side effects that Dr. Eitel considers, such as increased risk for metabolic syndrome. However, far more common were concerns regarding poor monitoring (53 percent), wrong treatment (41 percent), and drugs being taken too long (34 percent) [13]. This report suggests that psychiatrists are initiating SGA treatment in children but that many of these children are not being followed appropriately. Given Jordan's history of placement instability, these challenges are perhaps unsurprising.

In addition to being concerned about risperidone's side effects and monitoring, we should also question Dr. Eitel's assumption that risperidone alone could help mitigate Jordan's risk of social marginalization. We know that children in the foster care system, like Jordan, face a high risk of negative outcomes like homelessness, incarceration, and dropping out of high school [14, 15]. The social pressures on Jordan will continue to increase as he "ages out" of the child welfare system into independent adult living in a

few years. While risperidone treatment may reduce Jordan's impulsivity short term, an SGA alone is unlikely to aid him in improving the prosocial skills he needs to thrive as an adult. Therefore, in the absence of an ongoing active treatment plan, risperidone use to mitigate risk of future criminality seems doomed to fail and not without iatrogenic consequences.

Therapeutic Considerations

Jordan's case illustrates two key social justice concepts that we borrow from medical anthropology: *structural violence* and *failure of imagination*. Structural violence describes the economic, political, legal, religious, and cultural structures that impair individuals, groups, and societies from reaching their full potential [16]. Applied to foster care, it implicates the larger forces of poverty, gender inequality, and racism that likely contributed to Jordan being removed from his birth home. The concept also allows us to evaluate foster care's "failing systems" in a broader context. In the justice literature, the "fair opportunity" rule suggests that we should evaluate the justice of social institutions, including the foster care system, by their efficacy in counteracting people's lack of opportunity caused by unpredictable misfortune over which they have no meaningful control [17]. By applying this rule, it can be seen that the foster care system is unjust to demand more (e.g., self-discipline in the home) of the estimated 427,910 children living in it [18] to whom society has given less (e.g., family stability, economic resources, mentoring relationships). It is even possible that the foster care system fails to counteract lack of opportunity and instead exacerbates the problem with the structures it has created.

If structural violence perpetuates social injustice, then our failure of imagination as clinicians and students is what self-limits our efforts to improve health equity. Failure of imagination includes failure to consider solutions outside the realm of what is considered realistic, "sustainable," or "cost effective" [19]. Instead, we focus on small-scale interventions like pharmacotherapy that risk iatrogenic consequences without correcting the culpable forces at play. Dr. Eitel, perhaps like many clinicians, feels frustrated and trapped in her consideration of two possible maleficent outcomes: incarceration and increased social marginalization versus iatrogenic harm to a child. The paths to helping Jordan manage his aggressive behavior in the context of structural violence, however, are far from binary.

We favor a multimodal treatment approach that addresses some of the social injustices Jordan has experienced and that offers opportunities to correct his maladaptive behavior in a supportive environment. Like children born into stable families that attend well-resourced schools, Jordan deserves an effective trial of individual evidence-based [therapy](#) focused on reducing impulsivity, anxiety, and reactivity in possible conjunction with pharmacotherapy. Risperidone might increase his response latency to stressful triggers, but psychotherapy could help identify why he is reacting maladaptively

to teasing at school and help him avoid future altercations that could jeopardize his future. Given the strong support of his current foster family, another option might be multisystemic treatment (MST), which includes high-intensity case management and specially trained therapists who would follow Jordan's current family. These therapists emphasize empowerment and work to draw on collateral support from community and friends [20].

Strategies for addressing Jordan's behavior in the context of structural violence aren't limited to therapy and possible medication, however. A fair and, perhaps, more imaginative approach might attempt to counteract Jordan's behavioral issues by placing him in a stable, supportive community with opportunities for longitudinal relationships with foster family members, teachers, friends, social workers, and physicians. Fortunately, models for this approach already exist.

Hope Meadows is the first of at least five operational "intentional intergenerational neighborhoods" designed to promote sustained, caring relationships between members of vulnerable populations [21]. Established in Rantoul, Illinois, in 1994, it places new adoptive families of foster children alongside older adults [22-24] who receive a discount in rent in exchange for supporting the families with volunteer activities [25]. Hope Meadows reframes some of the stigma against foster children and the elderly through emphasis on multigenerational neighboring relationships. Children like Jordan who may have experienced multiple foster placement changes suddenly have the opportunity to develop long-term mentoring relationships in close geographic proximity. Structured community-based mentoring programs have been shown to reduce symptoms of trauma, anxiety, and depression and to promote prosocial behaviors among foster children [26, 27]. At Hope Meadows, foster children can learn prosocial behaviors in a more equitable, purposefully structured community that will help them better handle life's challenges as adults.

We recognize that the impact of intentional neighboring communities is limited to a small minority of children lucky to be adopted out of the foster care system [28]. However, the allying of groups traditionally victim to structural violence in a community redesigned to their mutual benefit should inspire us to imagine more just approaches to social inequalities. Meaningful institutional change requires advocacy and political engagement from individuals like Dr. Eitel who directly encounter the effects of structural violence but are more empowered to make their voices heard. This engagement could include serving on the board of a mentoring program for foster youth or lobbying for state support of evidence-based psychosocial interventions targeting foster youth as an alternative to psychotropic medications [29, 30]. In the meantime, we suggest that Dr. Eitel use a combination of interventions that have the highest efficacy and lowest risks. In most circumstances, this would tend to favor psychotherapy along with or in combination with medications.

There are various ethical issues in Jordan's case that have been discussed by other authors. These include ethical concerns regarding prescribing off label [31], such as informed consent [32] and coping with a child's conduct disorder [33].

Conclusion

We argue that leveling the playing field for Jordan and other foster children requires going far beyond modest reductions in impulsive behavior with psychotropic medications. Jordan deserves a multimodal treatment approach that provides stability, psychosocial support, and opportunities to remodel his aggressive behavior through long-term mentoring relationships. Foster care children need both advocates like Dr. Eitel to fight for more equitable mental health care and imaginative stakeholders to help reshape the institutional forces stacked against them and their success as adults.

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ETHICS CASE

How Should Physicians Help Gender-Transitioning Adolescents Consider Potential Iatrogenic Harms of Hormone Therapy?

Commentary by Thomas D. Steensma, PhD, S. Annelijn Wensing-Kruger, MSc, and Daniel T. Klink, MD, PhD

Abstract

Counseling and treatment of transgender youth can be challenging for mental health practitioners, as increased availability of gender-affirming treatments in recent years raises ethical and clinical questions. Is a gender identity diagnosis helpful? What is the right time to treat, and should the adolescent's age matter in decision making? In this article, we discuss these questions in light of a case in which an adolescent wishes to pursue hormone therapy. Our analysis focuses on the importance of balanced decision making when counseling and treating adolescents with nonconforming gender identities. We argue that clinicians' communicating appropriate expectations about the effectiveness and limitations of hormone therapy and the risks of psychological and physical iatrogenic effects is critical.

Case

Dr. Giles first met Jackie about a month ago when her father, Mr. Jensen, brought her to his endocrine clinic. Jackie was 12 and just starting to hit puberty, but she resented the changes that were happening to her body. She had lived the last year as "Jack," wearing "boy" clothes and keeping her hair short. "Jackie has shown tendencies toward traditionally male interests since childhood," her father explained. "She would take on male roles when playing make-believe and would prefer playing with the boys in her class."

As Jackie grew, however, she was not satisfied with being a girl who did "boy" things anymore. "I want to be a boy," she told her parents. The Jensens did not want their child to have to play make-believe for the rest of her life. They had heard about transgender children before, and after reading more about the subject, they came to believe that their daughter was transgender. When Jackie began going through puberty, things got difficult. The victim of bullying, she suffered emotionally. Her usual bright personality became subdued, and she struggled in school. Worried, the Jensens took Jackie to a therapist, but it didn't seem to help. A psychiatrist diagnosed Jackie with gender

dysphoria (GD), characterized by distress about the mismatch between gender identity and biological sex. As things escalated, they decided to seek out a more permanent solution, which brought them to Dr. Giles's door.

"We are interested in hormone therapy to prevent puberty and help Jackie look more like a boy," they explained, pamphlet in hand. Dr. Giles was apprehensive about starting hormone therapy in someone so young. He was aware that many children with GD outgrow the condition; additionally, he took issue with the classification of GD in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders*. He worried that framing nonconforming gender identity experiences as a pathology contributed to the psychological distress many transgender people feel and influenced their desire for gender-affirming therapy.

He also worried about long-term risks and side effects that come with hormone therapy and whether Jackie could understand at her age how these consequences would affect her over time. Jackie would most likely undergo puberty suppression, giving her more time to explore her feelings regarding her gender. Dr. Giles was concerned that this therapy could stunt her growth and lead to weight gain and fertility issues and could also cause her to experience menopause-type symptoms and possibly depression. If Jackie underwent androgen therapy for gender transition, she could even be at risk for developing insulin sensitivity, hyperlipidemia, and an increased hematocrit, compromising her metabolic health.

On the other hand, according to Jackie and her family, not going through with the treatment could cause Jackie significant psychological harm. Dr. Giles was now faced with the difficult decision of determining whether Jackie's experience of gender identity-related suffering justified accepting the iatrogenic risks associated with treating it.

Commentary

The problems experienced by Jack and the considerations with which Dr. Giles is confronted are a representative reflection of the challenges in transgender care. Growing up with gender dysphoria (GD) can be problematic for several reasons for the transgender teen. In puberty, the development of the body in an undesired direction is generally distressful. Being a victim of bullying and stigmatization as a consequence of rigid and stereotyped gender norms can have a strong negative effect on the psychological health and quality of life of an adolescent with GD [1]. And, in addition, interventions that can be provided by a (mental) health professional to reduce GD (e.g., hormone therapy) are generally efficient but may have iatrogenic side effects. Decisions about the diagnosis and gender-affirming treatment of gender nonconforming youth should therefore always involve weighing the potential benefits and harms for a given individual in a given situation, society, or culture. In light of the available guidelines and the scientific literature, we will discuss three important issues that are closely related to

those that Dr. Giles is confronted with: whether a diagnosis is helpful, how to determine whether hormone therapy should be offered, and whether and how the adolescent's age should matter in decisions about how to treat gender identity problems.

To Diagnose or Not to Diagnose?

In the two most widely used classification systems of (mental) diseases—the *International Statistical Classification of Diseases and Related Health Problems (ICD)* and the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*—a separate gender identity diagnosis was not described until the publication of *ICD-9* in 1975 and *DSM-III* in 1980 [2]. In the *DSM*, transsexualism was later changed to “gender identity disorder” (*DSM-IV*) and “gender dysphoria” (*DSM-5*) [2]. In the process of revising the *DSM-IV* (now the *DSM-5*) [3, 4] and in updating the *ICD-10* (into the *ICD-11*), the gender identity diagnoses generated several controversies, including the discussion of the need for a diagnosis per se [5, 6]. A central topic in these discussions is that diagnosing people as having a mental disorder can be pathologizing and stigmatizing [7, 8]. At the same time, having a diagnosis is, in many health care systems around the world, a requirement to access care, including gender-affirming medical treatment [9]. The possible stigmatizing and pathologizing effects of a gender identity-related diagnosis (e.g., increased chance of discrimination, social exclusion) should thereby be weighed against the drawbacks of *not* diagnosing with regard to the inability to receive specialized and possibly reimbursed care, support and advice, and legal protection or a protected status. It is thereby advisable that this harm-benefit analysis not be an individual undertaking by the (mental) health practitioner but rather be a joint process wherein clients (and in the case of minors, their families) are involved. In addition, it is important to keep in mind that the outcome of this analysis can vary widely among different individuals.

To Treat or Not to Treat?

A central question in the counseling of children and adolescents with GD is: What is the right time to treat?

Prepubertal children. With regard to prepubertal children, the *Standards of Care (SOC)* of the World Professional Association for Transgender Health is clear in that no medical interventions should be provided before the onset of puberty [10]. The primary reason for this recommendation is that GD in childhood does not always persist into adolescence or adulthood. A review focusing on the development of children with GD showed that the gender nonconforming children in the studies were likely to identify as lesbian, gay, or bisexual adolescents or adults at the time of follow-up and that the GD had remitted around or after puberty for the majority of the children (85.2 percent) [11]. In addition, the ability to predict whether gender nonconformity in a child will persist or desist in the future is limited [12-15]. Therefore, it is generally seen as strongly inadvisable to intervene medically in this period [11].

In consequence, the role of a mental health professional should be supportive and focused on helping the child and the parents to deal with the uncertainty of a future outcome (i.e., whether the GD will persist or not) and possible gender-related problems (e.g., stigma) or nongender-related problems (e.g., coexisting depression or anxiety) and on exploring the child's feelings as he or she continues to develop. For most adolescents with GD, the experience of their body's development in puberty, their changing social position, and their first explorations of love and sexuality provide valuable information about their feelings of GD, leading to the intensification of GD in some and the remittance of GD in others [16].

Adolescence. In the event that GD persists into adolescence, medical interventions (i.e., hormone therapy) are a realistic option for treatment. However, whether to introduce hormone therapy is not a one-time decision after a diagnosis of GD but rather a gradual decision process within a multidisciplinary stepwise treatment approach. The approach is multidisciplinary in the sense that the mental health professionals (e.g., psychologist, psychiatrist) and medical health professionals (e.g., pediatric endocrinologist, pediatrician) work closely together in counseling the client; stepwise treatment always first starts with a psychological assessment without medical interventions, after which fully reversible interventions (i.e., puberty suppression) may be provided, followed by partially reversible interventions (i.e., cross-sex hormones) and irreversible interventions (i.e., gender-affirming surgery) [17].

In the first (psychological) diagnostic phase, the nature and characteristics of the adolescent's gender identity and psychosocial functioning are explored. Treatment to suppress puberty can be initiated if: (1) the criteria for a GD diagnosis are met; (2) puberty has started (Tanner stage 2-3); (3) the adolescent has demonstrated long-lasting and intense GD; (4) the GD feelings intensified with the onset of puberty; (5) coexisting medical, psychological, or social problems have been addressed; and (6) both the adolescent and parents have consented (if the adolescent has not reached the age of medical consent) [10]. [Puberty suppression](#) using gonadotropin-releasing hormone analogues (GnRHa) prevents the development of undesired secondary sex characteristics (i.e., feminization in birth-assigned girls and masculinization in birth-assigned boys), allowing adolescents to further explore their GD without the distress of a further-developing body and possibly preventing "risky" (unnecessary) surgical interventions when the patient reaches the age of medical consent [18].

Before this extended diagnostic phase with the use of puberty suppression is started, it is of great importance that both the mental and medical health professional communicate appropriate expectations about the effectiveness and limitations of hormone therapy and the risks of psychological and physical iatrogenic effects of hormone therapy as well as possible future gender-affirming interventions [19]. Although puberty suppression has a positive effect on psychological functioning for

many adolescents [20] and is fully reversible (since puberty reinitiates when treatment is stopped), and although adverse events have not been reported in evaluation studies [21-23], iatrogenic risks have to be taken into account. It has been shown that GnRHa treatment influences bone mass development in delaying peak bone mass accrual [23] and that it may cause hypertension (especially in birth-assigned girls) [24]. Adolescents are therefore advised to maintain a healthy lifestyle through appropriate weight maintenance, sufficient weight-bearing exercise, and adequate calcium and vitamin D intake [25]. In addition, from our clinical experience, most adolescents and parents experience puberty suppression as the first step in gender transitioning. It is therefore important to discuss the iatrogenic risks of possible future gender-affirming treatments (e.g., cross-sex hormones and gender-affirming surgeries), although it may be several years before the adolescent is eligible for such treatments. Such discussions might, for instance, include informing patients about genital sensitivity after genital surgery and about the possibility (in case of hormonal therapy) or certainty (in case of removal of the uterus and ovaries) of fertility loss [26].

Whether certain treatment interventions are offered to adolescents with GD is not the mental health professional's decision of what is in the best interest of the adolescents but rather a decision in which the adolescents are involved [10]. The role of the (mental) health professional is thereby to evaluate whether an adolescent fulfills the criteria for treatment according to the *SOC* [10] and inform the patient (and parents) about treatment effectiveness and safety, taking into account the degree of the individual adolescent's psychosocial functioning and social support. The adolescent (and parents) may then decide, based on the provided information about a treatment's potential risks and limitations, whether to start with a certain treatment or not.

What about Age?

After the introduction of puberty-suppressing treatment for adolescents with GD in 2000 in the Netherlands [27], the availability of the treatment has gradually increased, and it is now offered in several parts of the world [21, 28, 29]. In contrast to the early days, treatment procedures nowadays generally do not use age as a criterion to intervene with puberty suppression or to start hormone therapy [28, 30]. The current *SOC* guidelines do not set strict age criteria for the start of either intervention [10]. This is somewhat remarkable since the only scientific evidence of the psychological efficacy [20, 31] and medical efficacy and safety [21-24, 32] of the treatment is based on the "Dutch protocol" as it was introduced. At that time, the protocol set strict minimum age criteria for starting puberty suppression (12 years of age), cross-sex hormone treatment (16 years of age), and gender-affirming surgeries (18 years of age) [33].

Although the evaluation of the different treatment protocols contributes to knowledge of the safety of using puberty suppression and hormone therapy in transgender youth, from a clinical perspective, it seems reasonable that the age of adolescents with GD

should not be the primary focus. The decision of whether puberty suppression or hormone therapy is offered should be based on not only the aforementioned criteria of bodily development, degree of GD, and psychological suffering and stability but also the degree to which the adolescent is able to oversee the consequences of certain treatments and make a [well-informed decision](#). The extent of the adolescent's "psychological maturation," although often a natural derivative of age, may well differ among adolescents. Therefore, "psychological maturation" seems to be a more valid criterion for transgender youths' eligibility for treatment than a strict age criterion.

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THE CODE SAYS

The AMA *Code of Medical Ethics'* Opinions Related to Iatrogenesis in Pediatrics

Filzah Iqbal, MSc

It is well-established that iatrogenesis, particularly due to errors, is associated with increased patient morbidity and mortality [1, 2]. Although any patient can experience an iatrogenic outcome, pediatric patients are the most vulnerable to life-threatening complications [3]. The *Code of Medical Ethics* does not have any opinions that address iatrogenesis in pediatrics specifically, but it does offer guidance on pediatric decision making, preventing error and harm, and disclosing errors.

Pediatric Decision Making

Opinion 2.2.1, "Pediatric Decision Making" [4], recognizes the complexity of how decisions are made for pediatric patients. Because minor patients (with some exceptions) are not legally permitted to make health care decisions on their own [5], physicians must work with a child's parents or guardians, whose consent is required, to make decisions. Both physicians and parents or guardians have fiduciary duties to promote a child's health-related interests, but the opinion recognizes that the two parties' duties can conflict.

Decisions for pediatric patients should be based on the child's best interest, which is determined by weighing many factors, including effectiveness of appropriate medical therapies and the needs and interests of the patient and the family as the source of support and care for the patient. When there is legitimate inability to reach consensus about what is in the best interest of the child, the wishes of the parents/guardian should generally receive preference [6].

Although minor patients are not fully autonomous in making medical decisions, physicians still should promote the child's developing autonomy and engage them in decision making at a developmentally appropriate level. Opinion 2.2.2, "Confidential Health Care for Minors" [7], notes that a [minor's decision-making capacity](#) depends on factors including, but not limited to, chronological age, emotional maturity, and medical experience. The opinion also calls on physicians to protect the confidentiality of minor patients except when doing so would violate the law, threaten the patient's life or health, or cause serious harm to others.

Preventing Error and Harm

Opinion 1.1.6, “Quality” [8], which explains that physicians are obligated to ensure that the care their patients receive is safe, effective, patient centered, timely, efficient, and equitable, is particularly relevant for pediatric patients. Children—especially neonates in the NICU—are at greater risk of potential adverse drug events than are adult patients [9]. While it’s important to note that not all adverse events are the result of errors, *Code* guidance on [preventing medical errors](#) can also be applied to adverse events; Opinion 8.6, “Promoting Patient Safety,” states that it is important that physicians “play a central role in identifying, reducing, and preventing medical errors” [10]. Examples of opinions in the *Code* that address the prevention of medical errors include Opinion 8.11, “Health Promotion and Preventive Care” [11], which explains that physicians should “keep current with preventive care guidelines ... and ensure that the interventions they recommend are well supported by the best available evidence,” and Opinion 1.1.6, “Quality,” which states that physicians should commit to “develop, implement, and disseminate appropriate, well-defined quality and performance improvement measures in their daily practice” [12]. In addition to preventing error, Opinion 1.2.3, “Consultation, Referral and Second Opinions” [13], suggests that physicians consult other physicians for advice or refer patients to other professionals to enhance quality of care.

Disclosure

Although Opinion 8.6 explains that physicians are obligated to inform patients about medical errors [10], it does not explicitly comment on the responsibilities of physicians when minor patients are harmed. However, when this opinion is taken in conjunction with physicians’ obligation generally to give preference to the wishes of the parents or guardian of minor patients when there is disagreement about the child’s best interest [4], it can be inferred that physicians should at least disclose the error to the parents or guardian. Importantly, the American Academy of Pediatrics (AAP) has not established guidelines about whether to include children in these discussions [14, 15]. The AAP has, however, implied that physicians should consider parental preference regarding [disclosure of error to children](#) [14] and recommended that institutions and individual physicians develop guidelines for identifying and disclosing preventable adverse events, including how investigations are conducted and findings communicated to patients and families [15].

Opinions in the *Code* similarly provide guidance to physicians who have erred in caring for adult patients, and particular recommendations can be applied to pediatric patients. Opinion 8.6 notes that, after disclosing the event, physicians should explain that “efforts ... are being taken to prevent similar occurrences in the future” and “provide for continuity of care to patients who have been harmed ... including facilitating transfer of care” [10]. Opinion 8.8, “Required Reporting of Adverse Events” [16], addresses the ethical responsibilities of physicians whose patients have been involved in adverse events, such as communicating the information to the professional community.

In sum, while physicians have obligations to inform adult patients and parents or guardians of minor patients about errors, there is no explicit guidance about whether and how to disclose errors to harmed children.

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STATE OF THE ART AND SCIENCE

Clowning as a Complementary Approach for Reducing Iatrogenic Effects in Pediatrics

Alberto Dionigi, PhD

Abstract

Hospitalized children who undergo painful procedures are more susceptible than others to experiencing iatrogenic effects, such as anxiety, pain, and severe stress. Clowns in clinical setting have been found to be effective in reducing children's experiences of these effects during hospitalization and before procedures. This article provides an overview of clowning in health care settings; reviews major studies conducted on clowning for hospitalized children, discussing evidence that clown interventions decrease pain and distress in pediatric patients; and concludes with a discussion of health care clowning as a profession.

Introduction

Surgery and hospitalization are significant stressors for children that can provoke negative health effects [1]. It is estimated that up to 60 percent of children who undergo surgery experience anxiety in the holding area and during the induction of anesthesia [2]. During the preoperative period, it is likely that specific symptoms of anxiety such as worry, fear, nervousness, and tension will appear [3, 4]. Children's greater vulnerability to the [stress of surgery](#) is due to developmental characteristics such as their limited cognitive capacity, lack of self-control, greater dependence on others, and fear of pain [5]. Moreover, children's preoperative anxiety can have marked distressing and traumatic consequences for their families, regardless of whether they are psychologically ill prepared [6].

What can be done to mitigate children's preoperative anxiety? Over the past 30 years, there has been a surge of interest in the use of complementary and alternative medicine (CAM) in Western industrialized nations to supplement patients' allopathic care [7, 8]. CAM includes approaches that are not considered to be conventional medical practice in a given society over a given period of time [9]; this variety of approaches includes acupuncture, osteopathy, homeopathy, and neural therapy, all of which can be used to treat acute and chronic diseases in adults and children [10, 11]. One such CAM approach is "therapeutic clowning," a goal of which is to providing humor-based distraction to improve hospitalized pediatric patients' moods and reduce their anxiety.

Hospital clowning is an interdisciplinary art that involves a wide variety of skills, such as humor, drama, music, and dance, and has a notable beneficial and therapeutic impact on patients [12]. First established in the US in 1986 by professional clown Michael Christensen, therapeutic clowning has since become a popular practice in hospitals worldwide, especially with, but not limited to, children [13, 14]. The main aim is to distract patients during the preoperative period [14, 15] and during medical procedures [16], induce positive emotions, and decrease negative emotions in order to demystify medicine and help in the healing process [12]. Clowns in clinical settings are organized into clown care units (CCUs). These units are made up of humor practitioners who work alone or in pairs and are colloquially called “clown doctors,” as they dress in a colored medical coat. Clown doctors use gentle play and humor to provide ill children with a different avenue for emotional expression during hospitalization [13].

The purpose of this article is twofold: to summarize the literature on the effectiveness of therapeutic clowning in children, particularly in reducing iatrogenic effects of health care such as anxiety and pain; and to discuss clinical clowning as a profession, focusing on the ethical stakes of working as a clown doctor.

The Efficacy of Clown Interventions in Hospital Settings

The use of clowning in health care settings has increased in the past 15 years, thanks in part to several studies evaluating the effectiveness of this practice in improving the psychological and physical health of hospitalized children, especially those who have had to undergo painful procedures, by reducing iatrogenic effects such as anxiety and pain. Research shows that anxiety related to invasive medical procedures can lead to behavioral problems, increased analgesic consumption, and general anxiety [17]. Moreover, the memory of painful procedures can increase anxiety about subsequent procedures by influencing the child’s perceived pain [18]. In this section, I present some of the most relevant studies that have tested the efficacy of clowning.

Clowning and anxiety. Original research on this topic was first published in 2005 [19], when a group of Italian researchers conducted a randomized controlled trial at Meyer Children’s Hospital in Florence [14]. The researchers found that the group of children accompanied by clowns and a parent experienced significantly less anxiety in the operating theater, as measured by the modified-Yale Preoperative Anxiety Scale (m-YPAS), compared to the control group, who only had the company of a parent. No difference in anxiety in the waiting room was found between the groups. The design of this study has since been replicated, and clown intervention has been found to decrease children’s preoperative anxiety effectively in a wide variety of situations. For example, Fernandes and Arriaga in Portugal [20] and Dionigi et al. in Italy [15] replicated this study with a larger sample of children and parents with similar positive results. An Israeli study [21] compared the effects of clowning to medication in three groups of children: one group did not receive any premedication, one group received oral benzodiazepine 30

minutes before surgery, and one group had two clowns present during the period from the preoperative area to the operating room (OR). The study found that clowning was the most effective treatment for reducing preoperative anxiety in the waiting area and that the effect was equal to the drug in the OR before the anesthesia mask was applied. Vagnoli et al. [17] also tested the possible effects on preoperative anxiety of parental presence, clowns, and sedative premedication. They found that children accompanied to the preoperative room by two clowns and a parent were significantly less anxious than both the control group and the group premedicated with oral benzodiazepine and accompanied by a parent. These studies thus demonstrate that clowning can be used to reduce preoperative anxiety without the potential iatrogenic effects of drugs.

Clowning has been shown to have other benefits for different groups. For example, a recent randomized trial [22] found that children aged 2-16 years who were undergoing outpatient penile surgery (meatotomy) and received clown visits had lower pre- and postoperative anxiety, shorter induction times for anesthesia, and were discharged more quickly after surgery than their peers who did not receive the clown visit [22].

Clowning and pain. Several studies indicate that therapeutic clowning can reduce pain in children. In an Italian study [16], children hospitalized with respiratory pathologies who received the clown intervention (i.e., a play session) experienced less pain and lower levels of stress as measured by diastolic blood pressure, respiratory frequency, and temperature than children who received standard care. Clowning can also reduce pain during procedures. A randomized study conducted in Israel [23] found that a clown intervention during insertion of an intravenous catheter reduced pain relative to standard care in children aged 4-7 years but not in older children. The role of clowning in reducing children's pain was also assessed in another Israeli study [24]. Children suffering from juvenile idiopathic arthritis who underwent multiple treatments of intra-articular corticosteroid injection with a clown present while being sedated with nitrous oxide reported lower levels of pain and stress than children in an earlier study [25] who received the same treatment without a clown present. A third Israeli study found that abused children aged 1-17 years undergoing anogenital examinations "expressed less fear, reported lower pain levels, and had fewer invasive thoughts" as measured by the Posttraumatic Stress Disorder Symptoms Scale (PSS-I) when accompanied by a clown than when accompanied only by a parent [26]. In addition, a Danish study of children, the majority of whom had spastic cerebral palsy, found that girls who received multiple injections of botulinum toxin in the presence of a female clown cried for a significantly shorter duration than girls treated with no clown present [27]. Clown presence thus appears to be helpful in providing emotional support during painful medical procedures, reducing the iatrogenic effects of pain, distress, and PTSD resulting from the procedures.

In summary, these studies indicate that clown interventions have positive health effects on hospitalized children, suggesting that combining clown intervention with traditional

anxiety-reduction approaches might be useful for reducing preoperative anxiety, fear, and pain in children who must undergo anxiety-inducing and painful procedures [28]. The deployment of clowns in a variety of settings has the potential to render these situations less scary, leading children to recollect the procedures as not unpleasant [24].

Profession of Therapeutic Clowning

Clown doctors offer the pediatric patient a positive and supportive relationship through playful interactions, distraction, and opportunities for empowerment. Specifically, four positive effects can be identified in the work of hospital clowning: (1) the cognitive effect (distraction from the medical procedure); (2) the physiological effect (the release of endorphins that stimulate the immune system, lower heart rate and blood pressure, and reduce pain); (3) the social effect (improving social interaction between the clown and the child); and (4) the emotional effect (inducing positive emotions or reducing anxiety) [29]. Clowns, if they are to be an integral part of the health care system, must adjust their interventions according to hospital rules. Research conducted to evaluate the appreciation of clown interventions speaks in favor of integrating this practice into the hospital setting, as it is well received by patients, relatives, and hospital staff [30, 31].

Ever since the first CCU was set up in New York City in 1986 [12], the number and diversity of clowns in health care settings has steadily increased. Soon after the first CCU, several other CCUs were established in the US (e.g., in Boston, Los Angeles, and San Francisco) [12]. These units catalyzed the development of programs around the world, and other associations of clown therapists have been set up in Europe, Canada, Australia, and Brazil [12, 13]. Although the first CCU was composed of professional circus clowns, nowadays clown units in clinical settings bring together a wide variety of practitioners—from well-intentioned volunteers with little training and understanding of the role and its potential to professional clowns who are respected complementary care practitioners who have adapted their behavior and knowledge for health care settings [12, 13].

Unfortunately, in the current state of the art, there is no accreditation or certification body for these practitioners. Given the importance of clowns' function and the need to make clear the clowns' roles, responsibilities, and training methods, several countries have set up specific federations uniting various organizations that are points of reference for institutions and individuals. Examples of such federations are the Federazione Nazionale Clown Dottori (FNC) in Italy [32], the Fédération Française des Associations de Clowns Hospitaliers (FFACH) in France [33], the Canadian Association of Therapeutic Clowns (CATC) in Canada [34], and the European Federation of Hospital Clown Organizations (EFHCO) in Europe [35]. The main aims of the federations are to clarify the work of clown doctors and to standardize the vocational training required to become a clown doctor in order to integrate these practitioners in the most effective way possible into clinical settings [12].

From an artistic and ethical point of view, clown doctors are required to maintain the highest standards during interventions in the hospital setting. This means changing the negative emotional state of the patient into a positive one (called the “climax”) and taking part in ongoing training [12]. Performances are evaluated by the artistic director of the clown care unit, and hospitals and medical staff offer feedback about the contributions and benefits of regular clown doctor visits [36]. Moreover, clowns are responsible for maintaining their own physical and mental well-being, and the organizations to which they belong should provide psychological support in order to ensure safety and quality of care and adherence to best practices, support professional development, and help mitigate stress-related syndromes [37].

Because clown doctors need specific competencies to behave appropriately in health care settings, [codes of ethics](#) have been drawn up and adopted by CCUs belonging to federations to assist members in providing the best practices [12] and are enforced by the federations. The different ethical codes around the world share some specific aspects [12]. First, the clown doctor must follow the code of conduct and the procedures of the health care setting, with a particular focus on hygiene, safety, and confidentiality. The clown doctors are responsible for the interactions in which they are involved, and they are required to safeguard the physical, psychosocial, and spiritual well-being of each person they approach. Second, they must serve people impartially, regardless of (for example) gender, age, religion, illness, or disability.

To sum up, working as a clown in clinical settings requires the ability to elicit positive emotions, to be able to focus on the activity, and to possess high emotional intelligence in order to deal with patients, many of whom are facing grave illnesses [38]. For these reasons, there is a need to define a specific and widely adopted code of ethics.

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STATE OF THE ART AND SCIENCE

Etiology and Manifestations of Iatrogenesis in Pediatrics

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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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POLICY FORUM

What Do Clinicians Caring for Children Need to Know about Pediatric Medical Traumatic Stress and the Ethics of Trauma-Informed Approaches?

Nancy Kassam-Adams, PhD, and Lucas Butler, MD

Abstract

Medical experiences can be frightening and traumatic for children. Ill and injured children can experience pediatric medical traumatic stress—psychological and physiological distress responses related to their medical event and subsequent medical treatment experiences—which can lead to symptoms of posttraumatic stress disorder (PTSD) and suboptimal health outcomes. Trauma-informed care provides a framework for acknowledging, addressing, and mitigating the risks of psychological trauma associated with medical treatment experiences and is congruent with the ethical principles of respect for autonomy, beneficence, nonmaleficence, and justice. Health care systems and professionals are encouraged to apply the principles of trauma-informed care to address the effects of pediatric medical traumatic stress.

Introduction

For the sick or injured child, being treated in the emergency department (ED) or admitted to the hospital can be a frightening and confusing experience that leads to subsequent psychological distress [1]. Experiencing pain, feeling helpless and out of control, and being separated from one's parents are all factors that contribute to the potentially traumatic nature of medical events. How does a physician's ethical obligation to "first, do no harm" square with the prospect of providing a therapeutically necessary procedure for a frightened child who does not understand what is being done and why? How do we understand the ethical issues involved when a medically beneficial course of treatment for a pediatric patient also has the potential to engender stress, fear, anxiety, pain, or discomfort for this child? In this brief review, we first describe two concepts that are key to understanding and addressing the psychological distress that can affect ill and injured children: *pediatric medical traumatic stress* and *trauma-informed pediatric care*. We then discuss four core principles of medical ethics (respect for autonomy, beneficence, nonmaleficence, and justice [2]) and explain how the application of these principles underscores the need for trauma-informed care.

Pediatric Medical Traumatic Stress and the Need for Trauma-Informed Care

Pediatric medical traumatic stress is a set of psychological and physiological responses of children to potentially traumatic events such as pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences [3]. During and immediately after acute treatment, it is common for ill and injured children to experience distressing traumatic stress reactions such as unwanted and intrusive thoughts, bad dreams, hypervigilance, exaggerated startle response, and avoidance of reminders of the medical event [1], which are symptoms of posttraumatic stress disorder (PTSD). Pediatric medical traumatic stress is not a diagnostic entity; rather, it is a conceptual framework for understanding children's negative responses to medical experiences. These responses include, but are not limited to, symptoms of PTSD. On average, a substantial minority (12 to 20 percent) of ill and injured children will develop symptoms of PTSD that persist for months and interfere with quality of life [4]. In children, PTSD symptoms related to medical events are associated with poorer health and functional outcomes [1], including decreased adherence to treatment or poorer health-related quality of life for up to two years posttreatment [5-8]. A burgeoning empirical literature regarding pediatric medical traumatic stress is beginning to identify potentially modifiable elements of medical care related to the risk of developing traumatic stress in pediatric patients. Pertinent factors that can be targets for intervention in the acute care setting include the child's fear and subjective sense of life threat, pain, acute physiological arousal (e.g., elevated heart rate), severe anxiety or traumatic stress during acute care, and the availability of interpersonal social support [4, 9-12]. The principles of trauma-informed care illuminate ways in which health care professionals can intervene to address these risk factors.

Trauma-informed care for vulnerable children has been defined across a variety of service systems, from schools to law enforcement to health care [13]. A trauma-informed system is one that recognizes the impact of trauma exposure for children in that system and applies knowledge about trauma to policy and practice in order to prevent retraumatization (i.e., iatrogenic harm) and reduce negative sequelae [14]. (Note that in this context, the term "trauma" refers to psychological or emotional trauma rather than physical injury.) Following this definition, a health system providing trauma-informed pediatric care (a) recognizes the potentially traumatic nature of medical events and medical care for children and (b) incorporates this understanding into organizational culture, policies, procedures, and each encounter that pediatric patients and their families have with the physician and health care team. Trauma-informed health care also incorporates an understanding of the impact that children's prior traumatic exposure (e.g., to violence, abuse, or other frightening experiences) could have on their current health status and on the clinician-patient encounter.

Practice Standards and the Ethical Case for Trauma-Informed Care

There is little empirical data about the extent to which current practice in pediatric care is trauma informed, although several indicators suggest that there is room for improvement. For example, among level I trauma centers that see children, only 20 percent systematically address posttraumatic stress in pediatric patients [15], and surveys of health care professionals indicate wide variation in knowledge and practice of trauma-informed pediatric care [16-18]. Nevertheless, practice standards are beginning to enumerate elements of trauma-informed care as key components of pediatric health care in such diverse areas as pediatric oncology [19] and pediatric trauma care [20].

Building on an understanding of the potentially traumatic nature of medical experiences for children and the risk for ongoing pediatric medical traumatic stress, we can now apply core principles of medical ethics (respect for autonomy, beneficence, nonmaleficence, and justice [2]) to delineate an ethical case for provision of trauma-informed pediatric care.

Respect for autonomy. The principle of respect for autonomy asserts that physicians must respect their patients' decision-making capacities and involve patients in their own care by providing information, choices, and control [2]. Children in the acute care setting commonly report feeling lack of control over what is happening to them [21, 22], which increases the potential for a challenging medical event to be experienced as traumatic. The legal capacity to consent to treatment generally falls to a child's parents or guardians, who are the primary decision makers throughout the course of pediatric medical care [23]. Nevertheless, physicians can ensure that children are provided with developmentally appropriate information and involved (even informally) in [assenting to care](#) [23]. Presenting opportunities for children to exercise some degree of control and providing choices (e.g., as to their position or their selection of a distracting activity) in the midst of painful or distressing symptoms or procedures can mitigate the traumatic nature of these experiences [24, 25].

Beneficence and nonmaleficence. With regard to pediatric medical traumatic stress, the principles of beneficence and nonmaleficence suggest that physicians and health care systems must strive to provide care that does not cause iatrogenic emotional distress during treatment and that maximally protects against the development of ongoing traumatic stress reactions. The challenges in achieving this care are clear. Providing effective medical care often involves the risk, or even the certainty, of pain or discomfort that is not easily remedied. Despite the use of pain management strategies, during their hospital admission many children experience pain that is not well controlled [26]. Many medically necessary procedures can be perceived as frightening by young patients, and children in acute care settings are often exposed to sights and sounds that can frighten them (e.g., machines, alarms, and other patients' pain or distress) [21, 22].

Fortunately, there is a growing empirical evidence base to guide practices that reduce a child's risk for immediate and long-term traumatic stress. Promising practices grounded in this evidence base include managing pain through pharmacological and nonpharmacological interventions, supporting parental presence and involvement, and providing effective support for children during procedures [24, 27]. As one example, when a child shows distress during a procedure, many clinicians (and parents) naturally want to provide emotional reassurance, saying things like "You're OK" or "Don't worry." Counterintuitively, a large body of research has found that this kind of verbal reassurance from parents or clinicians during procedures can exacerbate a child's pain and distress [24, 28]. The evidence also suggests that active [distraction strategies](#), such as engaging the child in interactive play or in nonprocedural talk, are most effective in reducing distress [29]. By optimizing pain management, promoting parental presence, and helping parents use distraction techniques effectively during a potentially painful or frightening procedure, trauma-informed physicians and health care teams are acting consistently on the principles of beneficence and nonmaleficence.

Justice. The principle of justice requires that physicians work to uphold a fair and just distribution of benefits and risks. Physicians should be aware of, and strive to prevent, health disparities that increase their patients' risk of experiencing pediatric medical traumatic stress. Relevant disparities can be seen across settings. Surveys of pediatric readiness suggest that EDs at community hospitals are less likely than pediatric EDs to have clear policies supporting family presence for their pediatric patients [30]. And research has documented racial and ethnic disparities in care that could impact children's risk for medical traumatic stress. For example, one study showed that black children in the ED were less likely than white children with similar levels of abdominal pain to receive analgesic medication [31]. In another study, children whose parents had limited English language proficiency had their pain assessed less frequently during postsurgery care and experienced greater pain levels before receiving analgesic medication [32]. And a growing body of research demonstrates that physicians and other health care professionals exhibit implicit (i.e., unconscious) biases based on race [33, 34]. To actively combat [unconscious bias](#) in pain management and other aspects of trauma-informed pediatric care, professionals can take concrete steps such as acknowledging their own susceptibility to implicit bias and practicing taking the perspective of stigmatized groups; there is empirical support for at least short-term reductions in implicit bias based on these steps [35]. However, persistent reductions in implicit bias may require more sustained and strategic interventions [36].

Conclusion

In summary, the concepts of pediatric medical traumatic stress and trauma-informed pediatric care are essential for understanding the potential iatrogenic psychological effects that medical care can have on children and how to mitigate those effects. The process of providing medical care has the potential to be protective and to ameliorate

risk for traumatic stress in ill or injured children or to inadvertently engender traumatic stress reactions in these children. Improving health care practice for the good of our pediatric patients (beneficence) and avoiding iatrogenic harm (nonmaleficence) will require continuing research and systematic quality improvement efforts. The research and quality improvement agenda begins with identifying promising trauma-informed policies and practices, such as those delineated in this brief review, and then systematically evaluating the effectiveness of those practices in reducing immediate and longer-term pediatric medical traumatic stress. Although there is a strong empirical basis for specific trauma-informed practices [1, 37], we know of no study to date that has addressed the impact of systemic implementation of trauma-informed pediatric medical care.

Effective implementation of trauma-informed care will require changes not only in the knowledge and practice of individual professionals but also in institutional protocols and policies [37], such as protocols for supporting family presence during procedures or for optimizing pain management. It is also likely to require a commitment from institutional leadership to train all staff who interact with pediatric patients in specific new skills and sensitivities (e.g., recognizing the psychological impact of medical events and treatment on children, providing effective support for children during challenging treatment experiences, and helping parents provide effective assistance to children throughout a child's ED or hospital stay) [37]. Even brief training can increase professionals' knowledge and confidence in implementing trauma-informed practices in their daily interactions with pediatric patients, an important first step [38]. Physicians can play a key role in training medical staff and in providing leadership in trauma-informed care in collaboration with nursing leaders and psychosocial staff. Tools—including brief, focused, online training resources—are available to help physicians and health care teams learn and implement specific skills necessary for trauma-informed pediatric health care [25, 39-41].

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MEDICINE AND SOCIETY

Should Euthanasia Be Considered Iatrogenic?

Silvana Barone, MD, and Yoram Unguru, MD, MS, MA

Abstract

As more countries adopt laws and regulations concerning euthanasia, pediatric euthanasia has become an important topic of discussion. Conceptions of what constitutes harm to patients are fluid and highly dependent on a myriad of factors including, but not limited to, health care ethics, family values, and cultural context. Euthanasia could be viewed as iatrogenic insofar as it results in an outcome (death) that some might consider inherently negative. However, this perspective fails to acknowledge that death, the outcome of euthanasia, is not an inadvertent or preventable complication but rather the goal of the medical intervention. Conversely, the refusal to engage in the practice of euthanasia might be conceived as iatrogenic insofar as it might inadvertently prolong patient suffering. This article will explore cultural and social factors informing families', health care professionals', and society's views on pediatric euthanasia in selected countries.

Introduction

In 2016, a terminally ill 17 year old was the first publicly reported minor to die with the help of a physician in Belgium since age restrictions in the country were lifted in 2014 [1]. Establishment of laws permitting euthanasia in 2002—initially in the Netherlands, followed shortly thereafter in Belgium [2], and the laws' subsequent extension in those countries to minors [3, 4]—has provoked an international debate concerning whether euthanasia for minors is both a legally and a morally acceptable option for infants and children suffering from incurable conditions [5-13]. Jotkowitz et al. strongly argue against active euthanasia for suffering infants, stating that a protocol for neonatal euthanasia “violates the traditional ethical codes of physicians and the moral values of the overwhelming majority of the citizens of the world” [14]. Conceptions of what constitutes harm to patients are fluid and highly dependent on a myriad of factors including, but not limited to, the societal and cultural context in which they exist [14, 15]. An accepted definition of medical iatrogenesis that will be used throughout this manuscript is the inadvertent and preventable induction of disease or complications by the treatment or procedures of a physician or surgeon [16].

Iatrogenesis and Euthanasia

In a traditional sense, the provision of euthanasia could be viewed as iatrogenic in that it constitutes a deliberate act, by a physician, which leads to the undesirable outcome of death. However, this presupposes that death is always an undesirable outcome, which might not be the case for young patients or parents of infants who request euthanasia to end what they consider unbearable suffering. From this perspective, the refusal of a physician or other members of the medical community to engage in the practice of euthanasia might be conceived as iatrogenic—in this case, by *refraining* from providing euthanasia, unbearable suffering is perpetuated.

A question raised by these different perspectives is, *What constitutes iatrogenesis and harm in pediatrics?* To illustrate, one need only imagine early experiences of many extremely premature newborns; most would not survive were it not for life-sustaining interventions, including intubation and mechanical ventilation. These interventions prolong life but often contribute to disability [17]; accordingly, they are intrinsically iatrogenic. And yet a prevailing view remains that these interventions are noble and constitute the “right thing to do” because they aim to protect and preserve life by giving every baby and family a chance at a happy and fulfilling life.

Whether euthanasia is perceived as iatrogenic will likely depend upon a variety of factors. For example, physicians’ and family members’ past experiences with patients or loved ones who endured prolonged suffering might shape their views on whether euthanasia is a deliberate act aimed at alleviating suffering (noniatrogenic) or an act whose consequence—death—is unintended and preventable (iatrogenic). Undoubtedly, an individual’s views on whether euthanasia for minors is morally justifiable will be shaped by not only past experience but also religious convictions and the dominant medical and societal cultural norms. To better understand the influence of these factors, one must consider a brief history and the current state of practices in various countries.

Euthanasia for Minors in the Netherlands and Belgium

Euthanasia in the Netherlands is regulated by the Termination of Life on Request and Assisted Suicide (Review Procedures) Act, in force since 2002 [18]. This act prescribes *due care* criteria to be met by a physician performing euthanasia and applies to patients age 12 and older. More specifically: (a) the physician must hold the conviction that the patient’s request is voluntary and well considered; (b) the physician must determine that the patient’s suffering is lasting and unbearable; (c) the physician must inform the patient about his or her situation and prognosis and ascertain that the patient has understood the information; (d) the patient must believe there is no other reasonable solution to his or her situation; (e) the physician must have consulted at least one independent physician who has also evaluated the patient and given a written opinion that the aforementioned due care requirements have been met; and (f) the physician must exercise due medical care in performing euthanasia, which includes following

approved guidelines for recommended substances, doses, and methods of administration and for performing appropriate checks to determine the depth of induced coma and having an emergency set of intravenous substances on hand [18, 19]. Termination of life for patients ages 12-16 years requires parental or guardian permission [18]. For patients ages 16-17, the parent(s) or guardian(s) must be consulted, but their permission is not required. The act does not address euthanasia for infants or younger children. In 2005, however, the Groningen Protocol (GP) for newborn euthanasia was published, which sought to regulate the practice of euthanasia in infants with “unbearable suffering” in an attempt to make it more transparent [3].

Shortly after the act establishing due care criteria came into effect, Belgium enacted legislation permitting euthanasia for patients older than 17 years who are severely ill, who experience constant and unbearable physical or mental suffering, and whose request for euthanasia is voluntary, well considered, and repeated [11]. In 2014, this legislation was extended to minors, with no mention of a specific age limit. The conditions of the law for minors are more restrictive and include the requirement for parental permission and determination by a psychologist or psychiatrist that the patient is capable of discernment [4]. Although Belgium does not officially subscribe to the GP, a comparison of end-of-life practices by Dutch and Belgian physicians for neonates and infants under the age of one year demonstrated that physicians administered drugs with the explicit intention of hastening death in similar percentages of infant deaths in both countries (9 percent versus 7 percent, respectively) [20].

These euthanasia laws and the GP are not without controversy, even within their countries of origin. Authors and supporters of the GP maintain that it serves the principle of beneficence [21]. As alluded to earlier, life-sustaining intervention, applied to premature or critically ill newborns, can itself induce chronic disease or result in disability. Proponents of the GP argue that, despite progress, modern anesthesiology cannot ensure the elimination of “unbearable suffering” of the newborn by palliative means [21]. Therefore, it would follow that physicians have a moral and professional responsibility to alleviate unbearable suffering, which, in part, can be caused by the very medical interventions physicians initially employed to preserve life at all costs. As a case in point, extremely premature infants often require prolonged intubation and mechanical ventilation as well as the insertion of central venous catheters for administration of parenteral nutrition. These invasive interventions, meant to preserve life, can have foreseeable, but unintended negative consequences, which by definition are iatrogenic. Central line-associated bloodstream infections can lead to septic shock and multisystem organ failure; prolonged mechanical ventilation increases the risk for chronic lung disease, with some infants remaining ventilator-dependent, and is also associated with retinopathy of prematurity [17]. Euthanasia for extremely premature infants thus might be viewed as a morally justifiable and even noble action, since the goal is to relieve suffering. Alternatively, refusal to euthanize these infants might be seen as a form of

iatrogenesis, particularly when technology or other life-sustaining interventions, which themselves might cause complications, are being used.

Europe: A Continent Divided

The view that providing euthanasia to terminally ill minors or infants is a morally justifiable role for physicians is not widespread in Europe. A recent study examining end-of-life decisions for newborns indicated diversity of opinion among European physicians and concluded that the most important predictor of how physicians responded to decisions about neonatal end-of-life care was the country in which the physician worked [22]. In fact, only the Netherlands, Belgium, and Luxembourg currently have laws pertaining to euthanasia in general, and no other European country permits or endorses euthanasia for minors [2]. Some opponents of pediatric euthanasia see it as an extension of Dutch “death culture,” which is feared as leading down a slippery slope, whereby approving this procedure for minors, even with strict requirements, could lead to overuse and abuse [21, 23]. Others believe that euthanasia is unacceptable under any circumstance and argue that pediatric euthanasia is in conflict with principles established after World War II, including the sanctity of life [21, 23]. In Greece, for example, the practice of euthanasia is forbidden and considered unlawful [21, 24]. Euthanasia’s legal status in Greece is consistent with the predominant opinion of members of the lay public, who believe that ending a person’s life intentionally, even if the person is terminally ill and requests to die, is unethical [24, 25]. Well-rooted religious and cultural values in Greece still play important roles in shaping public opinion on euthanasia and might also influence whether euthanasia for minors would be perceived as iatrogenic by health care professionals, many of whom subscribe to the country’s prevailing religion [24, 25].

Christians generally value “a fundamental humanitarian principle of the goodness in relieving a fellow person’s suffering” [26]. Within the Christian community, some might accept benevolent intent as a justification for euthanasia; however, for others, benevolent intent to relieve suffering might not necessarily justify death as the final outcome of an attempt to “help” the patient [24]. Regardless of whether euthanasia is considered justified, it would probably follow that euthanasia would not be regarded, from a Christian perspective, as iatrogenic because its intent would be to bring about death; death would not be an unintended consequence of an act aimed at relieving suffering, but rather a deliberate means to an end, which would be viewed as morally impermissible.

Countries of the so-called “Mediterranean bioethical zone” [21] often apply a form of virtue ethics emphasizing moral character and frequently prefer medical paternalism that favors preserving life above all else [27, 28]. In Southern European countries such as Italy and Portugal, laws often align with a form of ontological personalism, whereby human life, beginning at conception, is fully protected [21]. For example, Italian physicians feel legally obligated to continue treatment in all cases until the infant or child

dies [22, 29, 30]. Active life ending is not practiced anywhere in Italy (at least, not openly) [22]. Even as fewer people identify as Catholic, it appears religious tradition still plays an important role in shaping values and attitudes in the predominantly Roman Catholic country [31]. Although a recent poll suggests that public attitudes toward euthanasia might be shifting in favor of the practice, currently, Italian law is still very much in line with Roman Catholic doctrine [32, 33].

North American Context

Emphasis on individualism and autonomy typical of North American societies has produced a significant chorus of voices supporting a person's "right-to-die" on his or her own terms [34-36]. Yet euthanasia for adults remains an extremely controversial subject and views tend to correlate with religious affiliation and race [37, 38]. For example, in 2014, Quebec legalized euthanasia for competent adults with its Act Respecting End-of-Life Care [39], spurring Canada's parliament to pass legislation legalizing euthanasia for adults in June 2016 [40]. A special parliamentary committee examining medical assistance in dying stated that children should not be excluded from the right to euthanasia, referring to a Supreme Court statement that minors have a right "to a degree of decision-making autonomy that is reflective of their evolving intelligence and understanding" [41]. The possible extension of legislation legalizing euthanasia for children in Canada has not yet been resolved, and, at the time of this article's publication, only patients 18 years and older are eligible for medical assistance in dying in Canada [39, 40].

In the US, no national euthanasia law exists. However, between 1997 and 2015, five states—Oregon, Washington, Montana, Vermont, and California—introduced and enacted right-to-die legislation [42-46], and on February 20, 2017, the DC Death with Dignity Act went into effect, making Washington, DC, the sixth jurisdiction in the US to enact an assisted dying statute [47]. Current laws in the US refer specifically to physician-assisted suicide (PAS). PAS involves the physician prescribing or supplying lethal drugs at the patient's request; those drugs are self-administered by the patient with the aim of ending his or her life [48]. This practice contrasts with euthanasia, whereby a physician administers medication to intentionally end the patient's life; euthanasia remains illegal in all US states [48]. It is also important to note that current PAS laws in the US only apply to adults over the age of 17 and require patients to have a prognosis for survival of six months or less [48]. Legislation legalizing PAS in various US states and Washington, DC, was likely spurred by a variety of factors, including strong voices from right-to-die advocacy groups, highly publicized individual cases [49], and data showing increasing support from both the public [50] and some physicians [51].

Physicians' Roles in Patients' Dying Processes

Despite introduction of legislation legalizing PAS in a number of states, the idea that physicians have a role to play in helping patients' dying processes remains contentious,

particularly within the medical community [52-56]. The American Medical Association (AMA) *Code of Medical Ethics* states, "Permitting physicians to engage in euthanasia would ultimately cause more harm than good. Euthanasia is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks" [57]. Moreover, the American Academy of Pediatrics (AAP) staunchly stands against the practice of euthanasia for children [58]. Both the AMA and the AAP acknowledge that unrelieved pain and suffering is an unacceptable state. To manage debilitating symptoms, relieve suffering, and improve quality of life for patients with life-limiting or painful conditions, the AAP advocates access to high-quality palliative care [58]. Nonetheless, there might be a small subset of young patients who experience undue suffering despite maximum therapy, e.g., an adolescent with relapsed and refractory cancer. If such an adolescent, capable of discernment and without significant psychiatric comorbidity, requests euthanasia, on what grounds should the request be denied? This is a difficult question and the medical community's response would likely depend on what it considers iatrogenic or harmful, whether adolescents should be granted equal decisional authority with adults, and whether hastening death can somehow be integrated into the physician's role as healer. If euthanasia is the act of intentionally ending a patient's life, then it would be difficult for the medical community to conceive of euthanasia as iatrogenic, as death would not be an unintentional consequence of a medical treatment or procedure that relieves pain and suffering.

It is generally accepted by the medical community that minors can and should participate in medical decision making commensurate with their developmental level and ability but that the parent or guardian generally has the final authority for decision making. Determination of a minor's capacity for medical decision making is complex and should include evidence that the minor is able to voluntarily make a choice free of undue influence from parents, guardians, or health care professionals; that the child's choice is both reasonable and rational; and that the child understands information relevant to his or her choice [59]. Since it is generally accepted that decision-making capacity is not strictly tied to age, courts have recognized an exception to the common law rule of parental or guardian permission (consent) for medical treatment of a minor called the "mature minor" doctrine [60]. A minor with adequate decisional capacity who is deemed able to understand short- and long-term consequences is considered to be "mature" and thus able to provide informed consent or refusal for medical treatment without parental permission [61]. This doctrine applies only to specific medical decisions and varies by state.

Ethically, a distinction can be made between consent to or refusal of general medical care of more limited consequence, on the one hand, and decisions regarding end of life, particularly about a euthanasia request, on the other. Although an adolescent's cognitive ability and capacity to reason might be similar to that of an adult [62], a decision to proceed with euthanasia is much weightier, given that its consequence is death.

Arguably, deciding whether and how to act upon a request for euthanasia should involve a nuanced and sophisticated deliberative process that allows a person to demonstrate clear understanding that the consequence of his or her request is final and irreversible. What remains unclear is whether adolescents are capable of this level of decision making even if they possess general decision-making capacity and, if they do, whether they should be allowed to make such decisions.

Physicians' Roles in Iatrogenesis in Caring for Dying Patients: Ethical Relevance of Intention, Action, and Results

The issue of euthanasia becomes more complex when one considers that a component of a patient's pain and suffering (and possibly the part that she or he considers unbearable) could actually be a result of medical intervention rather than the underlying illness itself. In such a scenario, does the physician have a responsibility to obviate suffering to which she or he might, at least in part, have contributed? One could easily argue that a physician does have an obligation to relieve this suffering; what remains contentious is whether euthanasia is a reasonable and morally acceptable way to alleviate the suffering when other means have failed.

It is important to note that, although major American medical associations and academies reject euthanasia [57, 58], [palliative sedation](#) (PS) to unconsciousness is considered an appropriate intervention of last resort for patients in very specific situations (e.g., patients with terminal illness or symptoms that are severe, refractory, and not responding to aggressive palliation) [63, 64]. Concretely, PS involves administering medication to patients with severe and refractory symptoms with the goal of lowering a patient's level of consciousness so that she or he is not aware of pain and discomfort [65, 66]. The level of sedation should be proportionate to the patient's level of distress and can lead to unconsciousness. Moreover, according to the American Academy of Hospice and Palliative Medicine (AAHPM), "Because patients receiving palliative sedation are typically close to death, most patients will no longer have a desire to eat or drink [and] artificial nutrition and hydration are not generally expected to benefit the patient receiving palliative sedation" [65].

PS is ethically distinguished from euthanasia by the physician's *intent*, which is to relieve unbearable suffering, rather than to cause death [66]. PS can also be distinguished from euthanasia by its *action*. That is, a physician performing PS gives the right medications in the right dosages and titrates them to effect (comfort), rather than giving lethal doses of medications to cause death [66]. Furthermore, PS usually does not alter the timing or mechanism of a patient's death, as refractory symptoms are most often associated with very advanced terminal illness [65, 66]. The AAHPM [65] specifies that "practitioners who use palliative sedation should be clear in their intent to palliate symptoms and to not shorten survival." Therefore, PS can also be ethically distinguished from euthanasia

in its *result* [66]. In this way, for some physicians, PS can provide a morally and ethically acceptable option for responding to suffering in young patients.

Since the intent of palliative sedation is to relieve unbearable suffering, death following PS could be conceived as iatrogenic because it is an unintended, though not unforeseeable, outcome. Death following PS might challenge the notion that iatrogenesis is, in and of itself, harmful and something to be avoided. In the case of PS, a physician is generally seen as performing an act that relieves intractable suffering; the outcome of death is not perceived as a physician having “caused harm” to a patient, but rather as having helped that patient by relieving suffering and distress.

Conclusion

Understandably, pediatric euthanasia is an emotionally charged and controversial issue for the public and for medical and legal communities. Although these concepts have been discussed and debated for centuries, what it means to cause harm or act in the best interest of a patient remains far from clear. Productive discussions must acknowledge that specific views will ultimately be shaped by past experiences, religious affiliation, sociocultural values, and political ideology. Moreover, debate and difficult discussions about the roles of physicians and iatrogenesis in the care of dying patients must be enriched by the engagement of stakeholders, including pediatric professionals, parents, health professions organizations, the public, and, when appropriate, patients who are minors. Current efforts within the AMA to study aid-in-dying as a potentially acceptable end-of-life option for adults is a positive first step in this direction [67].

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MEDICINE AND SOCIETY

Nontherapeutic Circumcision of Minors as an Ethically Problematic Form of Iatrogenic Injury

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Abstract

Nontherapeutic circumcision (NTC) of male infants and boys is a common but misunderstood form of iatrogenic injury that causes harm by removing functional tissue that has known erogenous, protective, and immunological properties, regardless of whether the surgery generates complications. I argue that the loss of the foreskin itself should be counted, clinically and morally, as a harm in evaluating NTC; that a comparison of benefits and risks is not ethically sufficient in an analysis of a nontherapeutic procedure performed on patients unable to provide informed consent; and that circumcision violates clinicians' imperatives to respect patients' autonomy, to do good, to do no harm, and to be just. When due consideration is given to these values, the balance of factors suggests that NTC should be deferred until the affected person can perform his own cost-benefit analysis, applying his mature, informed preferences and values.

Introduction

The foreskin is a complex genital structure that covers the head of the penis and performs a variety of sexual, immunological, and protective functions. With a total adult surface area of 30-50 cm² [1, 2] and dense innervation, the foreskin is highly touch-sensitive tissue [3]. Its contractible muscle fibers exclude contaminants [4], while its mucous surface provides a second, immunological layer of protection [5, 6]. The foreskin keeps the glans moist and facilitates a gliding action that promotes pleasurable sexual sensations [7-10].

The intact male and female genitalia have evolved to work together to optimize sexual sensation during sexual activity [7]. In the nineteenth century, British and American physicians introduced circumcision of boys (and also of girls) in a vain attempt to prevent masturbation [11]. American physicians came to view the male foreskin as the root of many medical and moral evils, believing that it contributed to conditions such as insanity, homosexuality, epilepsy, and deafness [12]. As each benefit of circumcision was shown to be false, new rationales were invented, and circumcision became entrenched as a cultural practice [12].

Nontherapeutic infant or child male circumcision (NTC)—the removal of a child’s foreskin in the absence of a valid medical indication—is an unnecessary surgery that causes pain, permanently alters the penis, and needlessly exposes a healthy child to risk of iatrogenic injury [13]. If a man assigns value to the foreskin itself, as most noncircumcised men do, the loss of this tissue constitutes a harm, regardless of whether there are surgical complications [14]. The American Academy of Pediatrics’ (AAP’s) 2012 position statement, which asserts that the health benefits of NTC outweigh the risks [15], is in conflict with a consensus of Northern European medical authorities [16]. As the AAP acknowledges, men rarely volunteer to undergo a circumcision [15]. Growing numbers of adult males are angry that the procedure was forced on them before they could decline [17, 18]. As will be demonstrated, removing healthy tissue from nonconsenting minors is inconsistent with widely accepted ethical norms.

Benefit versus Risk of Harm Is the Correct Standard

Although risks and benefits are commonly compared in evaluating circumcision, the risk-benefit calculation was developed for therapeutic procedures and is not applicable to a nontherapeutic procedure, especially one that removes a genital structure with known functions [14]. The correct standard for evaluating nontherapeutic surgeries thus is not risk of *surgical complications* versus benefit but risk of *harm* versus benefit [14]. Insofar as the foreskin itself has value, its involuntary loss is a harm per se that must be included in the analysis.

Other iatrogenic consequences of NTC include:

- *Trauma and pain.* Topical anesthesia cannot fully protect an infant from substantial pain when circumcised [19, 20], while general anesthetics must be avoided due to high risks [21]. Many practitioners still do not use any form of pain control, although Lander et al. showed that in their study, “every newborn in the [non-anesthetized] placebo group exhibited extreme distress during and following circumcision” [22].
- *Complications.* Complications of circumcision, even when performed in a sterile clinical setting, are possible. Krill, Palmer, and Palmer state that “postcircumcision bleeding in patients with coagulation disorders can be significant and sometimes even fatal. Other serious early complications include chordee [curvature], iatrogenic hypospadias, glanular necrosis, and glanular amputation.... *Late complications* include epidermal inclusion cysts, suture sinus tracts, chordee, inadequate skin removal resulting in redundant foreskin, penile adhesions, phimosis [inability to retract the foreskin], buried penis, urethrocutaneous fistulae, meatitis [inflammation of the meatus], and meatal stenosis” [23].
- *Sexual harm.* Since circumcision removes between one-third and one-half of the highly innervated penile skin system, as well as the majority of the

penis's specialized erotogenic nerve endings [24], it inevitably compromises male sexual response. At minimum, all sexual activities and sensations involving manipulation of the foreskin are precluded by circumcision. One recent study of heterosexual men and women reported that "Circumcision was associated with frequent orgasm difficulties in Danish men and with a range of frequent sexual difficulties in women, notably orgasm difficulties, dyspareunia and a sense of incomplete sexual needs fulfillment" [25]. Another study found that erectile dysfunction and difficulty in reaching orgasm increased in circumcised men [26].

Without an unambiguous medical rationale to counterbalance the trauma and pain, risk of complications, and iatrogenic harm—including sexual harm—that results from circumcision, it is difficult to justify ethically.

Benefits Do Not Outweigh Risks

Evidence suggests that circumcision can reduce the risk of urinary tract infections (UTIs) [16] and (when performed in adulthood) of female-to-male transmission of HIV in sub-Saharan Africa [27-29]. However, the first benefit has been questioned, and there is no evidence from controlled studies linking the second benefit to NTC in developed countries. Accordingly, I contend that neither benefit is great enough to outweigh the harm of the surgery or to justify performing it without informed consent from the affected person.

Urinary tract infections. Frisch et al. noted that the only relevant benefit of circumcision in infancy is a reduction in the risk of contracting a urinary tract infection (UTI) in early childhood [16]. According to the Cochrane Review, circumcision cannot be shown to meaningfully lessen the risk of contracting a UTI [30]. Moreover, even if NTC were able to substantially reduce the incidence of UTIs, this would not be sufficient to render the procedure ethically acceptable, because these infections are rare (approximately 1 percent) in boys, are generally confined to the first half year of life, and are susceptible to easy treatment with oral antibiotics [31, 32]. There is also evidence that circumcision can sometimes cause UTIs [33, 34]. Performing 100 circumcisions in an attempt to prevent one UTI will result in twice that number of complications, including "cases of hemorrhage, infection, or, in rare instances, more severe outcomes or even death" [35].

HIV-AIDS. Current claims that NTC has benefits exceeding the risks largely stem from three randomized controlled studies conducted in sub-Saharan Africa. These studies found that voluntary male circumcision reduces the [risk](#) of female-to-male transmission of HIV during unprotected intercourse [27-29], with a relative risk reduction of 38-66 percent [36]. The risk reduction in absolute terms only comes to about 1.3 percent [37], and long-term effects are not well established. Moreover, one of the RCTs found that NTC led to a 61.9 percent relative increase in male-to-female HIV transmission and an absolute increase in risk of 8.3 percent [38]. These latter findings suggest that any

reduced risk of women infecting men can be counterbalanced by a correspondingly increased risk of men infecting women [32, 39].

Nevertheless, studies performed in impoverished third-world settings cannot justify NTC in a first-world setting with populations having dramatically different HIV profiles [40]. In Western countries, HIV primarily infects men who have sex with men, a cohort that has not been reliably proven to be protected by NTC [41, 42]. In any event, as Frisch et al. state, "sexually transmitted HIV infection is not a relevant threat to children" [43]. Prominent AIDS researchers no longer consider circumcision a significant part of the effort in eradicating HIV [44-46], deeming the best preventive measures to be "condoms, treatment for HIV-infected individuals, or clean injection equipment" [47]. Since NTC provides no appreciable health benefits to the infant or young child, the procedure should be deferred until the affected individual can decide for himself.

Ethics of Nontherapeutic Circumcision

Catholic moral principles question consent by proxy to NTC, all the more so if the procedure is to be performed on a healthy child and can be predicted to effect a permanent change in normal anatomy or might negatively impact the functions of a nondiseased organ [48]. In what follows, it will be shown that NTC conflicts with each of four cardinal ethical principles of medicine.

Respect for patient autonomy. Respect for autonomy is perhaps the paramount ethical principle in Western medicine [49]. Circumcision before the age of consent deprives the child of a body part that he would otherwise likely appreciate [50] and thus fails to preserve his future autonomy. The Centers for Disease Control and Prevention (CDC) [51] states that "Delaying male circumcision until adolescence or adulthood obviates concerns about violation of autonomy" [52] and that any medical disadvantages associated with such a deferral "would be ethically compensated to some extent by the respect for the [bodily] integrity and autonomy of the individual" [53].

Nonmaleficence ("do no harm"). The principle of nonmaleficence prohibits infliction of unnecessary harm on the patient. As discussed above, since NTC imposes on a healthy child the risk of significant harms without certain and substantial countervailing benefits, it cannot pass the nonmaleficence test. Supporting this principle are two further ethical guidelines. First, physicians cannot ethically take orders from parents or guardians; the AAP maintains that it is a legal as well as an ethical rule that a [physician's duty](#) is to the patient alone [54]. Second, physicians should not normally perform unnecessary surgery on children, especially insofar as the procedure involves the removal of healthy, functional tissue [55]. Courts have upheld the same conclusion. In *Tortorella v Castro*, a California appeals court found it "self-evident that unnecessary surgery is injurious and causes harm to a patient. Even if a surgery is executed flawlessly, if the surgery were unnecessary, the surgery in and of itself constitutes harm" [56].

Beneficence (“do good”). Douglas Diekema has explained how the ethical principle of beneficence applies to the care of children:

To conform to the standard of care, all surgical or other interventions must be in the best interests of the patient, and have some reasonable prospect of providing a tangible benefit to him. In general, parents cannot subject a child to medical procedures that place the child at significant risk of serious harm unless there is a corresponding benefit that is likely to outweigh the potential harms. Non-therapeutic procedures that involve excessive risk should be avoided [57].

As noted, the balance of opinion among medical authorities in Northern Europe is that the risks and harms of NTC are not outweighed by tangible benefits [16]. Moreover, as discussed above, there are no valid medical indications for prophylactic circumcision [58, 59]. Accordingly, infant circumcision fails to meet the ethical requirement of beneficence.

Justice. To comply with medical ethics principles, physicians must treat their patients fairly and impartially. The ethical principle of justice is violated by the availability in Western countries of legal protections from unnecessary [genital cutting](#) for girls—but not for boys [32]. Males have a right to an open future [60] and, accordingly, justice mandates protecting their right to natural genitalia along with girls’ corresponding right.

Conclusion

In response to recent Danish research showing that the overwhelming majority (roughly 98.3 percent) of genitally intact (not circumcised) boys will not require a circumcision for medical reasons before an age of legal majority [61], a former member of the AAP Task Force on Circumcision, Andrew L. Freedman, conceded that circumcision is fundamentally a religious or cultural practice in search of a “medical” justification [62].

As argued here, nontherapeutic circumcision of male minors is not medically justifiable and violates the cardinal principles of medical ethics, including preserving a child’s future autonomy, nonmaleficence, beneficence, and justice. Circumcision should be at least delayed until the affected person reaches an age of understanding and is able to make his own risk-benefit analysis. Notably, the Danish Medical Association issued a policy paper in December 2016 that found NTC before the age of informed consent to be unethical [63]. Physicians’ legal right to operate on healthy children is also questionable. In 2012, a German court held that circumcision constitutes criminal assault by causing bodily harm and denying a child his right to physical integrity, although the decision was later legislatively reversed [64]. And in 2015, in a case involving female genital cutting/mutilation, a British judge found that nontherapeutic circumcision of male children is a “significant harm” [65]. As the balance of legal, ethical, and human rights discourse moves steadily against NTC, courts in the US and elsewhere might gradually

conclude that NTC is inconsistent with medical professionals' ethical and legal duties to the child.

The vast majority of medical practitioners have the best interests of their patients at heart; if they recommend or agree to circumcision, it is usually in the belief that it does more good than harm. As more physicians are coming to realize, however, this belief is misguided: many physicians to whom I speak these days now say that they would prefer not to circumcise and only do it because the parents ask for it. At the same time, it is often the case that the only reason parents ask for it is because they believe circumcision is medically beneficial, recommended by health authorities, or the normal thing to do. It is time for this vicious circle to be broken. Who better to take the initiative than the community that introduced NTC in the first place—the American medical profession?

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Are Physicians Blameworthy for Iatrogenic Harm Resulting from Unnecessary Genital Surgeries?

Samuel Reis-Dennis, PhD, and Elizabeth Reis, PhD

Abstract

We argue that physicians should, in certain cases, be held accountable by patients and their families for harm caused by “successful” genital surgeries performed for social and aesthetic reasons. We explore the question of physicians’ blameworthiness for three types of genital surgeries common in the United States. First, we consider surgeries performed on newborns and toddlers with atypical sex development, or intersex. Second, we discuss routine neonatal male circumcision. Finally, we consider cosmetic vaginal surgery. It is important for physicians not just to know when and why to perform genital surgery, but also to understand how their patients might react to wrongful performance of these procedures. Equally, physicians should know how to respond to their own blameworthiness in socially productive and morally restorative ways.

Introduction

In this essay, we discuss three types of genital surgeries commonly performed for sociocultural or aesthetic reasons in the United States and consider physicians’ roles in both causing and preventing harm associated with these genital surgeries. First, we consider surgeries performed on newborns and toddlers with atypical sex development, or intersex. Second, we discuss secular, nontherapeutic, neonatal male circumcision. Finally, we consider cosmetic vaginal surgery.

Because sex and gender are so closely tied to our social identities and self-conceptions, patients and parents might feel an especially acute need to discuss and hold physicians accountable for harms and to rebuild trust, even when physicians consider the surgeries “successful.” Thus it is important for physicians not just to know when—and when not—to perform genital surgery, but also to understand how their patients, when they are older, could reasonably react to wrongful performance of these procedures. Equally, physicians should know how to respond to their own culpability and complicity in ways that are socially productive and morally restorative.

Before proceeding, we should clarify what we mean by “blame” and “blameworthiness.” We are interested in the justified expression of what philosophers sometimes refer to as “negative reactive attitudes” [1]. Susan Wolf describes the attitudes we have in mind as:

A range that includes resentment, indignation, guilt, and righteous anger—they are emotional attitudes that involve negative feelings toward a person, arising from the belief or impression that the person has behaved badly toward oneself or to a member (or members) of a community about which one cares and which tend to give rise to or perhaps even include a desire to scold or punish the person for his bad behavior [2].

We consider whether genital surgical patients’ feeling and expression of these attitudes is justified in response to surgeries recommended or performed for social or aesthetic reasons. Specifically, we are concerned with the physical and emotional iatrogenic harms patients suffer when such unnecessary (not clinically indicated) genital surgeries are “successful,” and the nature and scope of physicians’ blameworthiness for these harms. Ultimately, we argue that when physicians encourage parents to authorize and then perform “normalizing” surgeries for nonmedical reasons, patients’ blame is a fitting response to the physical and emotional harms they suffer as a result and that it is, therefore, reasonable to view physicians as blameworthy (in the sense that they are rightful targets of such negative reactive attitudes). We argue that pediatricians should promote body positivity—acceptance of all types of bodies—to their young patients, their adolescent patients, and their parents, rather than encouraging so-called normalizing surgery.

Intersex Surgery

Surgeons have been performing surgeries in response to children’s atypical genitals since the mid-nineteenth century, although it was not until the 1950s that such [surgical “repair”](#) became standard protocol [3]. The surgeries have been largely cosmetic and social in nature rather than medically indicated [3]. In fact, throughout American history, fears of homosexuality often motivated intersex surgeries, as some physicians wanted to make sure that patients knew for sure which sex they were so that they wouldn’t be attracted to the “wrong” sex [3]. Many parents might consent to surgeries recommended by physicians, hoping that their children’s genitals would look more typical, but these surgeries can have iatrogenic consequences, including loss of sexual sensation, incontinence, scarring, and sterility [3-6]. More than one surgery is often done; in these cases, there is substantial risk of emotional trauma and of tissue breakdown in this sensitive region [4, 5, 7]. In the late-twentieth century, attitudes toward these surgeries began to change, largely because of intersex activism that began in the 1990s [4-6]. Intersex activists do not oppose surgeries required to ensure voiding, for example, but they are against the more common surgeries that alter the appearance of the genitals so that they conform more closely to typical genitals, such as removing or

minimizing a girl's enlarged clitoris or creating a vagina so that heterosexual penetration can be more easily accommodated [8]. In fact, the American Medical Association is currently considering a resolution that supports autonomy for patients born with differences in sex development, including atypical genitals [9].

If, as a society, we felt more comfortable with difference, we might not be so eager to surgically repair bodies that didn't actually need fixing, particularly when the alleged fix caused iatrogenic harm. It is possible for physicians and parents to choose a gender for a child born with genital difference based on a medical assessment of chromosomes, anatomy, and hormone levels and still decline surgical intervention. The urge to perform these unnecessary surgeries has not been based on empirical evidence, and in fact many intersex people have expressed anger at what happened to their bodies when they were too young to do anything about it [10].

We argue that physicians who recommend or perform genital surgeries that are not clinically indicated can be rightly blamed for, and are complicit in, both pathologizing natural variations in bodies and causing unnecessary iatrogenic harm. We will assume that surgeons, in performing these surgeries, do not express any malice or ill will: they might think, perhaps wrongly, that they are acting in the patient's best interest [4, 5]. Although good intentions should affect the way parents and patients express blame and hold physicians accountable for the negative consequences of intersex surgeries that are not clinically indicated, they are not fully exculpating. Physicians who, despite acting in good faith, are swayed by social pressure to attempt normalizing surgery have a moral and professional duty to inform themselves of the potential iatrogenic consequences of permanent sex assignments and other genital alterations that are not medically necessary and performed without the consent of the patient, of which there are numerous testimonials [10]. Accordingly, they should explain to parents that children born with ambiguous genitals are usually healthy and at no clinical risk and should have the right to decide whether to undergo normalizing procedures when they are old enough to make those decisions [8]. We maintain that the choice to undergo irreversible surgery for social or aesthetic reasons should be left up to autonomous and well-informed patients.

Equally important, physicians have duties to interrogate their motives for recommending or performing unnecessary procedures even, and perhaps especially, if those surgeries were once thought to be essential to patients' health. (This point applies to parents as well as physicians, but we leave the question of blame for parents aside in this article.) When surgeons perform "successful" intersex surgery on a patient that results in iatrogenic harms, a patient or a family member's expression of blame can play an important role in the process of rebuilding the patient-physician-family relationship. Expressing blaming attitudes can be a way of starting a productive and honest dialogue about the damage done and possible ways to move forward [11]. Expressing anger,

though often seen as socially unproductive, can be a means of prompting a blameworthy agent to reconsider her actions and to offer a humbling, restorative, apology, which in turn can be crucial to mending a relationship [12]. Blaming can also be a way of fostering self-respect [13]: in expressing blame, patients who were wronged as children and their parents can affirm their moral status and their moral equality with their physicians.

It is important to note here that blameworthiness does not mean that one is a bad person; unlike shame, blame primarily involves an indictment of one's action rather than one's character [14]. Thus, when confronted with the iatrogenic physical and psychological harms that result from genital surgeries that are not clinically indicated, physicians may properly feel a sense of guilt about endorsing and executing them. But they need not feel ashamed. We maintain that physicians who have performed or continue to perform clinically unnecessary genital surgeries should respond to their blameworthiness by offering an apology and rethinking their recommendation of, and participation in, so-called normalizing procedures; if possible, they should understand a patient's expression of blaming attitudes as an invitation to repair the damage that iatrogenic consequences can do to the patient-physician relationship.

Neonatal Male Circumcision

The principle that irreversible surgery performed for social or aesthetic reasons should be up to an informed and autonomous patient applies to male circumcision as well. In some religious and cultural communities, nonmedical reasons motivate decisions to circumcise newborn infant boys. Such cases fall outside the scope of the secular focus of this paper, as pediatricians' opinions are not usually sought in these instances. Most American parents, however, do not have religious concerns about circumcision; they simply ask—or are told by—their pediatricians what to do [15].

So many men in this country have been circumcised as infants—estimates range from 42-80 percent among various subpopulations [16]—that the surgery can strike us as normal. Indeed, the surgery is popularly perceived as a mere “snip” of skin [17]. But pediatricians should at least question the necessity and wisdom of recommending the procedure, given its risks [16], [iatrogenic consequences](#)—including its possible effect on sexual sensitivity or satisfaction [18]—its permanence, and the fact that its recipient might have chosen otherwise.

Secular parents may choose to circumcise their sons because they believe that it is a medically sound decision. Some studies conclude that removing the foreskin protects boys from urinary tract infections as children and then later from penile cancer or even HIV as adults [19]. The American Academy of Pediatrics (AAP) has vacillated in its support of circumcision over the years. In 2012, it released a report asserting that the potential health benefits of infant male circumcision outweigh the risks [16]. This pronouncement overturned the Academy's earlier policy statement, from 1999, which

asserted unequivocally that the potential health benefits of the procedure are insufficient to recommend that it be done routinely [20]. The 1999 statement in turn reversed a previous one made in 1989, which claimed that there were good medical reasons for infant male circumcision [21]. Yet a few years earlier, in 1971, the Academy had officially concluded that there was no definite medical indication for the procedure [22]. Clearly, circumcision is one of those surgeries about which opinion shifts back and forth [23].

In 2012, the AAP agreed that parents should be presented with honest and straightforward information about the care of the penis and the benefits and risks of circumcision [16]. Physicians might also discuss the following with parents: What is the foreskin for? What is being cut away? How is it done? How long does it take to heal? What do circumcised and uncircumcised penises look like at infancy and in adulthood? Many new parents do not know even these fundamental facts and so their decisions about their infants' bodies are based on myths, preferences, and often inaccurate information [18].

A physician's potential blameworthiness for performing infant male circumcision will rest in large part on her motives and her commitment to staying informed. Nevertheless, we endorse the general principle that pediatricians should not recommend irreversible surgery, such as the permanent removal of foreskin, on nonmedical grounds. When pediatricians perform circumcision out of deference to parents' unquestioned custom, they may be rightful targets of blaming attitudes, even anger, expressed by parents and by patients once they have grown up. However, if a physician fully in command of the current medical literature informs parents of the iatrogenic risks of the procedure, and then recommends circumcision because she views it as a medical necessity—for example, to correct phimosis, a condition where the foreskin does not retract—the physician would be blameless even if medical consensus changed after the surgery was performed.

Cosmetic Vaginal Surgery

Pediatricians have great influence over the ways in which parents, children, and teens learn and communicate about what constitutes a "good," healthy body. We see the increasing popularity of labiaplasty [24], described by the International Society of Aesthetic Plastic Surgery (ISAPS) as a "remodeling of the enlarged inner lips of the vulva" [25], as a sign that something has gone awry in the way our culture imagines what constitutes genital normality. Who decides when labia are "too large?" Why should anyone need "remodeling"?

Cosmetic vaginal surgery is being promoted by aesthetic plastic surgeons [26] and has found a ready audience of women who are dissatisfied with the normal appearance of their genitals. The ISAPS reported that 13,390 labiaplasty and vaginal rejuvenation

procedures were performed in the US in 2015 [27]. And in 2015, labiaplasty alone (excluding vaginal rejuvenation, a procedure that tightens vaginal muscle tone) increased 16.1 percent over the previous year [24]. Yet in 2007, the American College of Obstetricians and Gynecologists had asserted that “Absence of data supporting the safety and efficacy of these procedures makes their recommendation untenable” [28].

Physicians have debated whether vulvar [plastic surgery](#) is ever warranted [29]. Pediatricians, in keeping with their obligations to promote the physical and psychological health of their patients, should do more to disrupt the discontent of teenage girls and their constant scrutiny of their bodies. We believe that when children visit their pediatricians, they should see pictures of a wide variety of children, so that a range of bodies come to seem normal and healthy. For teen patients, accurate pictures would be welcome, so that teenagers can see that human bodies differ considerably and that there is no one perfect way of looking, even in the genital region. The enormous silence that obscures genital and reproductive variation can be broken by physicians willing to adorn their office walls with “The Great Wall of Vaginas,” for example, a sculpture made of plaster casts of four hundred women’s vulvas, or other such feminist art that celebrates difference and contributes to “changing female body image through art” [30]. Similar body positive art could serve as a teaching tool for boys and even gender-nonconforming children who may be considering delaying puberty and ultimately transitioning.

It would be odd for an adult to blame her physician for her own decision to undergo voluntary cosmetic surgery, but insofar as some physicians promote a narrow vision of what a healthy body looks like that can propagate damaging self-perceptions among patients, they might be reasonably resented by patients struggling with body image issues. For pediatricians who have endorsed surgical normalization, their reasonable feelings of guilt and remorse may lead to a laudable desire to play a larger role in promoting body positivity and acceptance and to actively disseminate the apt intersex rights slogan: No Body is Shameful® [31].

Conclusion

We have argued that physicians should not modify children’s genitals for nontherapeutic reasons. In addition, we believe that they should play a bigger role in educating their young patients about genital and body variability and consider their motivations when advocating surgical normalization. When physicians do perform genital surgeries for nonmedical reasons, a wronged patient’s feeling and expression of blaming attitudes can be both fitting and justified. In fact, the expression of anger can be part of a productive social interaction that can, under certain circumstances, prompt apology and facilitate psychological healing.

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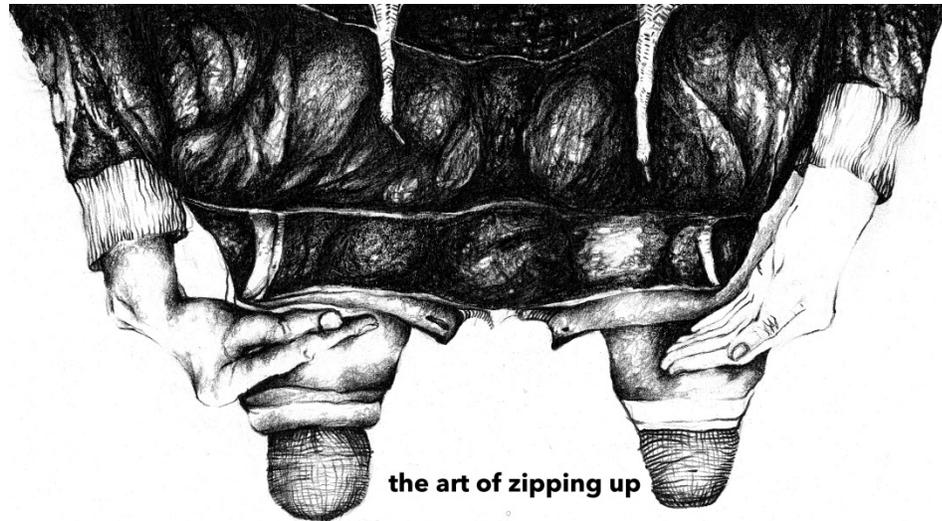
IMAGES OF HEALING AND LEARNING

Performing Pain and Inflammation: Rendering the Invisible Visible

Artwork and captions by Arseli Dokumaci, PhD

Abstract

These drawings represent everyday experiences of an artist who has been living with rheumatoid arthritis since her teenage years. Over the course of 20 years, the disease has damaged a series of joints in her body. Pain and inflammation accompany the most mundane of her movements and gestures. Fatigue and side effects of medications are routine parts of life. None of her impairments are publicly recognized and duly accommodated, as she is not (yet) visibly disabled. Asking for a seat on the bus, for instance, turns into a thorough social negotiation, as does having to constantly remind people that she actually is disabled. Lacking visual signs of disability, she is often accosted for “evidence”—an authentication, a reminder of “her” disability. With these drawings, each of which describes the artist’s daily negotiations with pain, inflammation, and fatigue, she seeks to render visible what remains locked up within the boundaries of her skin.



One morning, I was in the bathroom. Stood up from the toilet, pulled my jeans up in the slowest of motions. Then came the biggest challenge: How was I going to zip up? My hands, elbows, and shoulders were inflamed, tender, and painful (as they often are). My fingers were swollen to the size of mini-bananas. I could not bend them even to slightest degree needed to grasp the zipper. Sliding that tiny thing up meant pushing my fingers in the direction of pain, which would make my fingers bend outward. Within this constellation, that tiny zipper pull felt like a ton of weight put on one side of a lever, and I had nothing to put on the other side. *Dokumaci, 2015*

Figure 1. *The Art of Zipping Up*, by Arseli Dokumaci

Caption

A pencil drawing on a white surface of someone's upper body seen from the person's own viewpoint as the person is standing up. The person's arms and elbows are bent toward the person's belly, as if the person is about to engage in an action.

**Some arms carry things.
Some arms are carried in pockets.**

My left shoulder was damaged by inflammation a long time ago. It is relatively smaller in size than the right one. I can hardly ever move or do things with it. In fact, I often times carry it around. This is why I tend to wear clothes with pockets. I put my hand in my pocket, let the pocket carry my arm, and take its weight off my shoulder.

Dokumaci, 2015

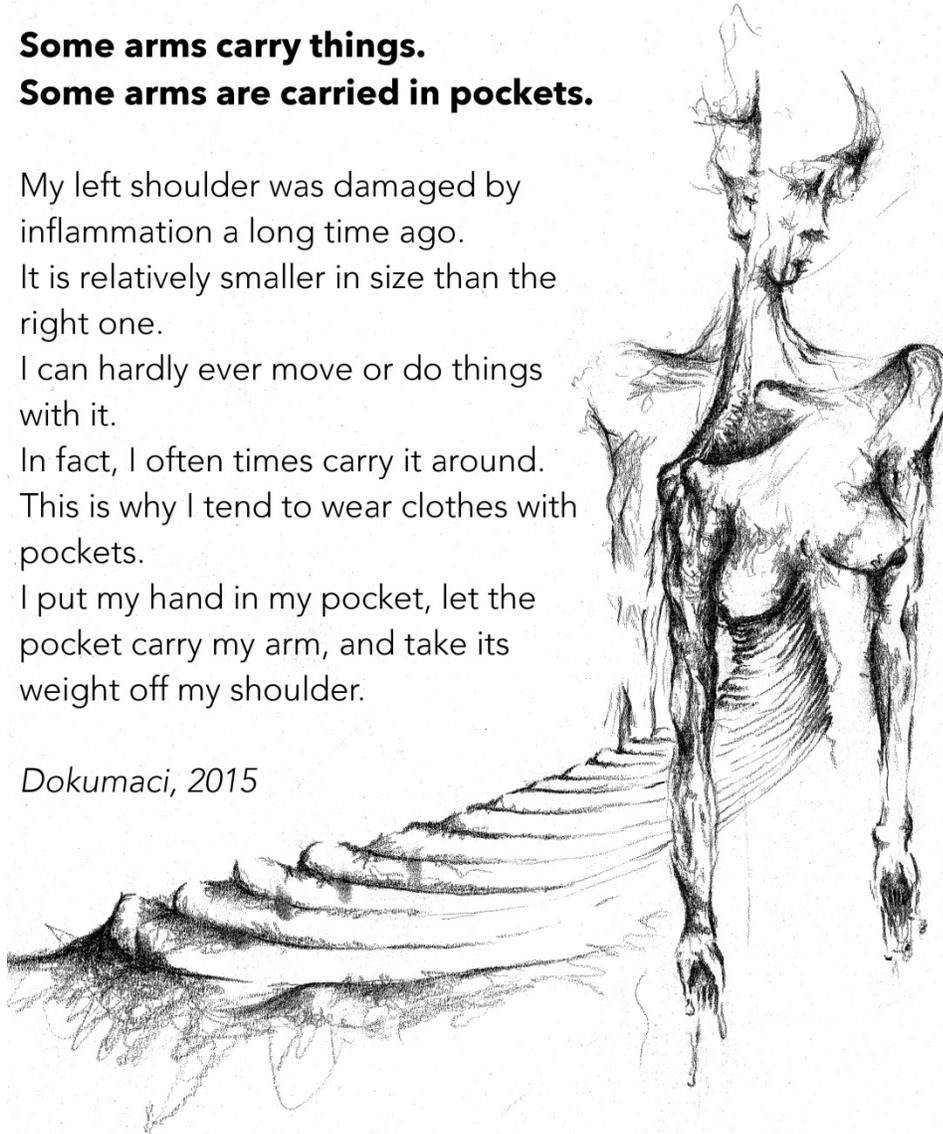
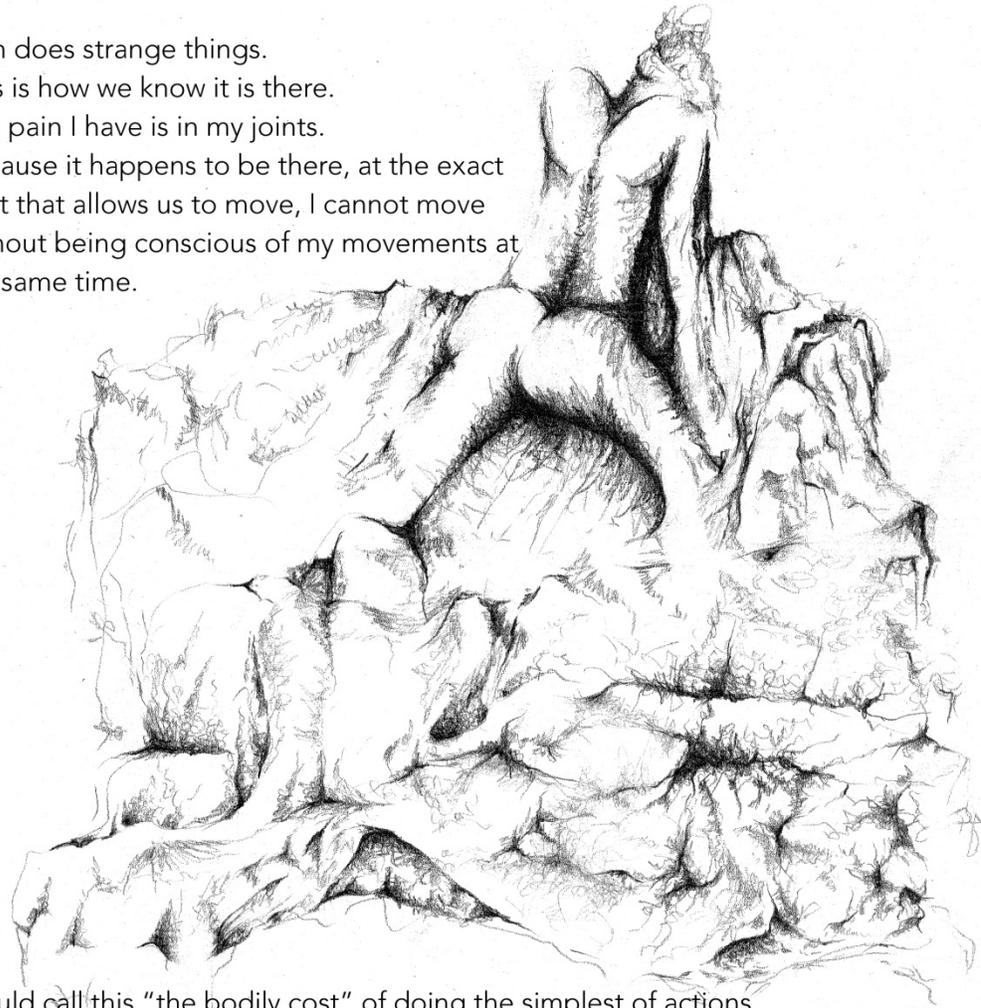


Figure 2. *Some Arms Carry Things. Some Arms Are Carried in Pockets*, by Arseli Dokumaci

Caption

A black-and-white drawing in which the body is split in half from the shoulders and the chest is transforming into steps.

Pain does strange things.
This is how we know it is there.
The pain I have is in my joints.
Because it happens to be there, at the exact
spot that allows us to move, I cannot move
without being conscious of my movements at
the same time.



I would call this “the bodily cost” of doing the simplest of actions.
The bodily cost of lifting a coffee mug to your mouth; the bodily cost of putting
on your socks; the bodily cost of turning the key in the lock; the bodily cost of
hugging a friend. And even, yes, even the bodily cost of pulling the feathery
sheets and fluffy duvet over your body while sleeping at night... Dokumaci, 2015

Figure 3. *Fighting with Feathery Sheets and Fluffy Duvet*, by Arseli Dokumaci

Caption

A pencil drawing in which a woman’s back is mostly exposed and her legs disappear under a cluttered surface.

Arseli Dokumaci, PhD, is a postdoctoral fellow in the Department of Anthropology at the University of Copenhagen in Denmark. She received her PhD in performance studies from Aberystwyth University in 2012 and completed a *Fonds Québécois de Recherche sur la Société et la Culture* postdoctoral fellowship at McGill University’s Department of Social Studies of Medicine in 2016. Her research interests include disability, daily living with

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