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From the Editor



Kelly Michelson MD, MPH, FAAP

One goal of this newsletter is to disseminate the exciting work of people dedicated to advancing pediatric bioethics. But when a publication in this newsletter leads to unexpected opportunities to further a worthy cause, it is a special reason to celebrate. In the fall 2016 newsletter, Ms Theresa Chmiel contributed to the first installment of the "Just an Expression?" column. As a result of that work, Ms Chmiel was asked to contribute to the book "Follow the Child: Planning and Having the Best End-of-Life Care for Your Child" written by Sacha Langton-Gilks. For Ms Chmiel, whose son Asher Chmiel bravely defied expectations in battling epilepsy and cerebral palsy before passing away at the young age of 12, this was a unique opportunity to share experiences and help other families. But Ms Chmiel did not stop there. She recently returned from England where she represented the United States at an event in Parliament, inspired by the book. Ms Langton-Gilks stood before Parliament members and urged them to consider policy changes that would make access to pediatric palliative and end of life care easier for all children. Upon returning home, Ms Chmiel spoke with her local Congressman about the issue of access pediatric palliative care, something that Ms Langton-Gilks calls, "a postcode lottery." Ms Chmiel was presented with a Congressional Record for her passionate advocacy. Also, as a result of her efforts, Ms Chmiel was asked to join the Patient and Family Advocacy Council of her local palliative and hospice care provider. What an extraordinary impact locally, nationally and internationally. Our warmest thanks and congratulations to Ms Chmiel on all her hard work and dedication.

While I cannot predict what unexpected opportunities will unfold for the authors who have contributed to this newsletter, I can tell you that you are in for quite a treat. This newsletter covers topics ranging from disastrous patient outcomes, to virtue ethics for mid-career physicians, bioethical challenges involved in pubertal suppression of transgender youth, the role of religion and spirituality in medicine, and immigration as a social determinate of health for children. In this edition of "Just an Expression" we also explore the terms "lethal" and "fatal" and read about the The Two-Headed Calf. I can't wait to see where all this will lead!

From the Chairperson



Brenda Mears MD, FAAP

In February 2011, Dr Hadiza Bawa-Garba (a registrar, the United Kingdom equivalent of a resident) was involved in a case with a disastrous outcome. Much contradictory information about the case has been published in both medical and non-medical publications. This summation appears to be accurate.

A six-year-old child with Down syndrome and a history of an atrioventricular canal defect was sent to Leicester Royal Infirmary in the morning with nausea, vomiting and dehydration. The child was initially thought to have gastroenteritis and given IV fluids. Although the first pH was 7.08, a repeat showed some improvement. The child was started on antibiotics for pneumonia. Dr Bawa-Garba's supervising consultant, Dr Stephen O'Riordan, spoke with her about the child later in the afternoon, at which time she informed him of the child's lab results. Dr Bawa-Garba neither asked him to nor did he offer to see the child. Though the child's heart medication, enalapril, was not ordered, the mother gave the child his evening dose without discussing this with the doctors or the nurses. The child arrested and did not recover, dying less than 12 hours after admission.^{1,2,3,4,5}



From the Chairperson (cont.'d)

Brenda Mears, MD, FAAP

Several problems and errors occurred during treatment of the child. Dr Bawa-Garba was returning from maternity leave to a new hospital environment. The hospital was short staffed and various sources say she was covering the work of 2-4 physicians; she worked a 13 hour shift with no breaks. Dr O'Riordan was teaching elsewhere and was not available until late in the day. The primary nurse was an agency nurse and not familiar with the hospital protocols. The hospital IT system was down, contributing to delays in performing and obtaining lab and radiology results. When the child arrested, Dr Bawa-Garba initially confused the child with another child who had a DNR order (however, the momentary delay this caused was thought not to have affected the outcome).^{1,2}

Several days after the incident, Dr O'Riordan met with Dr Bawa-Garba in the hospital canteen and asked her to reflect on the events in her electronic portfolio and sign a form stating what she might have done differently. The NHS trust, which runs Leicester Royal Infirmary, ultimately acknowledged that there were systemic failures that contributed to the outcome and initiated changes to improve support for trainees and improve safety.^{6,7,8}

Dr Bawa-Garba was initially told there would be no charges against her and she continued to practice medicine, apparently with no further problems. After further review, and some pressure from the child's family, both Dr Bawa-Garba and the primary nurse for the child were charged with manslaughter in 2014.^{5,7,9}

In Dr Bawa-Garba's 2015 trial, Dr O'Riordan testified against her. A jury found both Dr Bawa-Garba and the nurse guilty of manslaughter by gross negligence. Dr Bawa-Garba received a 2-year suspended jail sentence. At that time, the Medical Practitioners Tribunal Service, which adjudicates complaints made against doctors in the UK, suspended her license on the grounds that her fitness to practice was impaired. Initially, it was thought she would be able to resume practice after serving the suspended sentence but the General Medical Council (GMC), which regulates doctors in the United Kingdom, believed she should lose her license and appealed. In January 2018, London's high court removed Dr Bawa-Garba from the medical register.^{9,10,11,12}

The reaction among the medical community has been marked with concerns about problems with this case. As the supervising consultant, how much responsibility did Dr O'Riordan have? Why wasn't he charged? Why did he not see this child even if not specifically asked to do so? He knew she was returning to work from a maternity leave and was new to the hospital. He was aware of the lab results and x-rays. Presumably he was

aware the hospital was short-handed. Why were there were no corporate manslaughter charges? If Dr Bawa-Garba is so impaired she cannot safely be allowed to continue as a physician in 2018, why was she allowed to practice between the time of the incident and her conviction in 2015?^{1,6,13}

There has also been concern about the use of the reflections in her electronic portfolio. In the United Kingdom, all physicians are required to engage in reflections, which are reviewed in their annual appraisals for re-licensure. May such reflections be used against a physician to suspend their licenses and to bring criminal charges against them? Although Dr Bawa-Garba's reflections appear not to have been directly entered into testimony, they were available to Dr O'Riordan and other expert witnesses for review.^{6,10,12,13,14}

We all have made and will make errors in our careers. As a medical community, we have tried to foster a culture of improving patient safety. Narrative writing and reflections, at least in theory, enable us to learn from the experiences we have had and apply this knowledge to improve safety in the future. If our goal is to increase safety, we need truthful and complete communication about errors and near misses.^{6,15,16}

In this case, there were multiple errors and systemic problems. The NHS trust states that some changes have been made to fix systemic errors that contributed to the outcome of the case, but the brunt of blame seems to have been placed on a young physician and nurse. If individual doctors and nurses are singled out it may become much harder for any of us to be open and truthful.^{5,6,9,17,18}

Responses in the UK to this case have included less practical suggestions, including that physicians should "call out sick" when the working situation is unsafe. Others have suggested that physicians should report to the police anytime they are involved in an error or that physicians should refuse to do the required reflections.^{3,8,13}

The Academy of Medical Royal Colleges (the coordinating body for 24 medical royal colleges and faculties in the UK and Ireland) has released some guidance suggesting that physicians "fully anonymise" patients in all reflection entries. However, they also noted that physicians cannot be protected against legal inquiries. The GMC, courts, police and coroners may all request the entries. Other sources have sug-



From the Chairperson (cont.'d)

Brenda Mears, MD, FAAP

gested that physicians should write initial reflections on paper, avoid any admissions of error or negligence, and list external factors that contributed to negative outcomes. The British Medical Association (BMA) has launched a project where physicians may report concerns about patient safety.^{11,12,14,19}

The United States has also seen high-profile cases in which doctors faced criminal prosecution after a patient's death, including those involving "pill mills" and overdoses. After Michael Jackson's death in 2009, his doctor Conrad Murray was convicted and stripped of his medical license. Though the situation Dr Bawa-Garba faced seems less likely to occur here, perhaps we should review whether our reflective writings can be subpoenaed and consider how our writings may be perceived by those outside the medical field.^{20,21}

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The following article is a modified version of "Ethical Issues in Pubertal Suppression of Transgender Youth" to appear in Finlayson, C, ed. "Pubertal Suppression in Gender Non-Conforming Youth," Elsevier Publishing Inc., In press.'

Ethical Issues in Pubertal Suppression of Transgender Youth

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Introduction

Over the last decade, the medical treatment of transgender youth has evolved. In medicine and in much of Western society there is a movement to acknowledge that biological sex and gender identity are distinct entities. Furthermore, many now challenge the idea that gender identity only involves a binary male/female system; numerous individuals believe gender identity is fluid and can occur along a spectrum.¹

At this time, we lack precise data regarding how many children and young adults identify as transgender, though the prevalence may be as high as 1 in 200.^{2,3} Multidisciplinary clinics for transgender youth have experienced an increase in patient enrollment over the last several years, and the number of younger children presenting to clinics for gender nonconforming youth has increased.¹ These phenomena likely result from a combination of factors, including 1) increased access to information from the internet, 2) more media and other public attention to transgender individuals in society, and 3) increased awareness and openness of parents and professionals about gender nonconforming behavior.⁴ While there is no "typical age" at which recognition of gender incongruence occurs, a recent study found the average age was 8.3 years, with some children experiencing gender incongruence as early as under the age of four.⁵

Multiple factors affect the medical management of transgender

youth. First, transgender youth have high rates of mental health co-morbidities including depression, suicidal ideation, and self-harm compared to non-transgender peers.⁶ In one study, 35% of transgender youth had depression, more than 50% had suicidal ideation, and 33% had attempted suicide.⁵ Therefore, clinicians have an obligation to identify and secure treatment for these serious mental health conditions in addition to addressing any gender dysphoria. An additional challenge during the initiation of medical management of transgender youth is the difficulty predicting which children will "persist" and remain transgender and which children will "desist" and find congruence with their natal sex.

Here we review the ethical issues involved in pubertal suppression of transgender youth. We first provide background information on current methods of pubertal suppression, the known effects of gonadotropin releasing hormone (GnRH) agonists, and the benefits of pubertal suppression. We explore the ethical issues involved in pubertal suppression with GnRH agonists in transgender youth, looking at beneficence, nonmaleficence, autonomy, and informed consent and assent.

Pubertal Suppression

Pubertal progression begins with GnRH pulses from the hypothalamus, leading to production of gonadotropins, luteinizing hormone (LH) and follicle stimulating hormone (FSH), from the pituitary. The gonadotropins then stimulate the gonads to produce sex hormones (testosterone in natal males and estrogen in natal females). Clinically, the first sign of puberty in girls is thelarche, with development of breast tissue. On average, thelarche occurs between 8-11 years. In boys, the first sign of puberty is testicular enlargement. In natal males, secondary sex characteristics typically appear between 9-14 years.

Clinical pubertal suppression involves administration of GnRH agonists, which have been termed "blockers" as they "block" puberty. Treatment with a GnRH agonist results in tonic, rather than pulsatile, levels of GnRH. Without pulsatile GnRH, the hypothalamic-pituitary-gonadal (HPG) axis is suppressed, preventing production of testosterone or estrogen by the gonads, thereby halting pubertal progression.⁷

In 2006, a group in the Netherlands created a protocol for the use

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Ethical Issues in Pubertal Suppression of Transgender Youth (cont'd)

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of GnRH agonists in transgender patients as young as 12 years of age.⁹ The goal was to suppress puberty in order to treat gender dysphoria.⁴ In 2009, the Endocrine Society, along with the World Professional Association for Transgender Health (WPATH) and several other organizations, created a clinical practice guideline recommending the use of GnRH agonists for pubertal suppression in transgender children. Instead of stipulating an age for initiating the use of GnRH agonists, the guidelines support their use as soon as the first signs of puberty occur, which often occurs before 12 years of age.¹⁰ The Endocrine Society also recommended psychological assessments of patients to ascertain their readiness for treatment and ensure addressing mental health comorbidities along with gender dysphoria. The guidelines further encourage close patient monitoring by a mental health provider throughout medical treatment.¹⁰

GnRH agonists have become the standard of care for pubertal suppression in transgender youth.⁴ Clinicians generally believe that blocking puberty with GnRH agonists is fully reversible. However, there are limited safety and efficacy studies and medical science has essentially no data on the safety or effectiveness of GnRH agonists specifically in transgender children.¹

Benefits of Pubertal Suppression

Pubertal suppression with GnRH agonists constitutes the first step in the medical treatment of transgender youth with gender dysphoria.⁴ GnRH agonists provide several benefits to transgender youth. First and foremost, GnRH agonists prevent the development of natal secondary sex characteristics, which can cause substantial emotional turmoil in transgender patients, worsening dysphoria, and exacerbating psychiatric comorbidities.⁵ Additionally, postponing the “wrong” puberty, can allow the patient to focus more fully on mental health therapy.⁴ Second, delaying puberty provides transgender youth and their families time to think about their needs and goals before deciding whether to continue with more “permanent” aspects of the gender transition process.^{4,11} While some patients have had ample time to think through their circumstances and aspirations, it often takes family members longer to understand the situation, see things from the patient’s perspective, and accept a radical change in their expectations and hopes for their child. Families also often need time to learn about the benefits and risks of medical treatment. Third, if the child and the family decide to continue with the gender transition, preventing natal secondary sex characteristics allows for optimal gender transition in the future.¹² Preventing secondary sex characteristics by halting natal puberty can reduce or eliminate the need for surgeries to reverse or ameliorate physical changes (developed breasts, Adam’s apples, facial bone development in natal males, and so on).⁴

Ethical Issues

Research

Research focusing on transgender youth has been limited, though it is starting to expand.¹² Only over the last decade have investigations into the effects of the medical treatment of transgender youth occurred. The majority of clinical recommendations were based on expert opinion or extrapolated data from the adult transgender population, neither of which is ideal since anecdotal evidence is often biased and extrapolating from adult data in pediatric populations also has significant flaws.¹ In addition, the majority of studies of transgender adults have been observational, relying on accounts of previous events with resultant recall bias. Finally, developmental differences exist in how children and adults make decisions and analyses based on adult decision-making do not account for those differences.

The lack of high quality research in the transgender youth population has prompted an interest in developing evidence-based clinical practice for pediatric transgender patients. To this end, the first multicenter NIH-funded study in the United States investigating the impact of psychosocial factors and medical treatment on transgender youth began enrolling subjects in 2016.¹³ Multiple factors have contributed to the lack of research in transgender youth. First, children are considered a vulnerable class and numerous ethical and regulatory constraints limit research in these populations, though exceptions may apply.^{14,15} As a result, researchers may have difficulty obtaining Institutional Review Board (IRB) approval for studies involving transgender youth and, as a result, may hesitate to propose studies that include this population. However, this reluctance perpetuates the problem of few treatment options with proven effectiveness. It also creates a vicious cycle: transgender adolescents continue to have inadequate sexual and mental health care compared to their peers and the lack of research prevents progress in addressing these disparities.¹⁷ This exemplifies the need for ethically conducted research in vulnerable populations, including transgender youth.

Researchers, regulators, and ethicists debate what kinds of studies are ethically permissible. Most contend that randomized control trials (RCTs) provide the greatest rigor and yield the most reliable clinical information. In RCTs, subjects are randomly assigned to an unproven treatment arm, to a placebo arm, or to a conventional (standard care) arm, if applicable. Most stakeholders agree that for transgender youth, it would be morally unacceptable to provide GnRH agonists to some subjects and placebos to others in order to study the short and long-term effects of hormone blockers.¹² In addition, experience gained with GnRH agonists in other contexts suggests that they are associated with

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minimal harm, making a placebo arm unnecessary. However, some argue that the available information on the harm associated with GnRH blockade is circumstantial and has the potential to be so great that it is morally wrong not to conduct a placebo-controlled trial.

Balancing Beneficence and Nonmaleficence

In the transgender youth population, one way for clinicians to act with beneficence is to treat gender dysphoria with GnRH agonists, cross-sex hormones (CSHs), and gender-affirming surgery. However, treatment of gender dysphoria with medications not yet fully proven safe and effective in transgender youth involves unknown risks. While GnRH agonists in children with precocious puberty effectively halt puberty progression, that fact alone does not establish that these drugs relieve symptoms of gender dysphoria.¹⁹ There is limited data about the psychological impact of GnRH agonists. One study from 2014 by the group in the Netherlands explored the psychosocial impact of GnRH agonists, CSHs, and surgery in trans-youth and found that gender dysphoria and body image dissatisfaction persisted through puberty blockade with GnRH agonists but were relieved after CSHs and surgery.¹⁹ These results are not surprising as GnRH agonists halt pubertal progression but do not result in the development of secondary sex characteristics of the affirmed gender. However, their use *in conjunction with* CSHs and gender-affirming surgery has been shown to improve gender dysphoria.¹⁹

The long-term effects of GnRH agonists on bone formation, cognitive development, and future fertility are also unknown.¹ Regarding bone health, sex steroids promote bone growth and mineralization⁷ while pubertal suppression results in decreased production of sex steroids during the period of suppression. Therefore, use of GnRH agonists could negatively impact bone density. Additionally, as transgender youth may now receive treatment before age 12, this creates a population of children exposed to long courses of GnRH agonists, extending the period of low sex steroids.

The use of GnRH agonists in children with precocious puberty does not impair bone mass or final height.²⁰ However, trans-youth differ from individuals with precocious puberty in that the latter have already been exposed to pubertal sex steroids while young transgender children may have had very limited exposure. A longitudinal observational study from the Netherlands published in 2015 showed that trans-youth who had pubertal suppression with GnRH agonists *and* treatment with CSHs had decreased bone mineral density z-scores compared to pretreatment. The researchers concluded that either peak bone mass was delayed or attenuated. However, the study had several limitations: the small subject pool (n=34); the exact cause of the decreased bone

mass was unknown and confounded by variations in the duration of GnRH agonist treatment, low initial CSH dosing, and other factors, including the use of CSHs; many of the subjects had already started puberty and thus had some exposure to endogenous natal sex steroids; and the duration of GnRH agonist therapy was often brief. Also, the report provided no information about diet and exercise, which contribute to bone density.²¹ Taken together, these limitations highlight the need for additional research.

Another important area of research and consideration in the medical treatment of transgender youth concerns fertility preservation. Current methods of fertility preservation include sperm freezing for post-pubertal males and oocyte cryopreservation for post-pubertal females. For prepubertal individuals, fertility preservation techniques are still experimental. If a prepubertal transgender youth on GnRH agonists want to preserve oocytes or sperm, clinical protocols require them to stop the GnRH agonist and proceed through natal puberty in order to harvest gametes, which can be extremely distressing for the transgender individual.⁴ In the future, it may be possible to cryopreserve prepubertal gonadal tissue and mature the gametes *in vitro*, however this remains experimental.²²

To date, no studies have appeared on the isolated impact of GnRH agonists on future reproductive ability in transgender youth. The belief that GnRH agonists do not affect future fertility comes from inferences in patients with central precocious puberty (CPP).²³ The reproductive effects of GnRH agonists in CPP presents fewer challenges than assessing their impact in transgender individuals, as the latter typically have also received CSHs. It does not seem possible to isolate the impact of GnRH agonists from CSHs on the future reproductive potential of transgender youth.

Fertility research in trans-youth has thus far focused on the decision of whether to undergo preservation. In 2017, a retrospective review of 73 trans-youth patients showed that 72 had fertility counseling prior to CSHs and only 2 subjects attempted fertility preservation (both natal males). In that group, 45% discussed adopting and 21% did not want children.²⁴ Many reasons might lead the majority of trans-youth offered fertility preservation to decline this option. Children and adolescents may not be developmentally ready to make decisions about their future fertility. In addition, transgender youth often feel a sense of urgency with gender transitioning and do not want to delay or stop treatment to harvest sperm or eggs.¹² For some transgender youth who may want genetically-related children in the future, the idea of using natal eggs or sperm that do not align with their gender identity seems too discordant.²⁵ Other barriers to fertility preservation include: cost, insurance coverage, invasiveness of the proce-

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dures, potential societal pressure about what comprises a “nuclear” family, and objections by parents, other family members, or romantic partners.

Nevertheless, perspectives may change with age and maturity and once transgender youth reach adulthood they may regret no longer having the ability to produce genetically-related children because they did not preserve eggs or sperm. Data from transgender adults have been mixed, with some studies showing transgender adults would have considered fertility preservation if the option had been available and other studies showing relatively little desire for biological children.^{26–28} Unfortunately, transgender individuals may encounter difficulty adopting, as reports have appeared recounting challenges for transgender individuals in achieving approval to become adoptive parents.²⁴ For these reasons, it is important to 1) understand the impact of the medical treatment of transgender youth on future fertility and 2) discuss with the patient and family all of the potential options for future fertility before irreversible medical treatment occurs.

Respect for Autonomy: Assent and Consent

Autonomy refers to the ability of individuals to make their own decisions.¹⁸ Despite the lack of legal authority to make decisions about their own care, clinicians must engage all youth in the medical decision-making process, taking into account each patient's developmental stage, cognitive abilities, and maturity.

In the transgender youth population, the concept of autonomy has particular relevance and complexity. Children are presenting to gender clinics at younger ages than before and, as noted earlier, no definitive means to identify which children will persist along the transgender path exists. Some data suggest that two factors correlate with persistence of transgender identity: greater gender dysphoria and being a natal female. Of course, these population attributes do not predict what will occur for any particular patient.³⁰ The inability to know which patients will complete gender transition in the future creates difficulty in balancing the child's interest in making his or her own choices about the future with the desire for immediate medical treatment.^{30,31} Medical professionals understandably hesitate to initiate irreversible treatments knowing the patient may later view the treatment as unnecessary and regrettable.¹²

Another challenge to the ability of clinicians to respect the autonomy of transgender youth occurs when parents or legal guardians have differing medical opinions from the patient. Since all transgender youth below the age of 18 and not emancipated need guardian consent to proceed with medical treatment, conflict can arise when diverging opinions exist within the family unit.

Guardians who support the child's gender identity may provide consent for medical treatment with GnRH agonists and CSHs. However, medical treatment can be delayed for patients whose guardians are reluctant to accept their gender identity or who reject the child's feelings and choices and therefore will not provide consent. Postponing medical care can impose substantial distress on the transgender child or adolescent. In cases of guardian refusal to provide consent, the patient may have to wait until age 18 to start medical treatment, which means that patient will undergo full pubertal progression and will acquire secondary sexual characteristics of the non-intended gender.¹² In cases where parents share guardianship and one parent accepts treatment but the other parent does not, treatment may also be delayed until both guardians agree or the patient reaches the age of majority.

Further, the very notion of fully informed consent for transgender treatment can prove problematic. The patient and guardian can only learn what medical information is known. Where clinicians have limited understanding of the long-term effects of medications, full informed consent seems elusive. Professionals must clearly explain what they know and do not know and the potential long-term effects of available treatments. Families may find the uncertainty very difficult to grasp and/or accept, leading to unwillingness to proceed.

Conclusion

Pubertal suppression for transgender youth presents multiple ethically complex issues. The lack of knowledge about the long-term impact of GnRH agonists on transgender youth renders full informed consent and assent problematic, thereby undermining meaningful exercise of patient autonomy. This uncertainty also limits medical professionals' attempts to balance beneficence and nonmaleficence in counseling patients and families.

Nevertheless, it seems inappropriate and unrealistic to stop using GnRH agonists to suppress pubertal development in children with gender dysphoria while we wait for more data. Having these children progress through natal puberty would cause considerable emotional distress for many patients and makes later treatment, especially surgery, more difficult and less effective. Thus, refusal to use hormone blockade goes against the notion of nonmaleficence and would, indeed impose harm. Despite limited data about the positive psychological impact of GnRH agonists alone, we endorse the use of GnRH agonists due to the benefit of preventing natal secondary sex characteristics and providing time for patients and families to decide the best course of action.¹⁹ While GnRH agonists alone may not improve gender dysphoria, they constitute a vital part of the protocol for treatment of gender dysphoria.

To address the ethical issues in the medical care of transgender

Ethical Issues in Pubertal Suppression of Transgender Youth (cont'd)

Rebecca M. Harris, MD, PhD, MA —Irina N. Kolaitis, MD, FAAP — Joel E. Frader, MD, MA, FAAP

youth, the affected population and those that provide treatment need additional research about the long-term effects of treatment. Only with such evidence will medical professionals be able to act in a beneficent manner and enable patients and families to adequately exercise autonomous medical decision-making. For now, clear communication with patients and their families must acknowledge the limits of medical information regarding the offered treatment.

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Children, Immigration and the Public Sphere: When It's Not Safe to Play Outside

Minal Giri, MD, FAAP

Dr Giri is the Medical Director of Melrose Park Pediatrics in Illinois. She is also the Chair of the Refugee Immigrant Child Health Initiative. Her specific interests include unaccompanied immigrant children and medical forensic evaluations. Dr Giri has served as a consultant for the Office of Refugee Resettlement's Division of Unaccompanied Children's Services and the Department of Homeland Security in the development of trauma-centered regulations for children.

Article 31.1. States Parties recognize the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts. Article 31.2. States Parties shall respect and promote the right of the child to participate fully in cultural and artistic life and shall encourage the provision of appropriate and equal opportunities for cultural, artistic, recreational and leisure activity.

Convention on the Rights of the Child

United Nations High Commissioner for Refugees

Who gets to play

As physicians, we understand that the benefits of outdoor play go well beyond the obvious physiological requirements of Vitamin D for bone health or reducing the risk of obesity. Outdoor play allows for brain growth and development; increased opportunities to engage with the world in creative ways; and the development of cognitive and physical skills and imagination.ⁱ Furthermore, the ability to play outside freely reinforces a feeling of connectedness, belonging, and well-being in the world. However, what many traditionally take for granted as an integral part of a normal childhood does not exist in many parts of the world, including our own backyard.

In 2006, I worked with refugees in Cairo, Egypt at a nongovernmental organization housed at All Saints Cathedral. All Saints Cathedral welcomed refugees seeking asylum from atrocities committed in their homelands. Its comprehensive program provided health care along with education, housing, and employment training.

Most of the refugees I served were from the Darfur region of the Sudan. While the program offered a safe and welcoming environment within the confines of the cathedral grounds, there was little we could do to protect the Sudanese from the rampant racism, social rejection, and negativity they encountered daily on the streets of Cairo. My patients often told me, "we cannot let our kids play outside or walk around on the street. They must be kept inside. We are afraid that someone might hurt them." This was the reality of their new life in a foreign land. Nowadays, we hear about the embattled cities of Syria and the children who have been barricaded in basements for the last two years to escape constant shelling and bombardment. But these are far-away places.

Let us turn to our own streets and neighborhoods, for example, the parts of Chicago plagued by gun violence that claims the lives

of hundreds of children riding their bikes or playing on their front porches. On the national level, let us consider the millions of children living in immigrant families who no longer feel safe.

Our current national discourse around immigration directly and indirectly impacts the lives of children. Recent policy changes have led to increased fear and anxiety within certain populations. These changes have real health consequences for children. Whether passing bans or building walls, when the debate involves children, a heightened level of vulnerability exists. Children, the least able to advocate for themselves, have the most to lose as the long-term effects of toxic stressⁱⁱ have a lasting impact on their neurocognitive development.

The Immigrants among Us

Immigration, however contentious, is an ongoing thread in the narrative of our nation. Immigrants themselves are woven into the fabric of our communities. Let us not conflate debates regarding the contributions and "deservingness" of immigrants in our society with treatment of *children* in our society. Close to six million children (people under the age of 18) who are United States (US) citizens live with an undocumented parent or family member.ⁱⁱⁱ Over the next forty years, one in three US children will come from immigrant families.

When we serve children of immigrant families, we attempt to address the needs of truly diverse populations. These individuals hail from a variety of countries and live in the US for different reasons. They have a wide range of socioeconomic and political backgrounds. Immigrants include people crossing the border on foot; individuals who've been granted H1B visas; people who've overstayed their travel visas; and those "officially vetted" refugees from war torn countries.

As the population of immigrant children continues to grow, "health care providers will increasingly manage a wide range of complex issues related to immigration as a social determinant of health."^{iv} Whether voluntary or involuntary, migration challenges individuals and communities and has significant social, economic, and health consequences. Public health discourse acknowledges immigration itself as a complex social determinant of health. Heidi Casten and her public health colleagues are beginning to explore how being an immigrant impacts behavioral choices and can significantly alter the effects of other social positioning, such as race/ethnicity, gender, or socioeconomic status.^v "[Immigration] places individuals in ambiguous and often challenging relationships to the government and its institutions, including

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medical services. The health effects of immigration have an impact on the long-term development and well-being of children. Much is at stake for a large swath of our community. What happens to our children now will affect them for the rest of their adult lives.

Fear, Isolation and Access to Care

Recent negative rhetoric and increasing concerns about discovery and fear of deportation have had a chilling effect on the ability of immigrant families to move about in the world. This growing threat deters immigrant families from accessing all kinds of resources and services including medical, housing, legal, education, and community supports. Children miss school and forgo sports or activities that require travel. Families fear going to places of worship and being out in their communities. Immigrants change health-seeking behaviors for themselves and their family members because they fear being stopped by and potentially deported by police.

As an example, Mt Sinai, a large Chicago-based health system, has seen a significant drop in immigrant patients and clients in hospitals, offices of primary care physicians, Women, Infants, and Children (WIC) programs, family case management services, and rehabilitation services. Families are often not accessing services for which they do, in fact, legally qualify.

This scenario is playing out all over the country as evidenced by a recent Kaiser Family Foundation report, *Living in an Immigrant Family in America: How Fear and Toxic Stress are Affecting Daily Life, Well-Being, & Health*.^{vi} "Daily life has become more difficult for immigrant families due to increased fear and uncertainty. Some parents said that it is harder to find employment in the current environment, further increasing financial strains on families. Increased fears also are affecting some families' daily routines. Some parents, particularly those who are undocumented or who have an undocumented family member, said they are only leaving the house when necessary, such as for work; limiting driving; and no longer participating in recreational activities, like visiting their local park. As a result, they and their children are spending long hours in the house behind locked doors. Parents also indicated that they and their children are increasingly fearful of interacting with police or authorities."

As a pediatrician in an underserved, largely immigrant suburb on the outskirts of Cook County, IL, I see this play out daily in my clinic. One teenager suffered from headaches and had multiple episodes of chest pain that led him to the emergency room (ER). After several visits he revealed that his father's work place had been raided. He said he was, "scared that dad was going to get

deported" while he was at school. Recently, I heard the story of a two-year-old girl who carries around a backpack full of her favorite toys and possessions because she overheard her parents saying that the police could come and take her away at any moment. She wanted to be prepared.

My patients' parents are refusing to go to referral sites that require them to drive long distances. During this winter's influenza epidemic, I had to convince the mother of a child who was in respiratory distress that her son needed to be transferred to an emergency room (ER). She simply did not want to go. I called 911 in part due to the child's condition, but also because I was uncertain that she would take her child to the ER as directed. In tears, she asked me to hold off on calling the ambulance until her husband arrived. She was terrified that she would be questioned or asked to show papers.

Under previous government administrations, Immigration and Customs Enforcement (ICE) recognized hospitals, schools, and places of worship as *sensitive locations*^{vii} where enforcement actions should not take place unless "exigent circumstances" existed. However, in the last year there have been multiple reports of parents being detained in waiting rooms while their children are in surgery or obtaining necessary medical care.

For example, Rosa Maria Hernandez, a ten-year-old girl with developmental delay and cerebral palsy who had never been separated from her parents, was escorted to the hospital for a surgery by border patrol. Post operatively, Rosa Maria Hernandez was transported to a federally funded shelter in San Antonio where she was held for ten days.

Even the mere threat of deportation can have a traumatic impact on children. "When you're worried every day that your parents are going to be taken away or that your family will be split up, that really is a form of toxic stress... we know that it's going to have long-term implications for heart disease, for health outcomes for these children in adulthood." said a Minnesota pediatrician^{viii}

The actual deportation of a family member, especially a parent, results in both immediate and long-lasting damage to the overall well-being of children. "In addition to the loss of a parent and the immeasurable security that comes with having a stable family, deportations often leave children in the foster care system. Fathers in many immigrant families are often the bread winners and are more often than other family members to be detained or deported. Removals can therefore result in a large number of single mothers left behind to care and provide for the family."^{ix}

Research shows that when their parents have been deported, children go through a series of negative experiences. They suffer from psychological trauma, especially when they witness a parent's arrest and their family is separated. They are also

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likely to experience housing insecurity and economic instability.

Pediatrician Advocacy

The American Academy of Pediatrics (AAP) has taken a strong stand to “protect the health and well-being of all children—no matter where they or their parents were born.”^x At the 2017 AAP Annual Leadership Forum, the top three resolutions included: 1) building and improving access to legal representation for children, adolescents, and families seeking safe haven; 2) protecting the children of migrants; and 3) responding to the executive order limiting immigration and entry.^{xi}

The AAP has released policy statements advocating for the protection of immigrant children^{xii} and against the separation of children and parents along the border.^{xiii} “Many of the children who will be most affected are the victims of unspeakable violence and have been exposed to trauma. They are coming to the US seeking safe haven in our country and they need our compassion and assistance. Broad scale expansion of family detention only exacerbates their suffering.” stated Fernando Stein, AAP Past President. The Academy also endorsed the Fair Day in Court for Kids Act of 2016 (S. 2540), which provides unaccompanied children with access to counsel throughout their immigration proceedings.^{xiv}

In addition, the Council on Community Pediatrics Immigrant Health Special Interest Group developed a toolkit helps pediatricians navigate the medical and legal needs of immigrant children and their families.^{xv}

Several AAP Chapters have worked to address the needs of the immigration population by educating providers, developing educational models, and writing articles in local papers. Across the country, pediatricians are partnering with refugee immigrant advocates in the community and testifying in Congress. Many pediatricians continue to provide direct service through immigrant and refugee clinics. Additionally, they are volunteering at border detention centers and medical-legal partnerships.

Refugee Immigrant Child Health Initiative, the group I founded through the Illinois Chapter of the American Academy of Pediatrics, has identified several opportunities to mitigate the impact of these concerns on the health of young children. These opportunities include: 1) working with physicians, health clinics, and health systems to implement immigrant friendly policies and clinics; 2) providing practice resources that can help connect patients and their families to legal and other immigration resources; 3) identifying and training physicians to conduct forensic exams to provide critical evidence in asylum cases for young children housed in shelters throughout Chicago; and 4) developing a model for how pediatric providers can partner with

parents/caregivers to promote resilience and reduce the impact of stress and trauma on their children.

Many health care providers already support immigrant families and children through their efforts to understand the “back stories”, the journeys, the realities of how these families’ lives have been affected. By making these connections, pediatricians can guide the immigrant families to community and statewide advocacy groups that will further support and educate them on their rights.

Amidst all the turmoil, fear, and uncertainty, it is important to keep protective factors in mind when working with immigrant families. A positive disposition and supportive family environment will help reinforce a child’s resilience. Every child deserves the right to play and grow and thrive. All grown-ups were once children... but only few of them remember it.^{xvi}

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For questions, comments or interest in joining the Refugee Immigrant Child Health Initiative please contact Dr. Minal Giri at: minalgirimd@gmail.com



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Non-Hospital Religious Representatives: Needed Allies in Ethics Mediation for Parental Religious Objection?

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Among scientists and clinicians there is a tendency to dichotomize the proper roles of medicine and of religion. However, these two seemingly separate entities may both be important parts of an individual patient's life in a way that makes them indistinguishable. Who am I as a person? What do I value? How do I make decisions? These questions may be greatly impacted by a person's spiritual and religious beliefs and become essential during medical decision-making when a person is critically ill. These very personal choices greatly impact how providers guide a patient's medical care. Medical providers ought to be cognizant of how medical options may fit (or not fit) into the fundamental societal values of religion and spirituality.

For a child, the role that religion and spirituality will play in their life is determined by the child's parents' desire to incorporate spirituality or religion into the child's physical and cognitive development. Raising a child in a religious tradition can be an integral part of the parent's efforts to shape their child into an autonomous adult. Society grants parents wide latitude in this process: parents may choose to raise a child in a strict religious tradition or entirely devoid of religion.

In pediatrics, respect for this parental authority to raise a child in a particular religious tradition and to make decisions in line with that tradition must be balanced with a duty to protect the best physical interest of a child. Parental latitude is narrowed in medical decision-making for a child, as the physical best interest of the child and the child's future autonomy take precedent over a parent's right to raise religious objections to care that may pose harm to the child.

When conflicts arise due to parental objection to medical care based on religious grounds, guidelines encourage providers to 1) gain clarity in defining what the best physical interest of the child is amongst all parties, and 2) foster communication around the nature of the religious objection to this best interest.⁶ Chaplains, religious representatives trained in a hospital setting, have long served as support during these conflicts. Yet, limited hospital staffing of chaplains, family resistance to an unfamiliar religious leader, or differences in denomination or beliefs may all serve as barriers to chaplains fully responding to families in these times of crisis. In such cases the involvement of a personally trusted faith leader may be vital for a family to come to a decision.

To understand this need we must first appreciate the differences between hospital chaplains and community religious representa-



tives (Table 1). Chaplains, unlike most non-hospital clergy, have undergone specific clinical training to provide religious and spiritual support, regardless of denomination, in a medical setting. Chaplains are not meant to replace community faith representatives, but rather compliment their spiritual support. A personally trusted faith leader may continue to play an important role for families. Yet, despite this importance, recommendations for collaboration with non-hospital religious representatives in medical decision-making is conflicting.³⁻⁶ No studies to date have quantified the frequency with which non-hospital clergy were included in surrogate decision-making discussions, or qualitatively explored medical provider viewpoints on their inclusion.

We believe that religion's role in medical decision-making for many families is currently underappreciated, leading to increased and potentially preventable conflict. We propose that current recommendations for responding to conflict would be strengthened by first encouraging screening of a family's religious or spiritual beliefs *before* the conflict occurs. If conflict cannot be prevented, community spiritual leaders, when requested by family members, should be incorporated into mediation discussions in a timely and inclusive manner. While these cases are not infrequent, more can be known about how pediatricians currently respond to these conflicts, and their perception of the role community religious representatives should play in conflict resolution.

Optional online survey

<https://www.surveymonkey.com/r/7V5B7ZB>

The three authors of this piece appreciate your optional participation in a brief survey (total time: < 5 min) exploring how pediatric medical professionals respond to religious objections in medical

Non-Hospital Religious Representatives: Needed Allies in Ethics Mediation for Parental Religious Objection? (cont.'d)

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Elliot M. Weiss, MD, MSME, FAAP

Table 1: Characteristics of Hospital Chaplains and Non-hospital Religious Leaders

Hospital Chaplain	Non-Hospital Religious Leader
Religious Representative Clinically Trained in Healthcare Setting <ul style="list-style-type: none"> Familiar with medical jargon and systems 	Local Community Faith Leaders <ul style="list-style-type: none"> Often unfamiliar with medical system Knows family's background Trusted by family
Hospital Staff Member <ul style="list-style-type: none"> Available in hospital May be viewed suspiciously by family as sharing medical team's agenda New to family Needs to earn family's trust 	Not a Hospital Staff Member <ul style="list-style-type: none"> May view medical team with suspicion May not be able to visit hospital easily

care. This survey has gone through appropriate regulatory review by the Yale IRB. The responses will be used to inform our future work in this area. The survey is not affiliated in any way with the AAP or the AAP Section on Bioethics. Your responses are anonymous and your IP address is not being traced. If you have any questions, please contact the study PI, Matthew Drago, at matthew.drago@yale.edu or (203)-688-2320.

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Virtue Ethics at Mid-Career

Rosalind Ekman Ladd, PhD

Wheaton College & Brown University

Edwin N. Forman, MD, FAAP

Professor of Pediatrics, Icahn School of Medicine at Mt. Sinai

A young pediatrician answers the phone at 3 am and learns that one of her patients has been brought into the emergency department dead from SIDS. "That's terrible," she says, "Please tell the Smiths that I am so sorry and I'll talk with them first thing in the morning."

She hangs up the phone, but has a nagging feeling that she has not done enough to respond to the distraught parents. She has a busy day ahead and needs her sleep, but she wonders if she should go in now to be with the parents.

"What should I do?" she asks her husband. He answers, "What would Dr X do?" referring to her much-admired professor and mentor. "Well, I know what he would do," she answers, reaching for her clothes and shoes.

This little story illustrates the important role that older physicians play as role models in educating and influencing students' and younger colleagues' character and behavior. And it reflects an ethical theory called Virtue Theory, which poses the question, "What kind of person should I be?"

Recently the authors had the occasion to address a class of first year medical students, offering them an Introduction to Bioethics. In addition to the two traditional theories that focus on determining the right thing to do by considering consequences and/or rights, we encouraged the students to take seriously the question, What kind of doctor should I be? How can I practice medicine as an ethical person? Who is/will be my role model?

On later reflection, we realize that this is a question not only for students just beginning their careers, but is just as relevant for pediatricians at mid-career - or beyond. Thus in this paper, we challenge the reader to ask, What is my ideal of the good doctor and how close have I come to it in my own life?

Virtue theory had its beginning in Aristotle, who defines virtue as a disposition to act in a certain way, a habit of acting, e.g. courageously. Character is developed through education and practice. It is not enough to do the right thing; it must be done for the right reasons and with the right attitude. How does one learn the right thing to do and how to act? To be virtuous, Aristotle says, is to act as the virtuous person does. We teach and learn by being role models.

Role models are frequently teachers or mentors, but role models can be found in literature as well. The short story "The Use of Force" by William Carlos Williams, pediatrician and writer, portrays an old-fashioned doctor who takes a decidedly no-nonsense approach to a non-cooperative child whom he suspects may

have diphtheria.¹ A life-death decision rests on his being able to see her throat. He has her parents hold her down while he forces the tongue depressor into her mouth, leaving her screaming and bleeding. Does he do the right thing in using force? How many young doctors today would be horrified? How many would choose him as a role model?

Just as there may be many different people who can stand as role models, there are different styles of doctor-patient relationships which help define what kind of a doctor one is. Childress and Siegler characterize five ways that doctors can relate to patients: 1) as parent to child (paternalism), 2) as partners, 3) as contractual parties, 4) as friends, 5) as technician to customers.² In an oft-quoted article in JAMA in 1992, Ezekiel Emmanuel and Linda Emmanuel define four broad categories of doctor-patient relationship: 1) Paternalistic - doctor as parent, 2) Informative - doctor as technical expert, 3) Interpretive - doctor as counselor or advisor, and 4) Deliberative - doctor as friend. Emmanuel and Emmanuel defend the Deliberative model as closest to the ideal.³

There is general consensus that the Paternalistic model is old-fashioned and inappropriate in today's world. Younger physicians tend to be uncomfortable assuming near-total responsibility for patient choices and the ethical requirement to respect patient autonomy seems to rule it out as well. Yet, there are some patients in some situations, for cultural, personal, or emotional reasons, who would prefer this model, and a physician who reads the non-verbal cues may decide on a paternalistic approach. Some pediatricians argue that it relieves parents of the heavy responsibility and sometimes guilt of particularly difficult decisions, e.g. withholding or withdrawing treatment.

The Informative, or what is sometimes called the plumber model, makes a clean divide between the patient who sets goals and values and the physician who has the knowledge of how to try to achieve them. This model is a kind of business model; the patients are customers who pay experts for their services.

Another form of the business model is the Contractual model, which specifies the obligations and rights of each party. This is congruent with a society that has become litigious and where malpractice insurance for doctors and hospitals is a necessity. The assumption is that doctors and patients are strangers who need legal protection from each other.⁴ But it strays from the picture of the kindly physician who cultivates close personal ties with families, which has been an ideal for many.

Both the Interpretive and Deliberative models suggest the paradigm of shared decision-making, partners in deciding. On the

(Continued on page 17)

Virtue Ethics at Mid-Career (cont.'d)

Rosalind Ekman Ladd, PhD—Edwin N. Forman, MD, FAAP



Interpretive model, the doctor acts as counselor or advisor, helping the patient articulate his/her own values, e.g. how much do you value xxx over yyy? It assumes a more personal relationship than e.g. the Contractual model. However, because of the usually great differences in knowledge and the depend-

ency and vulnerability of patients, doctors and patients can never be equal partners. Patients have power in giving or refusing to give consent, but doctors have the power of knowing how medical intervention can help the patient and the power of controlling access to regulated drugs, admission to hospitals, endorsements to insurance companies, etc.

The Deliberative model puts the doctor in the role of friend or teacher, not only helping patients articulate their own values, but also persuading them, even to review and possibly change their values.

However, persuading patients to make a certain choice is to persuade them to make the choice the doctor thinks best. Unless the persuasion is accomplished by demonstrating the line of reasoning which led to the recommendation, it can come close to outright paternalism. In addition, in some situations there is no clear standard of practice where the expert can supply the best decision about treatment. Some decisions involve hard choices where either of two possible decisions may be ethically acceptable. If doctors are not careful about how they persuade patients, persuasion can become a matter of imposing the physician's own values on patients.

Another significant problem is that both the Interpretive and Deliberative models seem to assume long-term relationships with patients, where over time one learns their values and attitudes toward life. However, the practice of medicine today generally does not allow the time that such relationships require: office visits are short and the use of hospitalists for in-hospital care supplants the family physician relationship.

Parents often ask, "What would you do if it were your child, doctor?" Is it OK to answer this question? If the question is about vaccination, the answer is easy. In other cases, one may want to respond: "But it is not my child. Only you, the parents, can make that decision. You know your own child best, you know what is most important to you and your family."

A better response may be to give an answer, but always with a carefully reasoned explanation of why you think it is best. The family is then free to accept or reject the recommendation, with a

clear understanding of why they are making that choice. It is not based on deference to the doctor but based on reasons which they have adopted as their own. Thus the physician is fulfilling an important role as educator as well as advisor.

How useful is this delineation of models? Must one choose just one model as the ideal? Clearly, one might establish different relationships with different patients at different times or even different relationships with the same patient as circumstances and needs require. The family doctor may fall into the friend or counselor role over the years and when things are going well, but may as act as priest or plumber when a crisis occurs. Still, an ideal is useful if, among other things, it motivates self-examination so that one defends to oneself why a certain situation requires deviating from the ideal.

In all these roles, the good doctor ought to cultivate the habits that Aristotle calls virtues. Virtues are dispositions, according to Aristotle, and they are always the mean between two extremes: too little courage is cowardice, too much courage is foolhardiness. In a medical context: too little honesty is lying, too much honesty can be unfeeling. According to Aristotle, one becomes virtuous by doing virtuous things. How do you know what is virtuous? By copying a role model. Character development is an ongoing process. When doing virtuous things has become a habit and it gives you pleasure, then you have become a virtuous person.

Mid-career is a good time for reassessment, for asking what kind of doctor am I/have I been? Have I lived up to the ideal I had as a medical student? Do I see a different model as the ideal now? Perhaps changes in the practice of medicine in recent years have made it necessary to reevaluate the ideal of the good doctor e.g. increasing pressure from insurance companies, changes in patient expectations, the central role of patient autonomy, patients' access to internet information, use of computer record-keeping.

The central question remains: Do you think you have become a good doctor? Do you think you are a good role model for medical students and younger colleagues?

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“Just an Expression?” “Lethal” and its “Fatal” friends, Rest in Peace

Edited By Dalia Feltman, MD, MA, FAAP



Spring cleaning. Something about fresh air and the return of birds chirping gives us the urge to purge. Perhaps clinical hours and prepping for conferences doesn't allow for time to clean out closets, but pruning problematic phrases at work might be even more satisfying.

Our topic this issue, discussions of all things, “lethal,” and “fatal,” was suggested by Rebecca Benson, a Section of Bioethics member who wears many hats (including Director of Ethics and of Pain and Palliative Care at the University of Iowa), now dons the hat of a lay person to show us how these phrases are not interpreted by parents the way clinicians may intend them. Our second contributor, Matt Nestander, a neonatal-perinatal fellow at San Antonio Military Medical Center, reflects on how such euphemisms crowd out important concepts such as uncertainty in discussions with parents. Our first contributor, Benjamin Wilfond, director of the Treuman Katz Center for Pediatric Bioethics, has written extensively about how we discuss dire diagnoses with parents, especially as they relate to children with Trisomy 13 and 18. Here, he offers a poem published by Laura Gilpin, [The Two Headed Calf](#), which I won't spoil by trying to summarize the beauty of her sentiment.

Does our definition of lethal or fatal match a parent's?

Rebecca Benson, MD, PhD, FAAP

There are certain words and phrases that I think of as “short cuts” for medical professionals to communicate concisely with each other, but that I wish would never be used with parents. In my experience, however, words that we use frequently within the

medical community also become commonplace in discussions with families.

The terms “lethal” and “fatal” fall into the category of unhelpful shortcuts when used to describe most perinatal diagnoses. When we use these terms to describe conditions such as trisomy 13 or 18 to a medical student, for example, we might describe that the majority of infants born with one of these conditions will not live beyond a year. Many may live hours, days, or weeks, but fewer will live for months, and the minority will live for years.

However, when I put on my “before I underwent years of medical training” hat and think about what these words meant to me then, I would have had a very different expectation if someone had told me a condition was lethal. The Merriam-Webster dictionary gives the first definition of lethal as “of, relating to, or causing death” such as death by lethal injection. The definition of fatal, relating to disease, is “causing death” such as a fatal wound. Both of these seem to imply certain death within a very short time frame. Would either of these words adequately describe the range of potential outcomes for an infant with a trisomy, especially, in cases where the anomalies are not at the severe end of the spectrum?

I have found that when we use a term that has a different meaning to us than it does to a family, it can cause distrust. If a parent understands that their infant will certainly die soon after birth, if not before, and then the infant lives for hours or days, then were the medical professionals who counseled them wrong? Or is their infant now a proven “fighter,” who will defy all odds?

While it may take longer to explain the range of possible outcomes, or to use words and phrases that are not as prone to misunderstanding, I think it is well worth the effort in terms of partnering with parents. Families tell me it was helpful to hear that while we expected the life of their infant to be short, we were willing to help that life be as long and as good as it could be. They were open to acknowledging uncertainty along with us. Perhaps most importantly, they wanted us to talk to them about their baby, knowing specifically what was unique about their child, and not just give them information based on a typical infant with their condition.

Finally, if we want to improve our communication with parents, we must also pay attention to how we communicate with each other. If we continue to use problematic short cut phrases in our oral and written communication, and model this for trainees, we will hold ourselves back from a more ideal practice of medicine.

(Continued on page 19)

Just an Expression?

“Lethal” and its “Fatal” friends, Rest in Peace (cont.’d)

Edited By Dalia Feltman, MD, MA, FAAP

Euphemisms

Matt Nestander, MD, FAAP

The phrases “lethal diagnosis” and “incompatible with life” are difficult notions to grasp, even as I enter the second year of a neonatal fellowship where these words are used frequently during perinatal consults and family conferences. If the understanding of these phrases continues to be a challenge for me despite all my years of medical education, imagine how much harder it is for parents to grasp. Their child is very much alive and represents so much to them and here we are talking about the very real risks their child is faced with using a phrase.

We continue to use these phrases. At times, they are used so assuredly it amazes me. Despite only having a few years in the medical profession, I have already seen these phrases proved wrong multiple times. We as medical providers must recognize that despite all of our knowledge and scientific advances these phrases are not definitive. A “lethal diagnosis” does not become lethal until the patient has died.

Let us call these phrases what they really are, euphemisms. The real message we are trying to send is, “your child has a constellation of symptoms which will likely lead to an early death.” Such euphemisms seem like efficient ways to get the message across, yet they lack the key component of humility. They lack the recognition that we can be wrong, and that despite whatever diagnosis we are dealing with, there is an element we will not be able to predict or control no matter how much information we have. Perhaps a better solution than using these phrases is to present this uncertainty and face it with parents.

Final thoughts

Our contributors have raised several concerns about these phrases to describe serious diagnoses. When we tell a parent

their child’s condition is “lethal,” we may be conveying a timing of death that may: 1) be assumed by a parent to be sooner than we mean (or can predict); 2) be assumed by a clinician to mean too short a time to be worthwhile; or 3) become a self-fulfilling prophecy, influencing our readiness to offer certain treatments. We provide parents a disservice when we assume we know what length of life for a child is valuable. Discussing goals in the face of a life-limiting diagnosis is paramount to providing good care.

Slowly, a change is occurring in the pediatric literature, largely due to the efforts of clinical ethicists and engaged parents. Trisomy 18, for example, is no longer listed as an indication for withholding neonatal resuscitation in the Neonatal Resuscitation Program’s. The time has come to understand that “lethal” and its fatally-flawed friends are incompatible with good communication and must be laid to rest in our clinical vernacular.

For further reading on this topic, please see:

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2. Guon J, Wilfond BS, Farlow B, Brazg T, Janvier A. 2013. Our children are not a diagnosis: The experience of parents who continue their pregnancy after a prenatal diagnosis of Trisomy 13 or 18. *American Journal of Medical Genetics Part A* 164A:308-18.

Thank you so much again to our contributors!

In the Fall 2018 newsletter, we be exploring the old adage, “A Picture is Worth a Thousand Words.” Please send me your thoughts and/or pictures illustrating how visual images affect communication with our trainees, colleagues, and families in our care. The 2nd reference above has some terrific examples of the power of pictures for trisomy 13 and 18. Please also send me ideas for future topics at daliafeltman@gmail.com.





AAP Presidential Plenary and Annual Silverman Lecture

Sunday, May 6, 2018, 12:30-4:00 pm - Toronto Convention Center Rm 718

Moderator: Karen Remley, MD, FAAP, CEO, American Academy of Pediatrics

12:30 PM	Introduction Karen Remley, MD, FAAP, CEO, American Academy of Pediatrics
12:35 PM <i>Abstract Presentation</i>	Economic Downturns Are Associated with Increases in Neonatal Abstinence Syndrome Stephen Patrick, Laura Faherty, Andrew Dick, Theresa Scott, Judith Dudley, Bradley Stein
12:50 PM <i>Abstract Presentation</i>	Social Determinants of Research Engagement and Implications for Precision Medicine: Sociodemographic Factors Associated with Differential Enrollment in a Pediatric Critical Care Biorepository Erin Paquette, Avani Shukla, Susan Duyar, Tracie Smith, Sabrina Derrington, Matthew Davis
1:05 PM <i>Abstract Presentation</i>	Two-Year Outcomes of the Connect for Health Childhood Obesity Trial Elsie Taveras, Richard Marshall, Mona Sharifi, Earlene Avalon, Lauren Fiechtner, Monica Gerber, Endel Orav, Sarah Price, Thomas Sequist, Daniel Slater
1:20 PM <i>Abstract Presentation</i>	Impact of an Early Child Obesity Prevention Intervention on Diet- and Activity-related Behaviors and Attitudes of Chinese-American Parents of 12-month-old Infants Shonna Yin, Loretta Au, Regina Lee, Naumi Feldman, Linda van Schaick, Benard Dreyer, Eliana Perrin, Russell Rothman, Lee Sanders, Alan Delamater, Jeremy Yau, Margaret Lee, Evelyn Cruzatte, Qingyan Ma, Alan Mendelsohn
1:35 PM <i>Presidential Address</i>	AAP Presidential Address: Translating Research into Policy, Education and Practice Colleen Kraft, MD, FAAP, President, American Academy of Pediatrics
2:00 PM <i>Key Note Speaker</i>	A Pediatric Career: From the Personal to the Global Diana W. Bianchi, MD, Director, Eunice Kennedy Shriver National Institute of Child Health and Human Development
2:35 PM <i>Abstract Presentation</i>	Patterns of Use of Non-Ambulatory Services in Pediatric Patients with Attention Deficit/Hyperactivity Disorder July Cuevas, Sarah Soden, Hongying Dai, Suman Sahil
2:50 PM <i>Abstract Presentation</i>	Role of Limited English Proficiency in Rates of Adverse Events in Hospitalized Children Alisa Khan, Shonna Yin, Matthew Ramotar, Nancy Spector, Christopher Landrigan, Benard Dreyer
3:05 PM <i>Abstract Presentation</i>	The Relationship between Pediatric Respiratory Illness Measurement System (PRIMES) Scores and Outcomes of Care Karen Wilson, Derek Williams, David Johnson, Chen Kenyon, Ricardo Quinonez, Amy Tyler, Joel Tieder, Tamara Simon, Wren Haaland, Chuan Zhou, Rita Mangione-Smith
3:20 PM	Introduction of Silverman Awardee John Zupancic, MD, FAAP, Chair, AAP Section on Neonatal Perinatal Medicine
3:25 PM <i>Honorary Lecture</i>	Annual Silverman Lecture. Social Determinants of Health in Newborns: The Intersection of Clinical Care and Public Health Wanda D. Barfield, MD, FAAP, Rear Admiral, U.S. Public Health Service

Pediatric Academic Societies (PAS) Meeting May 5-8, 2018 | Toronto, Canada



The PAS Meeting brings together thousands of pediatricians and other health care providers united by a common mission: improve the health and wellbeing of children worldwide. This international gathering includes researchers, academics, as well as clinical care providers and community practitioners. Presentations cover issues of interest to generalists as well as topics critical to a wide array of specialty and sub-specialty areas.

Some sessions of interest may be:

- Saturday, May 5th: The Changing Ethical Landscape of Pediatric Genetics
- Saturday, May 5th: Ethical Considerations and Challenges Regarding Hormonal Therapy (pubertal suppression and cross-sex hormone therapy) in Children and Adolescents with Gender Dysphoria: An Evidence-based Debate
- Sunday, May 6th: Ethics of the New Therapy for Achondroplasia

[Click here](#) to view the complete program.

For additional information about this meeting, or to register, [click here](#).

Bioethics Essay Contest—Deadline June 15, 2018

The Section on Bioethics of the American Academy of Pediatrics and the Ethics Special Interest Group (SIG) of the Academic Pediatric Association (APA) are pleased to announce our first joint Ethics Essay Contest.

The contest is open to all residents in pediatrics or medicine-pediatrics, and all pediatric subspecialty fellows (including fellows in pediatric surgery, pediatric psychiatry, and pediatric neurology) in North America. Essays should focus on the ethical issues that residents and fellows face while caring for patients or conducting research. Possible topics include (but are not limited to) cases or issues related to clinical ethics, research ethics, organization ethics, public health ethics, or global health ethics.

Essays should be between 1000 to 1700 words. Essays longer than 1800 words will be disqualified without review. Essays must be original and unpublished works by a single author.

Two awards will be offered:

1st Place - \$300

2nd Place - \$200

One or both winners may be asked to read their essay at the Pediatric Academic Societies (PAS) meeting in Baltimore, MD. If able to present, winners will be provided with a \$300 travel scholarship to attend.

Winning essays will be published in the newsletters of both the APA Ethics SIG and the AAP Section on Bioethics. Winners will retain copyright of their works, and will be free (even encouraged) to submit their manuscripts to peer-reviewed journals for publication. The essay organizers will provide feedback and mentorship to winners to facilitate submission to a journal.

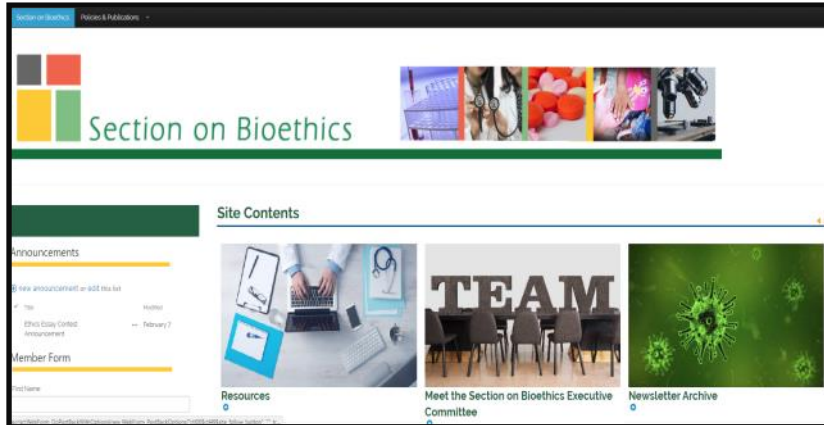
Deadline: June 15, 2018

Submit essays to: kyle.brothers@louisville.edu

Manuscript files should include a title page with the title and submitter's name, e-mail address, institution, specialty, and post-graduate year.

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Contribute to the newsletter!

Thanks to everyone who has submitted papers for the newsletter. Your work makes it great. We are always interested in hearing from others. Have an idea for a paper? Or a theme issue? Want to review a recent book or movie? Analyze a case?

The newsletter is a great way to share your ideas with friends and colleagues.

Please Contact Kelly Michelson, Editor, at k-michelson@northwestern.edu