Volume 32 • 2022 • Number 4

BENO

BIO QUARTERLY

A Publication of
The Bioethics
Network of Ohio

The Clay and the Potter:

The Cost of Shaping Patient Identities in the Electronic Medical Record

Dr. Keren Tanguay is assistant professor of Bioethics at Kettering College and Network Director of Clinical Ethics at Kettering Health. She holds a Masters of Divinity from Fuller Theological Seminary and a doctorate from The Ohio State University. Dr. Tanguay formally trained in Clinical Ethics at OhioHealth in Columbus, Ohio and is Healthcare Ethics Consultant-Certified through the American Society for Bioethics and Humanities. Her areas of research interest include the intersect of narrative medicine and medical chart documentation in addition to ethical dilemmas related to standards of care for substance use patients with infective endocarditis.

When I was in college one of the class elective offerings was a pottery class. My course schedule didn't allow me to enroll. I was in luck, however, because my boyfriend (now husband) did enroll. Many evenings I lived vicariously through him visiting during sculpting and tutorial sessions. It created an admiration in me for this incredible art. The craft of shaping pottery out of clay is a very delicate process that takes significant practice, skill, and meticulous caution. Go too fast and the formation goes awry. Too much pressure and you risk the entire piece collapsing. There is so much power, and yet such responsibility, in the hands of the artist.

Much of the same can be said of the hands of health care providers who craft chart notes in a patient's electronic medical record (EMR). Most hospitals in the 21 st century coordinate medical care through electronic patient records. My particular hospital specifically switched in 2016 to an operating system for their electronic records called Epic. Epic is a preferred EMR system used by more than 250 healthcare organizations nationwide, with that number growing daily. Over 45% of the US population have their medical records in an Epic system [1]. Switching to an electronic medical record is an historically important process that has provided numerous benefits. EMRs not only resolved challenges present with paper charts, such as illegible handwriting and the risks of misplacing sensitive patient information, but they also allowed for extensive innovations that improved patient care. Lab results are available almost instantly on the EMR system [2]. Years of patient history data—such as illness, surgeries, allergies, medications—are at the fingertips of any provider who encounters the patient. Additionally, the increased modality of algorithms made possible by metrics and data points in the EMR—such as length of stay, number of encoun-

continued on page 3...

CONTENTS

Bio Quarterly

is published four times a year by
Bioethics Network of Ohio
22425 Canterbury Lane
Shaker Heights, OH 44122
PH 216-403-2430
www.BENOethics.org

Submissions

to Bio Quarterly are encouraged. Manuscripts may be original material or reprint with permission. Appropriate subject/topics include: issue analysis, cases, report of institutional activity or programs, legisative and policy commentary and book reviews. Please submit your article electronically to **info@benoethics.org** for consideration. Quarterly deadlines are the 15th of February, May, August and November.

Reprint Permission

is granted to BENO members for professional/educational purposes unless otherwise indicated in the article. As a courtesy, please inform the editor of the purpose of volume copying. We are interested in what you are doing.

Josh Crites, PhD
President

Kathleen Grannan, RN-C, MSN
Alan Murphy, PhD
Editors

We welcome your Charitable Contributions

Your financial contribution to BENO, a qualified 501(c) (3) organization, is considered tax deductible. We appreciate all contributions to help further our mission and educational efforts. Contributions can be made by check or on our website, www.BENOethics.org. A receipt is available upon request.

Bioethics Network of Ohio
32
ANNIVERSARY
Serving Ohio Healthcare Ethics

President's Greetings

Welcome to the Fall Issue of BioQuarterly.

I hope this issue finds all of you winding down your year and making preparations for diving into new things in the new year—including time to spend time with family and other things that bring you renewal and energy.

In thinking about what I'd like to address in this issue's President Letter, I am reminded of the recent "pledge drives" on NPR. I was, for many years, largely a consumer of NPR content before deciding to contribute on a monthly basis. I share this not as a plea for financial support (though new and sustained members are always welcome!) but hopefully to inspire folks to help BENO provide content in BioQuarterly that is meaningful for our members. It would be great in 2023 to have more submissions from our members. The editors have done a fantastic job of diversifying the types of content included; my hope for 2023 is that our general members will feel inspired to "contribute" to BioQuarterly with articles, book reviews, art, poetry, and other content. Reach out to me, BioQuarterly editors, or anyone on the Board to learn more about how you can contribute.

In addition to the usual content types, we are happy to announce in this issue the dates and title of the BENO Annual Conference. After much consideration about cost and access, we have decided to hold the conference virtually again this year over an afternoon and morning, April 20 – April 21. The conference will focus primarily on diversity, equity, and inclusion. The conference chair and speaker selection committee are finalizing an exciting list of speakers, and we look forward to sharing more information in the coming month. Mark your calendars!

On behalf of BENO, have a wonderful holiday season everyone. See you in 2023!

My Best,

Josh

FOLLOW BENO ON:

***Clay and Potter** continued from page 1...*

ters, tracked diagnosis, etc.—has created new mechanism to account for quality improvement and patient safety agendas that were not possible, or were extremely cumbersome, with the use of paper charts.

Even so, most patients are unaware of all the features included in their electronic medical record and all the content there-in. One such feature is called Care Everywhere. Care Everywhere is a powerful interoperability tool that serves as a platform within the EMR for hospitals to seamlessly share patient records with one another. In one month alone, in the Fall of 2020, Care Everywhere had facilitated the sharing of patient records for 221 million patients [3]. Fifty percent of all records shared through Care Everywhere are with platforms other than Epic [4]. In other words, regardless of what operating system hospitals are using, Care Everywhere is an ethereal entity tied to no specific EMR system yet simultaneously encompassing all hospitals in any given region.

Care Everywhere is a powerful feature that has numerous benefits. One doctor spoke about the way she was able to access previous MRIs, EKGs, and full progress notes from another hospital across state lines within seconds. She writes, "…it completely changed the whole visit – what I was able to know and was able to do for [the patient]. That was my very first Care Everywhere experience and it immediately spoke to the power of this tool [4]." In an era where "continuity of care" is a buzz phrase in healthcare rhetoric, Care Everywhere is gold! In fact, I myself have used it numerous times in completing ethics consults. And yet, this kind of unrestricted, boundless access to all patient records in almost any hospital does have a price. For patient demographics that are perceived to be challenging or complex, features such as these can be burdensome.

One such patient demographic is intravenous drug users with infective endocarditis. Endocarditis is a serious condition that causes inflammation of the heart's chambers and valves caused by bacteria, fungi, or germs [5]. Intravenous substance users are at particularly high risk for acquiring infective endocarditis due to utilization of unsterilized needles. IV drug users are also at high risk for leaving against medical advice (also known as AMA discharge) which often contributes to their stigmatization as "difficult patients."

This perception is frequently translated to their electronic medical records. Leaving against medical advice is not uncommon in the hospital and is said to account for 2% of all hospital discharges [6]. However, substance users are one of the most prevalent patient demographics to leave hospitals against medical advice. In my dissertation research on substance users 78% of the patient charts reviewed included mention of the patient's leaving AMA either as an historical event that had already happened or a present event that was about to happen. In fact, the number one factor in predicting a self-discharge is a previous history of discharging AMA. It is cyclical. However, this reputation formed in the EMR can have catastrophic consequences for a patient's access to medical care.

Imagine this scenario. A few days ago you, the patient, were discharged from a local hospital. You were unsatisfied with the care and experience you received for a number of reasons. Because you were in the middle of an ongoing treatment, they wouldn't let you discharge any other way but an AMA discharge. You weigh your options but decide to discharge anyway in hopes of a fresh start at a new hospital. However, that's not what you're going to get:

Certainly there are benefits to the technological evolution of the EMR. Yet, these same benefits include an equally important weight of responsibility on us as chart note writers, story formers, and potters of a most delicate and fluctuating clay.

"Patient with history of IVDU and leaving AMA [7]."

"Polysubstance abuse history with multiple admissions with leaving AMA [7]."

"Patient left AMA from St. Martha's hospital for a smoke [7]."

"Patient left AMA today from Cambridge Hospital for treatment of IE. Patient [then] went to Outerbanks Hospital but left AMA citing a funeral as a reason to leave[7]."

"Went to St. Martha's Hospital and found to have vividran strep bacteremia with MV vegetation…went then to Cambridge hospital and left AMA once, and then returned and was discharged AMA due to noncompliance. Now at Municipal Hospital [7]."

As soon as your doctors open up your electronic medical record they see every single past offense and detailed account of every hospital encounter you've ever had in the last five or more years. You had been hoping for a fresh start; somewhere to start anew. However, unbeknownst to you, your previous actions, attitudes, and words have already been captured in what is perhaps one of the most permanent platforms – an electronic medical record.

There is a general lack of awareness and realization around the impact our crafted chart notes can and *do* have on patient's lives and their continued access to medical care. Particularly with tools such as Care Everywhere, chart note descriptions of patients such as "belligerent," "non-compliant," "uncooperative," "unpleasant" not only follow patients wherever they go, but serve to form their *perceived* identities before they even step foot in a new medical facility. For many providers, seeing these notations in a new patient's previous encounter creates significant room for forming biases, preconceived ideas, and a general hesitancy in providing medical treatment.

Epic has changed what providers are able to know and how they treat patients – and not always in a good way. The frustration and stigma that follows a patient who, for example, has a history of AMA discharges results in clinicians, who haven't even met the patient, assume they know exactly what this patient is like. This creates immediate relational barriers that prevent the establishment of a fiduciary relationship between patient and physician. An entire network of hospital systems across numerous zip codes, and even across state lines, becomes inaccessible to patients wanting a fresh start.

To this day the shelves of our home are decorated with the delicate pieces my husband made in that pottery class. Much like patients' electronic medical records they are a permanent artifact that have permeated the boundaries of space and time. Most of us casually pull up patient EMRs in our daily work to write a chart note. We're in a rush so perhaps our words are not as carefully selected as they could be. We're feeling frustrated by our conversation with the patient and it shows in the tone of our chart note. Or, we think nothing of it because this is our twelfth chart note of the day. We do it with ease assuming it is an easy, casual task.

Nothing could be further from the truth. As a potter shaping the clay of a patient's narrative, we must be meticulous when composing chart documentation in patient records. The question is not only how we want to care for our patient now, but most importantly how we want our patients to be cared for *later* – maybe by us, but maybe by someone else. These chart notes will remain as permanent artifacts in this patient's history. Certainly there are benefits to the technological evolution of the EMR. Yet, these same benefits include an equally important weight of responsibility on us as chart note writers, story formers, and potters of a most delicate and fluctuating clay.

Before clicking "publish" on our chart notes, it's worth considering a few things. First, we would do well to remember that what we see during a hospital encounter is but a momen-

continued on page 5...

Ethical Issues around the Resuscitation of Extremely Preterm Neonates

Alexandra Perry, Ed.D., M.Ed. is the interim Dean of the McDonough Center for Leadership and Business and an Associate Professor of Leadership and Ethics at Marietta College. She is also a clinical ethicist with OhioHealth. She is currently working on a book that looks at end-of-life care in American Hospitals, and projects surrounding the opioid epidemic, and rural and indigenous healthcare.

There is no clear consensus within the medical community about the exact point of fetal viability during pregnancy. This creates ethical complexity around how to treat extremely premature newborns, and in particular around decisions to withhold resuscitation. A typical pregnancy is 40 weeks long, and extremely premature infants are typically those born 15 weeks or more early. In the United States, the standard of care for infants born at 25 weeks and beyond has clearly been to resuscitate them at birth and to provide any support necessary for their developing lungs while admitting them to the NICU. The standard of care for infants born during or before the 21st week of pregnancy has been unequivocally not to administer life-sustaining interventions because of the almost certain risk of death. There is ambiguity, however, around the standard of care for extremely pre-term infants born between 22 and 24 weeks' gestation, and the optimal way to care for newborns born within this window has been widely debated.

Resuscitation can be invasive and can cause suffering based on the small size of a preterm infant. The reason that it is controversial is because it is considered a high-level intervention, which brings about a certain amount of risk to the patient. In extremely preterm infants there is often a high likelihood of death, so clinicians have to weigh the potential harms and benefits of resuscitating a fragile preterm newborn against the high risk of death.

At a minimum, the literature around interventions for extremely preterm infants (typically defined as infants born before 28 weeks and weighing under 1000 grams, though this definition is moving toward infants born before 25 weeks as outcomes for premature infants improve) suggests that parents of infants born between 22 and 24 weeks gestation should not be obligated to have their infants resuscitated, and this is particularly true with infants weighing less than 500 grams. For parents who decide to have their less-than 500 gram infant resuscitated, the literature around best practices is clear: parents must be educated on the risks and potential harms of resuscitation in extremely preterm infants.

> ***For parents who decide to have their less-than 500 gram infant resuscitated, the literature around best practices is clear: parents must be educated on the risks and potential harms of resuscitation in extremely preterm infants.***

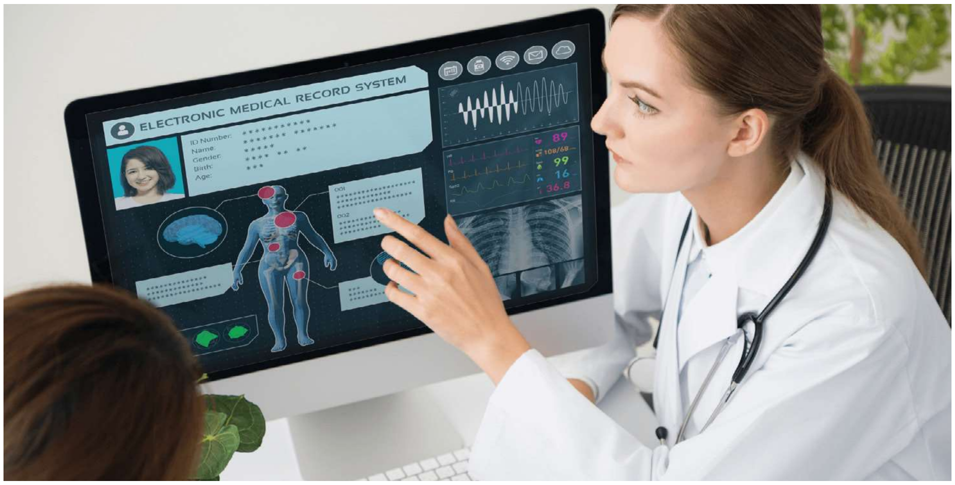
The most robust data around long-term outcomes for neonates in the United States is available from the Neonatal Research Network (NRN) which is part of the National Institutes of Health (NIH). The NRN has been researching premature infants since 1986 through a network of hospitals who care for the smallest infants and report their data.

The data from this research is housed in the NRN's Generic Database of Very Low Birth Weight Infants (GDB) study. This study focuses on morbidity and mortality data, and it began in January 1987, soon after the founding of the NRN. To date, the study has enrolled over 80,000 participants at 28 NRN care sites. The study enrolls infants born between 20 weeks and 0 days (20 and 0/7) to 28 weeks and 6 days (28 and 6/7). The range of birth weight is 401 grams to 1,000 grams. The inclusion criteria used to include infants up to 1,500 grams, but was changed in the last decade as outcomes for higher weight micro-preemies began to improve. The lower end of the inclusion criteria has not changed because survival of infants born weighing less than 401 ounces is so rare. There are anecdotal cases of survival, however, including an infant born in 2018 weighing 245 grams.

The GDB study is the largest database of information about pre-term infants in the world. It includes data on demographics such as sex, birthweight, race, and singleton or multiple birth. It also includes data on prior maternal health and labor and delivery (pregnancy history, complications, and administration of steroids and antibiotics). The infant's initial health is documented by an APGAR score and there is documentation of weight, length, respiratory effort and support, and delivery-room resuscitative efforts. Finally, medical outcomes are

continued on page 5...

Clay and Potter *continued from page 3...*



tary space in time. It is but a glimpse in a patient's life and often a very tumultuous one. I have often wondered how I would be captured in a medical record if I were to encounter healthcare in a less than pleasant time. I imagine I would not be my best-self; perhaps not as courteous as usual, and perhaps lacking some of my self-regulating internal tools that usually help me. I certainly would not want be judged in such a difficult time in my life.

Secondly, our job is not to opine on patient identities or their character, but rather to opine on their medical diagnosis. That can feel like a delicate line to walk but there is a meaningful and distinct boundary between the two. Thirdly, we would do well to increase awareness and conversation around this topic among those stakeholders who routinely document in patient's EMRs. More questions need to be asked and reflected on. Is it possible that the very platform used to protect patient privacy is now serving as a conduit for violating it? How do we determine what information is relevant for transcription into the EMR? How are boundaries constructed around this? What obligations towards the patient do we have to inform patients of the way their EMR can be accessed and might be used – by us and others? Are there reliable ways to check our motive and biases before clicking "publish" on a chart note? All of these questions, and others, will assist us in developing improved practices around documentation.

Although EPIC was introduced as a healthcare software system over five decades ago, I would argue we are still at the onset of understanding how we do electronic medical records well, and do them ethically. This is a journey all of us must embark on if we are to care for patients in the most responsible way.

REFERENCES

[1] *"Why Epic."* John Hopkins Medicine, accessed September 22, 2021, *https://www.hopkinsmedicine.org/epic/why_epic/*.

[2] *"Benefits of Switching to an Electronic Health Record."* Practice Fusion, accessed September 22, 2021, *https://www.practicefusion.com/health-informatics-practical-guide-page-1/*.

[3] *"Epic's Care Everywhere Interoperability Platform Shows Big Jump in Data Exchange."* Healthcare IT News, 2020, accessed September 22, 2021, *https://www.healthcareitnews.com/news/epics-care-everywhere-interoperability-platform-shows-big-jump-data-exchange.*

[4] *"Care Everywhere Adding Use Cases for Epic Users."* 2021, accessed September 22, 2021, *https://www.hcinnovationgroup.com/interoperability-hie/health-information-exchange-hie/article/21219496/care-everywhere-adding-use-cases-for-epic-users.*

[5] Y. Ji, L. Kujtan, and D. Kershner, *'Acute endocarditis in intravenous drug users: A case report and literature review,' Journal of Community Hospital Internal Medicine Perspective,* vol. 2 no. 1, (2012), 1-4.

[6] Yuan, S., S. Ashmore, K. R. Chaudhary, B. Hsu, and S. E. Puumala. *"The Role of Socioeconomic Status in Individuals That Leave against Medical Advice."* [In eng]. S D Med 71, no. 5 (May 2018): 214-19.

[7] Tanguay, Keren, *"Deviant Patients with Fuzzy Valves: The Practice of Infective Endocarditis in Substance Users."* PhD diss. The Ohio State University, 2021.

Neonates*...continued from page 4*

tracked including mortality; NICU stay lengths; infection history; heart, lung, nervous system, and GI system diagnoses; hearing and vision screenings; and developmental trajectory while admitted to the NICU.

Ethical Issues in the Provision or Withholding of Interventions in 22-24 week Gestational Age Infants

In the ethics literature there is general consensus that physicians have the right, if not the moral duty, to refuse to provide medically-inappropriate or non-beneficial treatment to infants born between 22 and 24 weeks gestation if they believe that it will cause significant harm and suffering to the infant without offering even minimal odds of survival. In addition to understanding and applying the longitudinal outcomes data there are other clinical factors that should be considered in an appraisal of the risks and benefits (and ultimate moral assessment) of attempting the resuscitation of a 22-24 week gestational age infant after birth. Those factors are outlined below.

Preterm-Premature Rupture of Membranes (PPROM)

PPROM occurs when the amniotic sac ruptures prematurely and results in pre-term delivery. When this happens, the risk of infection to both the pregnant woman and the fetus goes up significantly, while the infant's ability to access nutrients becomes compromised. When PPROM occurs with a clearly viable pregnancy, an emergency delivery is typically warranted. When PPROM occurs in a pre-viable second trimester pregnancy (often between 17 and 22 weeks gestational age), the patient will sometimes elect to attempt to carry to viability and will be admitted to the hospital for bedrest, the administration of antenatal steroids, and close monitoring for signs of infection, while other patients might choose not to prevent delivery and stillbirth. If PPROM has occurred, a neonatologist should begin a conversation with the patient and her support system about what interventions, if any, are appropriate to administer to the neonate after birth at each particular gestational age, and given various post-delivery scenarios.

Accuracy of Gestational Dating

Because we know that viability and outcomes for preterm infants can change by the day, the accuracy of gestational dating, or the assumption that gestational age might be inaccurate, is an important consideration in an ethical analysis centered on the potential resuscitation of a 22-24 week neonate. If assisted reproductive technology was used to aide in conception, gestational dating will be known without doubt.

continued on page 6...

***Neonates**...continued from page 5*

If ultrasound dating or dating based on the last menstrual period has been used, the care team should consider that the fetus might be a few days closer to viability in order to err on the side of caution. Since a few days of gestational age might both decrease the harm caused to the neonate and increase the likelihood of benefit, this is very important. For example, the data suggests that a 22-week singleton male preemie born with a birth weight of 500 grams has an average survival rate of 15%, while a 23-weeker with the same demographics and birth weight have a 19% chance of survival, and a statistically-identical 24-weeker has a 29% chance of survival. Therefore, a patient who has had poor prenatal care or inaccurate gestational dating and self-reports a gestation of 23 weeks could very well be off by a week, and have a survival to discharge likelihood of 15-29 percent: a significant difference in terms of the ethics of withholding resuscitation.

Availability of Interventions

Another factor to consider in looking at the ethics of initiating or withholding life-sustaining interventions to an extremely low birth weight neonate is the availability of the resources needed to successfully resuscitate and stabilize the neonate after delivery. In order to minimize the harm to the neonate relative to the potential benefit, resuscitative efforts should only occur if the care team has, for example, an appropriately-sized endotracheal tube. Using an ET tube intended for larger preemies, even those only larger by a few hundred grams, can cause unnecessary harm to an already vulnerable patient, without a justifiable likelihood of benefit. When patients deliver in facilities that do not have a NICU capable of admitting a neonate at such an early gestational age, physicians should also consider the risk of transferring the patient if the neonate is successfully resuscitated.

Factors that should not be included in considerations of the provision or withholding of neonatal interventions

The data collected by the NRN suggests that there are demographic determinants of good and poor outcomes for neonates born between 22 and 24 weeks gestation. For example, white female neonates had overall better outcomes than white male neonates in terms of both survival to discharge and in terms of number of complications during NICU admission. A recent article published in *Pediatrics* reports that a longitudinal study of racial and ethnic differences in preterm neonatal outcomes shows that African American infants had overall poorer outcomes than both white and Hispanic infants (Boghossian, et al., 2019). Despite knowledge that there are demographic predictors of morbidity and mortality, these factors should not influence a physician's advice to a patient, or his or her decision to provide or withhold treatment from a preterm neonate.

Another risk of prematurity that often finds its way into the ethics literature on resuscitation is disability. Extremely low birth weight neonates are at high risk for respiratory problems such as Bronchopulmonary Dysplasia (BPD), Respiratory Distress Syndrome (RDS), and Central Apnea. They are also at higher risk than their full-term peers for disabilities such as cerebral palsy, deafness, vision impairments, severe neurological damage, and severe developmental disability, in addition to the numerous cardiac, GI, and other defects common to prematurity. This high risk of disability should certainly be included in a physician's conversations with parents in order to fully inform them about preterm birth, but ethically, a physician's decision to withhold life-sustaining treatment from a neonate should be based on the imminent harm that might come to the patient, and not to the long-term risk of disability. This risk should be left to families to consider in determining goals of care for the patient, as these goals reflect their own individual, cultural, religious, and family values.

Ethical Principles and Models of Decision Making

Albersheim (2020) identifies four principles that are commonly employed in decision making about goals of care for extremely low birth weight infants. These principles are the best interest standard, the reasonable person standard, the "good enough parent," and the harm principle. She identifies a few models of decision making that are often used in pediatrics, but suggests that the model most commonly used in making decisions for extremely preterm infants is called the "Zone of Parental Discretion" which is based largely on the ethical principle that harm ought to be avoided or minimized, and that the parents ought to have a large amount of discretion to make decisions for their infant unless the decisions that they make will harm the infant without any reasonable chance of benefit.

The complexity of viability and NICU intervention makes it very difficult to apply either the best interests standard or the reasonable person standard that are both common in other pediatric specialties.

Bioethicists such as Ross (2002) and Coughlin (2018) also suggest that giving parents wide discretion in decision making for extremely preterm infants is appropriate given all of the uncertainty about medical outcomes. The complexity of viability and NICU intervention makes it very difficult to apply either the best interests standard or the reasonable person standard that are both common in other pediatric specialties. The limits of parental discretion, however, are typically defined in terms of allowing unnecessary harm to come to a child. Many clinicians agree that resuscitating infants at 22 or 23 weeks gestation, or those born with birthweights under 500 grams, necessarily exposes newborns to harm without any real likelihood of benefit. Overall, a physician's refusal to administer life-sustaining treatment to a neonate at 22 or 23 weeks gestation (even in cases where parents object) is still within the rough standard of care in neonatology.

John Lantos, a pediatrician and bioethicist, wrote two articles in 2018 in which he argued that shared-decision making, not parental discretion, should guide ethical decision-making for extremely preterm infants. Lantos argues that a physician's role is to supply expertise and to facilitate decision-making in a way that acknowledges biases and helps to clarify parental values. He shares important research on physician-family disagreement, and advocates for physicians to do more active listening, and to make more attempts to understand parents' values while supplying medical information that can inform their choices.

A final question is often raised in the literature about whether or not it is appropriate to resuscitate a neonate at the parent's request (despite concerns or moral objections from the physician), and to provide a time-trial of interventions in the NICU. This approach relies on the idea that withholding and withdrawing interventions are morally identical, even if emotionally they might feel very different. In theory this is reasonable, though applied in the case of extremely preterm infants this means that the infant would first have to be subjected to the harm caused by resuscitative efforts before eventual withdrawal whereas if

continued on page 7...

Neonates*....continued from page 6*

intervention is withheld and a palliative approach to delivery is taken, the infant is provided comfort-oriented interventions only, and is not subjected to potentially harmful (though otherwise-intended) interventions.

Overall, the principle of harm-avoidance seems to be the most appropriate ethical principle to apply to extremely preterm infants in light of the complexity of clinical predictions of neonatal outcomes, the variable nature of available interventions between care sites, and the fact that decisions often need to be made immediately.

In the case of care planning for extremely preterm infants, physicians should try to participate in shared-decision making whenever possible by facilitating conversations with parents in order to establish reasonable goals of care based on parental values, but ultimately should avoid causing harm through non-beneficial interventions to 22-24 week premature infants even at parental request. Of course, all treatment decisions, particularly unilateral decisions, should be data-driven. If no curative interventions are offered, non-invasive palliative interventions should be administered based on parental discretion.

REFERENCES

Albersheim, S. *The Extremely Preterm Infant: Ethical Considerations in Life- and-Death Decision-Making.* Front. Pediatr., 26 February 2020. doi.org/10.3389/fped.2020.00055

Boghossian, Nansi S., Marco Geraci, Scott A. Lorch, Ciaran S. Phibbs, Erika M. Edwards, Jeffrey D. Horbar. *Racial and Ethnic Differences Over Time in Outcomes of Infants Born Less Than 30 Weeks' Gestation.* Pediatrics Sep 2019, 144 (3) e20191106; DOI: 10.1542/peds.2019-1106

Brazier M, Archard D. *Letting babies die*. J Med Ethics. 2007;33(3):125-126. doi:10.1136/jme.2006.020099

Coughlin, Kevin. *Medical decision-making in paediatrics: Infancy to adolescence, Paediatrics & Child Health*, Volume 23, Issue 2, May 2018, Pages 138–146, https://doi.org/10.1093/pch/pxx127

Hintz SR, Bann CM, Ambalavanan N, Cotten CM, Das A, Higgins RD; *Eunice Kennedy Shriver National Institute of Child Health and Human Development Neonatal Research Network. Predicting time to hospital discharge for extremely preterm infants.* Pediatrics. 2010 Jan;125(1):e146-54. doi: 10.1542/peds.2009-0810. Epub 2009 Dec 14.

Lantos JD. *Tell Parents the Truth, but Tell It Slant.* Pediatrics. 2018 Nov;142(Suppl 3):S199-S204. doi: 10.1542/peds.2018-0516L. PMID: 30385628.

Lantos, J.D. *Ethical Problems in Decision Making in the Neonatal ICU.* N Engl J Med 2018; 379:1851-1860. DOI: 10.1056/NEJMra1801063

Mehler K, Oberthuer A, Keller T, et al. *Survival Among Infants Born at 22 or 23 Weeks' Gestation Following Active Prenatal and Postnatal Care.* JAMA Pediatr. 2016;170(7):671–677. doi:10.1001/jamapediatrics.2016.0207

Ross, L.F. *Children, Families, and Health Care Decision-Making.* New York: Oxford University Press. 1998.

Smith PB, Ambalavanan N, Li L, et al. *Approach to infants born at 22 to 24 weeks' gestation: relationship to outcomes of more-mature infants.* Pediatrics. 2012;129(6):e1508-e1516. doi:10.1542/peds.2011-2216

Te Pas, A., Davis, P., Kamlin, C. et al. *Spontaneous Breathing Patterns of Very Preterm Infants Treated With Continuous Positive Airway Pressure at Birth.* Pediatr Res 64, 281–285 (2008). https://doi.org/10.1203/PDR.0b013e31817d9c35

Tyson JE, Parikh NA, Langer J, Green C, Higgins RD; National Institute of Child Health and Human Development Neonatal Research Network. *Intensive care for extreme prematurity--moving beyond gestational age.* N Engl J Med. 2008 Apr 17;358(16):1672-81. doi: 10.1056/NEJMoa073059.

Wadhawan R, Oh W, Perritt RL, McDonald SA, Das A, Poole WK, Vohr BR, Higgins RD. *Twin gestation and neurodevelopmental outcome in extremely low birth weight infants.* Pediatrics. 2009 Feb;123(2):e220-7. doi: 10.1542/peds.2008-1126. Epub 2009 Jan 12.

MEMBER SPOTLIGHT

Robert Guerin, PhD
Clinical Ethicist, University Hospitals Cleveland Medical Center
Clinical Assistant Professor of Bioethics, Case Western Reserve University
Psychoanalyst-in-training, Private Practice
BENO Board Member for 4 years (2 terms)

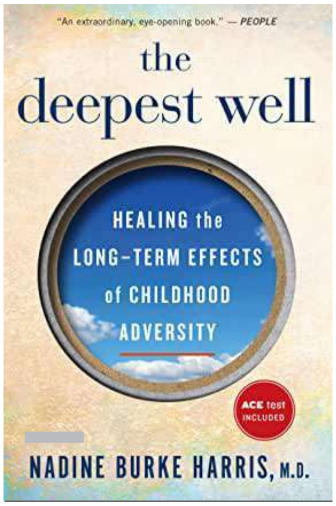
My path to bioethics and clinical ethics consultation seems intelligible in hindsight. But it was not always so as I was making my way. I did not set out from college with the goal to become a bioethicist. I studied philosophy, earning a bachelor's and a doctoral degree. I wrote a dissertation on the power of imagination in the philosophy of Immanuel Kant. I thought I would become a professor of philosophy at a university or college.

So how did I get from Kant to the hospital? During my graduate studies, I was teaching introduction to healthcare ethics to undergraduates. One evening, at a lecture by a visiting scholar, I happened to meet the university's hospital's bioethicist: "So you're the one who is teaching healthcare ethics," she observed. One thing led to another, and, before long, I was interning with the bioethics program, observing ethics consultations and participating in committee meetings and multidisciplinary rounds.

Once I completed my dissertation, I accepted an offer for the Cleveland Fellowship in Advanced Bioethics at the Cleveland Clinic. There, with excellent mentorship, I honed by competencies and gained the experience necessary for independent practice. After two years of fellowship, I accepted the position of clinical ethicist at University Hospitals Cleveland Medical Center where I currently offer consultation and education and serve on various hospital committees.

The final piece is psychoanalysis. My interest here is long-standing, beginning with a college course as an undergraduate. Once I completed my academic and fellowship training, I enrolled as a candidate in the adult training program for psychoanalysis at the Cleveland Psychoanalytic Center. I am currently an advanced candidate, having completed my course work and currently treating patients with psychoanalysis. Not wanting to leave this seemingly disparate interest siloed from clinical ethics, my intent is to bring together clinical ethics consultation and psychoanalysis. To date, I've published a few papers on what psychoanalysis can offer ethics consultation, what I have called advanced skills.

On a final note, and something beyond my professional course and development, I am a prospective homesteader and proto-farmer. My backyard has 7 raised garden beds, each of which is intensively planted throughout the season with peas, beets, lettuce, spinach, strawberries, asparagus, peppers, tomatoes, herbs, and brassicas; a cherry tree; blueberry, gooseberry, and currant bushes; several hazelnut trees; and an elderberry; not to mention plenty of native wildflowers for the pollinators. I also love to ferment: I have several sourdough starters, a kombucha SCOBY, as well as bokashi and hot composting systems.



BOOK REVIEW

The Deepest Well: Healing the Long-Term Effects of Childhood Adversity.

Nadine Burke Harris

New York: Mariner Books, 2019. Non-fiction; 272 pages

Reviewed by Josh Crites, PhD

Nadine Burke Harris, MD, who served as the first Surgeon General of California (2019-2022), is a pediatrician by training. In this fascinating book, Dr. Burke Harris recounts how her search for an answer for why one of her patients was not growing at a normal rate led her to the groundbreaking research of Vincent Felitti and Robert Anda. Largely ignored at first, and mostly rejected by physician peers, Drs. Felitti and Anda exposed a deep connection between "adverse childhood experiences"—ranging from abuse and neglect to other sources of toxic stress caused by poverty, observed violence, and chronic fear—and health outcomes. Their study measured 10 adverse childhood experiences (ACEs), and demonstrated that a higher score was correlated with riskier behavior and overall worse health outcomes. Subsequent studies across 39 states confirmed these initial results and, of those states reporting their data, demonstrate a profound prevalence: 55-62% of the population have experienced at least one ACE, and 13-17% of the population have an ACE score of four or more (p. 91).

Dr. Burke Harris went on to integrate the ACE score, in her words, "as a vital sign" for her patients in a pediatric health center she founded in San Francisco. Once this assessment became part of her regular practice, Dr. Burke Harris employed an interdisciplinary team of healthcare professionals to address the effects of ACEs in a uniquely holistic way. Care was provided that was responsive both to the symptoms of illness created by toxic stress **and** to the toxic stress itself. While not unaware of larger issues at the societal level, Dr. Burke Harris does a masterful job in *The Deepest Well* of informing readers about specific negative health outcomes associated with ACEs, as well as providing insight into challenges and rewards associated with community-based initiatives in neighborhoods where ACEs are most prevalent.

While perhaps not immediately clear how this book or Dr. Burke Harris's experiences might be relevant for bioethicists, there are threads in this text that help us remember to look for, and then to look at, the circumstances surrounding the situatedness of patients and families from angles perhaps hidden from even patients themselves. In the context of broader clinical ethics activities, Dr. Burke Harris's book has relevance for healthcare professionals engaged in the challenging work of creating longitudinal care plans for complex patients or for helping to reduce unnecessary readmissions. For bedside ethics consultation it is also an example of how asking questions that others may otherwise dismiss—sometimes the greatest contribution of clinical ethicists—can uncover pathways that lead to more compassionate care of our patients.

UPCOMING EDUCATIONAL OPPORTUNITIES

December 21, 2022 • 12:00-1:00pm

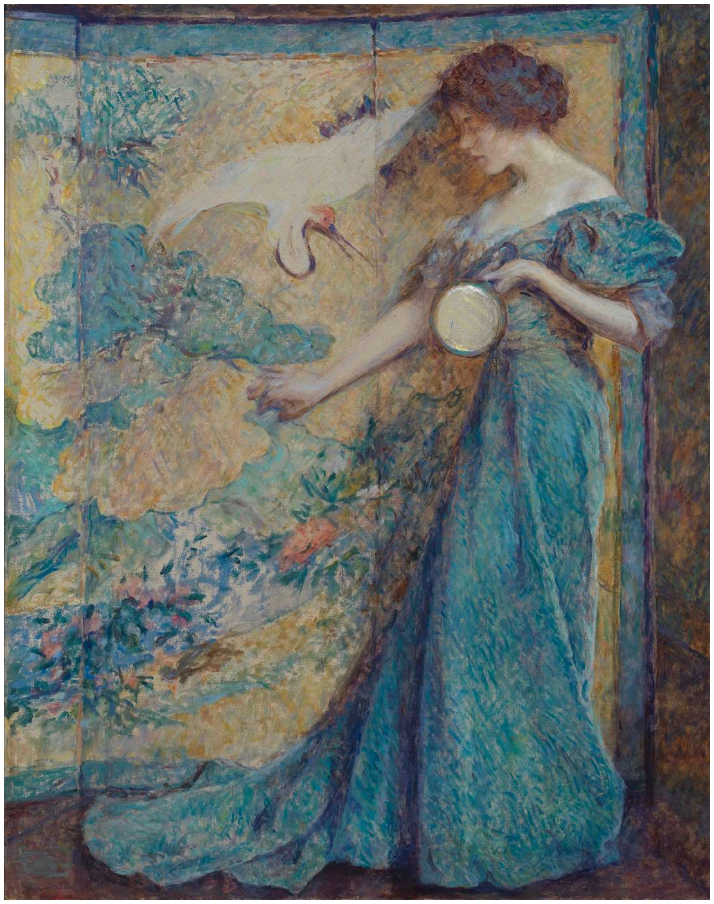
Bioethics Grand Rounds, Dr. Eric Singer.
CME credit available.
Moral Incontinence: Diagnostic and Therapeutic Interventions for Medical Education
https://osu.zoom.us/j/93857739774?pwd=SGM3MVd3dGk3NnpLZVZjRzBtdURGQT09
Contact: bioethics@osumc.edu

March 12-14, 2023

Conference on Medicine and Religion:
At the Limits of Medicine: Caring for Body and Soul.
Hosted at OSU. Information and registration here:
http://www.medicineandreligion.com/

ART SPOTLIGHT

Robert Reid, “The Mirror,” (ca. 1910), Smithsonian American Art Museum, Washington, DC.



Robert Reid (1862-1929) was an American painter whose murals appear in the Library of Congress and who exhibited alongside such well-known contemporaries as Childe Hassam. During his lifetime he was characterized as an Impressionist, though the accuracy of this description has been disputed. [1-2] Along with his murals, Reid was known for his many paintings of women with flowers, a whole genre unto itself in the Victorian era. [3]

“The Mirror” differs from those paintings in that the “nature” it includes is an overtly stylized representation of nature. The titular mirror seems to have little to do with the rest of the painting, though the mirror’s prominence in the visual field suggests it might be important. The virtue Prudence is often portrayed as a woman holding a mirror with which to clearly see the truth of herself, for better and for worse. But Reid’s subject has let the mirror slump in her hand as she is drawn to examine the nature scene on the decorative screen, a development that seems almost to have surprised the red-crowned crane on the screen. It may be that Prudence has preferred beauty over truth.

Fall is a time when we hear a lot about how the season’s natural beauty — of turning leaves, crisp air, and so on — is a reminder of merits of transience. But it’s very easy for nature in autumn to become a comforting abstraction rather than a timely reminder. Online photos of crimson foliage and piles of pumpkins are well and good, but we might learn more about transience (comforting or not) by taking a look in the mirror.

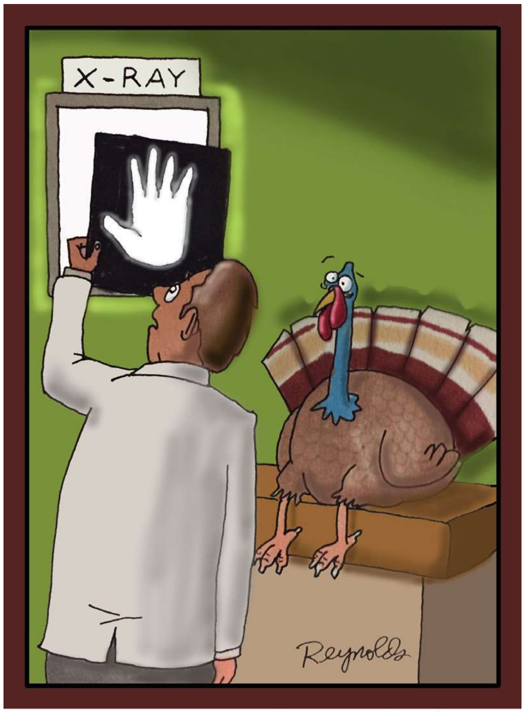
REFERENCES

[1] Christian Brinton, “Robert Reid: Decorative Impressionist,” Arts & Decoration 2, no. 1 (1911):13-15, 34.

[2] H. Barbara Weinberg, “Robert Reid: Academic ‘Impressionist’,” Archives of American Art Journal 15, no. 1 (1975): 2-11.

[3] Annette Stott, “Floral Femininity: A Pictorial Definition,” American Art 6, no. 2 (1992): 60-77.

HUMOR



CartoonStock.com

BΞNO
Bioethics Network of Ohio
22425 Canterbury Lane
Shaker Heights, OH 44122

SAVE THE DATE!!!

Bioethics Network of Ohio
32nd Annual Conference

Held virtually:

Thursday, April 20th
12pm – 3:30pm

Friday, April 21st
9am – 12pm
(times are approximate)

Member early pricing: $25
Non-member early pricing: $75
Student price: Free

Registration information to come early in 2023

FOSTERING AN INCLUSIVE OHIO: ANTI-RACISM, DIVERSITY, AND HEALTHCARE