

PARADIGMS OF DECISION-MAKING WITH THE MATURING CHILD OR ADOLESCENT

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GUEST CONTRIBUTOR

Pediatric bioethical issues are unique because children are not simply little adults. The term “minor” covers an age span that represents a wide spectrum of neuropsychological development which increases the complexity of decision-making in pediatrics, particularly with regards to the minor’s emerging autonomy.

The way we view and treat children today is the result of a dynamic process shaped by centuries-old debates about relevant questions regarding the nature of the child and who has the legal authority to make decisions for the child. Decision-making issues arise commonly within the clinical and research domains; however, minors can also access various services and alternative treatment choices that may impact their healthcare.

Adults with decision-making capacity have been recognized in ethics and the law as having the right to self-determination in healthcare decisions based on the principle of respect for autonomy and bodily integrity. By nature, children do not enter the world as autonomous agents but are dependent on others. Children are not presumed legally competent as moral agents with decision-making capacity, but each child still has dignity and is worthy of respect, for “morally the child is first and foremost an end in herself.”¹ The dependency of children highlights the fiduciary responsibility of both physicians and parents to protect and promote the health-related interests of the child and shifts the moral focus in pediatrics away from autonomy and toward protection.² This also raises questions about protections or privileges that should be ethically or legally sanctioned.

As children grow and mature physically, mentally, emotionally, and spiritually, they eventually become separate from their caretakers with their own identity and values. This gradual process, highly individual and context specific, prompts questions regarding when respect for the child’s emerging autonomy should move toward a model of shared decision-making.

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Where and how to draw the lines regarding decisional capacity and legal authority in healthcare decisions for the maturing child and adolescent and the degree of participation they should have in the decision-making process is an ongoing discussion.

Authority and Autonomy in Pediatric Decision-Making

All those who care for children and struggle with ethical choices do so in a complex web of cultural influences and legal boundaries. Children are embedded in families and cultures with worldviews, stories, and frameworks that shape their values and order their lives. This ordering always includes an orientation toward a single (or multiple) source of authority.

One of the more difficult tasks in reviewing the literature on healthcare decision-making in cases involving the maturing child is parsing through the complex history of the attribution of maturity to minors and the vast repository of legal cases and documents. The difficulty is compounded by the regulations concerning minors in various branches of the law and the inconsistencies in federal laws and state rulings. Individuals involved in healthcare or research concerning minors should always be aware that discrepancies exist and familiarize themselves with relevant state laws.

A person is considered an adult and granted the individual rights and responsibilities of adulthood according to the legally determined age of majority, which in most states is eighteen years of age. This has not always been the case and even now differs by state as statutory laws grant adult privileges categorically. Historically, changes in the age of majority have shifted for numerous reasons. Sometimes these changes have been the result of political movements, or they have simply been implemented to streamline procedures of the law. It has been noted that changes in the age of majority have even been based on utility, such as in times of war.³

Neither the U.S. Constitution nor the Bill of Rights makes explicit the rights of children or parental rights and responsibilities.



from the director's desk

BY PAIGE C. CUNNINGHAM, JD, PHD
EXECUTIVE DIRECTOR

When someone is in terrible pain at the end of their life, why isn't it the loving and compassionate thing to end their suffering?" I was confronted with this question, and variations on its theme, after a presentation I recently gave at a church on bioethics.

As I have reflected on our conversations in subsequent weeks, two aspects stand out: 1) their questions represent the public, secular views about death and dying popularized in American culture; and 2) they were more interested in avoiding physical pain than in thinking Christianly about the problem. I want to briefly describe the view they seem to have absorbed, and the consequences we already see from legalization of both euthanasia and physician-assisted suicide (PAS).

But first, here are some questions I wish I had asked them:

- How do you know what is the loving thing to do?
- Do you believe that as Christians we are free to control the timing and circumstances of our death?
- Is it part of God's plan that we should help someone to die in order to relieve suffering?
- If we agree that someone should not have to endure terrible physical pain, and that the most compassionate thing to do is end their life (in the words of King George III in *Hamilton* at the end of the American Revolution), *what comes next?* Would you do it? Why or why not?
- If you want the doctor to handle it, why? Should they be *required* to provide the lethal drug?

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American culture and "the most loving thing." The core of their question was that "the most loving thing" was to end the person's life. This phrase brings to mind Joseph Fletcher's situational ethics, and its core value of doing that which is most loving. The problem, of course, is that despite Fletcher's efforts to define "love" as *agape*, it has become vulnerable to potentially idiosyncratic and subjective interpretations. Although Fletcher's views are not widely accepted today, the idea of equating love with compassion and assisted suicide endures.

Arguments based on compassion appeal more to emotional response than to rational analysis. Brittany Maynard popularized support for PAS as a young, attractive 29-year-old victim of brain cancer who maximized social and mainstream media to generate sympathy for her decision to commit PAS, and who raised money for legalizing PAS. More admirable, but less adored by the press, was Lauren Hill, another young woman with inoperable brain cancer. She raised more than \$1.5 million for cancer research, and did not conceal the disfiguring effects of steroids and other treatments. Her desire was to play one basketball game as a college freshman before she died, which she did, in a sold-out arena, weeks before her death at 19. Which woman demonstrated the more thoughtful and generous death?

The PAS slope is "slippery." Physician-assisted suicide has been legal or permitted in the Netherlands, Belgium, and Switzerland for a number of years. Their experience serves as a warning that PAS cannot be confined to those who have a terminal illness and unmanageable physical pain. Patients who have requested PAS include those who are depressed, have a mental illness such as psychosis, have experienced sexual abuse, are disabled, are unhappy with their looks, are distraught over a sex change operation, or are bored with life. Couples who do not want to live apart have chosen to die together. Children are no longer protected, and have been euthanized even though they are not legally able to consent.

Although in 2001 the Dutch euthanasia law was inaugurated with safeguards such as a review committee, and expectations that the number of deaths would remain low, the reality quickly changed. Beginning in 2008, deaths increased by 15% per year. Professor of ethics at Protestant Theological Seminary in Groningen Theo Boer, who sat on the review committee for over a decade, publicly admitted, "We were wrong—terribly wrong, in fact."¹ The slippery slope he describes includes PAS as the 'default mode' for cancer treatment, and the impending option for everyone over 70.

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The exception to normal patterns of dying is becoming the rule. Autonomous choice is morphing into coercion by doctors, and pressure from relatives. We are encountering that pattern in the U.S. as well. American philosopher John Hardwig reflects the growing trend that a “right to die” becomes a “duty to die” when one’s life is burdensome to others, or the patient is consuming a “disproportionate share” of medical resources. He argues that if you are not ready to die by the age of 75 or 80, this is a “moral failing, the sign of a life out of touch with life’s basic realities.”²

PAS in the United States. PAS is permitted in six states (in chronological order, Oregon, Washington, Montana, Vermont, California, and Colorado). Oregon has the longest track record, and its reports indicate a disturbing trend. The top five reasons that patients in Oregon have given for requesting a lethal prescription are not related to physical pain:

1. Loss of autonomy (91%)
2. Less able to engage in activities (89%)
3. Loss of dignity (81%)
4. Loss of control of bodily functions (50%)
5. Feelings of being a burden (40%)³

Unmanageable physical pain, which engenders high levels of sympathy for PAS legislation, did not even make the list. Yet, this is the ostensible core of most people’s support for PAS. Including Christians.

Christians and thinking differently. We reject conformity to the world’s standards, and desire the mind of Christ. We are to think differently! (Opinion polls reveal otherwise.)⁴ We are called to live according to a higher standard, one that does not float on cultural currents. Not only in how we live, but also in how we die, we are called to do it all to the glory of God. John Dunlop’s book title captures it: *Finishing Well to the Glory of God*.⁵

As evangelicals, we hold the Bible in high regard, as our ultimate authority in all things, including ethical decisions at the end of one’s life. Although there is not an explicit prohibition of assisted suicide, Scripture is interwoven with applicable themes: God as creator and sustainer of all life; his sovereignty over his creation; his presence with us in our suffering; his promise of eternal life with him for those who believe in Jesus. We do find an explicit prohibition against murder (Exod 20:13), and choosing death. Moses urgently instructed the Israelites that in weighing their freedom to choose life or death, they choose life and blessing, rather than death and the curse (Deut 30:19). In the New Testament we are taught that our bodies are not our own, and that we were bought with a price (1 Cor 6:19–20). God, not we, has ultimate responsibility for our life.

Well-meaning support for PAS implies that our last days might be emptied of meaning, a bleak loss of *hope*. Yet, Christian faith finds hope when the world says there is no hope, because the object of our faith is not our physical well-being or material

comforts, but life in Christ through the love of God. “And hope does not put us to shame, because God’s love has been poured out into our hearts through the Holy Spirit who has been given to us.” (Rom 5:5).

Mark Blocher writes:

More than anyone else, Christians have a major stake in what happens to people at the end of life . . . If there exists a group of people a dying person should be able to count on to walk with him through the valley of the shadow of death, it is those who claim to belong to the Good Shepherd.⁶

Christians and compassion. Compassion is at the heart of Jesus’ ministry, and a core Christian value. Is helping someone to die in order to relieve their suffering an act of Christian compassion? Our tendency is to confuse emotional response or sympathy with being compassionate. Pope Francis said that assisted suicide gives us a “false sense of compassion.” We must ask the question: Is PAS an example of Jesus’ compassion? His ministry was characterized by paying attention to and healing the overlooked, the outcast, the hopeless, and yes, the privileged. How might that inspire expressions of compassion today, in our biomedically advanced society? Is an injection or lethal pill the best we can offer?

Suffering at the end of life is often *not* about physical pain. The patient may be struggling with other issues that need to be addressed: fear of dying; broken relationships; unconfessed sin; fear of loss of control; fear of an undignified death or a prolonged dying; or concern about being a burden to one’s family. Are people burdens, or do they *have* burdens? Genuine compassion encompasses caring for the whole person and their spiritual, psychological, and emotional needs, and not only their physical distress.

So, here is how I would answer the opening question: Alleviating suffering is good. Ending suffering through taking one’s life is out of bounds for the Christian, whether at the hands of the patient, physician, relative, or beloved friend. In the valley of the shadow of death, we fear no evil, because God is with us. ●●●

- 1 Theo Boer, “Assisted Suicide: Don’t Go There,” *EuthanasiaPreventionCoalition.org*, July 16, 2014, <http://alexschadenberg.blogspot.ca/2014/07/dutch-ethicist-assisted-suicide-dont-go.html> (accessed March 27, 2017).
- 2 As quoted in Wesley J. Smith, *Culture of Death: The Assault on Medical Ethics in America* (San Francisco, CA: Encounter Books, 2000), 157.
- 3 “Oregon’s Death with Dignity Act—2013,” Oregon Public Health Division, <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year16.pdf> (accessed March 27, 2017).
- 4 Polls show that about 83% of both Catholics and Protestants support physician-assisted suicide in certain circumstances. Craig McCartney, “When Is Killing Compassion?” *ChristianWeek.org*, February 4, 2015, <https://www.christianweek.org/killing-compassion/> (accessed March 27, 2017).
- 5 John Dunlop, *Finishing Well to the Glory of God* (Wheaton, IL: Crossway Books, 2011).
- 6 Mark Blocher, *The Right to Die? Caring Alternatives to Euthanasia* (Chicago: Moody, 1999), 190, 192.

Nevertheless, these issues have been addressed through American jurisprudence at the state and federal level.⁴ Adjudication of individual cases has had an extensive impact on views toward the maturity, moral responsibility, and legal culpability of minors. Laws governing parental/child rights and responsibilities have covered a wide range of concerns in the law: family law, civil law, health law, and criminal law. The courts have greatly impacted bioethical discourse, but legal opinions have been confounding because they are diverse, overlapping, and inconsistent. The problem often resides in the fact that the clinician seeks to find an acceptable moral solution at the bedside, while the law seeks to provide a judicial construct that will provide a legal solution for all of society.⁵ In a pluralistic society, this creates a conundrum for the clinician or researcher who is morally compelled to care for and assess the individual minor's capacity to participate in the decision-making process and to legally give consent or refuse services. In healthcare, laws or constructs that

hamper the clinician's ability to adequately assess decisional capacity compromise the process of informed consent, nullify the laws' ethical and legal intent, and can fail to protect vulnerable minors.

Many laws and policies created during the early part of the twentieth century reflected the conviction that the maturing child or adolescent, despite an increasingly adult appearance, was very different from adults and in need of legal protection and moral guidance. Ethically and legally, there was a presumptive understanding that parents were the proper surrogate decision-makers for their children. Four reasons were cited by Allen Buchanan and Dan Brock: 1) "[I]n most cases parents both care deeply about the welfare of their children and know them and [the child's] needs better than others do"; 2) "[P]arents must bear the consequences of treatment choices for their dependent children"; 3) A "right of parents, at least, within limits, [is] to raise their children according to the parents' own standards and values and

to seek to transmit those standards and values to their children"; 4) "[T]he family is a valuable social institution. . . . [and] must have some significant freedom from oversight, control and intrusion to achieve intimacy."⁶ This was reflected in an opinion by Chief Justice Burger in *Parham v. J.R.*:

Our jurisprudence historically has reflected Western civilization concepts of the family as a unit with broad parental authority over minor children. . . . The law's concept of the family rests on a presumption that parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life's difficult decisions. More important, historically it has recognized that natural bonds of affection lead parents to act in the best interests of their children.⁷

It is important to note that this was not an unrestricted right of parents, for the state claimed a right to protect children in cases of abuse or neglect.⁸ In *Prince v. Massachusetts* the Supreme Court concluded that the State was the child's



parens patriae (literally “parent of his or her country”). The court stated,

Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves.⁹

Controversy in bioethical discourse and the law revolves around if and under what circumstances the adolescent or maturing child is fully capable of making

otherwise.¹¹

This approach, though broadly utilized, has been criticized for not providing sufficient moral guidance for determining the competence of minors. It is inadequate because it does not reflect the high degree of variability in maturity, decisional capacity, and life experience among adolescents.¹² Paul Arshagouni, pediatrician and attorney, has noted that attempts to render ethical and legal decisions by assessing adolescent maturity according to strict demarcations based

autonomy of minors in healthcare decisions.¹⁵ Subsequently, distinct laws and statutes began to appear that expanded certain kinds of medical treatment without parental consent. A salient point is that these laws gave the appearance of acknowledging the minor’s competence based on decisional capacity, but in reality they were marginally connected. In this regard, the nature and scope of these laws has added to confusion in ethics and the law.¹⁶

Five categories exist in which a minor can legally make autonomous healthcare decisions:

- *Emergencies*—This protects both the minor and the clinician rendering care and presumes that a parent would have consented if available.¹⁷
- *Legal Emancipation*—This is a statutory exception which varies by state and may be partial or full. It requires formal procedures and is based on the minor’s status relative to special situations, i.e. married, financially independent, or pregnant. It provides legal consistency and ease of application.
- *Diagnostic Categories*—This is a statutory exception which varies by state and includes birth control, services for sexually transmitted diseases, for substance abuse or mental health, and in some cases for abortion (judicial bypass). It reflects concern that adolescents will experience personal harm from non-treatment or may jeopardize public health and safety.¹⁸
- *Mature Minor Rule*—This is not a law but a complex and amorphous rule that may be applied in a judicial determination in an attempt to recognize and respect the emerging maturity of a subset of adolescents. According to attorney Doriane Coleman, less than one fifth of states utilize the mature minor exception and broad overstating of its application has led to much confusion. Requirements for applying the rule vary but generally include some

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autonomous healthcare decisions.

Existing Paradigms in Decision-Making with the Maturing Child or Adolescent

It seems obvious that a child does not magically become mature upon turning eighteen. Even in the adult population, it is recognized that decisional capacity is relatively task specific and may fluctuate over time, requiring reassessment as needed.¹⁰ Regardless of these insights, bright lines of demarcation have been used in research, clinical medicine, and in the law to establish thresholds of maturity. For example, the “Rule of Sevens” has been invoked and used within the common law for centuries. The rule presumes a child’s decisional capacity according to a bright dividing line by age:

The Rule of Sevens states, roughly, that children under age seven do not have the capacity necessary to make their own decisions; children from seven to fourteen years of age are presumed not to have this capacity until proven otherwise in individual cases, and children over age 14 are presumed to have capacity to make their own decisions and lead their own lives, unless proven

solely upon chronological age inevitably lead to false-negatives and false-positives.¹³ This is an important point to note because there continue to be efforts to expand the autonomy of minors according to age categories rather than on a case-by-case basis.

Brian Partridge has stated that adolescent decisional capacity is qualitatively different from adults. The questions regarding adolescent decisional capacity and the extension of their autonomy must center on whether their capacity is “effective.” Effective autonomy, that is, “the capacity to choose in ways that effectively support [the adolescent’s] long-range interests,” in the words of Brian Partridge, “appears to depend on their development of the ability, at least in part, to choose non-impulsively and to envisage adequately the future consequences of their decisions.”¹⁴

Research in the latter part of the twentieth century concluded that by middle adolescence many minors had sufficient cognitive development to handle complex tasks, and some suggested that this was adequate evidence of decisional capacity sufficient to justify the

demonstration of maturity and cognitive capacity. In most states parental consent remains the default requirement.¹⁹ Based on new insights into adolescent decision-making, calls for broad expansion of the mature minor rule have been criticized.

- *Adolescent Parents*—These adolescents may be surrogate decision-makers for their children, which reflects their status, not their decisional capacity.

New Perspectives on the Decision-Making of Maturing Children and Adolescents

If one is to truly do justice to the concept of respect for the developing autonomy of the maturing child or adolescent, one must ensure that the necessary conditions are met. Early studies of decisional capacity based solely on cognitive development were misleading because other factors greatly influence the effectiveness and reliability of the cognitive capacity. Cognitive development lays the groundwork for moral reasoning, but adolescent reasoning abilities do not provide evidence that adolescents are capable of making consistently mature decisions.²⁰ Longitudinal neuroimaging studies utilizing magnetic resonance imaging have shown that the adolescent brain is far from mature structurally or functionally, and converging data is beginning to show how the brain's complex maturation process correlates with variances in how adults and adolescents make decisions.²¹

Neuroscientists currently believe that decisions are made through the complex interaction of dual systems within the brain: 1) the *socioemotional brain systems*, the limbic and paralimbic structures (amygdala, ventral striatum, and medial prefrontal cortex), which develop around puberty, and 2) the *cognitive control systems* (prefrontal and parietal cortical) which develop gradually through the third decade of life. A necessary factor for mature judgment is the integration of these systems, which is facilitated through a process of pruning and myelination in the brain.²² Because

these systems develop at a different rate an imbalance occurs which correlates with the expression of typical adolescent behaviors such as poor emotional control, difficulty interpreting emotions in oneself or others, susceptibility to peer influence, lack of ability to delay reward, and increased vulnerability to risky behavior. These common behavioral patterns have

incorrect to assume that emotional states can be adequately bridled in our constantly connected society. The malleable emotions of minors may be transient, turning on one Twitter or Instagram post. Psychometric studies that measure reasoning and understanding in hypothetical settings do not approximate real clinical situations, and interestingly the

A great deal of interpretive caution is necessary when assessing the minor in the clinical or research setting.

important implications for adolescent healthcare decisions. Adolescents tend to focus more on immediate benefits rather than the future costs of risky choices and although they are logically able to perceive risks, they may weigh them differently in certain contexts. Brian Partridge has noted there is an important difference

between possessing the capacity abstractly to rehearse the future causal outcomes of current decisions versus possessing the capacity effectively, that is, concretely to envisage and appreciate the significance of the near-term and long-term risks and benefits associated with one's choices. The capacity simply to rehearse the likely outcomes of decisions may falsely be taken as establishing a minor as having mature decisional capacity.²³

A great deal of interpretive caution is necessary when assessing the minor in the clinical or research setting. Researchers at Stanford have concluded that adolescents with heightened emotions or states of arousal are more likely to take risks.²⁴ Neuroimaging has shown that even the presence of peers causes significantly increased activity in the socioemotional brain regions, decreasing the ability to resist emotional and social influences and focus on long-term goals. Clinical assessments of emotional states will in most situations be subjective and determinations of decisional capacity will largely be based on a demonstration of cognitive ability alone.²⁵ It would be

typical criteria used to assess capacity for informed consent utilizes categories that may only capture cognitive skills. This ignores significant factors that interact with cognition in teens such as the influence of peers, variances in reward systems, impulsivity, less future-orientation, and lack of experience.²⁶ Those factors are difficult to measure but must be considered in order to properly assess if the adolescent has gained the wisdom, skills, and virtues necessary to make decisions that promote a lifetime of well-being. Some may respond that there are adults that lack these skills. Certainly this is true, but it does not release the clinician, researcher, or parent from their fiduciary responsibility to the developing adolescent.

Avoiding Reductionist Approaches

The use of neuroscience research to shape adolescent health-and-welfare policy and the criminal law has brought about conflicting results. Teens have been viewed as less culpable for crimes and yet paradoxically mature enough to have increased reproductive choices.²⁷ Good scientific evidence should inform ethical decision-making, particularly in matters related to life altering medical decisions, but translating scientific findings for legal and social policy requires discernment and caution.

It is vitally important to avoid a kind of "neuro-centrism" or "neuro-reductionism" that ascribes all human behavior

to neurologic processes in the brain, as it can deemphasize other important contributing factors to adolescent choices and behavior, subsequently having detrimental effects on capacity determinations and dehumanizing the maturing child. Traditionally, the family as a moral entity assumes the responsibility for being the child's moral agent until such a time as the child has formed their own moral identity, with separate values, beliefs, and life plans.²⁸ Religious or spiritual exploration is a typical component of an adolescent's search for mature identity formation. This exploration has significant implications for one's ultimate values and beliefs, and the content of those beliefs influences bioethical choices.

Religious integrity is more than the expression of sincerely held beliefs. Those beliefs should have become an integral

Developmentally, it has been noted that the adolescent's capacity to be future-oriented generally occurs late in adolescence (18–21 years), after the development of a sense of identity marked by the refining of moral, religious, and sexual values. Research by Jeffrey Arnett has demonstrated that there is a distinct period described as “emerging adulthood” approximately between the ages of 18–25, which expands opportunities for identity exploration through education, work, and a reexamination of beliefs and worldviews.³¹ This research emphasizes the fact that identity formation, with settled beliefs and values, even by age 18, may be a premature assumption. It is doubtful that these observations will or should have any effect on the legal age of majority, but the research highlights the precarious and sensitive nature of decision-making in the maturing child/

beliefs.³² What adult cannot attest to the veracity of that observation?

The Future of Pediatric Decision-Making

Bioethical decisions are not made in isolation but are increasingly intertwined with a global community influenced by international laws. Many have put forth arguments in favor of empowering children with more autonomy in decision-making. However, Lainie Ross has argued, “To empower children with the same rights as adults is to deny them the protection they need. It would mean the dissolution of child labour laws, mandatory education, statutory rape laws, and child neglect statutes. It would leave children more vulnerable than they presently are.”³³ A society which does not recognize this vulnerability is of little help to the adolescent endeavoring to work out moral struggles. Those who argue for increased adolescent autonomy may be deaf to the cry of the youth who longs for protection and moral direction.

How do we work through the challenge of balancing protection of the maturing child or adolescent with respect for their emerging maturity/autonomy? In our world of advancing technology, minors will be presented with more options in healthcare than ever before. The stakes are high and our responsibilities are great to both protect and prepare our youth for a future in a brave new world.

A forthcoming article will examine this issue in more detail and consider evolving paradigms including the process of pediatric assent and parental permission in informed consent. ●●●

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part of the individual's self-concept or identity manifested over time. Buchanan and Brock have noted that decision-making competence includes the capacity “to have and apply a set of values” so as “to ensure that the individual's choice is truly in line with his or her conception of well-being, and thus, deserving of respect as autonomous.”²⁹ Adults are presumed to have this capacity because they have had the time and life experiences necessary to form these abilities and beliefs. Similarly, Lainie Ross has argued that the adolescent's decisions are based on limited experience, so their decisions are not part of a well-conceived life plan, and they need a protected period in which to develop them and advance their future autonomy.³⁰

adolescent.

Robert Coles, in his noted work on the moral lives of children, found that in striving for independence adolescents may argue for their own authority, yet as they search for meaning in their lives most adolescents have some awareness of their own moral vulnerability. They may yearn for independence but not at the expense of kindred ties. In a culture with progressively fractured families, many youths long for at least one older person to be a moral companion on their journey. The process of moral formation which produces sound decisional agency occurs when moral thinking, the contemplation of right and wrong along with experience, yields to settled values and

1 Dena Davis, quoted in Sadath A. Sayeed, “The Moral and Legal Status of Children and Parents,” in *Pediatric Bioethics*, ed. Geoffrey Miller (New York: Cambridge University Press, 2010), 40, originally found in Dena Davis, *Genetic Dilemmas: Reproductive Technology, Parental Choices, and Children's Futures* (New York: Routledge, 2001), 34.

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- 3 Jonathan F. Will, "My God My Choice: The Mature Minor Doctrine and Adolescent Refusal of Life-Saving or Sustaining Medical Treatment Based Upon Religious Beliefs," *Journal of Contemporary Health Law and Policy* 22, no. 2 (2006): 237–239.
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- 6 Will, "My God My Choice," 247.
- 7 Parham v. J.R., 442 U.S. 584, 602 (1979), partially quoted in Will, "My God My Choice," 246.
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- 14 Brian Partridge, "Adolescent Psychological Development, Parenting Styles, and Pediatric Decision Making," *Journal of Medicine and Philosophy* 35, no. 5 (2010): 520.
- 15 Katz and Webb, "Informed Consent," 9.
- 16 Doriane Lambelet Coleman and Philip M. Rosoff, "The Legal Authority of Mature Minors to Consent to General Medical Treatment," *Pediatrics* 131, no. 4 (2013), 786.
- 17 Driggs, "The Mature Minor Doctrine," 691.
- 18 Will, "My God My Choice," 256.
- 19 Coleman and Rosoff, "Legal Authority," 786–787.
- 20 Laurence Steinberg et al., "Are Adolescents Less Mature Than Adults? Minors' Access to Abortion, the Juvenile Death Penalty, and the Alleged APA 'Flip-Flop,'" *American Psychologist* 64, no. 7 (2009): 583–594.
- 21 Jay N. Giedd, "The Teen Brain: Insights from Neuroimaging," *Journal of Adolescent Health* 42, no. 4 (2008): 335.
- 22 Katz and Webb, "Informed Consent," 7.
- 23 Brian Partridge, "The Mature Minor: Some Critical Psychological Reflections on the Empirical Bases," *The Journal of Medicine and Philosophy* 38, no. 3 (2013): 291.
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- 26 Ibid., 216–218.
- 27 Laurence Steinberg, "Does Recent Research on Adolescent Brain Development Inform the Mature Minor Doctrine?" *Journal of Medicine and Philosophy* 38, no. 3 (2013): 256–258.
- 28 Lainie Ross, *Children, Families, and Health Care Decision Making* (Oxford: Clarendon Press, 1998), 20–34.
- 29 Will, "My God My Choice," 243–244.
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- 31 Jeffrey Arnett, "Emerging Adulthood: A Theory of Development from the Late Teens through the Twenties," *American Psychologist* 55, no. 5 (2000): 469–480.
- 32 Robert Coles, *The Moral Intelligence of Children: How to Raise a Moral Child*, 1997 (Reprint. New York: The Penguin Publishing Group), 135–170.
- 33 Ross, *Children, Families, and Healthcare Decision Making*, 4.

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The Center for Bioethics & Human Dignity presents
THE 24TH ANNUAL SUMMER CONFERENCE

GENETIC & REPRODUCTIVE TECHNOLOGIES



JUNE 22 – 24, 2017

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PRECONFERENCE WORKSHOPS

Maternal-Fetal Conflict Workshop

Wednesday, June 21, 8:30am - 3:30pm

Workshop led by Byron C. Calhoun, MD, FACOG, FACS, FASAM, MBA & Donna J. Harrison, MD, Dip ABOG

Current Issues in the Ethics of Organ Transplantation Workshop

Thursday, June 22, 8:30am - 3:30pm

Workshop led by Gregory Rutecki, MD



COMMENTARY: DISPARITIES OF IMMIGRATION STATUS AND INSURANCE COVERAGE AMONG SOLID ORGAN TRANSPLANT DONORS AND RECIPIENTS

GREGORY W. RUTECKI, MD
GUEST CONTRIBUTOR

The recent U.S. presidential campaign, quickly followed by the initial days of the Trump presidency, have brought immigration policy front and center for Americans. This publication's readership is typically comprised of Christian healthcare professionals and bioethicists—not politicians, lawmakers, or immigration attorneys. Our voices may be able to articulate what it is in general that constitutes just practice in immigration policy, but our input would be more constructive if we as a group approach justice at the interface between immigration law and selected aspects of medical care, specifically organ donation and transplantation.

Solid organ transplantation allocation policy and its relation to immigration policy is one discussion that has critical life-altering ramifications for immigrants and foreign nationals as well as for American citizens in need of a donation. Such a dialogue includes the stance of voters on the many undocumented persons presently residing in America. Fundamental questions, such as the fairness of undocumented immigrants

receiving organs donated by American citizens, beg for thoughtful reflection and, consequently, informed policy. In what follows I explore three questions regarding the conversation of medicine-immigration-cost and contextualize this in a broader conversation on solid organ donation and just allocation.

First, though, we should briefly clarify terminology. Recent discussion of immigration has given prominence to “undocumented persons” residing in the U.S.¹ However, it is important for our discussion (specifically, our third question) to note that foreign nationals are occasionally labeled as “transplant tourists,” which has significant implications for immigration policy and organ allocation. In general terms a transplant tourist is an individual from another country who is here legally to await allocation of an organ for transplantation. Such an individual's presence may be justified by the inability to receive the same medical care in that person's country of residence. Some Americans are also transplant tourists in other countries.

Should Undocumented Immigrants in the U.S. Receive Organs Donated by American Citizens?

In contrast to a more stark approach such as suggesting a border wall to prevent undocumented immigrants access to the U.S., an ethical “frame” for American organ allocation policies should not begin with the “crime and punishment” of undocumented persons among us. A better frame to appraise the just allocation of organs for a target demographic is to ask whether undocumented persons, or other foreign citizens as a group, donate organs to American citizens, thereby sharing the “gift of life.” The answer is a resounding yes! In fact, undocumented immigrants and other foreign nationals living in the U.S. account for approximately 3.3% of donated organs in the U.S. (from March 2012—December 2013).² Since the organ pool for transplantation in the U.S. is enriched with the “gift of life” donated voluntarily by undocumented and to a lesser extent by other immigrants (such as visiting foreign nationals), justice would seem to dictate a 2-way street. As a result, American organs should be allocated to undocumented immigrants and foreign nationals. In fact, the United Network for Organ Sharing (UNOS) is cognizant of the impact undocumented

Gregory W. Rutecki, MD, “Commentary: Disparities of Immigration Status and Insurance Coverage among Solid Organ Transplant Donors and Recipients,” *Dignitas* 24, no. 1 (Spring 2017): 9-11.

immigrants and other foreign persons have on the supply of organs in the United States and therefore permit organ allocation to these persons in an effort to match the number of their gracious donations. As a result, UNOS placed an approximate 5% ceiling for organs donated by American citizens and allocated to non-U.S. citizens. According to the policy, exceeding this threshold was to trigger an audit of the individual transplant centers by the Organ Procurement and Transplantation Network (OPTN)/UNOS. However, in addition to confusion regarding the policy and its implementation, no disciplinary proceedings appear to have been pursued for any individual transplant centers. In fact, no program in the U.S. has ever been punished for excessive contributions to non-U.S. citizens.³ Reviewing the relevant statistics, organs allocated to non-U.S. citizens and/or “transplant tourists” from abroad, 2012–2013, were well under the proposed ceiling, with hearts, kidneys, and livers all less than 1% of the total pool of organs allocated in the United States.⁴

Should Persons Without Adequate Insurance Receive Heart Transplants?

The cost of a heart transplant is astounding. In 2011, the first year average cost for a transplanted heart—with the necessary care that follows—was \$997,700.⁵ Subsequent years after the transplant averaged approximately \$30,300 per year for maintenance costs (immune suppression medications and careful follow up).⁶ Although *prima facie* it should be clear that discussion regarding the remarkable costs of transplantation is not limited to undocumented immigrants (often disadvantaged in terms of costs) and other foreign nationals, as one might expect, prohibitive expenses may also impact un- and underinsured American citizens. Such a line of inquiry engages important principles impacting the vulnerable “have nots” that are fundamental to just allocation.

Applying an ethical frame similar to the one utilized for undocumented immigrants and other foreign nationals in answering the question, *how many*

hearts in the donated pool come from individuals who are uninsured? Although statistics are not kept to answer this question, plausible estimates are available. Utilizing Census Bureau statistics from 2004, King et al. noted that of the approximately 2,350 hearts donated per year in the U.S., it was estimated that 14% (approximately 330) came from uninsured donors. They further suggest that as many as 1 in 4 hearts may be donated by an uninsured donor.⁷ Of course these estimates were made prior to the passage of the Affordable Care Act, which has decreased the overall percentage of uninsured patients. Even accepting these decreases, in the specific context of hearts for transplantation, both undocumented immigrants and disadvantaged Americans (uninsured or otherwise underinsured) are sources of the “gift of life”—with only the latter not receiving reciprocity. Although the costs of renal transplantation fall under the aegis of Medicare which is available for older Americans, other solid organs such as liver and heart do not. As expected, most Americans are probably not aware of the potential inequity that characterizes the allocation of organs to vulnerable groups. I suggest that excluding these persons from available organs—be they foreign citizens or U.S. citizens—does not seem just.

Do Foreign Nationals with Financial Means Game the American Transplant System?

Although it may be apparent that foreign nationals contribute to the organ donation pool, there is more to this demographic story. From 1988–2005 there were 2,724 kidney and 2,072 liver nonresident or alien candidates (NRAs) listed with UNOS.⁸ NRAs had more self-pay and more foreign sources of monetary support than comparable American citizens who were listed at the same time. Transplants to NRAs were more frequent than deceased donations from NRAs and liver transplants were accomplished more rapidly and frequently in NRAs than in simultaneously listed U.S. Citizens.⁹ What do these statistics mean, especially in regard to just allocation? Recognizing

economic diversity among the NRAs, this group generally was more affluent than their American counterparts. How is their affluence relevant to this conversation? Listing with multiple transplant centers increases the potential recipient’s opportunity to access an organ. However, in order to list with more centers, one must have the means to travel greater distances in shorter periods of time.¹⁰ This ability presupposes private jets and other monetary advantages. In the context of transplantation/organ allocation policy, or more accurately the need for policies (in plural) addressing various advantages and inequities, Occam’s Razor fails—a simple explanation or single policy will not suffice.

Conclusion

There are approximately 11 million or more undocumented immigrants residing in the U.S. The Affordable Care Act presently excludes them from its safety net, although the future is uncertain.¹¹ Their vulnerable predicament may not improve. Compassionate immigration reform may not be forthcoming. Transparency and education regarding inequities already present in the allocation system must be incorporated into debate and future policy decisions. Doctors treat vulnerable patients, not their immigration status.

The reality of life as an undocumented person in the U.S. can be “nasty, brutish and short,” and this is no less true in their healthcare. Richard Nuila, a physician in Texas who cares for these vulnerable persons tells an empathetic story. A Guatemalan migrant worker (who had overstayed his visa) could not continue working, so his boss dropped him off at the local hospital and left. There it was discovered he had metastatic cancer. Nuila observed, “For many undocumented immigrants, terminal illness is a revolving door: they are admitted from the emergency department with severe pain or organ failure, we stave off death well enough for them to be discharged, and very soon, they return . . . until the day they don’t.”¹²

One of the most compelling narratives engaging transplantation, *Whither Thou Goest*, was written by the late Richard Selzer.¹³ As you already may have guessed, the title is no accident; the metaphors of “harvesting” and “gleaning” in the book of Ruth are applied to the transplantation of a heart. I was privileged to discuss Dr. Selzer’s love for the book of Ruth with him before he died. The “gift of life” in his short story is given with *hesed*, loving kindness, from the donor and donor family at a time of tremendous loss and grief. It also appears to be more than coincidence that Ruth was from Moab and resided in a foreign land. Yes, it is time to consider the alien among us. It is time to appreciate the *hesed* we share with others while giving and receiving the gift of life—a gift transcending any walls built to separate us. ●●●

1 For our purposes here, I will use the terms “undocumented persons” and “undocumented immigrants” interchangeably, though in technical discussions these along with other terms such as “nonresident aliens,” “undocumented

aliens” and others may carry specific distinctions and rhetorical nuances beyond the scope of this essay.

- 2 Alexandra Glazier, Gabriel Danovitch, and Francis Delmonico, “Organ Transplantation for Nonresidents of the United States: A Policy for Transparency,” *American Journal of Transplantation* 14, no. 9 (2014): 1743; Aaron Wightman and Douglas Diekema, “Should an Undocumented Immigrant Receive a Heart Transplant?” *AMA Journal of Ethics* 17, no. 10 (2015): 910.
- 3 Glazier, Danovitch, and Delmonico, “Organ Transplantation for Nonresidents,” 1741.
- 4 *Ibid.*, 1742.
- 5 Wightman and Diekema, “Should an Undocumented Immigrant,” 909–910. Bentley and Hanson suggest the cost has increased to \$1,242,200 as of 2014. T. Scott Bentley and Steven Hanson, “2014 U.S. Organ and Tissue Transplant Cost Estimates and Discussion,” Milliman Research Report, December 2014, page 3, http://www.milliman.com/uploadedFiles/insight/Research/health-rr/1938HDP_20141230.pdf (accessed February 14, 2017).
- 6 Wightman, and Diekema, “Should an Undocumented Immigrant,” 909–910.
- 7 Louise King et al., “Health Insurance and Cardiac Transplantation: A Call for Reform,” *Journal of the American College of Cardiology* 45, no. 9 (2005): 1389.
- 8 Jesse Schold et al., “Deceased Donor Kidney and Liver Transplantation to Nonresident Aliens in the United States,” *Transplantation* 84, no. 12

(2007): 1551.

- 9 *Ibid.*, 1548.
- 10 *Ibid.*, 1554–1555.
- 11 Nancy Berlinger and Rajeev Raghavan, “The Ethics of Advocacy for Undocumented Patients,” *Hastings Center Report* 43, no. 1 (2013): 14.
- 12 Ricardo Nulia, “Home: Palliation for Dying Undocumented Immigrants,” *New England Journal of Medicine* 366, no. 22 (2012): 2047–2048, doi:1056/NEJMp1201768.
- 13 Richard Selzer, *Imagine a Woman and Other Tales* (East Lansing, MI: Michigan State University Press, 1990), 1–21.

COMMENTS?

Would you like to offer comments or responses to articles and commentaries that appear in *Dignitas*? As we strive to publish material that highlights cutting-edge bioethical reflection from a distinctly Christian perspective, we acknowledge that in many areas there are genuine disagreements about bioethical conclusions. To demonstrate that bioethics is a conversation, we invite you to send your thoughtful reflections to us at info@cbhd.org with a reference to the original piece that appeared in *Dignitas*. Our hope is to inspire charitable dialogue between our readers and those who contribute material to this publication.

BOOK REVIEW: ADAM COHEN, *IMBECILES: THE SUPREME COURT, AMERICAN EUGENICS, AND THE STERILIZATION OF CARRIE BUCK* (NEW YORK: PENGUIN PRESS, 2016)

REVIEWED BY HEATHER ZEIGER, MS, MA
CBHD RESEARCH ANALYST

The Supreme Court Case *Buck v. Bell* allowed the state of Virginia to sterilize Carrie Buck who was classified as a “Middle grade Moron”¹ based on test scores and who the court determined was feeble-minded. Carrie Buck’s mother was also deemed feeble-minded and was a resident with Carrie at the Virginia Colony for Epileptics and Feeble-Minded. Carrie birthed a child out of wedlock as a result of her foster family’s nephew raping her. The child was also considered feeble-minded even though she was barely three years old at the time of the trial.

Buck v. Bell set the precedent for state enforced sterilization for eugenic purposes. As Oliver Wendell Holmes, Jr., author of the opinion for this case, stated “three generations of imbeciles is enough.”² The case was decided by an 8–1 vote. In 2002, the governor of Virginia made a formal apology for the state’s participation in eugenics on the seventy-fifth anniversary of the ruling of *Buck v. Bell*, but the case itself has never been formally overruled.

Journalist Adam Cohen in his book *Imbeciles: The Supreme Court, American Eugenics, and the Sterilization of Carrie Buck* takes a look at the major players during the time of the American eugenics movement who worked to get the case through state courts and eventually before the U.S. Supreme Court. Cohen explores how eugenics, which was birthed in the late nineteenth century and continued in some form until the 1970s, became a popular movement in the 1920s.

This book is well researched and provides a detailed and fair look at key factors contributing to the mindset at the time. While Cohen’s distaste for people like Oliver Wendell Holmes, Jr. is evident in his tone, he is fair in his treatment of the personal and cultural factors that influenced people like Holmes to sympathize with eugenics.

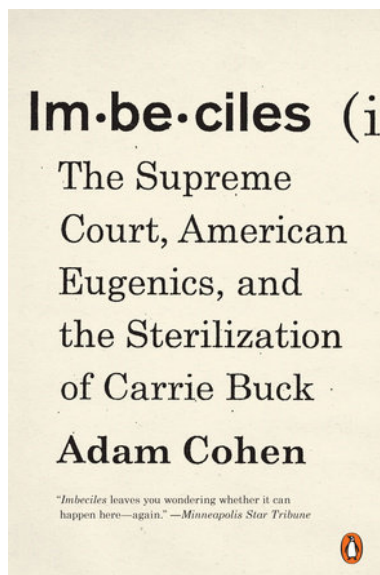
Cohen points out that state institutions for mentally ill people were started with

Prejudice and social control were dressed in scientific trappings, providing an air of legitimacy to their efforts.

Furthermore, from a medical standpoint, while castration, marriage restrictions, and isolation seemed inhuman and harsh, sterilization was a new medical technique that was safer and cheaper. Albert Priddy was a medical doctor who was on the front lines of caring for the mentally ill. After Virginia passed a law allowing for sterilization in state institutions, Priddy, who had sterilized many of the women at the colony where Carrie Buck and her mother lived, wanted a test case to show that the state sterilization laws were indeed constitutional. Carrie Buck was just the example that he needed to demonstrate the hereditary nature of feeble-mindedness.

The book’s structure centers on the four characters that led to the *Buck v. Bell* decision: Albert Priddy, Harry Laughlin, Aubrey Strode, and Oliver Wendell Holmes, Jr., with Carrie Buck portrayed as their political pawn. Each of these four men represented the pillar of their respective fields of medicine, academia, law, and the judiciary. As outlined in the book, each helped to get the test case through the courts so that eugenic sterilization was deemed constitutional.

The book has two chapters on each of these men. The first discusses the context of their field of practice and how they eventually landed in their position of authority, including interesting insights into their backgrounds, schooling, and motivations. The second chapter outlines how each worked the political system to



good intentions. The institutions were originally meant to provide compassionate care for the mentally ill as well as an alternative to jail or the slums. However, these noble motivations changed along with the prevailing worldview of the time. The moral landscape shifted from one that believed in the inherent moral worth of people to one that explained people in terms of heredity and the problems of society in terms of the proliferation of the mentally deficient and feeble-minded.

BIOENGAGEMENT:

The promise and perils of advances in technology, science, and medicine have long been fertile fodder for creative works in literature and cinema. Consequently, a variety of resources exist exploring the realm of medical humanities as well as those providing in-depth analysis of a given cultural medium or particular artifact. This column seeks to offer a more expansive listing of contemporary expressions of bioethical issues in the popular media (fiction, film, and television)—with minimal commentary—to encompass a wider

spectrum of popular culture. It will be of value to educators and others for conversations in the classroom, over a cup of coffee, at a book club, or around the dinner table. Readers are cautioned that these resources represent a wide spectrum of genres and content, and may not be appropriate for all audiences. For more comprehensive databases of the various cultural media, please visit our website at cbhd.org/resources/reviews. If you have a suggestion for us to include in the future, send us a note at msleasman@cbhd.org.

BIOFICTION:



Isaac Asimov, The Robot Series

The Naked Sun (Spectra Books, 1991).

The Robots of Dawn (Spectra, 1994).



Artificial Intelligence, Ectogenesis, Emerging Technologies, Human Enhancement, Human-Machine Interaction, Personhood, Reproductive Technology Ethics, Robotics, Robot Ethics.



Iain M. Banks, *The Hydrogen Sonata* (Orbit, 2012). *Human Enhancement, Transhumanism/Posthumanism, Artificial Intelligence, Radical Life Extension, Personhood.*



Ian Douglas, *Deep Space* (Harper Voyager, 2013). *Human Enhancement, Cognitive Enhancement, Neuroethics, Transhumanism, Brain-Computer Interfaces, Artificial Intelligence, Nanotechnology, Singularity.*



Neal Stephenson, *Seveneves* (Willow Marrow, 2015). *Designer Babies, Eugenics, Genetic Engineering, Transhuman/Posthuman.*



Allen Steele, *Arkwright* (Tor Books, 2016). *Embryo Cryopreservation, Genetic Engineering, Regenerative Medicine, Transhuman/Posthuman.*

"BOOK REVIEW: ADAM COHEN, *IMBECILES: THE SUPREME COURT, AMERICAN EUGENICS, AND THE STERILIZATION OF CARRIE BUCK*" CONTINUED

get bills passed and eventually *Buck v. Bell* before the Supreme Court.

Consequently, this non-linear structure lends itself to bit of repetition, particularly as the main characters' lives intersect at multiple points. Additionally, Cohen takes great pains to remind the reader that Carrie Buck was neither "feble-minded" nor a "moron" and that she was treated unfairly by reiterating this point several times throughout the book. While repetition for emphasis has its place, it became a bit tedious.

Cohen's didactic tone may seem overbearing at times, but this is not without merit. Carrie Buck was deprived of her

liberties for no better reason than to serve as a pawn in a political game in which some people had decided that they were qualified to determine the value of other people. Cohen shows how the system promoted forced sterilization for eugenic purposes starting from the bottom up and the very Court that was supposed to uphold the liberties enumerated in the Constitution instead upheld an oligarchical agenda that used science to bully and belittle.

Overall, *Imbeciles'* greatest asset is the research that went into this book. It is an excellent resource for those who wish to understand the American eugenics

movement and how the dysfunctional collaboration of science, politics, and medicine served to rob individuals of their most basic personal liberties. Five years before Oliver Wendell Holmes wrote his biting court opinion for *Buck v. Bell*, G. K. Chesterton tells us in *Eugenics and Other Evils* that "a man is not imbecile if only a Eugenicist thinks so."³ Cohen shows us this truth in his account of Carrie Buck. ●●●

1 Adam Cohen, *Imbeciles: The Supreme Court, American Eugenics, and the Sterilization of Carrie Buck* (New York: Penguin Press, 2016), 30.

2 Ibid., 2.

3 G. K. Chesterton, *Eugenics and Other Evils* (London: Cassell and Company, 1922), 37.

TOP BIOETHICS NEWS STORIES: DEC 2016 – FEB 2017

BY HEATHER ZEIGER, MS, MA
RESEARCH ANALYST

“Egypt Says It Has Busted Up Large Organ Trading Racket” by Mahmoud Mourad and Lin Noueihed, *Scientific American*, December 6, 2016

Egypt has uncovered a network accused of illicit international trafficking in human organs, arresting 45 people and recovering millions of dollars . . . Among those held were doctors, nurses, middlemen and organ-buyers, involved in what the ministry described as the largest organ-trafficking network exposed in Egypt to date. (<http://tinyurl.com/jeajxm>)

“Pakistani Police Rescue 24 from Organ Trafficking Gang” by Ruth Evans, *BBC*, January 25, 2017

Sadi Ahmed was held hostage for three months by an organ trafficking gang. In October last year, he was one of 24 people rescued by police in Rawalpindi, Pakistan. They had been imprisoned in a building in an affluent suburb, awaiting the forced removal of their kidneys. (<http://tinyurl.com/15l8ttu>)

“Syrian Refugees Selling Their Organs on the Black Market to Get to Europe: Experts” by Katherine Gregory, *Australian Broadcasting Co*, January 5, 2017

Syrian refugees desperate for money to get passage to Europe are selling their organs on the black market and the profits are lining the pockets of organised crime and terrorist networks, two experts say. (<http://tinyurl.com/lsv2aqp>)

There has been a marked increase in news coverage on the international black market for human organs, alongside heightened attention from recent documentaries and summits that have covered the issue. In all cases, whether it involves the poor in India, prisoners in China, victims of kidnapping, or refugees, the poor and vulnerable are exploited for the benefit

of the wealthy who need organs and the traders who make substantial profits.

“Senate Passes Landmark 21st Century Cures Act—But It Will Take Years to Implement” by Sheila Kaplan, *STAT News*, December 7, 2016

It took nearly three years for Congress to pass the 21st Century Cures Act. . . . The legislation, designed to accelerate the introduction of new medical treatments by speeding up some FDA approval processes and boosting federal funding, passed the Senate [December 7th] by a 94 to 5 vote. (<http://tinyurl.com/m4rkfsr>)

The 21st Century Cures Act is a 1,000-page document that is intended to improve medical research. Among other things, the act extends the U.S. Federal Drug Administration’s responsibilities over medical devices and implementing patient-specific drug development. It provides research money for several government initiatives including the BRAIN Initiative and the Cancer “Moonshot” Initiative. It will also call for greater transparency for conflicts of interest and research reproducibility. Included in the act is \$1 billion to combat the opioid epidemic. Critics of the act argue that it will favor pharmaceutical companies profiting from streamlined regulations.

“Drug Overdose Deaths Rise Dramatically in US” by Dennis Thompson, *UPI*, December 20, 2016

Drug overdose deaths continue to surge in the United States, with most fatalities linked to the illicit use of prescription painkillers, new government statistics reveal. Drug overdose deaths increased 23 percent between 2010 and 2014, with more than 47,000 Americans dying in 2014, the U.S. Centers for Disease

Control and Prevention (CDC) data released Tuesday shows. But updated numbers from the CDC also show that more than 52,000 people died from a drug overdose in 2015, and just over 33,000 of those deaths (63 percent) involved a prescription or illicit opioid. (<http://tinyurl.com/mn2oqvf>)

2015 saw substantial increases in the number of deaths due to drug overdose. These numbers plus the increase in deaths due to heart disease have led to an overall drop in U.S. life expectancy. The media also reported on an odd consequence of the number of overdose deaths: the number of donor organs has increased. CBHD hosted a lecture on opioids and the ethics of pain management last June. Video is available at <https://cbhd.org/content/opioids-and-ethics-pain-management-and-addiction> or directly through the Center’s YouTube Channel (youtube.com/bioethicscenter).

“Unexpected Risks Found in Replacing DNA to Prevent Inherited Disorders” by Jill Neimark, *NPR*, January 1, 2017

But for all the accolades, the method also has scientists concerned that the fatally flawed mitochondria can resurface to threaten a child’s health. Earlier this month, a study published in *Nature* . . . suggested that in roughly 15 percent of cases, the mitochondrial replacement could fail and allow fatal defects to return, or even increase a child’s vulnerability to new ailments. (<http://tinyurl.com/h3hqsyb>)

Great Britain formally allowed the creation of “three-parent” embryos as technique for women who suffer from mitochondrial disease and do not want to pass it on to their children. A report in *Nature* showed that there is likely a communication problem between the DNA from two different sources. Following

on the September announcement of the couple who went to Mexico to have this technique done (<http://tinyurl.com/jdrqcmk>), another news story reported the first use of this technique for infertility in the Ukraine (<http://tinyurl.com/kknhgb4>). It remains unknown whether babies born as a result of this procedure will experience any lasting effects given the experimental nature of this procedure. CBHD hosted a consultation on the theology and ethics of synthetic gametes in 2012 exploring the development of this technology. Video is available at <https://cbhd.org/event/ethics-theology-synthetic-gametes> or the Center's YouTube Channel.

“Scientists Create Part-Human, Part-Pig Embryo” by Amy Norton, *UPI*, January 26, 2017

It might sound like science fiction, but researchers have successfully used human stem cells to create embryos that are part-human, part-pig. Scientists said the long-range goal is to better understand and treat an array of human diseases. The researchers hope to ultimately cultivate human tissue that can be given to patients awaiting transplants. (<http://tinyurl.com/kbm3pp5>)

Scientists were able to create a hybrid embryo using human induced pluripotent stem cells and genetically-modified pig embryos. The pig embryos were injected with human stem cells and then placed within a sow. After gestating for several weeks, tests on the embryos showed that some of the human stem cells were beginning to form the precursors to tissues; all embryos were destroyed. While the aim is to eventually harvest human organs from pigs, a cautionary report from *Science* says that this is still a long way off (<http://tinyurl.com/m6sw3tn>). The creation of human-animal chimeras raises several ethical concerns including whether the eventual animal will have human characteristics or human cognition.

“‘We Simply Don’t Know’: Egg Donors Face Uncertain Long-Term Risks” by Emily Woodruff, *STAT News*, January 28, 2017

When Catherine Fonseca volunteered as an egg donor, the intake form asked for her SAT scores. It did not ask if she understood the long-term health implications of stimulating her ovaries to produce a bumper crop of eggs to be extracted and turned over to an infertile couple. (<http://tinyurl.com/le6zy8b>)

Even though there have been many anecdotal reports and smaller studies of the potentially fatal side-effects of egg donation, this has been one area that has had very little oversight. Egg donors are not legally protected, and the side effects are not well-studied. Even after the Centers for Disease Control and Prevention started collecting more data about donors, there are still no studies on long-term risks. Furthermore, many people turn a blind eye to the eugenic practices of selecting (and paying for) desirable egg donors.

“You Won’t Believe What Baby-Making Science Could Soon Deliver” by Joseph Bennington-Castro, *NBC News*, February 1, 2017

Now, the world is on the brink of another revolution thanks to an emerging technology called in vitro gametogenesis, or IVG, which would allow doctors to develop eggs and sperm from a surprising source: skin cells. These reproductive cells could then be used to create fertilized embryos to be implanted into a woman’s uterus (or, someday, an artificial womb). The potential impact of IVG on reproduction—and society at large—is staggering. Infertility may become a thing of the past. Same-sex couples could have children that are biologically related to both parents. And the world may eventually see children born with a single genetic parent or more than two genetic parents. (<http://tinyurl.com/l8joqdx>)

The production of oocytes from induced pluripotent stem cells created such a stir in the media, that it is included here even though it was only done in mouse studies. There are several ethical concerns with the production of gametes the lab, or gametogenesis, which echo many of the concerns ethicists have about cloning. However, also of concern is the way the media over-hyped a mouse study. In reality, particularly with reproduction, mouse models do not always translate to humans. CBHD hosted a 2012 lecture that explored the theological and ethical aspects of this issue. Video is available at <https://cbhd.org/content/theological-ethical-points-creating-gametes> or the Center’s YouTube Channel.

“The Big Moral Dilemma Facing Self-Driving Cars” by Stephen Overly, *The Washington Post*, February 23, 2017

How many people could self-driving cars kill before we would no longer tolerate them? This once-hypothetical question is now taking on greater urgency, particularly among policymakers in Washington. The promise of autonomous vehicles is that they will make our roads safer and more efficient, but no technology is without its shortcomings and unintended consequences—in this instance, potentially fatal consequences. (<http://tinyurl.com/meu9pbw>)

Self-driving cars are going to continue to be a point of debate among ethicists, who are concerned over what the self-driving car will do in situations where a person may become injured or die. Will the car preserve the driver at the expense of the pedestrian? Will the car choose the least number of casualties? Furthermore, how will we know when the cars are safe enough to use on the road?

Visit Bioethics.com, a public service provided by CBHD where you can follow stories like these as they happen.

updates & activities

ACADEMY OF FELLOWS CONSULTATION

In early February, CBHD hosted our 6th Academy of Fellows Consultation. This year's theme was "Bioethics and Being Human," exploring fundamental aspects of what it means to be human in light of advances in medicine, science, and technology, and anticipating the theme for the Center's 25th Summer Conference in 2018. Public sessions included lectures by Daniel Treier, PhD, and CBHD Distinguished Fellow Dennis Hollinger, PhD. Treier presented on theological anthropology with an emphasis on human finitude, while Hollinger explored what we should not change about being human in an age of biotechnology. Additional presentations by Fellows continued exploring the theme in closed-door sessions. Videos of the presentations will be available on the Center's YouTube Channel in the coming weeks.

COMING SOON: CONTEMPORARY ISSUES IN REPRODUCTIVE TECHNOLOGY

MEDIA RESOURCES



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The Christian BioWiki
christianbiowiki.org

STAFF

PAIGE CUNNINGHAM, JD, PHD

- Was featured in several radio interviews discussing topics including human-pig chimeras, and the importance of the body in research and death practices.
- Attended the second annual Evangelicals for Life conference in January and participated in a panel session called "Death and Disease—Respecting Human Dignity Throughout All of Life."
- Contributed an essay on the 20th anniversary of the cloning of Dolly, for *Salvo's* Winter 2016 issue.
- Presented a webinar for Global4Justice on

abortion and biblical justice.

- Was interviewed on *Chris Fabry Live* about the Women's Marches in January.
- Was quoted in *World* magazine providing a bioethical perspective on IVF practices and surplus frozen embryos.

MICHAEL SLEASMAN, PHD

- Published "Christian Physicians: Reclaiming Integrity through Conscience, Philanthropy, and Vocation," co-authored with Greg Rutecki, in the December 2016 issue of *Christian Bioethics*. The article explores the notion of an integrated Christian medical professionalism.

ON THE CBHD BOOKSHELF

For those interested in knowing what books and articles the Center staff have been reading and thought worth highlighting.

**Notes that the resource includes material by members of the Center's Academy of Fellows.

***Notes that the resource includes material by members of the Center's Advisory Board.

Bauckham, Richard. *The Bible and Ecology: Rediscovering the Community of Creation*. (Baylor University Press, 2010).

Bostrom, Nick. *Superintelligence: Paths, Dangers, Strategies*. (Oxford University Press, 2014).

Cole, Graham. *The God Who Became Human: A Biblical Theology of Incarnation*. (IVP, 2013).

Deane-Drummond, Celia, Bronislaw Szerszynski, and Robin Grove-White, eds. *Re-Ordering Nature: Theology, Society, and the New Genetics*. (T&T Clark, 2003).

DeFranza, Megan. *Sex Difference in Christian Theology: Male, Female, and Intersex in the Image of God*. (Eerdmans, 2015).

Emanuel, Ezekiel, Christine Grady, Robert Crouch, Reider Lie, Franklin Miller, and David Wendler, eds. *The Oxford Textbook of Clinical Research Ethics*. (Oxford University Press, 2011).

Fergusson, David. *Creation*. (Eerdmans, 2014).

Goodman, Kenneth. *Ethics, Medicine, and Information Technology*. (Cambridge University Press, 2015).

Articles of Note:

Juengst, Eric, Michelle McGowan, Jennifer Fishman, and Richard Settersten, Jr. "From 'Personalized' to 'Precision' Medicine: The Ethical and Social Implications of Rhetorical Reform in Genomic Medicine." *Hastings Center Report* 46, no. 5 (2016): 21–33.

Solomon, Mildred, David Vannier, Jeanne Ting Chowning et al. "The Pedagogical Challenges of Teaching High School Bioethics: Insights from the Exploring Bioethics Curriculum." *Hastings Center Report* 46, no. 1 (2016): 11–18.

Spaeder, Gwyneth. "The Moral Obligation to Vaccinate: Autonomy and the Common Good." *National Catholic Bioethics Quarterly* 16, no. 2 (2016): 245–254.

**Sulmasy, Daniel. "Tolerance, Professional Judgment, and the Discretionary Space of the Physician." *Cambridge Quarterly of Healthcare Ethics* 26, no. 1 (2017): 18–31.

Ubel, Peter, David Comerford, and Eric Johnson. "Healthcare.gov 3.0: Behavioral Economics and Insurance Exchanges." *New England Journal of Medicine* 372, no. 8 (2015): 695–698.

***Van Campen, Luann E., Albert J. Allen, Susan B. Watson, and Donald G. Therasse. "A Pharmaceutical Bioethics Consultation Service: Six-Year Descriptive Characteristics and Results of a Feedback Survey." *AJOB Empirical Bioethics* 6, no. 2 (2015): 53–62.

VanDrunen, David. "What Is Christian About Christian Bioethics? A Reformed, Covenantal Proposal." *Christian Bioethics* 21, no. 3 (2015): 334–355.

Vansteensel, Mariska, Elmar Pels, Martin Bleichner et al. "Fully Implanted Brain-Computer Interface in a Locked-In Patient with ALS." *New England Journal of Medicine* 375, no. 21 (2016): 2060–2066.

Volkow, Nora, and Thomas McLellan. "Opioid Abuse in Chronic Pain—Misconceptions and Mitigation Strategies." *New England Journal of Medicine* 374, no. 13 (2016): 1253–1263.

Wasson, Katherine, Sara Cherny, Tony N. Sanders, Nancy S. Hoan, and Kathy J. Helzlsouer. "Who Are You Going to Call? Primary Care Patients' Disclosure Decisions Regarding Direct-to-Consumer Genetic Testing." *Narrative Inquiry in Bioethics* 4, no.1 (2014): 53–68.