From the Editor

This newsletter celebrates work from experts who have made long standing contributions to pediatric bioethics as well as newcomers just beginning to make their mark in our field. Congratulations to John Lantos, MD, FAAP, this year’s William G. Bartholome Award recipient. This well-deserved honor reflects Dr Lantos' many years of service and his enormous impact on the public discussion of ethical issues in pediatric medicine. On behalf of the entire American Academy of Pediatrics Section on Bioethics, I would like to thank our outgoing chair, Brenda Mears, MD, FAAP for her 10 years of service and dedication to the Section Executive Committee. In this issue she has generously contributed her thoughts about transhumanism and biohacking, two issues resulting from emerging technologies which bring complicated ethical challenges. At the same time, we welcome incoming chair, Mark Mercurio, MD, FAAP. Dr Mercurio is Professor of Pediatrics, Chief of Neonatal-Perinatal Medicine, and the Director of the Program for Biomedical Ethics at Yale School of Medicine. In celebration of bioethics scholars newer to the field, we present work by winners of the American Academy of Pediatrics Section on Bioethics and the Academic Pediatric Association Ethics Special Interest Group first joint Ethics Essay Contest. This contest is open to residents in pediatrics or medicine-pediatrics, and pediatric subspecialty fellows. Congratulations to William Sveen, MD, our first place winner, and Kristina Brumme, MD, FAAP, our second place winner. Huge kudos to Catherina Pinnaro, MD and Sebastian Proano, MD who both received honorable mention. Finally, in this edition of “Just an Expression?” we learn “how a picture is worth a thousand words” as Chaplain Rachel Rigdon describes the impact of using images in working with a child impacted by abuse. We truly have much to celebrate. Congratulations to everyone.

From the Chairperson:

Transhumanism and Biohacking

by Brenda Jean Mears, MD, FAAP

The transhumanist, biohacker, and Ascendance Biomedical founder Aaron Traywick died in April of this year from an accidental drowning.1

Transhumanism is the idea that biotechnology can be used to treat disease, overcome human limitations, and improve the human condition beyond the normal. During his life, Traywick’s goal was to develop medical therapies without clinical trials or US Food and Drug Administration (FDA) oversight.1

Along with fellow transhumanist Tristan Roberts, he engaged in biohacking, which Merriam Webster Dic-
Transhumanism and Biohacking (cont.’d)

Brenda Mears, MD, FAAP

The dictionary defines as biological experimentation happening especially “outside of a traditional medical or scientific research environment.” In October 2017, Mr Roberts injected himself with an experimental gene therapy for HIV on Facebook Live. At a February 2018 body hacking conference in Austin, Mr Traywick injected himself with a substance that he claimed was developed by biohackers as a cure for herpes, which had not previously been tested in humans.\(^1\)\(^-\)\(^3\)

The efforts of humans to improve and prolong their lives have been long mythologized in stories, back to the myths of Tithonus and the Epic of Gilgamesh. Other stories include those from television, such as the Cybermen in Dr Who and Data in Star Trek, and literature, such as Arthur C. Clark’s Childhood’s End and Robert Heinlein’s Lazarus Long stories.

In modern life, we are already using artificial limbs, pacemakers and cochlear implants, which are considered by many to be transhumanist. However, the government is concerned about non-scientists biohacking at home. The FDA has issued a warning about do it yourself (DIY) gene therapy but when gene kits such as DNA Playground from Amino Labs and The Odin’s Genetic Engineering Home Lab Kit cost only $390 and $1849 respectively, it can be hard to dissuade consumers from experimenting.\(^4\)\(^-\)\(^8\)

Mr Traywick and his “biohacking stunts” are not the only transhumanist events in the news recently. In January, a research team published an article on creating horsepox by stitching fragments of DNA together. Chinese researchers are working on a new CRISPR technique, for those with Marfan Syndrome.\(^5\)\(^,\)\(^9\)\(^,\)\(^10\)

Neuralink, Elon Musk’s brain machine interface development company, is apparently trying to open an animal testing facility, with the goal of treating brain disorders and, within the next decade, enabling telepathy through neural implants.\(^11\)

Non-medical uses for transhumanist experiments are on the rise. In Sweden, microchip implants can be used as a replacement for keys, credit cards, and train tickets. In contrast, an Australian biohacker named Meow-Ludo Discogamma Meow-Meow recently implanted a chip from an Opal public transit card into his hand. In March, he was fined for violating the Opal terms of service and charged significant legal costs, but later had his conviction and fine overturned.\(^12\)\(^-\)\(^14\)

In April, MIT Media Lab stopped working with startup Nec tome due to controversy over the company’s touted “mind-uploading service” for those with terminal illnesses, which would require doctor assisted suicide. Critics call the startup’s efforts unethical and say that the technology to transfer memories from a brain to a recreated consciousness in a computer is at best decades away and potentially impossible.\(^15\)

David Pearce, co-founder of the World Transhumanist Association, claims, “It’s hard to think of any downside to a ‘Triple S’ civilization of superintelligence, superlongevity and superhappiness. The pitfalls of transhumanism derive not from the destination, but from how we get there.” Whether you agree with his central premise or not, there will undoubtedly be difficulties getting to “the destination.” We seem to be approaching these changes without knowing what is treatment, what is enhancement, what is more, or what is better.\(^16\)

There are numerous other issues to consider. Computers crash and can be hacked. If a computer is in our head, how do we reboot it or prevent hacking? Is the expense of life extension likely to widen gaps between wealthy and poor populations? In addition, germline modifications may correct disease or increase intelligence but also reduce human gene pool diversity.\(^16\)

If we make these changes, will there be a point at which experimented-on subjects are a different species? How do we protect those who wish to remain unaltered? Can we somehow put in fail-safes so that any change can be reversed when the unexpected or unwanted consequences are too large?
Transhumanism and Biohacking (cont.’d)

Brenda Mears, MD, FAAP

We already have a highly intimate relationship with technology. I find myself a bit nervous when I don’t know where my iPhone is. This evidence of dependency on technology, even when it is not part of our body, indicates a need for limits on biohacking experiments and a way to reverse the changes when unexpected negative consequences arise.

References:


Every year the AAP section on bioethics sponsors a bioethics essay contest. For 2018, the section held the first joint essay contest with the Academic Pediatric Association ethics special interest group 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. Below is the winning essay followed by the second place winner and two essays awarded honorable mention. The content in these essays do not necessarily reflect the opinions of the section or AAP.

Ist Place—Difficult to Swallow: Epidermolysis Bullosa, Esophageal Stricture, and the Boundaries
William Sveen, MD, MA
University of Minnesota

Case
The parents of a four-year-old girl with recessive dystrophic epidermolysis bullosa and severe esophageal stricture and gastrostomy tube dependence request an ethics consultation to discuss withdrawing medical nutrition and hydration (MNH) and allowing their daughter to die. The family relocated from Europe when the patient was an infant to undergo an investigational bone marrow transplant with an older sibling as a donor. The transplant engrafted successfully and improved the healing time of injured skin but was not fully curative. The patient continued to have blistering lesions covering large portions of her body. She required frequent, painful dressing changes and became dependent on opioids due to chronic pain. She also developed multiple joint contractures.

The esophageal stricture occurred prior to her transplant, and unfortunately she experienced progressive symptoms after her transplant. After multiple esophageal dilations and stents, her esophagus atrophied to the point of risking perforation with further procedures. Swallowing caused significant pain and anxiety and eventually panic attacks which occur multiple times daily for minutes to hours. She became dependent on benzodiazepines due to the anxiety of swallowing despite aggressive symptom management with palliative care and psychiatry. All nutrition was obtained by MNH via gastrostomy tube but she occasionally took small volumes orally for taste and comfort. The family has seen multiple specialists across different health systems to discuss medical and surgical therapies but was not satisfied with suggested options including esophageal reconstruction, esophageal transplant, salivary fistulas, tracheal diversion with tracheostomy, and increasingly sedating medications.

Her parents state they are "doing more to her than for her" and despite pursuing aggressive and experimental therapies to extend her life in the past, they are now considering withdrawing MNH to allow her to die. The ethics team determined that the parents' request was reasonable. The patient was enrolled in hospice, scheduled MNH was discontinued and instead MNH was provided orally or per gastrostomy for comfort by patient request only. The patient had a steady decrease in the amount of requested nutrition over the course of six weeks and died in her home surrounded by family. She had decreased anxiety associated with saliva management and decreased benzodiazepine use until the week prior to her death when she required increased anxiolysis. Child and family life specialists and social workers were closely involved to help the patient, her older siblings, and parents through the dying and bereavement process.

Discussion
The American Academy of Pediatrics (AAP) considers foregoing MNH as similar to foregoing other life-sustaining medical treatment (LSMT) such as mechanical ventilators, renal replacement therapy, pressors, etc. while recognizing that the emotional and social associations to eating and feeding often make foregoing MNH subjectively feel different to families and clinicians. The AAP 2009 policy statement describes situations where the burden of treatment may outweigh the benefits, making foregoing MNH an option for families. These include patients who are irreversibly comatose and do not experience the dying process, patients who are terminally ill and lack appetite, and patients with total intestinal failure requiring high morbidity and mortality treatments such as indefinite TPN or bowel transplant.

The policy briefly discusses "other conditions that are incompatible with long-term survival and for which significant burden is associated with continued existence or available treatment options." However, the paper then gives the example of infants with uncompensated heart failure with an inability to tolerate sufficient fluid volumes, making MNH actually harmful to the child. No discussion is made regarding children in whom MNH continues a burdensome existence but the MNH itself does not cause the harm. However, since forgoing MNH is considered similar to other LSMT, 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. Below is the winning essay followed by the second place winner and two essays awarded honorable mention. The content in these essays do not necessarily reflect the opinions of the section or AAP.
a reasonable parent may consider the burden of continued existence to outweigh the benefits of MNH. These burdens include not only physical pain but activity restriction, fear, anxiety, isolation, and other forms of emotional distress and do not need to be directly caused by MNH. This young girl lived at the uncomfortable intersection of incurable pathophysiology and significant daily distress despite aggressive palliative care. The patient had intestinal failure due to the esophageal stenosis, but her ability to absorb food enterally via gastrostomy makes it less severe than total intestinal failure cited in the guidelines. Few would argue that the parents were obligated to have her undergo esophageal reconstruction or intestinal transplant since these measures are highly invasive and have a high risk of failure and potential to increase harm.

Surgical salivary management such as fistulas and tracheal diversion with tracheostomy or increasing sedative medication may reduce symptoms but have further adverse effects on her quality of life. Furthermore, no treatment would relieve the physical pain associated with the underlying and progressive cause of epidermolysis bullosa. The best interest of a child is highly subjective, but typically parents are best suited to determine reasonable options. The parents made a reasonable assessment that the burden outweighed the benefits of continued treatment, making this case an example in which MNH was withdrawn due to the significant burden of continued existence.

**Objections Considered**

*She is not terminally or critically ill.* Many discussions about forgoing LSMT occur when patients are terminally ill or experiencing an acute decompensation and requiring critical care. While clinicians may be more comfortable with the parents’ decision in this context, there is no obligation to continue burdensome care even if she remains at her current state of health.

The parents did consider waiting for the patient to become ill and foregoing any increase in treatment at that time. They described a scenario in which she could have a skin infection or aspiration leading to sepsis and then no antibiotics or pressors would be provided. However, they determined this would prolong her current suffering, lead to increased suffering with her acute decompensation, and limit the family’s ability to control aspects of her death such as dying in her room with her sisters present.

*She has typical development and may starve.* Some of the patient’s clinicians were concerned that since she is developmentally typical, she would experience significant distress at the end of life compared with those who are minimally conscious or comatose. However, her parents noted the opposite was also true using the same reasoning. If she had more to lose in death, she certainly also experienced more suffering in continued life.

Specific concerns were raised that the child would be “starved to death.” Starvation is a provocative term that connotes symptoms of long term protein malnutrition such as muscle wasting, edema, infections, and skin breakdown. While the process of providing nutrition has strong emotional, social, and familial associations that need to be addressed, palliative care can address the symptoms associated with starvation in such a way that patients who die from foregoing MNH do not experience the grotesque symptoms of starvation. Due to the stigma surrounding starvation and the inaccuracies in describing the actual process of death, the AAP recommends that the term not be used.

Others were concerned about the need to obtain her assent to the treatment and to what degree she should be able to refuse withdrawing MNH. The parents informed the patient in a developmentally appropriate way using child life specialists that the scheduled feeds were stopping and that she would soon die but be kept comfortable. She was also given the option to request food or liquids orally or enterally whenever she wanted which gave her back control in the situation that previously left her feeling powerless. They ensured that her values and wishes were heard, and in this case, the child was relieved to discontinue MNH. Even if she had disagreed, reasonable parents are typically considered most suited to determine the best interest of a young child, even in serious decisions. However, in matters of life and death, these decisions need a high level of scrutiny, which is why the parents requested an ethics consult.

*She may require palliative sedation and euthanasia.* Some clinicians were concerned that aggressive symptom management would result in palliative sedation which could be
construed as euthanasia. Palliative sedation is the use of medications to decrease awareness of severe, refractory symptoms at the end of life. Palliative sedation may hasten death in some situations but not all and is not considered a cause of death when the intent is to treat symptoms. This patient would be a candidate for palliative sedation if the proportional increase in her medications required to adequately treat her symptoms resulted in a comatose state. However, although she needed an increase in benzodiazepines in the last week of life, full sedation was never required for this patient, further demonstrating that children who die from foregoing MNH can avoid symptoms associated with starvation.

Euthanasia is an active means of causing death to relieve suffering, typically administered by a caretaker or medical professional. Euthanasia is distinct from passive means of allowing natural death such as foregoing MNH, regardless of whether palliative sedation was involved. Allowing the patient to request food or liquids for comfort further distanced her case from others actively causing her death.

Conclusion
This case illustrates the need for further discussion on foregoing MNH in children with life-limiting illness and burden-some treatment. When limited options exist to correct the underlying cause of suffering, symptoms remain refractory to aggressive palliation, and access to multidisciplinary palliative care at end of life is available, reasonable parents may decide to allow natural death by foregoing MNH. The option to forego MNH should be discussed with families of patients who experience a burdensome continued existence and reasonable decisions to forego MNH should be respected.

References
1. Weise KL, Okun AL, Carter BS, Christian CW; Committee on Bioethics; Section on Hospice and Palliative Medicine; Committee on Child Abuse and Neglect. Guidance on Forgoing Life-Sustaining Medical Treatment. Pediatrics. 2017 Sep;140(3).
The call to the Emergency Department told us only, "Infant, possibly 7 months, cardiopulmonary resuscitation (CPR) in progress." No weight, no mechanism of injury, no further details. After an initial flurry of activity in the trauma bay, we wait. The members of the team have assembled, signed in, gowned up—now we pause, listening for the helicopter to land or the ambulance to arrive. The pause seems interminable: time for reviewing algorithms, checking equipment, and deciding how to begin. What we do not discuss is how to end, that is, how we establish team consensus for when it is time to stop, to call a halt, to end repeated attempts at resuscitation.

Considering criteria for cessation of resuscitative efforts even before the patient's arrival may seem cynical and counter to the missive "save better, save faster." However, in the rapidly evolving milieu of improving technological support of resuscitative efforts, considering not just what we can do, but also what we should do, is essential. Yet this question is rarely asked in pediatric emergency medicine. The normative underpinnings are rapidly lost amongst the reflexive and seemingly prescribed steps during an initial resuscitation. In trying to save a life, there simply isn’t time for reflection.

The infant arrives, and resuscitation is transferred from the emergency medical service (EMS) to the emergency department (ED) team. Rapid execution of Pediatric Advanced Life Support (PALS) for pulseless electrical activity ensues. Stunned family members watch from the doorway, unable to get to the bedside through the cluster of providers working to establish access, secure the airway, and continue high quality CPR. Despite an unknown down time at home and transport time, we give multiple rounds of epinephrine and continue more than 25 minutes of acute resuscitation before finally achieving return of spontaneous circulation. With each passing minute, the likelihood of a good neurologic outcome rapidly dwindles.

Transported to the intensive care unit (ICU), the infant had a heart rate, no spontaneous respiratory effort, and fixed pupils. The initial computed tomography (CT) confirmed significant hypoxic brain injury. Now, months later, I still think about whether we did this child and their family a disservice, if I failed in my promise to do no harm. Can I at least be reassured that the resuscitation was a “success” because the infant came into the emergency department with no heart rate and left with one? Periodically I review the infant’s hospital course. The child is ventilator dependent with a tracheostomy and no organized spontaneous respiratory effort; nutritional support is provided through a gastrostomy tube; and there is no discernable neurologic interaction with the environment. The family continues to be present at bedside struggling to adjust to their new reality. The child was saved, but is profoundly different from the child this family enjoyed days before the catastrophe of suffocation. And worse, it is unclear if I did harm in prolonging their child’s life and suffering. As a fellow trainee and not the ultimate decision maker, did I fail by not speaking up and advocating for transition towards comfort care as opposed to remaining silent during the continued aggressive resuscitation? Even more, how can we have this conversation regarding cessation of resuscitation while actively trying to save a life?

In sorting through my own feelings of moral distress regarding a prolonged resuscitation and poor neurologic outcome, it is difficult to find literature to specifically outline quantitative criteria that would be essential for the fast decisions necessary in pediatric emergency medicine. Formal adult protocols for termination of resuscitation in the field have high positive predictive power for survival and serve the secondary benefit of decreasing medical costs, improving safety for EMS providers, and often improving the family’s transition towards the grief process (Munoz 2017). Unfortunately, none of these protocols have been adapted to the pediatric setting.

Validated qualitative criteria for the cessation of resuscitative efforts are equally limited. In determining how to proceed, the concept of qualitative futility exists if a patient does not have the capacity to appreciate the benefits of life. For pediatric patients, providers must speculate on their patient’s future capacity to appreciate life (Miller-Smith 2017). There is a wealth of literature in neonatology and pediatric critical care that suggests we are poor predictors of outcomes and that prognosis varies vastly even with seemingly congruent initial presentations. So what
tools is a pediatric emergency medicine provider left with? We need a practical framework to identify signs or stages in a resuscitation for when to stop. More importantly, this practical framework needs to be applicable to the emergency care setting. There is no easy solution. There has been much literature devoted to the contentious topic of medical futility which has long represented conflict between patient and family wishes and the physiologic reality of the patient’s condition as the medical team views it. Eloquently stated, futility has indeed been abused. The term as been applied and misapplied, defined and redefined, molded and remolded until the real meaning is no longer understood. When a word loses its meaning, it loses its power (Miller-Smith 2017).

More recently the concept has been divided into physiologic futility, an inability to achieve the intended biologic goal of treatment, versus inappropriate treatment, where the goal of treatment is unreasonable (Truog 2017). Perhaps this delineation helps achieve clarity, but it remains an issue of semantics; we have succeeded in changing nomenclature but have not improved applicability. The moral murkiness is not from situations where goals of care are physiologically futile with no chance of a positive outcome, but from attempting to define the slippery spectrum between appropriate and inappropriate care. Discomfort in addressing this is secondary to provider discomfort in shifting goals based on patient presentation and poor transitions between curative and comfort care (Weiss 2018). Furthermore, in attempting to define criteria for inappropriate care, the bulk of the literature is centered in intensive care units, focused around technologically dependent, medically fragile children, or chronically ill children with few remaining options. Suggestions regarding how to resolve situations with potentially inappropriate care are measured, structured methods requiring a time-intensive, step-wise approach, ongoing conversations with the patient and family as well as the care team, and establishment of a therapeutic relationship (Paris 2018). All luxuries ill-adapted to the emergency department context.

For emergency medicine providers, issues of medical futility, inappropriate treatments, and how aggressively to pursue resuscitation are compounded by a number of unique considerations including: a profound information gap, multiple medical providers during resuscitative efforts, no relationship with the family, differences between previously healthy children versus chronically ill children, high emotions in pediatric resuscitation, language barriers, litigation – the list goes on. There is no consensus regarding termination of resuscitation despite multiple multidisciplinary statements by appropriate stakeholders. In 2014 a Joint Position Statement on behalf of trauma surgery, EMS, the American Academy of Pediatrics and American College of Emergency Physicians was released summarizing criteria specifically for traumatic cardiopulmonary arrest in which termination of resuscitation can occur after greater than 30 minutes of CPR or if the facility is greater than 30 minutes away. Additionally, on review of cases, for this specific subset of patients, there is only 5-10% overall survival with 0-12% having good neurologic outcome (Topjian 2008). Appeals to the use of parents as surrogate decision makers regarding termination of resuscitation in the field are equally fraught since the ability of parents to grasp the risks and benefits of extraordinary treatment, and provide informed consent for their child is compromised by the urgency of the process, guilt, incomplete information, and health literacy. Ultimately, with many caveats regarding
the strength of the literature, the recommendations leave considerable ambiguity, except for trauma victims with injuries obviously incompatible with life (decapitation) or patients for whom there has been a significant period of pulselessness (dependent lividity, rigor mortis) (Fallat 2014). This small subset of patients are not the patients where appropriate versus inappropriate care present a moral quandary.

It is difficult to have a discussion of medical futility or inappropriate treatment without addressing resource consumption, and furthermore, value judgements regarding quality of life for patients and their families following prolonged resuscitative efforts. It should be apparent from the above-mentioned literature that these are relative issues within the scope of the large arc of acute resuscitation. Technology is outpacing our ability to discuss the morality of provision of care and it is essential to engage in this discussion, specifically as emergency medicine providers, before the menu of extraordinary measures expands. Decisions to cease resuscitative efforts are enormously difficult, and are compounded by the added pressures of time and relative paucity of information in the emergency setting. However, these decisions have profound effects on the thousands of patients and families whose lives are irrevocably altered by the physiologic survival of a child with profoundly diminished capacity. There will be no one-size-fits-all guide that can capture the complexity of these cases, but this only further clarifies the necessity for an informed, rational dialogue about these cases that is currently lacking from the literature. If we cannot consider these cases with the luxury of time and rationality, we can never incorporate this into the team pause, as we wait, hoping to help the next patient coming in.

References:


I disagreed with your family in most of the decisions regarding your care. There were times when I was antagonistic and times when they were in denial. Your parents were amateurs in this topic, as expected; and I was trying to remember the four principles of bioethics. We had three encounters and I believe at the end it was a successful disagreement, leading me to cultivate cultural humility and teaching me to avoid the death-end road that is hostility. I trusted them and they trusted me; this allowed us to let you go in peace.

Loss of equilibrium—the symptom that led to a diagnosis that would change the life of this teenager and his family forever; I never thought it would change mine. I met the family the day he was diagnosed, when a colleague resident asked me to translate for her a conversation that included words such as: tumor, urgent, intensive care, brain. The parents immigrated from South America 14 years ago, the same age as their son who was being diagnosed with diffuse intrinsic pontine glioma. I explained what was going on, getting back that staring look that you get when someone is speaking in a different language. This time the language was not the problem, both parties spoke Spanish. The problem was my lack of empathy; after all I was just translating and I had my own patients in my mind. Once at home I ran the episode over and over again in my mind, how I was asked to ‘drop a bomb’ to a patient that wasn’t mine. How could I have spent more time empathizing with the family? After all they were from the same country as I was. But the biggest question in my mind was, am I being culturally insensitive towards my own culture?

We received a notification by the emergency medical services (EMS): “We are coming with a 14 year old in septic shock, estimated time for arrival 7 minutes”. The patient had a respiratory rate of 10 breaths per minute, or even less. His forehead was warm and full of perspiration. We connected him to the monitor. His blood pressure was below the lower limit for his age. He clearly had septic shock with respiratory failure and the next step was to intubate. The intubation was successful, my first one in an acute setting. I came to the waiting room, with my forehead held high, to speak with the parents. The father held, in his sweating hands, a discharge summary from another hospital with the diagnosis of brain tumor. Once I started the interview I realized that he recognized me. Later I realized how important I was in their life. I had pronounced the words ‘tumor cerebral’ for the first time when their son presented with loss of equilibrium. The father explained to me how rough the last months had been, they had been hopping from one hospital to another. The main reason for this ‘hospital tourism’ was because doctors considered that palliative care with minimal invasive interventions was in his best interest, an idea that the parents refused completely. They were convinced that their son would wake up soon and become the same person he was over a year ago. They asked me my opinion, I think because they found comfort in my Spanish accent. I also agreed that palliative care was the best option, emphasizing that my opinion was that of a newly second year pediatric resident. They felt antagonized and I felt they were not respecting the child’s autonomy.

Autonomy is one of the hardest concepts to define in pediatrics. Who does it belong to? Undoubtedly, it is a moral norm of high priority in medical ethics. Nevertheless, some cultures will drift away from the Western concept of individual autonomy, in that they consider the family as the smallest unit for moral considerations. This family was trading the best interest of their child for familial interests, a concept defined by Ross as ‘constrained parental autonomy’. In this model, parental decisions that do not significantly increase the likelihood of serious harm as compared to other options should be accepted, as long as the basic needs of the child are secured. This family’s decision was to keep this child alive and without a doubt they were caring for him in the most loving way.

We had a third encounter; now I was in the pediatric intensive care unit (ICU). He had gone through one long hospital admission since our last encounter, and I had become interested in the concepts behind end-of-life care decisions. I came to realize that difference in opinion when dealing with end-of-life discussions is common, if not expected, and this can be exacerbated by cultural, religious, or socioeconomic diversity. Again, the parents remembered me and I did remember them too. His parents, especially his father, had drifted away from Catholicism. He had now turned to alternative therapies: alkaline water, therapy with magnets, numerology, and positive thinking. According to this new way of thinking, accepting the diagnosis of his son would enhance tumor growth. It was a new challenge and I was prepared, or so I thought.
I wanted to understand their level of awareness of their son’s current situation. The father said he knows that ‘the thing,’ referring to the tumor, is there but he knew his son’s immune system will recover and heal his brain completely. We had a conversation to set goals for this specific hospitalization. They wanted him to be able to go home in the same state he was a week ago, breathing on room air via his tracheostomy tube and feeding via nasogastric tube. These were reasonable goals, I said, but we needed to fulfill the following criteria for him to go home: he needs to be off the ventilator or tolerate minimal ventilator settings, he needs to come off of pressors, and we had to bring his sodium down. He had a new diagnosis of diabetes insipidus, likely related to his brain tumor. Many individuals have a positive illusion that good things are more likely to happen to them and therefore initial goals are set with this background belief. These parents believed that their son would fully recover to become his previous self. Not being able to achieve highly valued goals causes significant distress in a family and often in the medical team. Engaging in new achievable goals can reduce the feeling of failure. Miller et al define the term ‘regoaling’ as the process of setting new goals, once the initial goals, such as complete recovery, are no longer realistic. They emphasize that hope is crucial in this process; proposing that high hope individuals experience less negative and more positive emotions when they are unable to achieve a goal, allowing them to engage more easily in the process of setting a new goal like limiting interventions or signing a do not resuscitate (DNR) order. I was about to embark on my first ‘regoaling’ experience with this family.

Within a few days we successfully achieved the goal of bringing the sodium down to normal values. I informed the family, but I also told them that we were far from reaching the other two goals. He slowly and steadily decompensated, to the point where he depended of the ventilator and intravenous drugs to live. “What is the next step” they asked, getting ready to engage to a new goal. We set a family meeting to discuss a brain function evaluation called ‘brain-death protocol’. You could see the parents grow anxious with the proposal, but they were curious about the idea of proving that their son’s brain was working, as they believed. The meeting went well, they stated they felt respected, and recognized that the team was doing everything to care for their son. Then we got to the point of explaining the evaluation. We disclosed that in New York State, as in most of the states, if a patient is diagnosed brain-dead he is legally dead. The father initially responded with anger. “Let’s say he is diagnosed brain-dead, which he is not. What would you do next? Do we have a say? Can I take him home? Can we have a second opinion?” We responded to all these questions, which seemed to calm him down. The father had read, in a hand out provided by our palliative care team about our hospital’s protocol, that an electroencephalogram (EEG) could read his brain waves the same way an electrocardiogram (EKG) reads heart electrical activity. This was attractive to him, as he had heard and read stories about people in a coma with brain activity captured by EEG who woke up years later. He agreed to the evaluation, only if an EEG was included. We arranged to perform the protocol the next morning. The entire team waited anxiously around the patient, I started a timer, and we started the protocol. It was evident that he didn’t have any breathing effort. He met all the criteria and was pronounced dead.

The family had requested time to arrange for the funeral before we disconnected him. We encouraged them to involve the sisters and family members who had not been to visit lately. That night, the entire family gathered around him as his parents dictated the next step. They wanted him to breath room air, so we slowly decreased the oxygen content to 21%. Then they requested to slowly turn down the vasopressor. Once we reached 0 mcg/min the father started talking out loud to his family and all of us who were in the room. “You will see his heart will beat on its own.” The family, hopeful, looked at the monitor. To my surprise, the blood pressure remained stable and even a little hypertensive during the first minutes, but then it gradually became profoundly hypotensive and his heart rate decreased until it stopped. Family members screamed and video-called relatives. His sister led a prayer with smart and beautiful words, which we joined. The father saw me across the room. I extended my hand which he ignored. He hugged me whispering, “You and your team are true professionals. Thank you for caring for my son.”

References:
The intergalactic noise of my hospital-issued phone sung out again. I chugged my large purple water bottle and hoped it was anything except another consult for severe diabetic ketoacidosis, but that is exactly what it was. The Pediatric Intensive Care Unit (PICU) resident calling was very competent at managing these patients, so I wondered why he was contacting me so early in the clinical course. He told me that a 12-year-old patient was comatose. Unarousable. His level of concern was palpable. Her pH was unreadable. I called him back quickly, told him to give mannitol and get her head imaged. I would be there when she was back from computed tomography (CT). My voice shook. I was nervous. I had yet to see someone this ill from diabetes. I hoped I'd given good advice. I'm just a first year fellow. My staff was in clinic. I wished I hadn't chugged that water.

I didn't need to ask for the patient’s room number, as the sweet smell of ketones filled the hallway. I was met by her grandmother, mother, step-brother and her caseworker. Her grandmother, who currently had custody, was battling her own serious medical problems and was trying to do her best for the patient. A lot of things went wrong prior to her admission, but after hearing the whole story, I felt that it was just a series of unfortunate events. She had been seen in urgent care, and then spent all day in the school nurse’s office. I knew that sorting out the rest of her complicated backstory would be a challenge to deal with when we did education with the family, when she was better, if she ever got better.

Fast forward seven days – she was in a coma and on continuous renal replacement therapy for acute kidney injury. She slowly awoke. And then she did great. She was transferred to the nephrology service and, shortly after, to the endocrine service because her kidneys had completely recovered. She seemed to be the luckiest girl in the world.

A difficult weekend conversation with her grandmother confirmed our team’s suspicions that it would be impossible for her grandmother to safely care for our patient with newly diagnosed diabetes. Her grandmother struggled with fine motor tasks and had limited mobility secondary to a recent stroke. She expressed concerns about being able to call our nurses and draw up and administer insulin. The Department of Health and Human Services agreed with these concerns—our patient would need to go into foster care. This put me at ease, as I was uncomfortable with the idea of this pre-teen being solely responsible for her diabetes care, especially after being in a coma for a week. However, our good intentions cast the spell that trapped Rapunzel in the tower of our children’s hospital.
It took two more weeks of this child being hospitalized for me to realize that she had become a prisoner of our institution. She was alone and had been for the majority of her time in the hospital. She only had pajamas and slippers. She desperately wanted a bra. She wanted to go outside. She had no shoes or coat or anyone to walk with her. By recommending foster placement, I felt we were now actively preventing her from living a normal life—albeit one with diabetes. Had we failed her?

One of the key points we emphasize with patients who are newly diagnosed with type 1 diabetes is that it is not their fault and that they will be able to live happy, successful, “NORMAL” lives. I thought about this every day she was in the hospital. I tried to underscore this every time I saw her, but it was so ironic that I can’t imagine it seemed genuine to her. I stopped by before rounds on a Friday and heard Rapunzel singing in the shower. I stayed. We had a long conversation. She revealed that she had a history of depression, but after moving in with her grandmother, she finally felt like she fit in at school and was no longer being bullied. My guilt spilled over—we were preventing her from going to school.

My attending staff and I were wildly conflicted about what to do as it was now Saturday, and we had limited social services resources. We both ultimately knew this couldn’t wait any longer. I went home and contemplated the appropriateness of buying her some necessities. My biggest concern was whether it was right to treat Rapunzel differently than my other patients. In this circumstance, I could see that she needed help. Both I and my attending showed up with clothes and other supplies on Sunday. I felt absolved.

A child life specialist was able to take her outside in her new sneakers and clothes later that day. I stopped by in the afternoon, and she showed me the grass and twigs she picked up on her walk. She was so happy she made it outside that she kept a bit of nature for herself because she wasn’t sure when she would get out again. She hugged me. I held back tears. I went home and reflected on how much we did medically, but how we really could do so much better. Despite (or maybe because of) having a team of over twenty doctors, nurses, physical and occupational therapists, social workers, child life specialists, and music therapists, we did not meet this patient’s basic human needs once she physically recovered.

Once we realized that there was an entire domain of her wellbeing that we weren’t addressing, we still met barriers. There wasn’t even a mechanism for her to get laundry done in the hospital, which was now serving as her home. She wasn’t eligible to go to outpatient appointments since she was still technically admitted. Things that seem so inconsequential compared to being on dialysis in a coma consumed my days as I began to realize the dichotomy of care that can arise when a pediatric patient does not have a constant advocate. Many children’s hospitals have websites and signage emphasizing that parents and families are critical members of the care team.1 But what about patients who are alone? A literature search yielded no studies comparing health or psychosocial outcomes between pediatric patients who consistently had a family member present versus those who did not, but it may be worth studying. As providers, we strive to treat our patients equally, and justly. However, I tried so hard not to treat this patient differently, that I did her a disservice. We must evaluate our motives when veering from the standard, but I now believe there are certain patients and situations that warrant additional attention.

Clinically we did everything right. She is a medical success story. We were beneficent, did no physical harm. However, she was in desperate need for someone to truly care for her, both in and out of the hospital. Her kidneys could not afford another major injury, and she could die if her diabetes was not appropriately managed.

Thus, Rapunzel became a member of a club that I am becoming more familiar with—children who cannot return home because their family is not equipped to care for them medically. As our medical technology continues to advance, there is an increasingly large population of children entering foster care specifically because they have complex medical needs that their families cannot meet. On any given day, there are 428,000 children in foster care in the United States, and nearly half of these children have chronic medical problems and unmet health needs.2,3 Approximately one third of licensed foster care providers lack placements because they are reluctant to take on medically complex children, and studies suggest that foster parents feel inadequately prepared to take care of such children.2,4 These children deserve a stable and loving environment in which they will be well-cared for, and the healthcare system will unlikely be able to sustain inpatient admissions for all medically complex children no longer requiring inpatient...
Honorable Mention: Our Rapunzel

Catherina Pinnaro, MD

level of care. Medically unnecessary admissions are expensive, and prolonged hospital stays have been associated with decreased quality of life in several chronic pediatric disorders.\(^5\)\(^6\) Thus, we have an ethical imperative to address this systems issue as the number of children with complex medical problems who need homes will only continue to grow as medical technology continues to advance.

This story eventually has at least a temporary happy ending. After almost a month of trying to identify a foster family willing to learn diabetes cares, Rapunzel was rescued from her tower by a great family. One of her foster mothers has type 1 diabetes herself and felt up to the challenge. We had frequent contact with her foster family in the weeks following her hospital discharge, and medically she has been doing great. Emotionally, I hope so. My colleague reported that Rapunzel has since taken over doing most of her diabetes care supervised, but without assistance, and seems to be thriving. I still think about her often and am grateful she was rescued. I just wonder how many more towers there are out there.

References
A recurring theme in literature about shared decision making is eliciting preferences and learning about values of parents. While I know in theory we as physicians need to do less talking and more listening, this is often easier said than done. We have information we feel compelled to convey. We are often rushed for time. Open-ended questions sometimes fall short.

When I asked for Section members to send me their thoughts about how images impact communication, or how “a picture is worth a thousand words,” I expected to hear about how we as clinicians can use images to teach, to convey, and to persuade (intentionally or not). That was my default position kicking in—the tendency toward a one-way street of communication—from clinician to parent, to patient, to trainee. But luckily, we have colleagues like Rachel Rigdon that challenge us to shake ourselves from our typical mindsets. Rachel is a chaplain that works with hospitalized children. She presents a refreshing perspective on how images truly are worth many words. Rachel uses published images called “Soularium Cards” to help encourage her patients to express emotions about experiences a child should never endure, but having endured them, might only heal through sharing. Special thanks go to Rachel for her contribution, and to Pam Foster at Cook Children’s and Anjie Emanuel from the Section for obtaining permission to reprint these images.

**Patient and chaplain conversation utilizing Soularium® Cards**

Context:
While covering the hospital on a Saturday morning, I received a pastoral care consult for the inpatient psychology unit. The consult read: *Patient fears her dead grandfather, who sexually abused her, will come onto the unit and kill her.* Responding to the consult in the inpatient psychology unit, I introduce myself to the weekend nursing staff. The nurse takes me back to a small classroom where three patients are watching a movie. I invite Darcy to join me, and we walk toward the main inpatient area, arranged like a family room, and make ourselves comfortable on the large sectional couch. The inpatient psychology staff are seated inside of an enclosed fishbowl room, in order to keep eyes on Darcy. Though we are in a public space the conversation is private.

Darcy (a pseudonym) is a nine-year-old Caucasian female with a history of anxiety and sexual abuse. She presented to the emergency department due to worsening anxiety and suicidal ideation. After evaluation, Darcy was admitted to the inpatient psychology unit.

Darcy’s father began drinking after Darcy’s mother left the family. Her great grandmother and great grandfather were awarded custody of Darcy, her twin sister, and two older brothers. The sexual abuse started when Darcy was in kindergarten (from age five until age eight) by her great grandfather, after Darcy’s great grandmother died. The siblings had minimal contact with their father, and their great grandfather threatened to shoot Darcy’s father if any one of them told.

The great grandfather was on the roof, where he suffered a heart attack and fell to his death. Darcy witnessed the entire incident. It wasn’t until almost a year later that Darcy’s twin sister confided in her father about the ongoing abuse.

Responding to the consult, I brought Soularium Cards with me. These cards are one of my favorite tools and serve as the perfect icebreaker for my interactions. The diverse pictures in the set allow me to dive in with my patients and engage them exactly where they are — even in the midst of sexual abuse.

Submitted by Rachel Rigdon
MDiv Cook Children’s Medical Center
Rachel.rigdon@cookchildrens.org
"I wonder what three images represent your life right now."

“I feel angry and want to kill myself.”

“I feel trapped.”

“This picture reminds me of a woman who put sharp stuff around her child’s bed because he was bad and it hurt him.”
“I wonder what three pictures you wish were a part of your life right now.”

“I want to be happy right now.”

“I want to see the sunset. I’ve never seen the sunset before.”

“I want to get a lot of money so I can give it to poor people so they can have somewhere to live. I want to have lots of money because everyone needs to have somewhere to live. Especially the poor people.”
“I wonder which picture reminds you of God.”

“Because she is in a church.”

“My mom told me that if kids commit suicide they don’t go to Heaven they go to Hell. But I don’t think that kids go to Hell if they kill themselves because kids don’t know any better. But I think grownups go to Hell. Do you think my grandpa is in Hell? I feel bad because I don’t know if I want my grandpa to be in Hell.”

In the Spring 2019 newsletter in Just an Expression? we will explore missed opportunities for communication. Was there ever a time that you wish you had asked or been told something about a patient or parent in the clinical setting? How would that have helped communication or clinical care? Is there something you do differently since then? Please consider sharing your experiences. You can send these and ideas for future topics to daliafeltman@gmail.com.
### Sunday, November 4th

**2:00pm – 2:45pm**

**F2086**

**No Can Do, Doc! I Have a High Deductible — John Lantos, MD**

An increasing proportion of the pediatric population has high-deductible health plans, introducing cost as a significant factor in medical decision making. Most pediatricians have trained in environments that are not cost sensitive and have fewer tools to address these concerns. The session will be grounded in the principles of beneficence, autonomy, and justice, and will address fair and just child health care financing policies. Participants will discuss how to handle situations when child health needs conflict with family concerns about costs.

### Monday, November 5th

**8:00am – 12:30pm**

**H3017**

**Joint Program: Council on Foster Care, Adoption and Kinship Care & Section on Bioethics**

**Ethical & Legal Challenges of Complex Decision Making for Children in Foster Care**

**Agenda**

- **8:00am**
  - Welcome/ Announcements
  - Moderators: Lisa Zetlet MD, FAAP & Steven Leuthner MD, MA, FAAP
- **8:10am**
  - The Balancing Act: Weighing the Best Interest of the Child vs Parental Rights in Permanency Decision— Making Cindy Lederman, JD & Mavel Ruiz
- **9:35am**
  - Q & A
- **9:50am**
  - Break
- **10:00am**
  - Investing in Healthy Attachments as a Matter of Best Interest for Children in Foster Care
  - Mary Dozier, PhD
- **10:45am**
  - Q & A
- **10:55am**
  - Opportunities & Barriers for Including Youth in Foster Care in Research
- **11:40am**
  - Q & A
- **11:50am**
  - COFCAKC’s Thomas F. Tonniges Lifetime Achievement Award (10 Minutes) & Bioethics Bartholome Award & Lecture (30 Minutes)
  - John Lantos, MD, FAAP
- **12:30pm**
  - End of Joint Program

### Tuesday, November 6th

**8:30am – 10:00am**

**I4027**

**Bioethics Mediation: A Useful Skill for Pediatric Practice — E. Haavi Morreim, JD, PhD**

Shared decision-making represents an increasingly popular model for medical decision-making. Increased involvement of families in medical decision making, however, also increases the potential for physicians and families to disagree about what medical options are best for a child. How can health care professionals best navigate parental refusals of recommended interventions, parental requests for interventions the provider believes to be unhelpful or even dangerous, or other conflicts that may arise over the care of a child? Join E. Haavi Morreim JD, PhD for a skill building session that will distinguish key features of conflict resolution methods such as coaching, negotiation, facilitation, mediation, arbitration. Participants will role play mediation concepts and skills applicable throughout pediatric practice.
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